The everyday life of young children through their cancer trajectory

LAURA DARCY
“That you are here—that life exists, and identity;
That the powerful play goes on, and you will contribute a verse.”

Walt Whitman  O Me! O life!

This thesis is dedicated to the children and families who allowed me the privilege of sharing their lives and their cancer journeys
Abstract

The young child’s experiences of living with cancer are crucial to providing evidence based care. The overall aim of this thesis was to explore and describe experiences of health and functioning in the everyday life of young children with cancer, over a three year period from diagnosis, to provide insights and suggestions to improve evidence based care.

The first and second papers in the series of four for this thesis used a qualitative content analysis to describe the child’s experiences shortly after diagnosis and six and 12 months later. The third paper used mixed methods to identify a comprehensive set of ICF-CY codes describing everyday health and functioning in the life of the young child with cancer. The fourth paper used the identified comprehensive set of ICF-CY codes to follow changes in everyday health and functioning over the study’s entire three year period from diagnosis.

Entry into the health-illness transition was characterised by trauma and isolation. Health and functioning in everyday life was utterly changed and physical difficulties were at their peak. The passage through transition was characterised by an active striving on the part of the child to make a normal everyday life of the cancer experience. Difficulties affecting health and functioning in everyday life decreased and changed during the trajectory, though feelings of loneliness prevailed. A new period of stability in the child’s post treatment life was seen from two years after diagnosis and onwards, with (re)-entry to preschool/school and other social activities. However, an increase in difficulties with personal interactions with others and access to, and support from healthcare professionals was seen. Variances were seen within individual children’s’ trajectories.

In summary it can be stated that the everyday life of young children with cancer changes over time and health care services are not always in phase with these changes. Young children living with cancer want to be participatory in their care and to have access to their parents as protectors.
They need access to and ongoing contact with peers and preschool. Although physical difficulties in living an everyday life with cancer reduce over time, new difficulties emerge as the child post cancer treatment re-enters society. A structured follow-up throughout the cancer trajectory and not just during active treatment is necessary. A child-centered philosophy of care would guide the child towards attainment of health and well-being.

Both the child’s own perspective and a child’s perspective as described by adults caring for them should be seen on a continuum, rather than as opposites. This view could help ensure that young children become visible and are listened to as valuable contributors to care planning. Knowledge of health-illness transition can be useful in illustrating everyday health and functioning through long term illness trajectories.

Keywords: young child, cancer, everyday life, health and functioning, transition
Original papers

This thesis is based on the following papers, which are referred to by their Roman numerals in the text:

**Paper I**

**Paper II**

**Paper III**

**Paper IV**

The articles have been reprinted with the kind permission of the respective journals.
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Go raibh mile maith agaigh go léir!

Bollebygd, Sweden, June 2015

Laura Darcy
## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
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<tr>
<td>HrQoL</td>
<td>Health related Quality of Life</td>
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<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
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<td>ICF-CY</td>
<td>The ICF for Children and Youth</td>
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<td>NOPHO</td>
<td>Nordic Society of Paediatric Haematology and Oncology</td>
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<td>QoL</td>
<td>Quality of Life</td>
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<td>UNCRC</td>
<td>United Nations Convention on the Rights of the Child</td>
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<td>WHO</td>
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Introduction

“I wish I was better and could play again...be like a normal girl”
(four-year-old with leukaemia, six months after diagnosis).

There have increasingly been improvements in prognosis for patients with childhood cancer diagnoses over the past 30 years or so, thanks to state of the art treatment protocols, supportive care and close national and international collaboration (Nordic Society of Paediatric Haematology and Oncology (NOPHO), 2011). Three out of every four children diagnosed with cancer in Sweden survive their illness. Receiving a cancer diagnosis at a young age requires intensive periods of treatment, often with debilitating side effects, painful investigations and procedures and long and frequent hospital stays (NOPHO, 2011). As survivorship increases, the focus of care has shifted to living an everyday life with the effects of treatment (Björk, Wiebe & Hallström, 2009; Woodgate & Degner, 2004).

In order to give qualified care, an understanding of children’s own experiences of living a life with cancer is necessary. Young children can offer subjective assessments about their health and should be encouraged to voice them, when possible (Deatrick & Faux, 1991). However, the child’s perspective is lacking in the present knowledge base, as it is mainly adults who voice opinions on what they believe the child’s experiences are. Giving young children the opportunity to participate in research focusing on their own experiences, as this study has done, is important (Nilsson et al., 2013). This thesis aims to contribute knowledge on young children’s own experiences of living an everyday life with cancer, over a three year time period from diagnosis, with a view to assisting the child’s attainment of health and well-being.

As an experienced children’s nurse and as the mother of young children, I hope I met the families and children in this study in a way that conveys understanding and respect for their situation, and contributes to the development of services within paediatric oncology.
Background

The young child

The everyday life of the young child in Sweden

For the purpose of this thesis the young child is defined as an individual from three to six years of age. Almost all children in this age group attend state provided and subsidised preschool (The Swedish National Agency for Education, 2015). The Swedish National Agency describes preschool, which is a part of the education system, as important in laying the foundations for the child’s future learning. It aims to create security for both children and parents and enable children to create, learn and explore through playing, cooperating with others, painting, building and singing. All children, aged three to seven years of age are entitled to 15 hours a week preschool free of charge and irrespective of parental income or employment. Additional hours are subsidised by the government and paid for by parents working more than 15 hours a week, with a cap on how high fees can be. Compulsory school start is from seven years of age but most children start at the age of six (The Swedish National Agency for Education, 2015). Due to the length of time spent in preschool and the development opportunities offered, preschool plays an important role in the lives of most young children in Sweden.

The young child's perspective

Children are the best sources of information about themselves (Eiser & Morse, 2001) and the United Nations Convention on the Rights of the Child (UNCRC) asserts the right of every child to self-determination, dignity, respect, non-interference and to make informed decisions (UNCRC, 1989). This requires that health professionals take the responsibility to ensure that children are encouraged and enabled to give their views on issues that affect them in regard to health care. In reality, children’s views have not been historically valued in medical care, and children in research, particularly young children under the age of six years, have been seen as a vulnerable group, difficult to access and unable to tell their story. Sick children have traditionally been seen as thinking and feeling as adult care givers say they
do (Coyne, 2006). Despite the fact that that parent reports may not be consistent with children’s own reports (Eiser & Morse, 2001), it is mainly parents’ views on children’s experiences that have been sought in published studies (Enskär, Björk, Knutsson, Granlund, Darcy & Huus 2014a). In order to ensure quality care, young children should be encouraged to give subjective assessments about their health when possible, and parent reports should be seen more as a complement to children’s reports (Woodgate, 2000; Chaplin, Koopman and Schmidt, 2008).

Recent literature (Nilsson et al., 2013; Söderbäck, Coyne & Harder, 2011) discusses the need for health care to differentiate between having a child perspective and taking the child’s perspective. A child perspective has been characterised by Sommer, Pramling Samuelsson and Hundeide (2009) as an adult perspective on children’s conditions, experiences, perceptions and actions, with the child’s best interests in mind. A child’s perspective, on the other hand, requires the child’s own perspective and experience, based on what the child regards as important (Sommer et al., 2010). Nilsson et al (2013) argue for both perspectives as different ends on a continuum rather than polarities of each other, and depending on the research question, the design of a study may benefit from taking either perspective (Nilsson et al., 2014). Including young children in research generally requires both perspectives, such as in this thesis.

A family-centered approach to the care of sick children has been promoted and accepted as standard practice. Within this approach, planning, delivery and evaluation of care is seen as a partnership between paediatric personnel as consultants and parents who are presumed to know the child best (Shields, Pratt, Davis & Hunter, 2007). However, this approach may not always benefit the child. Acknowledging and respecting children as actors and promoting their opportunities to contribute to health care interactions requires a child-centered approach. Söderbäck et al (2010) propose that a truly child-centered approach includes both the adult’s child perspective on best interests in terms of care, as well as giving due weight to the child’s perspective with respect to the child’s own preferences (Söderbäck et al., 2010).
The young child’s understanding of health

The commonly held view on young children’s understanding of health and illness is based on Piagetian theory. Cognitive thought has by tradition been regarded as being dependent on the level of maturity of the child and limited by a structural stage of logical thought, such as proposed by Piaget (Piaget, 1976). Piaget’s pre-operational stage spans 2-6 years and suggests that this age group thinks in a concrete and egoistical way, with an inability to distinguish between reality and fantasy and whose understanding of the meanings of words are not the same as older children. This theory views young children as cognitively limited and egocentric of thought and has long led adults to believe that young children, if they think of health and illness at all, think of it in terms of a polarity between health and ill-health (Piaget, 1976).

Despite this commonly held view, young children have in fact the ability to view health as something multi-dimensional. Almqvist, Hellnäs, Stefansson and Granlund (2006) have shown that preschool-aged Swedish children see health as taking part in what they understand to be daily activities for their family and peers and ill-health as the inability to participate in everyday activities (Almqvist, Hellnäs, Stefansson and Granlund, 2006). Children’s understanding of illness and health is dependent on their previous experiences and supportive environment rather than on intelligence (Doverborg & Pramling Samuelsson, 2000). According to Chaplin et al (2008), a three-four year old child has sufficient mental ability, cognition and concepts to give graphic descriptions and have excellent recall of experiences related to adverse events, such as illness and hospitalisation—just not in the same way as adults (Chaplin et al., 2008).

The young child with cancer

Childhood cancer

Cancer remains the most common cause of disease related childhood death in children over one year of age and although genetic factors are thought to play a part, the causes of childhood cancer are largely unknown (Gustafsson, Kogner & Heyman, 2013). Treatment is dependent on the type of cancer
diagnosis and can vary in intensity and length from a few months to two and a half years of planned treatment (Gibson & Soanes ed. 2008). The most common diagnosis is Acute Lymphoblastic Leukaemia (ALL) with an incidence peak at 2-4 years, followed by brain and other solid tumours. The treatment for leukaemia consists of intensive chemotherapy and requires many hospitalisations. Chemotherapy, while successful in impeding and eliminating the cancer itself, causes many troublesome side effects such as nausea and vomiting, effects on muscles and nerves, alopecia, skin problems, effects on mouth and throat, diarrhea, constipation and various other short and long-term effects. Brain and other solid tumours require surgery in combination with radiation and/or chemotherapy and the prognosis depends on the type and location of the tumour. Cranial radiation in children, in order to remove a tumour or provide symptom relief, damages surrounding normal cells and is more problematic than in adults because of side effects to the developing brain (Gibson & Soanes ed. 2008).

Internationally, the Nordic countries have some of the best treatment results, thanks to a substantial cancer register and follow-up of treatment (NOPHO, 2011). A recent article on sustaining innovation and improvement in the treatment of childhood cancer (Prichard-Jones et al., 2013) claimed that the Nordic Countries represent a survival gold standard to which other countries can aspire. Treatment within the framework of a multi-disciplinary collaboration, long term follow-up for survivors and focus on quality of life for children undergoing treatment for cancer have been highlighted as areas requiring attention (Gustafsson et al., 2013). Considering the impact that experiences of illness in early childhood are likely to have on long term outcomes, children’s experiences are vital to providing quality care (Eiser, Mohay, & Morse, 2000).

**The young child’s experiences of being ill with cancer**

The physical and psychological distresses of repeated invasive and painful treatments and procedures, as well as adverse side effects, are well documented in the literature. The most prevalent symptoms reported in children were fatigue, nausea, pain, vomiting hair loss and feeling sad (Anderzén-Carlsson, Kihlgren, Svanntesson & Sorlie, 2007; Enskär, Knutsson, Huus, Granlund, Darcy & Björk 2014; Gibson, Aldiss, Horstman, Kumpunen & Richardson, 2010; Miller, Jacob & Hockenberry, 2011). The
child’s symptoms and symptom burden peak at diagnosis and at the start of treatment and reduce over time (Hedén, Pöder, von Essen & Ljungman, 2013). Distress and feeling sad also appear to decline over time but this decline may take a period of several years (Enskär et al., 2014a).

The few known studies in which preschool aged children (three-six years of age) themselves were asked about their experiences described dramatic disruptions of everyday roles and routines and limited possibilities for relationships and activities (Gibson et al., 2010, Björk, Nordström & Hallström, 2006). Difficulties with collaborative play with other children have also been reported (Hildenbrand, Clawson, Alderfer & Marsac, 2011).

