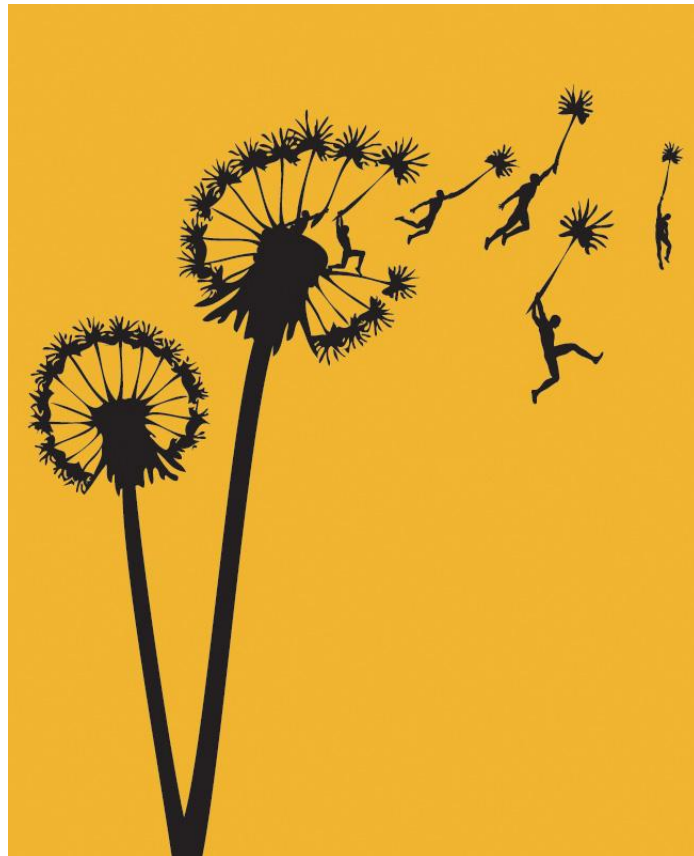


Thien Thanh Le

**Resilience and mental health in parents of children surviving
Acute Lymphoblastic Leukaemia**



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Department of Social Work and Health Science
Faculty of Social Science and Technology
Norwegian University of Science and Technology

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Abbreviations

ALL Acute Lymphoblastic Leukaemia

AML Acute Myelogen Leukaemia

GHQ General Health Questionnaire

PACS Parental Account of Children's Symptoms

RSA Resilience Scale for Adults

REK Regional Committees for Medical Research Ethics

Background information

Each year, approximately 130 Norwegian children under the age of 15 are diagnosed with cancer, of which 1/3 are diagnosed with leukaemia. The majority of all cases of leukaemia are acute lymphoblastic leukaemia (ALL) (Bringager, Hellebostad & Sæter 2005; Reinfjell, Diseth & Vikan 2007). In the western world cancer is still the most frequent cause of death by disease for children between 1 and 15 years of age, but as a result of new treatments combining chemotherapy, radiation and surgery, the survival rate for leukaemia has increased from 20 % in the 1960s to 80 % today (Gatta, Capocaccia, De Angelis, Stiller, Coeberg & the EURO CARE Working Group 2003).

The present thesis gives an overview of data concerning resilience and mental health among parents of children with ALL, collected in “Children with Acute lymphoblastic leukaemia: A study of health-related quality of life, mental health and intellectual aspects”, a doctoral study by Trude Reinfjell (2007). The sample consisted of 40 children in remission from ALL, and their parents. Thirty-six mothers and 21 fathers were interviewed, and filled out two questionnaires: the Resilience Scale for Adults (RSA) and the General Health Questionnaire (GHQ-30). The thesis consists of two parts: Part I is a theoretical introduction of relevant literature on childhood leukaemia, the children’s perspective and the familys’ perspective, as well as the concept of resilience and its historical background. Part II presents an empirical study of resilience in parents of children surviving ALL, and the association between parental resilience and mental health based on data from the mentioned doctoral study.

Part I: Literature and previous research on children with acute lymphoblastic leukaemia and the concept of resilience.

1. Introduction

1.1 General introduction

In Norway, approximately 130 children under the age of 15 years are diagnosed with cancer each year, and approximately 40 children die yearly (Mathisen 2004; NHI 2011). In the western world, cancer is still the most frequent cause of death by disease for children between 1 and 15 years of age, and the incidence has remained stable (NHI 2007; Kreftregisteret 2008).

Leukaemia accounts for approximately 1/3 of all cancer cases, and the majority of leukaemia cases are acute lymphoblastic leukaemia (ALL) (Bringager, Hellebostad & Sæter 2005; Reinfjell, Diseth & Vikan 2007). New treatments that combine chemotherapy, radiation and surgery have resulted in a survival rate of 80 % for leukaemia today compared to 20 % in the 1960s. The treatment for ALL lasts up to 2 – 2.5 years (Gatta, Capocaccia, De Angelis, Stiller, Coeberg & the EURO CARE Working Group 2003).

1.1.1 Personal reflections and choice of topic

Since I started my studies in psychology in 2005, I have become more interested in the concept of health, particularly mental health, as well as health science and research. In December 2009 I worked as an assistant in the home care nursing, and was informed that the nursing manager was on leave because her daughter was sick. Her nine year old daughter had been diagnosed with cancer of the ear. Unfortunately it resulted in the family having to cancel their summer holiday in Australia. It was a particular sad situation to see the family struggle. About a year and a half after the child's diagnosis during the summer of 2010, the nursing manager started back at work and I asked her about her daughter's illness. She said that her daughter was now well and she was cured of her cancer sickness, something they were very grateful for. She explained further that her daughter needed regular follow-up and check-ups because of her cancer diagnosis, and there was always the fear of relapse. I was extremely touched and fascinated by our conversation mainly because of all the unanswered questions I had: 1) How do children cope with such a severe diagnosis? 2) What do you do as a parent, and how do you cope with your children being seriously ill with cancer? 3) How do nurses, doctors and other professionals cope over time? These questions along with the curiosity for the term "resilience", which I learned about during a guest lecture in a health science class, lead to the choice of the topic for this master thesis.