Creating good relationships with health care professionals (Björk et al., 2006) and the comfort and protection of parents (Björk et al., 2009; Kästel, Enskär & Björk, 2011) are described as vital components for the young child’s health and functioning. Making sense of being ill with cancer depends not only on the child’s understanding but also on family relationships (Björk et al., 2009; McCubbin & McCubbin, 1993). Parents, in particular, are recognised as important actors in the child’s cancer trajectory from the very beginning (Kästel et al., 2011, Gibson, Aslett, Levitt & Richardson, 2005; Ringnér, Jansson, & Graneheim, 2011) and support from parents is one of the most important aspects of care described by children aged 4-19 years old (Gibson et al., 2010). Swedish social insurance gives possibilities for both parents to be present and financially compensated for being with the long term sick child over an extended period (The Swedish Social Insurance Agency, 2015). It is therefore common for parents to stay with and care for their children when they are ill at home or in hospital. Siblings are also important actors in the child’s experiences of being ill with cancer. Siblings report feelings of worry, grief and concern for the sick sibling and also describe experiences of being a forgotten and unimportant member of the family (Jenholt Nolbris, Enskär & Hellström, 2013).
Health and functioning in everyday life

Health and functioning according to the International Classification of functioning, disability and health for children and youth (ICF-CY)

This thesis sees health as a multi-dimensional concept in which both illness and health are dimensions that can be present at the same time, rather than polarities of each other. Health can then be seen as the product of a process rather than something an individual has, and health becomes “a resource for everyday life, not the objective of living” (World Health Organisation (WHO), 1986).

The WHO developed the International Classification of functioning, disability and health (ICF) to classify different dimensions on individuals health as a unified standardised common language and framework, to be used across disciplines (WHO, 2007). (Figure 1). It acknowledges that health- illness concepts are complex and propagates for a biopsychosocial model of health, in which context is as important as the individual and his/her needs.

Figure 1. The International Classification of Functioning Framework, adapted from WHO (2007)
A child version has been developed, the ICF for Children and Youth (ICF-CY), which relates more to child development and environment, allowing a more precise classification of factors of importance for children’s health (Simeonsson et al., 2003; Simeonsson, Scarborough & Hebbeler, 2006).

The ICF-CY provides classification as a hierarchical system by organising information on health into four interacting components designated by letters: Body Structure (s), Body Function (b), Activities and Participation (d) and Environmental Factors (e). The components Body Structure and Body Function cover all body systems and functions, Activities and Participation cover all life areas from basic learning to social tasks and Environment Factors include physical, social and attitudinal aspects of support. Personal factors such as age, gender and race provide social and cultural background but are not as yet included in the ICF-CY due to the large social and cultural variance associated with them. Qualifiers, denoting grade of difficulty in a particular component are generally used to rate the degree of a difficulty a problem may mean to a person as impairment to body structure, limitation in body function, restriction of activities and participation or barrier to environmental factors (WHO, 2007).

Each component consists of categories with specific code numbers giving detailed information. Furthermore, each of the four ICF-CY components can be categorised to four levels, from chapter to increasing levels of detail. For example, the first chapter within the component environmental factors (e1) (Figure 2) describes *products and technology*. The code e115 is at second level and describes *products and technology for personal use in daily living*. At third level, e1152 describes *products and technology for play* and at fourth level e11520 describes *general products and technology used in play e.g. building blocks*. 
Childhood cancer impacts on functioning and relationships between children and the various contexts of their lives; family, hospital, preschool and the larger community (Labay, Mayans & Harris, 2004). Children must be seen within a context and a biopsychosocial model, such as the ICF and the ICF-CY makes it simpler to understand how the child is influenced by and influences others. The original ICF-CY classification consists of over 1500 codes describing characteristics of complex, long term health conditions. For practical reasons, shorter sets of codes have been developed to guide delivery of care for some illnesses but few of these are for children and none for childhood cancer (Simeonsson, 2009). Knowledge of the impacts childhood cancer has on functioning and relationships, through the trajectory, could be assisted by the use of descriptive ICF-CY codes.

**Describing health and functioning as Health related Quality of Life**

The ICF is a tool that assists in the decision of what to assess concerning a child’s health. It looks at functioning rather than the Quality of Life (QoL) as experienced by the individual child. QoL is a dynamic, multi-dimensional concept that aims to describe an individual’s happiness and satisfaction with life. Health related Quality of Life (HrQoL) encompasses the achievement of goals and aspirations as well as the constraints imposed by ill-health and
treatment. This concept adds a health perspective which is unique, dependent on stage of development and the illness trajectory in young people with a long term illness (Taylor, Gibson and Franck, 2008). It can provide important information about individual’s health and everyday life (Cremeens, Eiser & Blades, 2006). The concept is useful in identifying outcome variables which can assess the extent to which disease and treatment influence domains of functioning and well-being and to describe satisfaction with life, for persons with long term illnesses. For health care professionals working in the clinical assessment of young children with cancer, assessment of the child’s QoL and HRQoL are essential in order to be able to meet their needs and provide necessary support.

Research has shown that children can begin to report concrete domains of their HrQoL, such as physical activity, between four and six years of age, but abstract domains such as emotional impact on illness are more appropriate for older children (Irwin & Johnson, 2005). The age limit also varies according to individual differences in their experiences of illness and treatments (Cramer & Spilker, 1998; Matza, Swensen, Flood, Secnik, & Leidy, 2004). With young children, Granlund and Björck-Åkesson ask us to keep in mind that self-rated or parent-rated QoL generally measure involvement in everyday activities. The focus is on engagement and in participation on a situation or activity in the present, rather than contentment with what has been, or hopes for the future, as is often the focus of quality of life (Granlund & Björck-Åkesson, 2005). Participation in everyday life activities is described in terms of positive experiences while physical limitations are described in terms of negative feelings. Thus ill-health can be described in terms of lack of functioning in everyday life.

**Transition**

**Transition theory**

Life events produce disequilibrium between two stable points. As a process of transition between these two points, there is an entry, passage and exit and completion of the transition generally results in a period of greater stability relative to what has happened before (Chick & Meleis, 1986). Transition
theory (Meleis, Sawyer, Im, Messias & Schumacher, 2000; Meleis, 2010) provides a suitable theoretical framework for this thesis as it introduces a broad view of rationality that includes relationships, change over time and the person in particular situations and contexts. Knowledge of transition offers professionals new possibilities for providing support, assistance and guidance.

Transition consists of three phases which have certain characteristics influencing the effects the transition has on individuals’ everyday functioning: 1) before transition/breaking point, 2) zone of transition, and 3) adjustment/after transition (Foley, Dyke, Girder, Bourke & Leonard, 2012). Transitions are embedded in the context and trajectory of an illness. How an individual perceives their situation determines how the transition will continue.

**Health-illness transition**

The health-illness transition is a specific type of transition which may involve processes of getting ill, being diagnosed, recovery, adapting to a chronic illness and accessing health care services and support. When a child falls ill, health care professionals work with children and families to facilitate movements towards a healthier state of perceived health and well-being (Schumacher & Meleis, 1994). Schumacher and Meleis describe facilitating transition not just as the focus of professional care giving but as its very mission.

Characteristics of health-illness transition may influence how health care professionals help to prepare the individual for the transition and support the individual during and after transition. The way in which different organisations and service systems collaborate and coordinate their services are important for the process outcome. Health care professionals can facilitate or inhibit patterns of response (Meleis et al., 2000; Meleis, 2010).

Application of health-illness transition to the study of childhood cancer is appropriate as it facilitates health care professionals understanding of cancer as a dynamic experience marked by critical events throughout the complete trajectory (Wilkins & Woodgate, 2006).
Rationale

Treatment is successful for the majority of young children who receive a cancer diagnosis in Sweden, but requires many hospitalisations, procedures and care over a long period of time. Living with illness and the side effects of treatment in the transition from diagnosis to health and well-being, affects the child’s ability to function in everyday life. The present knowledge base is mainly informed by adult’s views of children’s experiences and lacks young children’s own experiences, which they have a right to contribute and which are fundamental to caring for them. Without research in this area, approaches by care givers and health professionals lack children’s informed opinions which could have significant influences on the type of care provided. Research with young children is not without methodological challenges but this thesis hopes to contribute in providing access to the child’s everyday life, from their own experiences.

There is a dearth of longitudinal studies with young children living with long-term illness, which this thesis hopes to amend. Accessing the child’s long term experiences of living an everyday life with the effects of illness and treatment could offer new possibilities for providing support, assistance and guidance, through the entire cancer trajectory. Health-illness transition theory can facilitate the understanding health professionals and others caring for young children have of cancer as dynamic and lengthy.

The view of health as having a functioning everyday life can be assessed using the ICF structure of body structure, body functioning, activities and participation and environmental factors. The use of the ICF and its version for children and youth, the ICF-CY, could contribute to the present knowledge base of the lives of young children with cancer, with an international and interdisciplinary language.
Aim

The aim of this thesis was to explore and describe the young child’s experiences of health and functioning in their everyday life with cancer, over a three year period from diagnosis.

The specific aims were:
- To describe the child’s health and functioning in everyday life, at entry into the health-illness transition period (I, IV)
- To describe changes that occur in health and functioning in the child’s everyday life during the passage through the zone of transition (II, IV)
- To describe adjustments in the child's health and functioning in everyday life towards exit from the transition period (IV)
- To describe and follow changes in health and functioning in the child’s everyday life, over a three year period from diagnosis, using ICF-CY codes (III, IV)
Method

Design

This thesis consists of four scientific papers which intended to generate a new area of knowledge from empirical research with young children with cancer and their own experiences of everyday life, through their cancer trajectory (Table 1, Figure 3). In order to answer the overall aim of the thesis, an explorative, descriptive, longitudinal design combining qualitative (I, II), quantitative (IV) and mixed methods (III) papers were considered most appropriate to meet the challenges presented due to the children’s illness and young age.

Table 1. Study Design

<table>
<thead>
<tr>
<th>Paper</th>
<th>Aim</th>
<th>Design</th>
<th>Method</th>
<th>Analysis</th>
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<tr>
<td>I</td>
<td>To explore young children's and their parents' perceptions of how cancer affects the child’s health and everyday life shortly after diagnosis.</td>
<td>Explorative descriptive</td>
<td>Interviews at 3-9 weeks post diagnosis</td>
<td>Qualitative content analysis</td>
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<tr>
<td>II</td>
<td>To explore the everyday life of young children as expressed by the child and parents at six months and one year post cancer diagnosis.</td>
<td>Explorative descriptive</td>
<td>Interviews at six and 12 months post diagnosis</td>
<td>Qualitative content analysis of data from two time-points</td>
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<td>IV</td>
<td>To follow young children’s everyday health and functioning through their cancer trajectory.</td>
<td>Longitudinal deductive</td>
<td>Interviews and questionnaires at diagnosis, six, 12, 18, 24 and 36 months post diagnosis</td>
<td>Quantitative descriptive statistics</td>
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<tr>
<td>III</td>
<td>To (a) document health and functioning in the everyday lives of young children with cancer using ICF-CY codes and (b) to identify a comprehensive set of codes that can aid clinical assessment.</td>
<td>Theoretical deductive</td>
<td>Interviews at diagnosis, six, 12 and 18 months post diagnosis</td>
<td>Qualitative content analysis &amp; Quantitative descriptive statistics</td>
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Data was gathered from children aged three years and older, and the parents of all children from one year of age, by interview (at five time points) and questionnaires (at six time points), over a three year period from 2011-2014. Data collected at several time-points was necessary to capture the continuous adjustments children had to make to their lives due to the prolonged nature of childhood cancer (Bearison, 1991; Docherty & Sandelowski, 1999). Similar time points for data collection have been used in an Australian quality of life study of children with long term illness (Sawyer et al., 2004) where data was collected longitudinally from older children aged 10-16 years with asthma, diabetes or cystic fibrosis, at baseline, six, 12, 18 and 24 months post baseline. This thesis extended the data collection time-points by a further year in order to incorporate data at the period post cancer treatment.

Figure 3. Data collection time line

The purpose of papers I and II was to explore the everyday life of young children as expressed by children and their parents during the first year after receiving a cancer diagnosis. The focus of parental contributions in this thesis was rigorously kept on their child’s experiences. Qualitative design was employed in papers I and II as an appropriate means of gathering meaningful data from children (Deatrick & Faux, 1991; Irwin & Johnson, 2005). The flexible methodology of qualitative design offered sensitivity which enhanced the child’s empowerment and allowed the researcher to enter the child’s world of meaning and belief (Coyne, 2006; Eiser & Morse, 2001). Content analysis (Krippendorff, 2013) was used to make replicable and valid inferences from the data gathered. An inductive approach with semi-structured interview questions was deemed most appropriate as the research in this area was meager (Elo & Kyngäs, 2008) and a proven way to encourage children to tell their story (Runeson, Martenson & Enskär, 2007). An inductive, qualitative content analysis according to Elo and Kyngäs (2008) was used to explore these strategies.
Paper IV aimed to identify, and follow young children’s health and functioning in everyday life, throughout the cancer trajectory, using the international language of the ICF-CY. This required a quantification of data from questionnaires and interviews in the form of ICF-CY codes, at all data collection time-points, over the study’s three years. Paper III provided the foundation for paper IV by (a) documenting health and functioning in the everyday lives of young children with cancer using ICF-CY codes and (b) identifying a comprehensive set of codes that could aid clinical assessment. A mixed methods sequential design (Cresswell, Klassen, Plano Clark & Smith, 2011; Teddlie & Tashakoori, 2010) was considered a pragmatic approach to the complex research questions. This sequential process required an interpretation of qualitative interview data, followed by a quantitative analysis, to arrive at a comprehensive set of ICF-CY codes which described health and functioning in the everyday life of the young child with cancer. Paper IV then utilised the comprehensive set of ICF-CY codes identified in paper III to identify and follow changes in children’s health and functioning in questionnaires and interviews at all data collection time-points over the study’s three years. This provided information on if, which and how health and functioning in everyday life changed over time.