2. Childhood cancer

Cancer in children is very rare. Nordic data shows that one of 435 children or adolescents get diagnosed with cancer before the age of 15 (NHI 2007). One third are diagnosed with blood cancer, about one fourth diagnosed with a brain tumour, 10 % with lymphatic cancer, 6-7 % diagnosed with carcinoma adrenal cancer and even fewer with renal cancer or bone cancer. A few percent are diagnosed with cancer in the soft-tissue and retinoblastoma (NHI 2007). Generally can childhood cancer be divided into three groups: one third leukaemias, one third brain tumours of different forms, and one third consisting of several rare tumours in most organs in the body. Common for childhood tumours is that they originate in tissues that are similar to embryo tissues. They are therefore often called blastoma (SNL 2011). Childhood cancer accounts for less than one percent of all cancer cases in Norway, but yet, cancer in children is the most frequent cause of death by disease for children after the age of one. In contrary to adult cancer, where it is known that lifestyle and environment factors play a part in the development of several cancer forms, the reason for cancer in children is still unknown (NHI 2007; SNL 2011). In general, cancer is caused by several mutations in the gene of the cells. Certain diseases also increase the risk of getting cancer, such as Down's syndrome. In addition, certain environmental factors such as mothers taking x-rays during pregnancy may also increase the probability for childhood cancer. Another theory is that infections can trigger cancer, but there is still not enough knowledge concerning this (NHI 2007).

2.1 Acute Lymphoblastic Leukaemia (ALL)

ALL is the most common form of cancer among children, and constitutes about 80 % of leukaemia cases, 10-15 % are acute myeloid leukaemia (AML) and <5% have chronic myeloid leukaemia. ALL is a form of blood cancer where a certain type of white blood cells, lymphocytes, reproduces uninhibited. The body loses control over these immature lymphocytes, and they increases in number and crowd out the healthy red blood cells, normal white blood cells and platelets that the body needs (Bringager et al. 2005; NHI 2006).

The typical symptoms for ALL develop during a short period, and include: 1) listlessness and tiredness due to the low blood percent, 2) frequent infections because of the reduced number of normal white blood cells, 3) bleeding in the skin and mucosa due to less platelets. Other symptoms can be blurry eyesight or double-vision, skin eruption, headache, nausea and vomiting (as a result of irritations in the meninges), and some may also experience

bone- and joint pain. The diagnosis is given after an assessment of blood tests, and the most typical age for an ALL diagnosis is between 2 to 5 years old (NHI 2011).

2.1.1 ALL treatment

Treatment for ALL can extend over a 2 - 2,5 year time period, and the goal of the treatment is in most cases recovery. The main treatment of leukaemia is to eliminate the sick and immature white blood cells (cancer cells) with chemotherapy. ALL treatment normally involves a combination of different types of chemotherapy (NHI 2006).

The treatment is separated by four different phases: 1) Remission induction (with the induction phase taking up the first 7 weeks of treatment), 2) CNS (central nervous system) preventative-/prophylactic therapy, 3) consolidation and 4) maintenance (Reitan & Schjøberg 2004; Bringager 2005). The goal is to obtain a complete remission from the disease with normal blood, normal bone marrow and a normal general health condition in the first remission induction phase. This is done by an intensive period of chemotherapy, and typically lasts about 7 weeks. Approximately 98 % of all children and 85 % of all adults with ALL achieve complete remission (Reitan & Schjøberg 2004; Bringager 2005; NHI 2006). The next phase can last from several weeks to months, and the goal is to prevent CNS relapse. The treatment involves chemotherapy and in some cases, in combination with cranial radiation therapy. This phase is followed by consolidation, which is used to intensify therapy following remission induction. This treatment period lasts for several months, and is followed by maintenance therapy. Maintenance therapy includes chemotherapy and normally lasts for about 2 years (Reitan & Schjøberg 2004; Bringager 2005). In cases where recovery cannot be obtained, the aim of the treatment is to give the patient relief for pain and symptoms. And in case of relapse, the only cure of the disease is a bone marrow transplantation (NHI 2006).

Intensive treatment can involve high levels of acute distress, generally caused by anxiety and pain associated with some of the medical procedures, such as bone marrow aspirations, lumbar and venous punctures. Injections with chemotherapeutic agents with bouts of nausea and vomiting resulting from chemotherapy, as well as the anxiety associated with the treatment can also involve high levels of acute distress (Varni & Katz 1997; Bringager et al. 2005). In addition, children undergoing treatment for ALL experience a number of bodily changes. Side effects of the cancer treatment such as weight loss or gain, hair loss and mouth ulcers may be reversible, but others, such as sterility and organic brain damage may be permanent. These side effects, especially the visible changes to the physical appearance, may

affect the child's self-image and self-esteem (von Essen, Enskår, Kreuger, Larsson & Sjøden 2000; Zebrack & Chesler 2001).

2.2 The children's perspective

Research shows that children's adaption to chronic illness is affected by several factors: 1) the illness' characteristics (to what extent it is life threatening and limits movement and social activities or experiences), 2) situational factors such as stressors in the child's treatment daily life (treatment procedures, side-effects and complications), 3) the child's characteristics (age, sex, personality or coping style and previous experiences, and 4) the family's characteristics (the ability to solve problems, communication skills, and the extent of openness in the family), and social support from friends and family (Kupst & Schulman 1988; Van Dongen-Melman, Pruyn, Van Zanen & Sanders Woudstra 1986; Varni, Katz, Colegrove & Dolgin 1993; Bringager et al. 2005).

Research demonstrates that certain factors act as protective factors in children who face traumas and loss (Rutter 1985; Masten, Best & Garmezy 1990), and can contribute with valuable information concerning the mechanisms and resources that children possess (Bringager 2005). It is well known that children with a chronic illness experience loss in different ways, such as the loss of the possibility to go to kindergarten or to school for a long period and the loss of daily interaction with siblings because they often have to stay in the hospital for long periods (Bringager 2005). Therefore, it is important to gain knowledge about the child's perspective on the new situation, including the child's coping strategy.