Participants

A convenience sample of children being treated at a paediatric oncology center in the West of Sweden, were consecutively included in the study. The inclusion criteria were that the child was between one and six years of age when receiving their first cancer diagnosis and able to communicate in Swedish. Verbal and written information was initially given to a total of 28 families by the oncology unit’s outreach nurses who agreed to the researcher’s contact by telephone. Nine of these declined to participate in the study when contacted by telephone by the researcher. Three families withdrew from the study due to difficult family situations or very ill children and three more families changed their minds about participating prior to the first meeting. Thirteen children of mixed gender and diagnosis were included in the study, during 2011 and the final data collection was conducted in September 2014. Children living in the immediate area, seven of the children in this study, received their ongoing treatment at the paediatric oncology center. The remaining six children in the study received the majority of their
ongoing care at one of six local hospitals in the catchment area. The 13 participating families were again contacted by telephone at each data collection time point, given the same information about the study and asked if they wished to continue voluntary participation. One year after diagnosis, one family decided not to continue with the study due to a changed family situation. Data were gathered from children aged three years and older at each data collection time-point. Six of the children were aged one and two years at inclusion in the study and data was gathered from these children as they reached the age of three. The participation of some of the children aged three years and over was sporadic, particularly at the beginning of the cancer trajectory, as they were quite ill and traumatised. A progression in the children’s ability to answer questions was seen at sequential interviews, as they felt better, matured cognitively and developed their ability to express themselves. Parents were included in the data collection as a complement to children’s participation. The number of participating parents also varied from time-point to time-point, depending who was present each time the researcher met the child. Towards the end of the study all children and all parents participated in data collection (Table 2).
<table>
<thead>
<tr>
<th>Data collection time-points after diagnosis</th>
<th>3-9 Weeks (n=13)</th>
<th>6 Months (n=13)</th>
<th>12 Months (n=12)</th>
<th>18 Months (n=12)</th>
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<td><strong>Parents filled in questionnaires</strong></td>
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Data Collection

Seven pilot interviews were performed by the researcher with healthy children aged three to six years of age to ascertain how best to phrase the questions, engage the children and improve the interview guide and questions. These pilot procedures led to refined interview strategies highlighting the need to be flexible and open to follow the child’s lead. Refinement of the interview guide required that questions from questionnaires were interwoven with semi-structured interview questions. This data collection was not included in the total sample.

As suggested by previous research with children, interviews in this study were conducted at home or at hospital, as wished by the child and family (Deatrick & Faux, 1991). Children were told in advance by their parents that the researcher was coming and what they were going to talk about, as suggested by Irwin and Johnson (2005). The importance of establishing trust in the personal relationship between interviewer and child has previously been highlighted (Deatrick & Faux, 1991; Kortesluoma, Hentinen, & Nikkonen, 2003) so the researcher and child often talked and played for a short time at the beginning of the interview. Children were assured that there was no right or wrong answer, as they were generally experts at trying to work out what answer they should give. Parent interviews and questionnaires were also gathered at each meeting, as a complement to child data, as suggested by Irwin and Johnson (2005) and Deatrick and Faux (1991).

The first data collection with children and parents showed the need for extreme flexibility to keep focus on the child and gather necessary responses, often with a very limited time frame of child engagement. The child was generally unwell and lacking in energy and sat at the table a while or lay on the sofa or daybed, all the while in close proximity to their parents. It was impossible to separate parents from children and play from interviews, requiring the researcher to be flexible and follow the children’s leads during the whole interview process. If the child was reluctant to participate, the parent(s) were interviewed first, thus providing the child with the time and space that s/he needed before becoming involved in the process. By the time for the second interview, the children had more energy and could be engaged a little longer in the interview and questionnaire process,
often sitting and playing with the researcher in another room. At the third and subsequent interviews, the child was able to contribute more time and energy to the interviews and fill in questionnaires themselves, which often took place in the child’s own room.

**Interviews**

The interview questions consisted of semi-structured open-ended questions that focused on areas as defined by the ICF-CY of the child’s experience of activity and participation, environment, body structure and function in everyday life (WHO, 2007). The interview began with an open question “Tell me who you are and what you like to do?” This was followed by questions such as “What do you do every day and with whom? Has your body changed? Who supports you/Do you have the help you need?” Follow on questions were subsequently asked for clarification and understanding: “Tell me more”, “How does that make you feel?”. These questions were adapted to the child and interview as necessary and made developmentally appropriate, as suggested by previous research with young children (Irwin & Johnson, 2005; Spratling, Coke & Minick, 2012). The five smiley faces from the DISABKIDS<sup>®</sup> questionnaire, from very happy to very sad, were used as a complement to help the child answer the questions – the faces were cut out the size of playing cards and placed in no order in front of the child. The child was asked “Which face shows how you feel/felt?” With some children if they could not choose between five different faces, only three smiley faces were used (Figure 4). This was discerned at each interview from talking to and playing with the child at the beginning of the interview.

![Smiley faces](image)

**Figure 4. Smiley faces**
Sometimes the child responded to the researcher using a doll or puppet to answer questions indirectly. The researcher asked questions such as “this puppet had to go to hospital when he was ill. What do you think he thought of that?” or sometimes the doll became hoarse and couldn’t answer and the child was asked to answer instead. Similar methods have been successfully used previously (Adliss, Horstman, O’Leary, Richardson & Gibson, 2009; Almqvist et al., 2006; Gibson & Hopkins, 2005, Gibson & Tywcrross, 2007). Children told of experiences that were important to them, sometimes long and winding narratives which the interviewer followed, re-introducing interview questions when necessary. Questions were directed to children in the three to five year age group as children as young as three years of age have previously shown the ability to participate and articulate experiences (Docherty & Sandolowski, 1999). Some younger children joined in as they wished.

Parents were also interviewed using the same basic questions but with focus on the child’s everyday experiences: “Tell me about your child and what s/he likes to do?”, “What does your child do every day and with whom? How has the child’s body changed? What support does the child need to live an everyday life with cancer?” Follow on questions were subsequently asked for clarification and understanding: ”Tell me more”, ”How does that make the child feel?”. Everyone was in the same room during the child-led interview as the availability of parents makes children secure and able to express their needs and experiences, in accordance with Bowlby (1988). The following quote from an interview with a three year old, one year after diagnosis, illustrates the role one parent had in accessing a three year old child’s experiences, one year after diagnosis:

Interviewer talking to child: What’s that on your face?
Child: no idea
Interviewer: I see that you have a tube in your nose
Child: have I?
Interviewer: What do use that tube on your face for?
(Child turns away)
Father talking to child: we’re talking about the time you were very ill
Child: when was that?
Father: when you were so ill you couldn’t walk
Child: why not?
Father: you were so sick you couldn’t play?
Child: no way!
Father: you didn’t have the energy to climb up and go down the slide
Child: Oh yeah! I remember, it hurt so much and I was so sad then
Interviewer: are you able to play now?...

The literature agrees that gathering verbal information from the very young child is challenging, and therefore parental contributions to children’s perspectives on the child’s everyday life can also contribute to our adult understanding of the child’s world (Adliss et al., 2009; Anderzén-Carlsson, Kihlgren, Svantesson & Sorlie, 2010; Doverberg & Pramling Samuelsson, 2000; Irwin & Johnson, 2005). Interviews were recorded and transcribed verbatim at each data collection time-point.

Questionnaires

There was no standardised instrument for young children with cancer in Swedish at the time of the study, so responses to DISABKIDS® (Bullinger, Schmidt & Petersen, 2002; Chaplin et al., 2008), EQ5D-Y (Wille et al., 2010) and a Study Specific Questionnaire (Enskår, Carlsson, Golsäter, Hamrin and Kreuger, 1997; Enskår & von Essen, 2008) were gathered from children and parents at each of the six data collection time-points.

DISABKIDS® is a generic questionnaire common to several European countries, including Sweden, with statements and smiley faces that measure HrQoL in young children and the level of distress caused by a long term illness (Bullinger et al., 2002; Chaplin et al., 2008). It covers the dimensions of independence, social exclusion and limitations due to illness and treatment and helped capture the child’s feelings about how they feel about themselves, in relation to others and about aspects of their everyday life such as going to hospital or preschool. It consists of six statements, each with a five point Likert scale of smiley faces from very happy to very sad. The child picked the face that described how s/he felt about each statement. The questionnaire is validated for use with children from four to seven years of age with long term illness (Chaplin et al., 2008) but is not specific for children with cancer. A longer, generic version has been successfully used to
capture school aged children feelings of the effects having cancer has on their lives (af Sandeberg, Johansson, Hagell & Wettergren 2010). DISABKIDS is available in both child and parent versions.

EQ5D-Y is a generic questionnaire which helped capture aspects of what the child was able to do or limited in doing in their everyday life. It measures HrQoL in children by describing health in five dimensions of movement, hygiene, activity, pain/discomfort and worry/sadness, on a scale of three (none, some, or a lot). It is validated for use in children in several European countries, including Sweden (Wille et al, 2010), for children aged eight years and upwards, but can be used in an age appropriate manner for children of a younger age (Burström, Egmar, Eriksson, Lugnér & Svartengren, 2011). The same version was used by parents.

The Study Specific Questionnaire developed for this study was based on the results of previous research on children’s life situations (Enskär & von Essen, 2008) and problems of children with cancer (Enskär et al., 1997) and modified for preschool aged children. It covers the areas of life with cancer, symptoms and side effects of treatment, and care in hospital, in order to capture aspects of the effects having cancer has on the child’s body and environment. Both child and parent versions were created. The child version consisted of 15 questions and the parent version of 17 questions. Children had three response choices of never, sometimes or always. Parent had five response choices of never, seldom, sometimes, often or always.

Procedure for gathering child responses to questionnaires
Questionnaire responses were elicited from children from three years of age and upwards, to gather their own unique perception of aspects of their everyday lives. Assistance was given by the researcher where necessary e.g. reading the questions out loud, linking the items in the questionnaires to children’s experiences and using concrete examples of the intention with each item. Consistent measures were taken not to influence child responses. Child questionnaires were kept on hand and when child responses corresponded to a questionnaire question, the researcher encouraged the child to mark or colour in the appropriate response choice, or if the child did not want to then the researcher marked the child’s response herself. Parents answered parent versions of the same questionnaires, as a complement to
rather than a substitute for the young child. Similar methods have successfully been used to capture children’s experiences of having a long term illness (Eiser et al., 2000; Eiser & Morse, 2001).

Data collection at the fifth time-point in the study, two years after diagnosis, consisted of questionnaire responses only, due to practical difficulties with the study. At this time contact was taken with each family via telephone and child and parent questionnaires were posted home to each family. All children were aged three or older at this stage of the study and all but one child filled in the questionnaires. Both mothers and fathers received copies of parent questionnaires and responses were received from all but one father.

Children with health difficulties grow up and mature quickly which may influence their understanding in spite of their age. Young children can have a limited communicative capacity in relation to healthy peers but be very competent in many other ways, related to their experiences of their disease (Kortesluoma et al., 2003). In this study, data collection benefited from the younger children being interviewed several times, as they learned how to talk about what was in focus in the interview, and to fill in the questionnaires. A rapport was built up between researcher and child, as they met several times over the course of the study.

**Data analysis (papers I and II)**

*Materials used in the data analysis*

Interviews were performed with 13 families, three to nine weeks, six months and 12 months after diagnosis (Table 2). Nine children and 13 parents participated in the initial interview, three to nine weeks after diagnosis. Five interviews took place in the child’s home and eight interviews in a hospital setting. The interviews lasted between 49 and 104 minutes. At the second data collection time point, six months after diagnosis, 10 children and 12 parents participated in the interviews which lasted between 43 and 135 minutes. Eight of these interviews were conducted in the child’s home and five in a hospital setting. Twelve months after diagnosis, 10 children and 12 parents participated in the interview. Ten interviews were conducted in the
child’s home and two in a hospital setting and lasted between 55 and 144 minutes. All interviews were recorded and transcribed verbatim.