Coping styles are used to reduce or eliminate problems. There are many ways for a child to cope, for example to seek information, to try to change the situation or to accept the situation. A child seeks information from books, TV-programs, the hospital staff, or informal sources such as others who have had similar experiences. Seeking information is used to reduce insecurity and negative emotions, and studies showed that collecting precise information may reduce the feeling of insecurity and symptoms related to depression (Van Dongen-Melman et al. 1986).

According to Lazarus (1966) the attempt to change the situation is the most active coping style, including all activities where the purpose is to remove expected threats. In this context, it can be to take the medication to cure the cancer. The attempt to remove negative consequences reinforces the feelings of coping, and rebuilds the child's self-esteem (Lazarus 1966).

Due to the limitation of influence on a life-threatening disease, a cancer sick child eventually accepts the situation as it is. Accept can make it easier for children to adapt to a new reality, and this is a strategy which is often used after a period of denial (Van Dongen-Melman et al. 1986). Further on, Lazarus (1966) stated that because children's coping style is dependent on themselves and the situation, the relation between stressors and coping strategies has to be seen as a process. Generally, a child's manner of coping with an illness is dependent on the diagnose, medical procedures and cognitive abilities. Moreover, research shows that girls in preschool-age talk more about their feelings compared to boys in the same age (Dyregrov, Matthiesen, Kristoffersen & Mitchell 1994). This is also the case for adolescents. Girls tend to focus more on expressing emotions while boys more often express themselves physically (Dyregrov et al. 1994; Brenner & Salovey 1997). In the everyday life with treatment, the boys' physical display will be difficult to carry because of the side-effects the treatment. This is important to be aware of when children are diagnosed with cancer. Additionally, studies show that children with chronic illness have two to three time higher risks for developing psychosocial difficulties (Gortmaker, Walker, Weitzman & Sobol 1990; Wallander & Thompson 1995). A child's perspective is therefore necessary for parents, caregivers and health professionals to be able to maintain their needs concerning adjustment and coping.

2.3 The family's perspective

Bronfenbrenner's (1979) social-ecological theory suggests that an individual's well-being is dependent on not only personal characteristics, but also on the social systems and resources around them. For children with a chronic illness, the family system is an important factor (Kazak, Rourke & Crump 2003). How children adjust to a stressor may be affected by how those around them adjust, and the available resources of the family. A stressor such as a chronic illness requires all family members to adapt to new changes and responsibilities such as medical appointment, financial strain and physical absence of multiple family members (Reitan & Schjølborg 2004). It is therefore important to consider the whole family's adjustment when examining the child's adjustment to distress (Robinson, Gerhardt, Vannatta & Noll 2007).

One of the strongest contributors to adjustment both in children with chronic illness and healthy children (Drotar 1997) is a well-functioning family. Several studies have demonstrated that parents' distress is positively related to distress in children (Robinson et al. 2007). Therefore, a cancer diagnosis can pose a considerable threat to a normal parent-child-relationship (Eiser 2001). Results from longitudinal studies show that despite the fact that many parents adapt well to the child's cancer diagnosis, there is still a significant number of parents

who struggle with mental fatigue, anxiety and symptoms of post traumatic stress after treatment of the child's cancer illness (Maurice-Stam, Oort, Last & Grootenhuis 2008). Studies demonstrate that children with a chronic illness have twice the risk of having behavioural and emotional problems compared with healthy children (Lavigne & Faier-Routman 1992 in Gannoni & Shute 2009). These results should be taken into consideration, along with the fact that interaction between the child and their parent is regarded as fundamental for the child's development and adaptation (Masten & Shaffer 2006). There may therefore be a reason to believe that the child's development can be disrupted as a result of parental anxiety, worry and stress.

Research showed that the combination of high family cohesion and low family conflict consistently predicted better adjustment in youths with chronic illness; children in a positively family environment with high expressiveness and cohesion, and low conflict are more likely to adjust well (Drotar 1997). At the same time, studies showed that children raised in high conflicted environments are more exposed to adjustment problems (Hammen, Brennan & Shih 2004; Varni, Katz, Colgrove & Dolgin 1996). In addition, research showed that negative parental emotional responses, such as depression are related to poor adjustment both in children with cancer and healthy children (Mulhern 1992). According to Varni et al. (1996) cohesion and expressiveness are related to fewer child internalizing problems in families with a child newly diagnosed with cancer.

Most research suggested that when it comes to coping with emotional and instrumental demands and responsibilities related to caretaking, mothers are more involved than fathers (Hanson 2001). In a prospective study by Goldbeck (2001) data showed that mothers reported more effective coping compared with fathers, and parental dissimilarity in coping and information seeking have differential effects on the family members. Despite the child's illness fathers often remain more involved in everyday life, and this may affect the fathers' own situation and needs; by staying at home or at work while the child is having treatment, fathers will not be able to get adequate help for their emotional needs. This may result in adjustment problems later (Eiser 2005). Even as research participants, fathers are less involved longitudinally than mothers (Janus & Goldberg 1997). It has therefore been suggested that more data is needed due to fathers being underrepresented in many studies. However, a cancer diagnosis and a chronic condition in the family have different effects: each family member will experience changes differently, as well as the family environment as a whole will be altered (Hanson 2001). In general, parental adjustment and coping, and levels of support and stress in the family have been consistently correlated in earlier research (Thompson & Gustavson 1996).

It is also worth mentioning that studies that have investigated parents' reactions to the child's cancer have largely focused on the weaknesses and formations of psychological or psychiatric symptoms in psychopathology, and rarely focused on a resource-oriented perspective (Gudmundsdottir, Schirra & Boman 2010), such as resilience. Therefore, the concept of resilience will be emphasized in this study.

3. Resilience in the past, present and future

The concept of resilience has been translated directly from the English term "resilience" and at the moment there is no fully adequate translation into Norwegian, but alternative Norwegian words such as "resiliens" and "mestring" have been used (Borge 2010). Resilience is used for both physical and human phenomena in dictionaries and in the daily speech of the English language. The English-Norwegian School Dictionary defines resilience as "elasticity, resistance; (in person) toughness" (Lingua 2002). In a more advanced English dictionary resilience is defined as: "the ability to quickly return to your usual health or state of mind after suffering from an illness, difficulties etc: *resilience of character*", as well as "the ability of a substance to return to its former shape when pressure is removed; *flexibility*" (Longman 2001).