**Data Analysis**

Transcribed interview data from 3–9 weeks, six months and one year after diagnosis were analysed using qualitative content analysis with an inductive approach according to Elo and Kyngäs (2008). A sense of wholeness was gained by initially reading the interviews a number of times before narrations concerning the child’s everyday life were highlighted. Texts with the same meanings were marked in the text as initial codes, describing the content related to the study aim. Agreement on coding was reached through discussion with the papers’ co-authors. Codes were merged to form subcategories based on similarities and differences of content as proposed by Elo and Kyngäs (2008). Subcategories were merged to form generic categories based on similarities and differences of content in the subcategories (Table 3).

Table 3. Sample of the Coding Process

<table>
<thead>
<tr>
<th>Text</th>
<th>Code</th>
<th>Sub-category</th>
<th>Generic category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child: I fall all the time ...(silence)</td>
<td>Independent before</td>
<td></td>
<td>Feeling like a stranger</td>
</tr>
<tr>
<td>Mother: She doesn’t want to do anything herself...before she was very independent now it seems she doesn’t...she is so unsure of herself...if she sits on the sofa by herself she is afraid she is going to fall...unsure of what can happen it seems...a totally different child than before. (Four year old girl and mother)</td>
<td>Totally different</td>
<td>The suddenly changed child</td>
<td></td>
</tr>
<tr>
<td>Child: We had to buy that buggy</td>
<td>Changed mobility</td>
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<tr>
<td>Interviewer: why?</td>
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<tr>
<td>Child: For me to sit in...I can’t walk anymore</td>
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<tr>
<td>Interviewer: Why not?</td>
<td></td>
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<td></td>
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<tr>
<td>Child: My legs are too strange...it was different before</td>
<td>Different before</td>
<td></td>
<td></td>
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<tr>
<td>(Four year old girl)</td>
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</table>

A synergy of the data from two time-points was made to address the aim of Paper II, exploring children’s experiences at six months (T2) and one year (T3) post diagnosis (Figure 5). Independently of each other, codes were merged to subcategories and generic categories for each data set, using the same coding method for both data sets (Holland, Thomson & Henderson,
A combined synergy analysis of the sub and generic categories from each time point was undertaken. The synergy of the two data sets occurred at subcategory level, to stay near the text but both subcategory and generic categories were helpful in the abstraction process. This process resulted in main category findings over the two-time point period.

**Figure 5. Synergy of data**

**Data analysis (paper III)**

**Material used in the data analysis**

A purposeful sample of three data rich interview transcripts were selected from each of the first four data collection time-points in the study; at 3-9 weeks, six, 12 and 18 months post diagnosis (Table 4). The selected interviews were from 11 different children and 19 parents. Two interviews came from the same child but at different time points. Seven of these interviews took place in the child’s home and five interviews in hospital. The children were aged between one and five years of age, three boys and eight girls, with mixed cancer diagnoses. Interviews lasted between 44 and 120 minutes and were recorded and transcribed verbatim.
Table 4. Characteristics of interviews used in paper III

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</tr>
<tr>
<td>Active treatment</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Follow-up to treatment</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Gender of the child</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Male</td>
<td>2</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Child participated in the interview</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Parents participated in the interview</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother and father</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Mother</td>
<td>-</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Father</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Average length of interview (minutes)</td>
<td>54</td>
<td>74</td>
<td>93</td>
<td>59</td>
</tr>
</tbody>
</table>

Data analysis

Qualitative analysis: The 12 transcripts were read through several times and meaning units described as words or sentences that revealed information about the child’s body structure, function in everyday life, activity, participation or environment, were then picked out from the text (Graneheim and Lundman, 2004). One or more labels describing meaningful concepts were identified from the meaning units and linked to ICF-CY codes, using a modified version of Cieza’s rules for linking text to ICF-CY codes (Cieza et al., 2002; 2005) (Table 5).
Table 5. Example of the linking process

<table>
<thead>
<tr>
<th>Rule description</th>
<th>Meaningful units</th>
<th>ICF-CY codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Have good knowledge of the ICF-CY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Link each meaningful concept to the most precise ICF-CY category</td>
<td>She was bright red and sweating and you could see panic in her eyes and she didn’t have any control over her own body and couldn’t fight back (Mother to two-year-old girl)</td>
<td>b152 body functions (Chapter 1, emotional functions)</td>
</tr>
<tr>
<td>3. Document additional information if content of a meaningful concept not explicitly named in corresponding ICF category</td>
<td>You can’t take the last lot of medicine in the naso-gastric tube, you see (Five-year-old girl)</td>
<td>e1101 products or substances for personal consumption + e1151 assistive products and technology for personal use in daily living, environmental factors (Chapter 1 products and technology)</td>
</tr>
<tr>
<td>4. Use lower level categories rather than “unspecified” categories</td>
<td>Before, you couldn’t even drag yourself forward, but look at you now…you run and hop and can get what you need and wipe your nose and everything like that (Mother to five-year-old girl)</td>
<td>b7 body functions (Chapter 7 neuromusculoskeletal and movement-related functions)</td>
</tr>
</tbody>
</table>

The linking process in this paper focused on the first three levels of detail such as described in Figure 2 (e.g. e1, e115, e1152 but not e11520). Meaningful concepts that could not be linked to the ICF-CY were assigned to categories of non-definable content.

Quantitative analysis: An initial count of the 10 most commonly used ICF-CY codes resulted in 55 codes. A second code count of the five most commonly used ICF-CY codes was undertaken to encourage as descriptive a set of codes as possible (marked # in Table 6). Code e420, for example, which had been used to describe attitudes of other children with cancer, could then be included in the code set. This resulted in a comprehensive code set of 70 ICF-CY codes describing everyday health and functioning of young children with cancer (Table 6).
Data Analysis (paper IV)

Material used in the data analysis

The comprehensive set of ICF-CY codes (n=70), describing the everyday health and functioning of young children with cancer identified in paper III, was used as the base for paper IV (Table 6).

Ten of these ICF-CY codes (marked with an * in Table 6) did not add extra relevant knowledge to health and functioning in everyday life of the young child with cancer; b144 memory functions, b160 thought functions, d330 speaking, d475 driving, d5201 caring for teeth, d640 doing housework, e1150 general products and technology for personal use in daily living, e1152 products and technology for play, e220 flora and fauna and e4 attitudes. These codes were therefore excluded in the longitudinal analysis, following discussion in the research group. This left 60 ICF-CY codes to be identified in questionnaire or interview data.

Data collected by interview with children and parents, and questionnaire responses from the Study specific, DISABKIDS® and EQ5D-Y questionnaires, at all collection time points, over the study’s three years, were used in paper IV (Figure 3). Responses from Study specific questionnaires were favoured as these gave most information on the everyday health and functioning of young children. If these responses were missing in the data, then DISABKIDS® responses were used and thereafter EQ5D-Y responses. Questionnaire responses from mothers were used as a first step, as it was primarily mothers who filled in the questionnaires. If mother responses were missing, then responses from fathers were used and if these were not available, then responses from children were used. Data not identifiable in questionnaire responses were identified in interview data.
Table 6. Comprehensive set of ICF-CY Codes (n=70)

<table>
<thead>
<tr>
<th>Codes describing body structures (n=2)</th>
<th>Codes describing environmental factors (n=18)</th>
<th>Codes describing body functions (n=23)</th>
<th>Codes describing activities and participation (n=27)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chapter s3 structures involved in voice and speech</td>
<td>Chapter e2 natural environment and human-made changes to environment</td>
<td>Chapter b1 mental functions</td>
<td>Chapter d2 general tasks and demands</td>
</tr>
<tr>
<td>s320 structure of the mouth</td>
<td>*e220 flora and fauna</td>
<td>b114 orientation functions</td>
<td>d230 undertaking a single task</td>
</tr>
<tr>
<td>Chapter s8 skin and related structures</td>
<td>Chapter c3 support and relationships</td>
<td>b125 dispositions and intra-personal functions</td>
<td>d250 managing one’s own behavior</td>
</tr>
<tr>
<td>s840 structure of the hair</td>
<td>c310 immediate family</td>
<td>b1253 dispositions and intra-personal functions, predictability</td>
<td>Chapter d3 communication</td>
</tr>
<tr>
<td>Chapter e2 products and technology</td>
<td>c315 extended family</td>
<td>b126 temperament and personality functions</td>
<td>*d330 Speaking</td>
</tr>
<tr>
<td>e1100 general products and technology for personal consumption, food</td>
<td>c320 friends</td>
<td>b1262 temperament and personality functions, activity level</td>
<td>Chapter d4 mobility</td>
</tr>
<tr>
<td>e1101 products or substances for personal consumption, drugs</td>
<td>c325 acquaintances, peers, colleagues, neighbors and community members</td>
<td>b128 energy and drive functions</td>
<td>d450 Walking</td>
</tr>
<tr>
<td>e1150 general products and technology for personal use in daily living</td>
<td>c335 health professionals</td>
<td>b1283 energy and drive functions, appetite</td>
<td>d455 moving around</td>
</tr>
<tr>
<td>e1151 assistive products and technology for personal use in daily living</td>
<td>*c44 attitudes</td>
<td>b134 sleep functions</td>
<td>d457 using transportation</td>
</tr>
<tr>
<td>*e1152 products and technology for play</td>
<td>c4 attitudes</td>
<td>b144 memory functions</td>
<td>*d475 Driving</td>
</tr>
<tr>
<td>*e120 products and technology for personal indoor and outdoor mobility and transportation</td>
<td>c420 individual attitudes of friends</td>
<td>b152 emotional functions</td>
<td>Chapter d5 self-care</td>
</tr>
<tr>
<td>Chapter e2 natural environment and human-made changes to environment</td>
<td>*c425 individual attitudes of acquaintances, peers, colleagues, neighbors and community members</td>
<td>*b160 thought functions</td>
<td>d5201 caring for teeth</td>
</tr>
<tr>
<td>*e220 flora and fauna</td>
<td>Chapter d6 mobility</td>
<td>b180 experience of self and time functions</td>
<td>d530 Toileting</td>
</tr>
<tr>
<td>Chapter c3 support and relationships</td>
<td>Chapter d7 interpersonal interactions and relationships</td>
<td>Chapter b2 sensory functions and pain</td>
<td>d540 Dressing</td>
</tr>
<tr>
<td>c310 immediate family</td>
<td>d710 basic interpersonal interactions</td>
<td>b280 sensation of pain</td>
<td>d550 Eating</td>
</tr>
<tr>
<td>c315 extended family</td>
<td>d720 complex interpersonal interactions</td>
<td>Chapter b5 functions of the digestive, metabolic and endocrine systems</td>
<td>*d560 drinking</td>
</tr>
<tr>
<td>c320 friends</td>
<td>d740 formal relationships</td>
<td>b510 ingestion functions</td>
<td>Chapter d8 domestic life</td>
</tr>
<tr>
<td>c325 acquaintances, peers, colleagues, neighbors and community members</td>
<td>d7504 informal relationships with peers</td>
<td>b5106 Vomiting</td>
<td>*d640 doing housework</td>
</tr>
<tr>
<td>c335 health professionals</td>
<td>d760 family relationships</td>
<td>Chapter b7 neuromusculoskeletal and movement related functions</td>
<td>Chapter d7 interpersonal interactions and relationships</td>
</tr>
<tr>
<td>*Chapter e4 attitudes</td>
<td>d7602 siblings relationships</td>
<td>b730 muscle power</td>
<td>d710 basic interpersonal interactions</td>
</tr>
<tr>
<td>*c4 attitudes</td>
<td>d7603 extended family relationships</td>
<td>Chapter b8 functions of the skin and related structures</td>
<td>d720 complex interpersonal interactions</td>
</tr>
<tr>
<td>c420 individual attitudes of friends</td>
<td>Chapter d8 major life areas</td>
<td>b810 protective functions of the skin</td>
<td>d740 formal relationships</td>
</tr>
<tr>
<td>c425 individual attitudes of acquaintances, peers, colleagues, neighbors and community members</td>
<td>d815 preschool education</td>
<td>Chapter d9 community, social and civic life</td>
<td>d7504 informal relationships with peers</td>
</tr>
<tr>
<td>Chapter c6 services, systems and policies</td>
<td>d840 engagement in play</td>
<td>Chapter d9 community, social and civic life</td>
<td>d760 family relationships</td>
</tr>
<tr>
<td>c5800 health services</td>
<td>d8800 solitary play</td>
<td>d920 recreation and leisure</td>
<td>d7602 siblings relationships</td>
</tr>
<tr>
<td>c5801 health systems</td>
<td>d8803 shared cooperative play</td>
<td></td>
<td>d7603 extended family relationships</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Codes describing body functions (n=23)</th>
<th>Codes describing activities and participation (n=27)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chapter b1 mental functions</td>
<td>Chapter d2 general tasks and demands</td>
</tr>
<tr>
<td>b114 orientation functions</td>
<td>d230 undertaking a single task</td>
</tr>
<tr>
<td>b125 dispositions and intra-personal functions</td>
<td>d250 managing one’s own behavior</td>
</tr>
<tr>
<td>b1253 dispositions and intra-personal functions, predictability</td>
<td>Chapter d3 communication</td>
</tr>
<tr>
<td>b126 temperament and personality functions</td>
<td>*d330 Speaking</td>
</tr>
<tr>
<td>b1262 temperament and personality functions, activity level</td>
<td>Chapter d4 mobility</td>
</tr>
<tr>
<td>b128 energy and drive functions</td>
<td>d450 Walking</td>
</tr>
<tr>
<td>b1283 energy and drive functions, appetite</td>
<td>d455 moving around</td>
</tr>
<tr>
<td>b134 sleep functions</td>
<td>d457 using transportation</td>
</tr>
<tr>
<td>*b144 memory functions</td>
<td>*d475 Driving</td>
</tr>
<tr>
<td>b152 emotional functions</td>
<td>Chapter d5 self-care</td>
</tr>
<tr>
<td>*b160 thought functions</td>
<td>d5201 caring for teeth</td>
</tr>
<tr>
<td>b180 experience of self and time functions</td>
<td>d530 Toileting</td>
</tr>
<tr>
<td>Chapter b2 sensory functions and pain</td>
<td>d540 Dressing</td>
</tr>
<tr>
<td>b280 sensation of pain</td>
<td>d550 Eating</td>
</tr>
<tr>
<td>Chapter b5 functions of the digestive, metabolic and endocrine systems</td>
<td>*d560 drinking</td>
</tr>
<tr>
<td>b510 ingestion functions</td>
<td>Chapter d6 mobility</td>
</tr>
<tr>
<td>b5106 Vomiting</td>
<td>Chapter d7 interpersonal interactions and relationships</td>
</tr>
<tr>
<td>b530 weight maintenance</td>
<td>d710 basic interpersonal interactions</td>
</tr>
<tr>
<td>b522 Defecation</td>
<td>d720 complex interpersonal interactions</td>
</tr>
<tr>
<td>Chapter b7 neuromusculoskeletal and movement related functions</td>
<td>d740 formal relationships</td>
</tr>
<tr>
<td>b730 muscle power</td>
<td>d7504 informal relationships with peers</td>
</tr>
<tr>
<td>Chapter b8 functions of the skin and related structures</td>
<td>d760 family relationships</td>
</tr>
<tr>
<td>b810 protective functions of the skin</td>
<td>d7602 siblings relationships</td>
</tr>
<tr>
<td>Chapter b9 community, social and civic life</td>
<td>d7603 extended family relationships</td>
</tr>
<tr>
<td>d920 recreation and leisure</td>
<td></td>
</tr>
<tr>
<td>d9202 arts and culture</td>
<td></td>
</tr>
</tbody>
</table>
Data analysis