In resilience research there has been suggested a number of definitions, among others a definition by Masten, Best & Garmezy (1990) who define resilience as: "*the process of, capacity for, or outcome of successful adaptation despite challenging or threatening circumstances*". Bernard (1991 in Howard & Dryden & Johnson 1999) has a similar definition; resilience is "*a set of qualities, or protective mechanisms that give rise to successful adaptation despite the presence of high risk factors during the course of development*". Regarding children's resilience, Garmezy (1974) stated that the resilient child is one who "*.....works well, plays well, loves well and expects well*". A more detailed description of resilient children can according to Masten et al. (1990) be divided into three groups: 1) Children who do not succumb to adversities, despite their high-risk status for example babies of low birth-weight, 2) Children who develop coping strategies in situations of chronic stress for example children of drug-using or alcoholic parents, and 3) Children who have suffered extreme trauma for example through disasters, sudden loss of a close relative or abuse, and who have recovered and prospered. Concerning resilient children, it is natural to give a presentation of a comprehensive survey "The Kauai Study", a prelude to the resilience research (Borge 2010).

3.1 The Kauai study

This study is about a group of children born in 1955 and followed up by more than 40 years (Borge 2010). In the 1950s, Emmy Werner found that research on white middle-class children's mental health in the United States did not provide sufficient knowledge about the development of at-risk-children. She then travelled to the island of Kauai in Hawaii where there were many families with children living in poverty and at risk, making it harder for them to survive compared to children growing up in a middle-class family in the city. Werner worked with psychologist Ruth Smith on the island, and their study was based on a cohort of newborns in 1955 (1000 pregnant women were included) to identify families and children who were at risk from birth (Borge 2010). In the prospective follow-up survey 698 children were included and data was collected when the children were born, when they were 2 years, 10 years, 18 years, 32 years and 40 years of age. Results from the study showed that one third of all newborns fell within the criteria for at-risk-children (Borge 2010). Risk factors included birth defects or other health problems that doctors believed would affect their condition, disorganized family environment, and considerable instability in the family, as well as neglect (Borge 2010). Results from the study showed that despite the fact that the majority of the at-risk-children developed learning disabilities, behavioural problems and mental disorders as 10 and 18 years old, one third of these at-risk-children became well-functioning, happy and caring people at 18, 32 and 40 years (Borge 2010). There were many risk factors (e.g. mental illness of parents) and resilience factors both in the child (e.g. independent, good quality communication skills) and in the environment (e.g. good relationship with siblings) that influenced the child's development. This happened from birth and was decisive for the children's adaptation and adult life (Borge 2010).

3.2 Other studies on resilience

Resilience has gained greater attention in research, and according to Hjemdal (2007) during the last decade there has been an increase of 85 % in publications that involve resilience factors and protective factors. Moreover, this greater attention in research on resilience is due to the ability to identify essential protective factors, and mechanisms that prevent the development of mental disorders such as depression, despite having been exposed to significant life stressors (Hjemdal 2007). Hjemdal (2007) therefore define resilience as *“protective factors, processes and mechanisms that contribute to a good outcome despite the experiences of stressors that have been proved to involve significant risk for the development of psychopathology”*. This definition corresponds well with a number of other definitions. In a recently published Nordic

study on long-term stress in Swedish and Icelandic parents' adaptation to childhood cancer (Gudmundsdottir et al. 2010) is resilience defined as “*the absence of severe stress*” or “*the capacity to resist the negative psychological reactions when one is suffering from risk-experience*”.

In other studies (Brody & Simmons 2007; McCubbin, Balling, Possin, Friedrich & Bryne 2002), resilience has been described in the context of family functioning and not just between parents, therefore the term “family resiliency”. These studies revealed that family members’ reaction to stress factors are not only as individuals, but also as part of an interactive network (Brody & Simmons 2007; McCubbin et al. 2002; Barbarin, Hughes & Chesler 1985). Family resiliency is achieved through the family's ability to bond in difficult times of stress and crisis and to receive support and encouragement from each other (Patterson 1995 in Brody & Simmons 2007). In addition the parents’ coping strategy is associated with higher marital quality in childhood cancer (McCubbin et al. 2002). Resilience research has also studied the difference between mother and fathers’ coping strategies as well as their experiences. In the early study of Barbarin et al. (1985) results show that mothers and fathers' different experiences towards having a child with cancer can lead to problems related to marriages, relationships and partnerships. The wife's perception of support from her husband can be often related to his involvement in the care of the child. In contrast, the man's view on the support of his wife can be associated with her availability in the home as opposed to the hospital. Furthermore, the study shows that support from the spouse is the most important social support (Barbarin et al. 1985). Therefore, it would appear that if both parents are able to cope with the stress factor in a positive way, the sick child will also most probably function well. This is due to the importance of family and parental interaction. Many studies have shown that attachment and family functioning is fundamental in the child’s adjustment and development (Carlson & Sroufe 1995; Sroufe & Waters 1977; Cicchetti 1990; Maccoby 1980; Waters, Vaughn, Posada & Kondo-Ikemura 1995 in Masten & Shaffer 2006). The same applies in relation to the parents’ coping and adaptation (Frank, Blount & Brown 1997).

One study illustrated that the level of hopelessness in children was positively correlated with concern by both parents and negatively associated with family adaptation (Blotcky, Roczynski, Gurwitch & Smith 1985). Similar results were found by Sanger, Copeland & Davidson (1991) where children with cancer having parents who succeeded in maintaining family integration and had an optimistic outlook on the disease, had fewer psychological difficulties. Another study on paediatric cancer research showed significant associations between parent and child distress where children having parents who were distressed, were

more likely themselves to be distressed (Robinson et al. 2007). Parent-child relationships are also considered as key regulator of children's behaviour through actions such as comfort, care or safety maintenance (Masten & Shaffer 2006). It would appear that parents and family interaction are of great importance for how the child copes with the disease and its treatment. It should also be mentioned that previous research and studies have suggested that further studies need to pay more attention to the fathers' experiences since their participation in cancer studies have been minimal, and lack of information about fathers' needs and desires make it difficult for health professionals to offer appropriate help (Brody & Simmons 2007).

3.3 “Dandelion children”

As a result of the history of resilience research, a Norwegian term has derived to describe children who are able to go through a difficult childhood and function well in their adult life (Borge 2010); *Dandelion children* (“Løvetannbarn”) refers to children that can adapt to a variety of environments and function well, despite a difficult starting point in childhood. Just as the dandelions' ability to burst itself through pavement, and survive and flourish despite seemingly impossible growing conditions. More scientifically, the dandelion children are at-risk-children who use their special abilities in their environment. For example, children growing up in families with severe alcohol abuse take responsibility for household chores (do the grocery, cleaning and cooking) and take care of siblings. The children can get acknowledgement and praise from the community, even though the neighbourhood can be worried about their childhood (Borge 2010).

The protective characteristics varied because resilience is obtained through a unique interaction between the child's individual qualities and the qualities of environment. These qualities contribute to the child improving its situation over time, and the child can therefore be called a “dandelion child” (Borge 2010). In Norway, this term is particular related to one group of at-risk-children, children in child care protection that show good development. At-risk-children can also be children with varied childhood-environment, such as children growing up in disharmonic families, in institutions or in strained city-environment. In addition, resilience is associated with children that are exposed to more specific individual risks, such as children with cancer or severe behavioural problems (Borge 2010).

Another resilience related term is *coping* (Norwegian: ”mestre”). Coping is also a popular term, but it is not synonymous with resilience. Coping is based on learning to a greater extent compared to resilience (Borge 2010). Oxford American Dictionary defines coping as: “to manage successfully” and the definition therefore excludes the importance of being at-risk

which was mentioned earlier. It is not necessary to be exposed to risk to demonstrate coping, and everyone can get better in coping in their daily life and problems (Borge 2010). Resilience on the contrary, is insoluble related to risks. Another key difference between coping and resilience is that one can cope in a bad, neutral and negative way, while resilience concerns positive coping. For example, children learn different forms of coping in kindergarten and at school, related to daily challenges (Borge 2010). Resilience cannot be learned in the same way because it develops during interaction in the real life, with a proper amount of real risk and the child's individuality (Borge 2010). In this thesis, the focus is on parental resilience; the parents' resistance to such a critical and stressful situation as having a child with a life threatening illness.

3.4 Issues related to resilience

It is necessary to give a brief overview of a number of issues related to resilience before using it in this study. The issues concern the use of the term resilience and terms related to resilience, what underlying risk factors, the discussion about assumptions regarding "high" and "low" risks, as well as resilience research on children versus adults.

The first issue concerns the difference between "resilience" and "resiliency", when to use what? When referring to the process or phenomenon of competence despite adversity, Luthar, Cicchetti & Becker (2000) stated that the term "resilience" should always be used. In contrary, the term "resiliency" is only used when referring to a specific personality trait. Moreover, the terms "protective" and "vulnerability" should be used when describing the overall effects of adversity.

The second issue to be addressed concerns what really underlies risk factors. It is known that risk factors tend to coexist (Rutter 1987; Sameroff, Gutman & Peck 2003), but how do we know which factor is of high risk? In this study, the aim is to assess and identify resilience factors among parents with children surviving leukaemia; social resources are seen as a protective factor, but what is it about social resources that may promote resilience? Is it the feeling of support or security, or is it the feeling of not being alone? The issue can also be related to children and their coping strategy towards a cancer diagnosis. Their coping strategy and adaption is affected by not only one factor, but several factors, such as they have divorced parents, living in a disharmonic family or having other health problems.

The third issue concerns the assumptions regarding "high" risk and "low" risk, what defines a risk condition? An example concerning children in relation to socioeconomic status can demonstrate the issue about assumptions about what a risk condition is (Luthar, Sawyer &

Brown 2007). Commonly, youth in urban poverty are seen as being at high risk, but evidence shows that those on the opposite side of the socioeconomic latter can demonstrate as much disturbance or more (Luthar et al. 2007). Based on data gathered a decade ago, affluent, suburban youth reported significantly higher levels of substance (cigarette, alcohol and marijuana) use compared to their seriously poor counterparts (Luthar & D'Avanzo 1999). Compared to normative samples, suburban youth also have higher levels, and recent replicated findings have been shown (Luthar 2003; Luthar & Goldstein 2006 in Luthar et al. 2007). This example indicates that researchers need to be careful when it comes to make assumptions about certain demographic groups being at "low" risk.

The fourth and last issue to be addressed is regarding conceptual differences in research on resilience in children versus adults. In making assessments on children, it is normally based on reports from their parents, teachers and classmates; whether they acquire good grades, get along with peers, and are generally well behaved. In the contrary, research on adults focus on how they feel; assessments are based on self-reporting and subjective well-being and happiness etc. (Luthar et al 2007). Few, if any studies on adult resilience have defined doing well in terms of others giving rates, and for some reason, it is not common for researches to ask children about their subjective well-being and happiness (Luthar et al. 2007). This can be related to the measuring scales for resilience; the Resilience Scale for adults (RSA) and the Resilience Scale for Parents (READ-P) where parents in the RSA report for themselves, while in the READ-P parents report for their children. In future resilience research, it will be important to take into account both the subjectively perceived and proxy reported well-being in order to define and explore resilient adaption.

3.5 The concept of resilience in this study

In this study, the concept of the term resilience mainly refers to success in face of adversity; parents experience the adversity of their child being life-threatening sick with leukaemia, and still manage to live their life well. Parents who manage to function well are often dependent on the protective factors, such as social support, a meaningful employment, and the ability to structure and organize both their daily life and future plans. All these protective factors are considered to contribute to a positive outcome. In this case the positive outcome is positive parental coping, which can result in high resilience, despite major life stressors involving significant risks for the development of mental health problems.