Thirty ICF-CY codes were identified in questionnaires and thirty by listening to interviews.

*Questionnaires:* Thirty ICF-CY codes were identified in questionnaire items. ICF-CY codes had previously been identified in DISABKIDS® and EQ5D-Y questionnaire items (Petersson, Simeonsson, Enskär & Huus, 2011) and were identified in the Study Specific Questionnaire items, through discussion and revision with research colleagues and mentors. Item responses were then dichotomised as “no difficulty” for the child or “difficulty for the child”. The Study Specific Questionnaire had five response alternatives from never to always. Responses *never or seldom* were labelled as “no difficulty” (0). Responses *sometimes, often and always* were labelled as “difficulty” (1). DISABKIDS® also had five response alternatives from very happy to very unhappy. These were labelled as “no difficulty” (0) for responses *very happy or happy* and “difficulty” (1) for responses *okay, unhappy and very unhappy*. EQ5D-Y had three possible response types from no to a lot. Responses marked *no* were labelled as “no difficulty” (0) and *a little or a lot* were labelled as “difficulty” (1) (Figure 6). Similar dichotomisation of response alternatives has been performed (Eriksson & Sellström, 2010), and found valid.

---

**Figure 6. Dichotomisation of questionnaire and interview data**
Interview data: Data related to the 30 ICF-CY codes not identifiable in the questionnaires were examined for content and meaning, using the ICF-CY code book (WHO, 2007). This examination resulted in eight content areas that were identified by listening to interviews from children and parents at each of the five interview data collection time-points during the study’s three years (Table 7).

Table 7. Content areas identified in interview recordings

<table>
<thead>
<tr>
<th>Content area</th>
<th>Content</th>
<th>ICF-CY code</th>
</tr>
</thead>
<tbody>
<tr>
<td>The child’s body</td>
<td>Structure of mouth</td>
<td>s320</td>
</tr>
<tr>
<td></td>
<td>Functions of skin</td>
<td>b810</td>
</tr>
<tr>
<td></td>
<td>Functions of bowels</td>
<td>b525</td>
</tr>
<tr>
<td></td>
<td>Weight</td>
<td>b530</td>
</tr>
<tr>
<td></td>
<td>Toileting</td>
<td>d530</td>
</tr>
<tr>
<td>The child’s personality and</td>
<td>Predictability</td>
<td>b1253</td>
</tr>
<tr>
<td>behavior</td>
<td>Managing behavior</td>
<td>d250</td>
</tr>
<tr>
<td></td>
<td>Interacting with others</td>
<td>d720</td>
</tr>
<tr>
<td>Friends</td>
<td>Support and attitudes of other children</td>
<td>e320,</td>
</tr>
<tr>
<td></td>
<td>Playing with other children</td>
<td>e420</td>
</tr>
<tr>
<td></td>
<td>Playing with other children with cancer</td>
<td>e325</td>
</tr>
<tr>
<td></td>
<td>Relationships to and support from siblings and</td>
<td>d7602</td>
</tr>
<tr>
<td></td>
<td>extended family</td>
<td>d7603</td>
</tr>
<tr>
<td></td>
<td></td>
<td>e315</td>
</tr>
<tr>
<td>Relatives</td>
<td>Being engaged in play</td>
<td>d880</td>
</tr>
<tr>
<td></td>
<td>Playing alone</td>
<td>d8800</td>
</tr>
<tr>
<td></td>
<td>Playing with other children</td>
<td>d8803</td>
</tr>
<tr>
<td></td>
<td>Attendance at community activities</td>
<td>d9202</td>
</tr>
<tr>
<td>Play</td>
<td>Attendance at preschool</td>
<td>d815</td>
</tr>
<tr>
<td></td>
<td>Interactions with personnel</td>
<td>d740</td>
</tr>
<tr>
<td>Preschool</td>
<td>Awareness of illness and necessary procedures</td>
<td>b114</td>
</tr>
<tr>
<td></td>
<td>Participation in care</td>
<td>b1252</td>
</tr>
<tr>
<td></td>
<td>Interactions with personnel</td>
<td>e115</td>
</tr>
<tr>
<td></td>
<td></td>
<td>d210</td>
</tr>
<tr>
<td></td>
<td></td>
<td>d740</td>
</tr>
<tr>
<td></td>
<td></td>
<td>e355</td>
</tr>
<tr>
<td>Hospital visits and procedures</td>
<td>Using a buggy for transportation</td>
<td>d470</td>
</tr>
<tr>
<td></td>
<td>IV-stands, pumps, dressings etc.</td>
<td>e1100</td>
</tr>
<tr>
<td></td>
<td></td>
<td>e1151</td>
</tr>
<tr>
<td></td>
<td></td>
<td>e120</td>
</tr>
</tbody>
</table>

The ICF-CY codes identified in the content areas were classified as impairment to body structure, limitation in body function, restriction of activities and participation or barrier to environmental factors, in accordance with the ICF-CY code book (WHO, 2007). These were then dichotomised to being a difficulty for the child or no difficulty for the child: codes describing impairment in everyday body function (b codes), were dichotomised to “no impairment” (0) or “impairment” (1); codes describing limitations in
everyday life caused by body structure (s codes), were dichotomised to “no limitation” (0) or “limitation” (1); codes describing restricted activities and participation in everyday life (d codes) were dichotomised to “no restriction” (0) or “restriction” (1); codes describing barriers to the child’s everyday life in the form of physical, social and attitudinal factors in the environment (e codes), were dichotomised to “no barrier” (0) or “barrier” (1) (Figure 6).

Both questionnaire and interview data responses (as 0s or 1s) were then fed into IBM SPSS data program version 21 for Windows.

The ICF-CY codes described in this paper had been linked at the first three levels of the ICF-CY classification structure, in-order to give details of the appropriate category (Figure 2). These 60 ICF-CY codes were covered by 17 chapters at the first level of classification. Describing the codes at chapter level allowed a more manageable amount of variables to be followed statistically over time, while maintaining the overall category meanings. The number of responses for each code, within each of the 17 chapters, was aggregated to a mean and weighted by percent for each child. Calculating the means of aggregated responses has been successfully used previously (Eriksson & Sellström, 2010). This resulted in the possibility to follow changes in everyday health and functioning of this group of young children, as 17 statistical variables (Table 8).

Table 8. Variables describing difficulties experienced by children in everyday health and functioning.

<table>
<thead>
<tr>
<th>Variables describing limitations in body functions (n=5)</th>
<th>Variables describing impairments in body structure (n=2)</th>
<th>Variables describing restrictions in activities and participation (n=6)</th>
<th>Variables describing barriers to environmental factors (n=4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>b1 feelings</td>
<td>s3 mouth</td>
<td>d2 doing</td>
<td>e1 products</td>
</tr>
<tr>
<td>b2 pain</td>
<td>s8 hair</td>
<td>d4 mobility</td>
<td>e3 friends</td>
</tr>
<tr>
<td>b5 ingestion</td>
<td></td>
<td>d5 self-care</td>
<td>e4 attitudes</td>
</tr>
<tr>
<td>b7 movement</td>
<td></td>
<td>d7 relationships</td>
<td>e5 health services</td>
</tr>
<tr>
<td>b8 skin</td>
<td></td>
<td>d8 school &amp; play</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>d9 community activities</td>
<td></td>
</tr>
</tbody>
</table>

Finally, a descriptive analysis of the means of the 17 variables was made using SPSS version 21 for Windows. This revealed patterns of difficulties in the children’s health and functioning in everyday life at group level and differences at individual level, over the study’s three years.
Ethical considerations

This study has followed the Guidelines for Ethical Evaluation of Medical Research involving Human Subjects (SFS 2003:460). Ethical approval has been given by the Ethical Review Board, Linkoping, Sweden (dnr2010/343-31) and the four ethical principles of autonomy, beneficence, non-maleficence and fairness (Beauchamp & Childress, 1994), have been taken into account throughout this study.

Dates, times and places for the data collection time points were decided by each family, at each time point (Deatrick & Faux, 1991). The majority of interviews took place in the child’s home. At each contact the parents were reassured that their participation or non-participation in the study would not in any way affect their treatment and that they could withdraw consent at any time without an explanation (CIOMS, 2002). Names and contact details of the responsible researchers were included in the consent form (Deatrick & Faux, 1991). Both parents gave their informed consent for the child’s participation. Children themselves assented to participate in the study (Neill, 2005) as minor children are not legally capable of entering into a contract and therefore unable to give legal consent (Leikin, 1993). Each child received a child version of the informed consent form with figures and simple language to explain the purpose of the study and voluntary nature of participation. Children were encouraged to draw a picture on the back of the form and this was brought along and shown to them at each meeting as an introduction to explaining and endorsing informed assent, at all data collection time points. It was explained to the child each time that there was no right or wrong answer and that they did not have to talk about things they did not want to. At the final interview each child received a small present as thanks. This did not compensate for the time and effort participation required over the study’s three years, but was a way of thanking them (Neill, 2005). Steps were taken to ensure that the children are not identifiable in the resulting material, in accordance with laws on confidentiality (SFS 1998:204). The questionnaires and banded interview material are kept in a safe place at Jonkoping University that only the research group have access to.
Research with children is important for all children and does not need to directly benefit the informant (The British Paediatric Association, 1992). Children are seen as a vulnerable group in the area of research due to both their dependency on caring adults and their developmental level of understanding (Liamputhong, 2007). Research challenges involving children, such as the relatively small numbers of children with serious medical difficulties, the need for developmentally appropriate outcome measures, the complexities of parental involvement, specific child friendly adaptations in procedures and settings and special ethical and regulatory protections, makes research with and on children, more challenging than on adults (Field & Berman, 2004). Children can be seen as having the right to be researched on and with (Beauchamp & Childress, 1994; United Nations, 1989) and it can in fact be seen as both unethical and unscientific to exclude those that cannot make their own decision (Beazley, Bessell, Ennew & Waterson, 2009).

As a paediatric nurse the researcher was bound by a professional code of conduct as well as ethical research guidelines. Ethical dilemmas occurred in some interview situations, something that has been pointed out as likely to occur when a professional researcher is at the same time a caring professional (Mauthner, Birch, Jessop & Miller, 2002). Meeting children and families several times over a period of years incurred an insight to their everyday situations and dilemmas: a four year old with mouth pain who refused to brush her teeth, resulting in rotting teeth; a father whose grief over his child’s situation led to aggressiveness towards the child’s mother; a hospitalised child suffering from extreme pain but receiving inadequate pain relief. As a professional, the law is black and white as regards to children in danger (Neill, 2005; SFS 2001:453). Dilemmas can occur for the researcher when knowledge is gained in the research situation, which raises concerns but which has nothing to do with the study. The dilemmas experienced by the researcher in this thesis were discussed anonymously with a consultant expert for guidance. The awareness of possible differences in research contra clinical roles, as pointed out by Mauthner et al (2002) should be an important aspect of training for research students, who happen to be caring professionals (Mauthner et al., 2002).
Results

The results are presented as four main findings:

- The child's health and functioning in everyday life at entry into the health-illness transition period
- Changes in health and functioning in the child’s everyday life during the passage through the zone of transition
- Adjustments in the child's health and functioning in everyday life towards the end of the transition period
- Using ICF-CY codes to describe and follow health and functioning in the child’s everyday life

The child's health and functioning in everyday life at entry into the health-illness transition period (I, IV)

The child’s entry into illness was characterised by trauma and isolation (I). Health and functioning in everyday life was utterly changed for all children and difficulties were at their peak (IV) (Figure 7).

Figure 7. The young child’s everyday life at entry into illness
Trauma

The previously playful, social, mobile, competent child was suddenly replaced by a child who felt like a stranger. The nasogastric tube, central venous catheter and intravenous drip stand became symbols of illness for the child. Many hours were spent looking at old photographs and films of the child prior to start of treatment. The suddenness of diagnosis and start of treatment led to feelings of being abused by the treatment. The experience of parents as assisting with rather than protecting them during painful procedures left the child powerless and suffering. Allowing for the whole family to be present in hospital gave the child a sense of security. Parents expressed a changed and unfamiliar role with a child who was changed by the illness, which left the child unsure of the parent’s role (I).

Physical difficulties

Physical difficulties were greatest immediately after diagnosis and start of treatment (Figure 8). The greatest difficulties the child experienced immediately after diagnosis and start of treatment were limitations in body functioning related to pain and difficulties in eating and defecating. These were followed by aspects of self-care such as difficulty with mobility, feeding oneself and going to the toilet oneself (IV). The child required help with eating, going to the toilet, sleeping and moving around (I). Children were bothered by going to hospital (IV) and described difficulties in communication with health care services (IV). A sense of control was experienced when health care professionals treated the child with respect (I). The area of least physical difficulty was related to the child’s skin (IV).
The amount of difficulties experienced was partially related to diagnosis and type of treatment. For children with leukaemia, physical difficulties started to reduce immediately after treatment. Physical difficulties for the children with brain or solid tumours rose immediately after diagnosis, when they underwent surgery and received chemotherapy and/or radiation treatment (IV).

**Isolation**

A strong sense of loneliness and isolation was expressed. Children missed their preschool, teachers and friends and longed to return to them. The child was where the parents were and life was spent mainly in the kitchen or sitting room and sleeping in their parent’s room or bed. Play was important but had changed to something children did individually or with adults rather than together with other children (I).

**Changes in health and functioning in the child’s everyday life during the passage through the zone of transition (II, IV)**

The passage through transition roughly covered the time from six months to 18 months after diagnosis, based on the participants’ experiences of the
illness and treatment. This phase was characterised by an active striving on the part of the child to make a normal everyday life of the cancer experience but with prevailing feelings of loneliness (II). Difficulties affecting health and functioning in everyday life declined and changed over this time period (IV) (Figure 9).

Figure 9. The young child’s everyday life in the zone of transition

**Active striving for a normal life**

Gaining knowledge and understanding of the illness and treatment through adequate information and through play helped the child gain control in everyday situations. Deciding how and when procedures should be carried out, how much they wanted to be involved and at what pace it should happen, allowed the child to participate in their care and experience control. Learning to live with a changed body helped in the striving for normality and the central venous catheter and naso-gastric tubes in particular were expressed as part of themselves. The child made a normality of the illness and treatment by incorporating hospital visits and procedures into everyday life. Going to hospital was mostly fun and relaxing, and birthdays and holidays such as Christmas or Midsummer were celebrated there. A normal home and home life was strived for by accommodating illness and treatment needs and it became more “normal”. Access to parents for comfort and security continued to be important but parents also became more proficient
in giving cancer related care, which led to feelings of control for the child (II).

**Psychosocial difficulties**

Difficulties with temperament and personality, self-confidence and eating due to lack of energy, were experienced by the child during this period (IV). The child’s ability to do things increased as energy levels and self-confidence increased and health was expressed of terms of physical activity and independence in activities of daily living (II). Bodily impairments had minimal impact but those mentioned during this time were with the mouth and mucous membranes (IV).

The need for structured psychosocial support was an area that came to the fore six-twelve months after diagnosis. Relationships with and support from the immediate family, including access to parents and siblings were highlighted, alongside difficulties related to communication with and support from health services (IV) (Figure 10).

![Figure 10. Barriers to the child’s supportive environment](image)

For the children with leukaemia, difficulties with pain, emotion, ingestion and skin decreased steadily during this period. An increase in difficulties with personal interactions with others and socially inappropriate behavior was seen at 18 months after diagnosis when the children with leukaemia finished active treatment and no longer required hospital admissions and
painful procedures. For the children with brain or solid tumours all areas of difficulty continued to decrease (IV).

**Feeling Lonely**

The majority of children attended or had contact with preschool in some form, during this period. Attendance was generally for short periods and mostly for outside play with the group. Despite a strong desire to take part in activities with other children and with preschool, the children complained that they did not quite fit in, when given the opportunity to be there. They did not have the same energy levels or balance as the other children and had difficulties in terms of social competence. Playing with children with similar diagnosis they met in hospital helped them feel less lonely (II). Difficulties expressed included not feeling part of a peer group or difficulty with the child’s behavior such as with taking turns when playing with others (IV).

**Adjustments in the child's health and functioning in everyday life towards exit from the transition period (IV)**

The period of the cancer trajectory from two years after diagnosis and onwards marked a new period of stability in the life of the child post cancer treatment. This phase was characterised by the child’s (re)-entry to preschool/school and other social activities. Although an overall decrease in all areas of difficulties was seen, an increase in difficulties with personal interactions with others, inappropriate social skills and access to and support from healthcare professionals was described (IV) (Figure 11).
Figure 11. The young child’s adjustments in everyday life at exit from illness transition

**Feeling different**

Two years after diagnosis an increase in difficulties with activity and participation was seen for children. The difficulties described at this time related to the treatment’s negative affect on everyday activities such as feeling left out of the peer group. Difficulties in emotional functioning, such as the child’s socially in-appropriate behavior, were those visible three years after diagnosis. Difficulties with personal interactions with family, peers, health care and preschool personnel came to the fore for the child, during this time (IV).

**Difficulties with access to and support from health care services**

Difficulties with the child’s access to, support from and communication with health care services increased again post treatment. At this time, the difficulties described were related to the child’s and families’ needs of where to turn to for information on starting school, concern about long term effects of treatment and for support for parents and siblings (IV).

Towards the end of the trajectory, similar patterns of emotional difficulties are described for all children, independent of diagnosis. Overall, difficulties
in the area of emotions were low and steady throughout all children’s trajectories but changed from the child feeling sad and having low energy levels, to being aware of side effects of treatment and bodily changes. Difficulties with health services, activities, attitudes of others and with skin and movement started to rise again slightly, for the children with brain or solid tumours, two years after diagnosis (Figure 12). This increase coincided with contact with rehabilitation services.

Figure 12. Difficulties for a child with a solid tumour

An increase in difficulties with personal interactions with others and socially inappropriate behavior was described for the children with leukaemia from 18 months after diagnosis and onwards. This increase coincided with children finishing active treatment and starting to return to preschool/school (IV) (Figure 13).
Using ICF-CY codes to describe and follow changes in health and functioning in the child’s everyday life

Almost 3,000 ICF-CY codes describing the child’s health and functioning in everyday life were identified in interview texts. Seventy ICF-CY codes occurred most frequently (Table 6). The majority of these, roughly 40%, related to restrictions to participating in activities (d codes), and described social relations with family, peers and professionals, preschool attendance and play, as well as issues related to support from health services. Limitations in body functioning (b codes) covered 33% of the ICF-CY codes and described issues of emotions, temperament, energy, sleep and pain. Codes describing barriers in the child’s environment (e codes) accounted for 25% of ICF-CY codes, particularly those related to products and technological support and to support from family and friends. Impairment of body structures (s codes) was the least prominent area, covering only 3% of ICF-CY codes. This comprehensive set of 70 ICF-CY codes described the child’s health and functioning in everyday life (III).

In order to identify changes in everyday health and functioning for the child, the 60 most relevant ICF-CY codes were identified from child and/or parent data at six data collection time-points, and followed over the study’s three years. The ICF-CY codes were covered, at the next ICF classification level,
by 17 ICF chapters. These 17 chapters were then identified in corresponding interview text or questionnaire responses and dichotomised to being a difficulty for the child or not. Descriptive statistics gave a quantitative picture of difficulties experienced by the child at both group and individual levels, and how these difficulties changed over time (Figure 14).

![Figure 14. Difficulties in health and functioning in everyday life](image)

Individual variances in patterns of experienced difficulties were seen for each child, over time. Experienced difficulties in all areas subsided over time at group level but increased again at 18 months to two years after diagnosis. Some chapters, which described seemingly stable difficulties for the child over time, showed changes at code level within the chapter itself (IV).
Discussion

Methodological discussion

Trustworthiness or truth value can be assessed by a combination of credibility, dependability, confirmability and transferability as described by Lincoln and Guba, (1985) and validity and reliability as described by Kazdin (2003) and Polit and Beck (2008). Throughout the study different steps were taken to ensure the trustworthiness of the research design, methods and findings.

Credibility refers to confidence in the “truth” in the findings (Lincoln & Guba, 1985). The descriptions used to capture the richness and meaning of the child’s experiences, feelings and thoughts, strengthen credibility in this study. Mentorship with senior researchers and peer debriefing in the form of dialogue with co-researchers added to the trustworthy results. The researcher, a paediatric nurse with many years of experience, had not directly worked with children with cancer previously and did not have a pre-understanding of the everyday lives of young children with cancer. This meant that questioning the child and parents required an openness that enhanced the study’s credibility with genuine questions to participant statements e.g. “what do you mean by that”, “can you explain what that is” etc. Trustworthy results of analyses involved discussions with expert research colleagues until agreement was reached. Lincoln and Guba suggest member-checking as a technique for establishing credibility but this was decided against in this study as it could have negatively influenced the several data collection time-points in this study (Lincoln & Guba, 2005). The longitudinal design of this study with data collection at six time-points over a three year period is deigned appropriate for studying time-related processes, by Polit and Beck (2008). Attrition or loss of participants, over time could have threatened the study’s credibility, according to Polit and Beck (2008), however only one family discontinued participation after the first two data collections due to a changing family situation. A qualitative analysis of interview texts from the period towards the end of the study would have highlighted the child’s experiences again, rather than parental
reports of the child’s experiences. However, the fifth time point, two years after diagnosis, consisted of data collection from questionnaires only, due to financial constraints and the final interviews have yet to be analysed due to time constraints.

*Dependability* refers to the study’s consistency and replicability (Lincoln & Guba, 1985). The focus of the study, selection of context, participants and approach to gathering data, were observed as aspects of dependability. Consecutive sampling, as described by Polit and Beck (2008) was performed as children were diagnosed and met the inclusion criteria. Although the interview context with each child and family was unique for each of the five times they were interviewed, the focus was kept on the young child’s experiences rather than parent or sibling experiences by keeping the child’s experience in the center of the interview when gathering data and in the analyses process. A variety of methodological approaches were used to capture the child’s perspective, seen as necessary by Punch (2002) when gathering data from young children. Other approaches such as using photos of the child him/herself rather than drawings of faces, as pointed out by some of the children themselves, could have further encouraged the child’s participation. The children matured both physically and cognitively during the study period. To counteract any threats to trustworthiness in the design from maturity (Polit & Beck, 2008), attempts were made to include a control group of healthy children from the child’s social circle, at the beginning of the study. However, this proved to be practically difficult, as the child’s social network decreased dramatically after diagnoses.