4. References

- Barbarin, O. A., Hughes, D. & Chesler, M. A. (1985). Stress, Coping, and Marital Functioning Among Parents of Children with Cancer. *Journal of Marriage and the Family*, 47 (2), 473-480.
- Blotcky, A. D., Roczynski, J. M., Gurwitch, R. & Smith, K. (1985). Family influences on hopelessness among children in the cancer experience. *Journal of Pediatric Psychology*, 10, 479-493.
- Borge, A. I. H. (2010). *Resiliens. Risiko og sunn utvikling*. Oslo: Gyldendal Akademisk
- Brenner & Salovey (1997). Emotion regulation during childhood. Developmental, interpersonal and individual considerations. In Salovey, P. & Sluyter, D. J. (Eds), *Emotional development and emotional intelligence* (pp. 168-192). New York: Basic Books.
- Bringager, H., Hellebostad, M. & Sæter, R. (2005). *Barn med kreft. En medisinsk og sykepleiefaglig utfordring*. Oslo: Gyldendal Akademisk.
- Brody, A. C. & Simmons, L. A. (2007). Family Resiliency During Childhood Cancer: The Father's Perspective. *Journal of Pediatric Oncology Nursing*, 24, 152-165.
- Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.
- Drotar, D. (1997). Relating parent and family functioning to the psychological adjustment of children with chronic health conditions: What have we learned? What do we need to know? *J Pediatr Psychol*, 22 (2), 149-165.
- Dyregrov, A., Matthiesen, S. B., Kristoffersen, J. I. & Mitchell, J. T. (1994). Gender differences in adolescent's reactions to the murder of their teacher. *Journal of Adolescents Research*, 9, 363-383.

- Eiser, C. (2001). Cancer. In Koot, H. M. & Wallander, J. L. (Eds), *Quality of life in child and adolescent illness, concepts, methods and findings* (pp. 267-295). New York: Brunner-Routledge.
- Frank, N. C., Blount, R. L. & Brown, R. T (1997) Attributions, Coping, And Adjustment in Children with Cancer. *Journal of Pediatric Psychology*, 22 (4), 563-576.
- Garnezy, N. (1974). The study of competence in children at risk for severe psychopathology. *In The Child in His Family, Vol. 3: Children at Psychiatric Risk*, ed. by R.J. Anthony, 77–98.
- Gannoni, A. F. & Shute, R. H. (2009) Parental and child perspectives on adaption to childhood chronic illness: A qualitative study. *Clinical Child Psychology and Psychiatry*, 15 (1), 39-53.
- Gatta G., Capocaccia R., De Angelis R., Stiller, C., Coebergh, J. W., & the EURO CARE Working Group (2003). Cancer survival in European adolescents and young adults. *European Journal of Cancer*, 39: 2006-2610.
- Goldbeck, L. (2001). Parental coping with the diagnosis of childhood cancer: Gender effects, dissimilarity within couples, and quality of life. *Psycho-Oncology*, 10, 325-335.
- Gortmaker, S. L., Walker, D. K., Weitzman, M. & Sobol, A. M. (1990). Chronic conditions, socioeconomic risks, and behavioural problems in children and adolescents. *Paediatrics*, 85, 267-276.
- Gudmundsdottir, E., Schirren, M., Boman, K. K. (2010). Psychological resilience and long-term distress in Swedish and Icelandic parents' adjustment to childhood cancer. *Acta Oncologica*, 1-8.
- Hammen, C., Brennan, P. A. & Shih, J. H. (2004). Family discord and stress predictors of depression and other disorders in adolescent children or depressed and non-depressed women. *Journal of the American Academy of Child and Adolescent Psychiatry*, 43, 994-1002.

- Hjemdal, O. (2007). The Protective Factors: The Development of Two Resilience Scales in Norway. *Child Adolesc Psychiatric Clin N Am*, 16, 303-321.
- Howard, S., Dryden, J. & Johnson, B. (1999). Childhood Resilience: review and critique of literature. *Oxford Review of Education*, 25 (3), 302-323.
- Janus, M. & Goldberg, S. (1997). Factors influencing family participation in a longitudinal study; Comparison of pediatric and healthy samples. *J Pediatr Psychol*, 22 (2), 245-262.
- Kazak, A. E., Rourke, M. T. & Crump, T. A. (2003). Families and other systems in pediatric psychology. In Robers, M. C. (Ed), *Handbook of pediatric psychology* (pp. 159-175). New York, NY: The Guilford Press.
- Kreftregisteret (2008). Institutt for populasjonsbasert kreftforskning. Årsrapport for 2008.
- Kupst, M. J. & Schulman, J. L. (1988). Long-term coping with pediatric leukemia. *Journal of Pediatric Psychology*, 13, 7-22.
- Last, B. F., Grootenhuis, M. A., Eiser, C. (2005). International comparisons of contributions to psychosocial research on survivors of childhood cancer: Past and future considerations. *J Pediatr Psychol*, 30, 99-113.
- Lazarus, R. S. (1966). *Psychological stress and the coping process*. New York: McGraw-Hill.
- Lingua (2002). Engelsk-norsk, norsk-engelsk skoleordbok. Oslo: Kunnskapsforlaget.
- Longman (2001). Longman Dictionary of contemporary English. Essex: Pearson Education Limited.
- Luthar, S.S. & D'Avanzo, D. (1999). Contextual factors in substance use: a study of suburban and inner-city adolescents. *Dev. Psychopathol.* 11: 845-867.

- Luthar, S. S. & Cicchetti, D. (2000). The construct of resilience: implications for interventions and social policies. *Dev Psychopathol* 12, 857-885.
- Luthar, S. S., Sawyer, J. A. & Brown, P. J. (2007). Conceptual Issues in Studies of Resilience. Past, Present and Future Research. *Annals of the New York Academy of Sciences*, 1094, 105-115.
- Masten, A., Best, K. & Garmezy, N. (1990). Resilience and development: contributions from the study of children who overcome adversity. *Development and Psychopathology*, 2, pp 425-444.
- Masten, A. S. & Shaffer, A. (2006). *How Families Matter in Child Development: Reflections from Research on Risk and Resilience*. New York: Cambridge University Press.
- Mathisen, I. S. (2004) in Reitan, A. M. & Schjølberg, T. K. (eds). *Kreftsykepleie: Pasient – Utfordring – Handling*. Oslo: Akribes Forlag AS.
- Maurice-Stam, H., Oort, F. J., Last, B. F. & Grootenhuis, M. A. (2008). Emotional functioning of parents of children with cancer: the first five years of continuous remission after the end of treatment. *Psycho-Oncology*, 17, 448-459.
- McCubbin, M., Balling, K., Possin, P., Friedrich, S. & Bryne, B. (2002). Family Resiliency in Childhood Cancer. *Family Relations*, 51 (2), 103-111.
- McGrath, P. (2001). Identifying support issues of parents of children with leukaemia. *Cancer Practice*, 9 (4), 198-205.
- Mulhern, R. K., Fairclough, D. L., Smith, B. & Douglas, S. M. (1992). Maternal Depression, Assessment Methods and Psychological Symptoms Affect Estimates of Depressive Symptomatology among Children with Cancer. *J Pediatr Psychol*, 17 (3), 313-326.
- NHI (2007) "De fleste barn med kreft blir friske", Norsk helseinformatikk. Retrieved 15/09/2010 from <http://nhi.no/foreldre-og-barn/barn/sykdommer/intervju-om-barn-og-kreft-26617.html>

- NHI (2006) “Akutt lymfatisk leukemi”, Norsk helseinformatikk. Retrieved 15/09/2010 from <http://nhi.no/foreldre-og-barn/barn/sykdommer/akutt-lymfatisk-leukemi-1054.html>
- NHI (2011) “Leukemi hos barn”, Norsk helseinformatikk. Retrieved 15/09/2010 from <http://nhi.no/foreldre-og-barn/barn/sykdommer/barneleukemi-2865.html>
- Patterson, J. M. (1995). Promoting resilience in families experiencing stress. *Pediatric Clinics of North America*, 42 (1), 47-63.
- Reinfjell, T. (2007). *Children with acute lymphoblastic leukaemia: A study of health-related quality of life, mental health and intellectual aspects*. Doctoral thesis, NTNU, 2007:189.
- Reinfjell, T., Diseth, T. H. & Vikan, A. (2007) Barn og kreft: Barns tilpasning til og forståelse av alvorlig sykdom. *Tidsskrift for norsk psykologiforening*, 44, 724-734.
- Reitan, A. M. & Schjølberg, T. K. (eds). *Kreftsykepleie: Pasient – Utfordring – Handling*. Oslo: Akribe Forlag AS.
- Robinson, K. E., Gerhardt, C. A. Vannatta, K. & Noll, R. B. (2007). Parent and Family Factors Associated with Child Adjustment to Pediatric Cancer. *Journal of Pediatric Psychology*, 32 (4), 400-410.
- Rutter, M. (1985). Resilience in the face of adversity. Protective factors and resistance to psychiatric disorder. *Br J Psychiatry*, 147: 598-611.
- Rutter, M. (1987). Psychosocial resilience and protective mechanisms. *Am. J. Orthopsychiat*, 57: 316–331.
- Rutter, M. (2000). Resilience reconsidered: conceptual considerations, empirical findings, and policy implications. In: Shonkoff, J. P. (Ed) & Meisels, S. J. (Ed). *Handbook of early childhood intervention* (2nd ed.) (pp. 651-682). New York, US: Cambridge University Press

- Sameroff, A., Gutman, L. J. & Peck, S. C. (2003). Adaptation among youth facing multiple risks: prospective research findings. In *Resilience and Vulnerability: Adaptation in the Context of Childhood Adversities*, Luthar, S. S (Ed) (pp 364–391). New York, US: Cambridge
- Sanger, M. S., Copeland, D. R. & Davidson, E. R. (1991). Psychological adjustment among pediatric cancer patients: A multidimensional assessment. *Journal of Pediatric Psychology*, 21, 380-387..
- SNL (2011). ”Barnekreft”, Store norske leksikon. Retrieved 17/06/2011 from http://snl.no/sml_artikkel/barnekreft.
- Thompson, R. J. & Gustafson, K. E. (1996). Adaptation to chronic childhood illness. Washington, DC: American Psychological Association.
- Trask, P. C., Paterson, A. G., Trask, C. L., Bares, C. B., Birt, J. & Maan, C. (2003). Parent and Adolescent Adjustment to Pediatric Cancer: Associations with Coping, Social Support, and Family Function. *Journal of Pediatric Oncology Nursing*, 20 (1), 36-47.
- Van Dongen-Melman, J. E. W. M., Pruyn, J. F. A., Van Zanen, G. E. & Sanders-Woudstra, J. A. R. (1986). Coping with childhood cancer: A conceptual view. *Journal of Psychosocial Oncology*, 4, 147-161.
- Varni, J. W., Katz, E. R., Colegrove, R. & Dolgin, M. (1993). The impact of social skills training on the adjustment of children with newly diagnosed cancer. *Journal of Pediatric Psychology*, 18, 751-768.
- Varni, J. W. & Katz, E. R. (1997) Stress, social support and negative affectivity in children with newly diagnosed cancer: A prospective transactional analysis. *Psychooncology*, 6 (4), 267-278.
- von Essen, L., Enskår, K., Kreuger, A., Larsson, B. & Sjøden, P. O. (2000) Self-esteem, depression and anxiety among Swedish children and adolescents on and off treatment. *Acta Paediatr*, 89, 229-236.

Wallander, J. L. & Thompson, J. R. J (1995). Psychosocial adjustment of children with chronic psychical conditions. In M. C. Roberts (Ed), *Handbook of pediatric psychology* (2nd ed.) (pp. 124-141). New York: Guilford.

Zebrack, B. J. & Chesler, M. (2001) Health-related worries, self-image, and life outlooks of longterm survivors of childhood cancer. *Health Soc Work*, 26 (4), 245-256.

Part II: Parental resilience and mental health in relation to children surviving acute lymphoblastic leukaemia (ALL).

Abstract

Aim: The main aim of this study is to describe and explore resilience factors among parents (mothers and fathers) of children surviving acute lymphoblastic leukaemia (ALL) compared to parents of healthy children. As well as exploring the relationship between parental resilience and mental health.