*Confirmability* concerns the researcher’s neutrality and for other researchers to arrive at similar conclusions, derived from participants rather than researcher bias (Lincoln & Guba, 1985). Confirmability was ensured by constantly confirming and clarifying information during the interviews, with both children and parents. Clear descriptions of steps taken in this thesis make the interpretation of the text visible to the reader and show that findings are grounded in the data. The researcher became more skilled at meeting the child over time and children’s’ responses can have been influenced by her interviewing skills. Families themselves decided which parent would be interviewed at each time point. Both Mothers and Fathers
have taken part in interviews but it was mostly mothers that were the main
care givers in this study and mainly their views on the child’s experiences
that are visible. The researcher became aware of the lack of father’s opinions
on the child’s experiences as the study progressed. Two of the fathers to the
13 children in the study had been the child’s main caregiver while in hospital
and both complained that health care professionals inevitably turn to the
child’s mother in communication, or asked if they should wait until the
child’s mother was present, to give or gather information.

Transferability judges the extent to which the findings can be transferred to
other settings and groups (Lincoln & Guba, 1986). This study aimed to be
clearly written, with extensive descriptions of context, procedures, selection
and characteristics of the participating children, data collection and process
of analysis. The study was designed as heterogenic so to include children
with all cancer diagnosis, so that findings could be generalised to all children
with cancer (Polit & Beck, 2008). However, it is mainly the voices of
children with leukaemia are heard as the majority of the children had a
leukaemia diagnosis. This fact reflects the high incidence rate of leukaemia
in this age group (Gibson & Soanes ed. 2008). The transferability of the
findings in this study may be limited to young children with cancer in
Sweden, but it is plausible to believe that findings would be similar if a
similar group in a similar context were studied in the same way. The
findings may also be applicable to other groups of young children with long
term illness who experience limitations in everyday functioning.

Parents often answered for the child or commented on the child’s responses,
particularly in the beginning of the study, which could have affected the
study’s transferability. The researcher rigidly steered focus on the child’s
experiences, to help counteract this threat. Siblings played a vital role in the
children’s everyday lives but were not included as informants in this study
so as to keep focus on the sick child’s perspective.

Validity and reliability

Reliability refers to a measure’s consistency and accuracy such as an
instrument or questionnaire, while validity refers to the degree to which the
instrument or questionnaire measures what it is supposed to measure (Polit & Beck, 2008).

Although the strength of interviews far outweighs those of questionnaires for gathering valid data of individuals’ experiences (Polit & Beck, 2008), questionnaire data were gathered from children and parents in this study as a complement to interview data. The use of questionnaires can reduce interview bias and gather data not gathered through interview (Polit & Beck, 2008). Responses to questionnaires were elucidated from children as young as three years of age as this was a longitudinal study with several data collections time-points during which the child matured cognitively. The researcher assisted the younger children with questionnaires by reading the questions and in some cases filling in the answers based on child responses but strived not to influence or interpret the responses. The researcher’s expectations and cues could have affected how the child and or parent answered the questionnaires, particularly in relation to the fact that the researcher met them several times over a three year period so the child could have learned to give “unintentional expectancy effects” as referred to by Kazdin (2003). Questionnaire responses from mothers were chosen first for analysis and fathers responses used when these were unavailable were. Responses from children were used only if mothers or fathers responses were missing. This was a conscious effort to capture uniformity in responses over time. Ideally, children’s responses would have been chosen first but these were too erratic in number to give a uniform picture over time. Fathers were given increased opportunities to respond to questionnaires as the study progressed, as seen in Table 1.

DISABKIDS® and EQ5D-Y questionnaires were feasible instruments for use in young children. The alpha coefficients for child and parent versions of DISABKIDS have been shown to have satisfactory internal consistency (Chaplin et al., 2008). The EQ5D-Y was validated for use with Swedish children from six years of age (Burström et al., 2011) and it was concluded by the authors that younger children had the ability to answer the questions and had the ability to think conceptually about health.

The ICF-CY provided a valid way to follow health and functioning in the everyday lives of young children with cancer. Validity and reliability in the
process of coding meaning units from text to ICF-CY codes in paper III was enhanced by the performance of an inter-rater reliability test whereby every tenth meaning unit was coded by a second person. This revealed a congruence of 74 %, an acceptable level of validity and reliability (Polit & Beck, 2008). The structure of the ICF-CY, body structure and functions, activities and participation and environmental factors, allowed for coverage of important aspects of living a life with cancer. Following these aspects, in all interview and questionnaire data collected over the study’s three years, gave new perspectives on changes occurring over time.
Discussion of the findings

The overall results of this thesis reveal that the child’s health and functioning in everyday life is highly affected, both physically and socially, at the beginning of their cancer trajectory. Negative effects of illness and treatment on health and functioning reduce over time as the child actively strives to live an ordinary everyday life. As the post treatment child emerges and starts to reintegrate to a normal life, new challenges are revealed, related to personal interactions with peers and support from health care services (Figure 15).

**Health-illness transition theory**

This thesis demonstrates the value of transition theory for providing an understanding of the nature, conditions and processes associated with cancer, as experienced by a group of young children in Sweden. Transition theory has encouraged identification of the child as well as the environment in the transition process, similar to that seen by Wilkins and Woodgate (2006) in their conceptual analysis of transition in siblings of children with cancer (Wilkins and Woodgate, 2006). The entry and exit time periods in this study were dictated by the study’s results and related to the periods the child was on or finished with active systemic treatment. Knowledge on critical times and events in health-illness transitions is vital to the individual child’s well-being. Functioning in times of transition is probably dependent on the orchestrated effect of several factors. Transitions may not only be a matter of personal change and several transitions occur simultaneously, particularly for the maturing, growing child and his/her context (Schumacher & Meleis, 1994). This thesis could for example have looked at other transitions for guidance such as the child’s transition between service systems. The achievement of health and well-being is the goal of health-illness transition, and is characterised by feeling connected, interacting, being situated and developing confidence and coping (Meleis et al., 2000). These characteristics are not evident in this group of children’s reported experiences three years after diagnosis. The results show that the children continue to live with negative effects of illness and treatment, rather than reaching a state of health and well-being, as suggested by the theoretical outcome of transition theory. This suggests that while health-illness
transition theory helps structure the child’s cancer trajectory, it is not all encompassing towards the end of the child’s cancer trajectory. This finding concurs with those of Wilkins and Woodgate (2006) where they suggest that transitions theory needs to be further developed (Wilkins and Woodgate, 2006). An advantage of working within a transitions theory framework is its openness to collaborative ideas and flexibility to be influenced by research and practice, as heralded by Im (2011). Paediatric oncology care needs to continue to evolve and empirical gaps to be filled according to Bryant, Rodgers and Stone (2013) and transition theory can be useful in these processes.
Figure 15: The Health-Illness Transition of the young child with cancer
Entry into illness

At entry into the health-illness transition, the young child experienced trauma, physical and participatory difficulties as well as isolation. The child’s movement through this phase of transition can be eased by allowing them their parents as a safe haven from trauma and by collaborating with preschool services to ensure meaningful relationships with peers are kept intact (Figure 16).

Figure 16. Suggestions to ease difficulties in the young child’s everyday life at entry into illness

Young children with cancer need their parents as protectors

At diagnosis and start of treatment health care professionals need to re-evaluate the newly diagnosed child’s care routines so as to shift focus from the illness to the child (I). The trauma described by children and parents was partially due to the suddenly changed caring role parents’ play. Parents help constrain the child and take part in painful and unpleasant procedures and treatments. Both children and parents in this study strongly expressed the need to have parents as a refuge – a place of safety and comfort they can retreat to. Bowlby’s Attachment Theory describes the need for the young child to have a secure base or safe haven to turn to where the child can feel protected at times of trauma and uncertainty (Björk et al., 2006; Bowlby, 1988). The role of assistant to health care professionals, assumed by many parents in caring for young children with cancer, has been previously
challenged (Kästel, Enskär & Björk, 2010). Strategies for collaboration and role definition for parents and health care professionals need to be reassessed. This parental role changes over time as child and parent become more knowledgeable and proficient in care, but role definition is necessary at the traumatic start of their arduous journey through their cancer trajectory.

**Young children with cancer need contact with preschool and peers**

At entry into illness children described missing preschool and their peers and the importance of being remembered while they were not present. The children revealed a goal of getting back to preschool (I). The attainment of health and well-being requires keeping meaningful relationships and contexts (Dalberg & Segesten, 2010). Young children miss their everyday life while ill with cancer and have reported feeling left out (Hedström, Haglund, Skolin & von Essen, 2003). Previous literature has shown that ongoing contact with preschool and opportunities to meet peers is vital for the child’s strive to make the illness and treatment part of everyday life (Björk et al., 2006; Stewart, 2003).

Previous studies have highlighted the need for informing preschool about the child’s illness (af Sandeberg et al., 2008; Enskär & von Essen, 2008) and Swedish outreach nurses do this shortly after diagnosis and if requested by the family at (re)entry to preschool or school. However increased awareness in addition to this, is necessary. Preschool awareness of the isolation felt when unable to attend, and the loneliness expressed when able to attend, could influence present preschool practices. Practices could become more child-centered to allow for flexibility with attendance, increased opportunities for outside play and keeping in contact with and remembering the child, particularly at special events such as the child’s birthday, Christmas celebrations or end of term activities.

Existing Swedish National Recommendations for preschool attendance focus on infection risks and state simply that the child with cancer can attend preschool if the child’s general condition allows for it. These guidelines have been written by outreach nurses and consultant paediatric oncologists in collaboration with all six paediatric oncology centers in Sweden (National Recommendations for a Social Life with Cancer, 2008). The Swedish
National Education Agency (2015) states that children with cancer have the same right to education as healthy children and efforts should be made to ensure this. Preschool falls under the same law but there are no clear guidelines for the preschool child’s contact with or attendance at preschool. Af Sandeberg et al (2008) have shown the social benefits of school attendance or contact with school for older children with cancer. Those children who attended school felt better, experienced a higher quality of life and increased sense of independence (af Sandeberg et al, 2008). There is every reason to believe that younger children would enjoy the same benefits regarding preschool.

**Zone of transition**

The period of disequilibrium that is the zone of transition is characterised by the child’s active striving for an everyday life. Physical difficulties decrease and the child post treatment emerges who wants to, but doesn’t, fit in with their peers, resulting in feelings of loneliness. Expert nurses can assist the child’s striving by encouraging the child to feel a sense of control, by collaborating with preschool to ensure continued interaction with peers and by providing proactive psychosocial support (Figure 17).

![Figure 17. Suggestions to assist the young child’s everyday life through the zone of transition](image-url)
Young children with cancer need to be given a sense of control

Children start moving forward after the initial trauma and actively strive for an ordinary everyday life (II). Health care professionals have a major role to play in the process by giving and updating information, making children participatory in their care and assuring access to both parents and peers (II). This process of “getting used to it” (Björk et al., 2009; Stewart, 2003) and “keeping the spirit alive” (Woodgate & Degner, 2003) is highly influenced by health care professionals. The degree to which children with cancer can understand and make sense of their experiences of being ill might determine how well they adjust to the demands of cancer and its treatment (Bearison, 1991).

Young children with cancer need to interact with peers

As children returned to preschool over time, they continued to feel isolated and lonely, as they didn’t fit in with the other children (II). Attendance was often sporadic and unplanned, as everyday life was dictated by hospital visits and the child’s general health. Children expressed that they could not physically keep up with the other children, had difficulty taking turns and identified more with the adults at the preschool than the other children (II). A recent review study of children’s and young people’s experience of living with a long term condition revealed challenges of feeling different and lonely (Lambert & Keogh, 2014). Although findings of studies of children living with diabetes, epilepsy and asthma were reviewed, rather than children with cancer as in this thesis, the consistency of the results between the two studies illustrate the importance of social connectivity.

Difficulties with personal interaction with peers and others are described, when treatment has finished and the child returns to an ordinary everyday life (IV). The child is described as different from the other children and has difficulty with the social rules, despite wanting to fit it. The lack of some social skills for children returning to a life without cancer has received attention in the literature (Björk et al., 2009; Hildebrand, Clawson, Alderfer & Marsac, 2011; Woodgate, 2006). Starting, or starting back to school or preschool can be difficult for all children and not just those with a long term illness. Integrating in to school environment and re-establishing peer relationships has been described as a difficult process (Labay et al., 2004).
Professional care givers need to be aware of the importance of, and plan for, ongoing contact with school services, beyond the treatment period.

**Young children with cancer require proactive psychosocial support**

Psychosocial support should be strategically planned as part of a structured follow up to standard care. The current care strategy of families themselves making contact with psychosocial services as needed, beyond the treatment period, needs to be reassessed. Planned and structured psychosocial support beyond the initial trauma and treatment period could help the child and family through social crisis points along the transition. Experiences of psychosocial issues are a main research focus in Swedish paediatric oncology (Enskär et al., 2014a). However, clinical implications from studies are diffuse suggesting that there is an urgent need to transform research results into clinical practice. The results of this study, which show the need young children have for proactive psychosocial support (II, IV), add weight to Enskär et al’s argument for urgent implementation of research results in this area (Enskär et al., 2014a).

**Adjustments at exit from transition**

The period from 18 months after diagnosis and onwards marks a period of increased stability for the children in this study as they move towards exit from the health-illness transition and the child post treatment emerges. Many adjustments to everyday life ensue and the child returns to a more ordinary everyday life, without cancer. However, children continue to report experiences of difficulties as the exit from illness to health and well-being have not been quite reached. Difficulties in personal interaction with others due to inappropriate social skills and lack of access to and support from health care services are reported (Figure 18). A child centered approach to planning, delivering and evaluating care, as a partnership between the child, family and health care professionals could ease the adjustments that need to be made at exit from the health-illness transition.
Young children with cancer need a structured follow-up beyond the treatment period

The time from 18 months and onwards after diagnosis and start of treatment marked a new period of stability in the everyday lives of children finished with treatment (IV). However dissatisfaction with access to and support from health care services was expressed (IV).

The negative effects of cessation of treatment are well documented yet few effective interventions are described (Soanes, Hargrave, Smith & Gibson, 2009). Completion of treatment is seen only as a partial recovery and symptoms occurring after completion of treatment are extremely stressful for families (Björk et al., 2009; Rignér et al., 2011). Labay et al (2004) point out that completion of cancer treatment is another period of crisis for family, as they adjust to the “new normal”. Returning to an ordinary life, without cancer, is not the same “normality” as before (Björk et al., 2009; Hildenbrand et al., 2011) but rather a process of reintegration. The need for support is still paramount, even after treatment is completed (Gibson et al., 2005; Woodgate, 2006). A structured follow-up beyond treatment and not just during treatment could help with children’s attainment of the goal of
health and well-being in everyday life, as propagated by WHO (WHO, 2007).

**Young children with cancer require child-centered care**

Paper IV showed that different children, diagnosis and treatments generate variations in difficulties (IV). An understanding of the symptom trajectory during different phases of the child’s illness and grounded in children’s experiences, is essential in providing comprehensive person-centered care (Woodgate & Degner, 2003). Children might therefore benefit from individualised caring and supportive strategies. Those strategies need to be evidence based, structured and person-centered (Enskär et al., 2014c).

The child’s experiences are influenced by health care professionals’ competencies and caring approaches (I, II, IV). Nurses in particular have a leading role in ensuring that children attain the best possible health and functioning in everyday life, throughout the entire cancer trajectory. Nurses, according to Bryant, Rodgers and Stone (2013) are highly motivated to create the best possible environment of healing for their patients. Care givers may be aware of the importance of including the child’s perspective in care planning, delivery and evaluation (Coyne, 2008), but elucidating that perspective often depends on how those caring for the child perceive the child’s capacity (Alderson, 2007). A truly child-centered approach requires knowledge of the specific child in the specific situation as well as their life condition and development (Söderbäck et al., 2011). Shared Decision Making (SDM) in the care process between children, parents and professionals would be a true indicator of child-centered care. This type of collaboration has strong support from decision makers but weak evidence in practice, according to a recent Cochrane review (Coyne, O’ Mahúna, Gibson, Shields & Sheaf, 2013), suggesting a need for studies in this area. A named key worker, proficient in child-centered care, could establish a structured follow-up plan for each child and family and follow them through the trajectory. Such a role could ease exit from illness and specialised paediatric oncology services to more general primary care services.
Conclusions

The results from this thesis reveal emerging issues that need to be addressed as young children learn to live an everyday life with cancer and the effects of treatment. This thesis adds unique knowledge to current information on the young child’s everyday life through their cancer trajectory.

Insight was gained on young children’s suffering shortly after diagnosis that has not previously been highlighted in the literature. Health and functioning in everyday life was utterly changed at entry into the health-illness transition. Lack of access to parents as protectors was experienced as traumatic. Physical difficulties were at their peak but these started to decrease almost immediately. Lack of access to peers and preschool led to experiences of isolation for the child.

The longitudinal design gave insight to previously unacknowledged experiences beyond the treatment phase. Experiences of loneliness related to the child’s environment prevailed throughout the trajectory. When the child returned to preschool and/or social activities with peers, they found they no longer fitted in, socially and/or physically. Difficulties with personal interactions were expressed as the child without cancer began to interact with others in everyday settings. Although ultimately striving to attain health and well-being, as the outcome of the health-illness transition, the child’s everyday health and functioning continued to be negatively affected, even when treatment was finished.

The methodologies employed in the thesis showed that it is possible to access the experiences of young children with cancer and to illustrate differences within individual children’s’ trajectories.

The thesis has shown that the ICF-CY can be used to assess health and functioning in everyday life, through the cancer trajectory.
Clinical Implications

The findings from this thesis can deepen health care professional’s present understanding of the everyday life of young children with cancer. A number of findings can be incorporated into existing care and others used to guide necessary changes in care that would enable health care professionals to follow the young child through the entire trajectory.

- **Young children with cancer need an active social life**
  Despite the fact that young children with cancer are very ill and require intensive and aggressive treatments and procedures, they still need functioning social lives. Interdisciplinary collaboration between professional caregivers, health care and preschool services, with the child’s needs in focus, is necessary. Clear guidelines to ensure young children with cancer have functioning social lives such as those available for school aged children, are required.

- **Young children with cancer need structured, child-centered care, beyond the treatment phase**
  This thesis shows that the transition process of health care services is not in sync with children at critical time points. Care practices and support strategies that aid health and functioning in everyday life, need to be developed, both during and beyond the treatment period. Psychosocial support needs to be planned for by health care professionals and not left to parents to plan or ask for. An information pathway is required, beyond treatment, to ensure access to health care services. Individual variances should be taken into account for each child and family. A named key worker could ease the child’s journey through the health-illness transition and ensure a successful transition from highly specialised paediatric oncology care to primary care services.

- **Children need to be seen and heard**
  Young children should be acknowledged as valuable contributors in their care process. Encouraging participatory actions in planning and implementing care will give the young ill child a sense of control and ease
the journey towards health and well-being. Enabling children to become visible and listened to as competent individuals in care requires using both the child’s own perspective and a child perspective by adults caring for them.
Future Research

The findings from this thesis revealed new areas of research.

- **Clinical Interventions**
The findings of this thesis should be transformed into clinical practice. This would require interventions that address interdisciplinary collaboration with preschool services, health care professionals, parents and young children themselves, with the goal of ensuring preschool contact. Planned care and information pathways need to be developed by health care professionals, beyond the treatment phase, for each child and family. Interventions that encourage the child’s participation in planning, implementing and evaluating their own care should be prioritised by all caring for children. Evidence based guidelines for Shared Decision Making (SDM) does not exist at present, requiring intervention studies.

- **Development of Clinical Assessment Tools to guide delivery of care**
The ICF-CY codes identified and followed in this thesis could be used to develop a clinical assessment tool (CAT) for those caring for young children. Such a tool could be used to guide the delivery of care towards living an everyday life with a long term illness. The universal and interdisciplinary language of the ICF means that such a CAT can have wide reaching effects for care of young children with cancer, and perhaps other groups of children with long-term illnesses. It’s international language means that ongoing clinical assessment, based on variables describing changes over time, could have wide reaching effects for the care of young children in need.

- **Research with young children**
Children can and should be included in research – as a valid way of ensuring their voices are heard. Capturing young children’s experiences through interview at several time points and using parents, smiley faces and puppets to elicit information, have worked in this thesis. It is likely that many methods are necessary to fully capture the young child’s experiences.
Exploring methods such as photo-voice, draw and tell, observation by film and the development of other methods to access young children’s perspectives need to continue to be developed. Children’s participation in research should be encouraged already from planning the study design, to achieve best access to their worlds.

- **Longitudinal studies**
  The results showed there is a need for studies which follow young children with a long term illness, through their health-illness transition. The longitudinal design of this thesis was a pioneering work which revealed information that could have not been gathered from the young child otherwise. Longitudinal studies are needed to give health care professionals and others caring for young children knowledge on critical time and events in health-illness transitions. Transition theory could guide the development of clinical interventions.
Summary in Swedish

Små barns vardagsliv under sin cancerresa

Bakgrund
Barncancervården blir alltmer framgångsrik och numera botas 75 % av alla barn som får cancer. Vården innebär dock intensiva behandlingsperioder, med svåra bieffekter och långa sjukhusvistelser för barnen. Trots att incidensen av cancer under barnaåren är som högst i åldersgruppen 1-6 år, finns endast ett fåtal studier publicerade som beskriver dessa barns hälsa. Det är framförallt kvantitativa studier som gjorts utifrån ett vårdar- och föräldraperspektiv. För att kunna ge kvalificerad och evidensbaserat vård/omvårdnad av barn i alla åldersgrupper krävs en större kunskap om hur cancersjukdomen påverkar det lilla barnets liv.

Syfte
Syftet med den här avhandlingen är att undersöka och beskriva små barns hälsa och vardagsfungerande under en treårsperiod efter att barnen blivit diagnosticerade med cancer.

Metod

I delstudie I och II, genomfördes intervjuerna 3-9 veckor, 6 och 12 månader efter barnet fick sin cancer diagnos. Dessa analyserades med en kvalitativ innehållsanalys. Data från sex och 12 månader fördes samman för analys och presenteras på kategorinivå för att ge en samlad bild av barnens upplevelser

Resultat

Delstudie I


Delstudie II

Resultaten visar hur barnen aktivt strävar efter att hitta en vanlig fungerande vardag med cancer. Strävan efter kontroll ses i barnens jakt på kunskap och förståelse för sin sjukdom och behandling, i viljan att bestämma och vara delaktig i sin vård och genom att ha sina föräldrar närvarande och delaktiga i

Delstudie III
Barnens upplevelser av vardagslivet med cancer under första 18 månaderna sedan diagnos, beskrivs som 70 ICF-CY koder. Majoriteten av dessa, nästan 40 %, beskrev barnens vardagliga aktivitet och delaktighet såsom sociala relationer med familjan, kamrater och vårdpersonal, deltagandet i förskola och lek, och stöd från hälsocentraler. ICF-CY koder som beskrev barnens kroppsfunktion täckte 33 % av koderna och beskrev känslor, temperament, energi, sömn och smärta. ICF-CY koder som beskrev barnens omgivningsfaktorer som mest relaterade till stöd från produkter och teknologi och stöd från familj och kamrater, omfattade 25 % av koderna. ICF-CY koder som beskrev barnens kroppstruktur var minst i antal.

Delstudie IV

Slutsatser/Kliniska Implikationer
Små barns upplevelse av hälsa och förmåga att fungera i vardagen under sin cancerresa förändras över tid. Hälsocentraler och sjukvårdsinstanterna är inte alltid i fas med dessa förändringar. Barnen vill ha tillgång till sina föräldrar, vara delaktiga i sin hälsoproces, ha möjlighet att träffa andra barn samt ha en fortsatt kontakt med förskolan. Även om de fysiska svårigheterna blev mindre över tid, tillkom nya svårigheter under tiden efter behandlingen. En
strukturerad plan både under och efter behandlingen behövs. Barncentrerad vård skulle kunna hjälpa barnet igenom hela sin cancerresa till hälsa och välbefinnande. Det är viktigt att barnet görs synligt i vården och barnets röst blir hörd, så att barnet kan bli en medaktör i planering, utförande och utvärdering av barnets egen vård.
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This thesis is comprised of four scientific papers, with the overall aim of describing the everyday life experienced by young children with cancer. Through interviews and questionnaire data collected from young children and their parents over a three year period from diagnosis, the findings show that the everyday life of young children with cancer changes over time and health care services are not always in tune with these changes. Children living with cancer want to be participatory in their care and to have access to their parents as protectors. They need access to and ongoing contact with peers and preschool. Although physical difficulties in living an everyday life with cancer reduce over time, new difficulties emerge as the child post cancer treatment re-enters society. A structured follow-up throughout the cancer trajectory, and not just during active treatment, is necessary. A child-centered philosophy of care would guide the child towards attainment of health and wellbeing.

The results from this thesis reveal emerging issues of survivorship that need to be addressed as young children learn to live an everyday life with cancer and the effects of its treatment. This thesis adds unique knowledge to the existing range of information about young children’s everyday life, through their cancer trajectory.

The findings from this thesis deepen the current understanding of the everyday life of young children with cancer for those caring for them. A number of findings can be incorporated into existing care practices, and other findings could be used to guide necessary changes in care practices that would embody the best care for young children through the entire cancer trajectory.

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