Methods: A cross-sectional study of the parents of children surviving ALL, and healthy controls. Parental resilience and mental health were assessed by the Resilience Scale for Adults (RSA) and the General Health Questionnaire (GHQ-30).

Results: Both mothers and fathers of children surviving ALL showed significantly better resilience regarding future planning and structuring compared to parents of healthy children. The results also indicate a weak correlation between parental resilience, such as family cohesion and mental health. The strongest correlations were between “GHQ coping” and “resilience family cohesion” ($r = -.524, p < 0.01$) for mothers, and “GHQ depression” and “resilience family cohesion” ($r = -.624, p < 0.01$) for fathers.

Conclusion: Both mothers and fathers of children surviving ALL showed an equal level of resilience compared to healthy controls. The relationship between parental resilience and mental health is fairly weak. The results indicate the need to keep supporting parents with children surviving ALL regarding the aim to maintain their resilience level.

Keywords: childhood cancer, parents, resilience, mental health

1. Introduction

Cancer is still the most frequent cause of death by disease for children between the age of 1 and 15 in the western world (NHI 2007). Leukaemia accounts for about 1/3 of all incidences, and the majority are acute lymphoblastic leukaemia (ALL) Bringager, Hellebostad & Sæter 2005; NHI 2007). Over the last decades survival rates of children treated for leukaemia have increased dramatically, from approximately 20 % in the 1960s to about 80 % today. This is a result of new treatments that use chemotherapy, radiation and surgery in combination. The progress in medical treatment has changed focus toward the illness' impact on the psychosocial situation of the child and the family during and after treatment (Last, Grootenhuis, Eiser 2005).

Treatment for ALL last up to 2 – 2,5 years (Gatta, Capocaccia, De Angelis, Stiller, Coeberg & the EURO CARE Working Group 2003), and therefore it is most likely that the whole family will be affected in some way by the illness. Previous studies have mainly focused on psychopathology symptoms while investigating the parents' reaction to the child's cancer, and rarely focused on a resource-oriented perspective (Gudmundsdottir, Schirra & Boman 2010). At the same time the concept of psychological resilience, which concerns individuals' abilities during adversities and risks, has received greater attention during the last decades (Hjemdal 2007). Resilience deals with resources or factors that reinforce each individual's ability to cope with crisis and adapt to stress better than others. In this context, it is the parents' resistance to the critical and stressful situation of having a child with a life threatening illness.

Parental functioning is one of the strongest contributors to adjustment in children with chronic health conditions (Drotar 1997), and interaction between the child and their parent is regarded as fundamental for the child's development and adaptation (Masten & Shaffer 2006). Studies have shown that emotional distress among parents of children with cancer remained heightened in the beginning, but were reduced to normal levels during the first two years after treatment (Maurice-Stam, Oort, Last & Grootenhuis 2008). However, results from longitudinal studies show that despite the fact that many parents adapt well to the child's cancer diagnosis, there is still a significant number of parents who struggle with mental fatigue, anxiety and symptoms of post traumatic stress after treatment of the child's cancer illness (Maurice-Stam et al. 2008). There may therefore be a reason to believe that parents' coping style can affect the child's adapting and development.

1.2 Aims

The main aim of this study is to describe and explore resilience factors among parents (mothers and fathers) of children surviving ALL compared to parents of healthy children. The secondary aim is to explore the relationship between resilience and mental health.

1.3 Hypotheses

The aims are specified by the following study hypotheses: For parents of children surviving cancer compared to healthy controls, based on previous research it is expected to find:

- 1) Weaker resilience in parents of children surviving ALL compared to parents of healthy children.
- 2) Parents with strong resilience will have a good mental health.

2. Methodology

2.1 Study design

This study is based on a cross-sectional design. The information needed to register treatment related factors was gathered retrospectively from the medical records at the two participating university hospitals: Norwegian Radium Hospital, Oslo and St. Olav's University Hospital, Trondheim.

2.2 Participants

The sample in this study consisted of 40 children in remission from ALL between 8 to 15 years of age, and their parents. The study was conducted in 2003 – 2006. Children who had a decline in disease symptoms were recruited from the Norwegian Radium Hospital in Oslo and St. Olav's University Hospital in Trondheim. The children were born between 1989 and 1995, and had a mean age of 11.8 years, and participated in the study from 4.2 to 12.5 years after being diagnosed with ALL. Children who had relapsed or had other forms of serious medical condition (e.g. Down's syndrome) were excluded. The mean age when ALL was diagnosed was 4.0 years (range 0 – 7.6), and the mean time since diagnosis was 7.9 years (range 4.2 – 12.5). Information about the parents came from 36 mothers with a mean age of 40.0 (range 30 – 55), and 21 fathers with the mean age of 43.0 (range 32 – 58).

The parents of children surviving ALL were compared to a group of parents of healthy children. The children's control group was recruited from two elementary schools and two junior high schools from both urban and rural areas in the middle part of Norway, and had similar age and gender distributions (n=42). Children with a psychiatric diagnosis or other specific and relevant medical problems (e.g. cognitive dysfunction) were excluded. Informed consent was obtained from all of the children, adolescents and their parents (Appendix 3 and 4)

2.3 Procedures

The available data on resilience that has been collected during the doctoral study "Children with Acute lymphoblastic leukaemia: A study of health-related quality of life, mental health and intellectual aspect" (Reinfjell 2007) were used, as well as data on mental health (Reinfjell 2007; Reinfjell, Lofstad, Nordahl, Vikan & Diseth 2009).

All assessments of both children surviving ALL and their parents were carried out at the hospitals in Trondheim and Oslo. Leaders of the Paediatric departments of Norwegian Radium Hospital in Oslo and St. Olav's University Hospital in Trondheim were contacted, and permission was given to contact the patients whose names were taken from their patient pool. Written information about the project and consensus formulas for parents and older children were sent to the parents of 56 survivors by ordinary mail. They were contacted by phone for further information. After informed consent was received from the families, appointments for the interview were made by phone, which was often planned to coincide with their follow-up appointment at the hospital. Parents were interviewed separately by a psychologist who used a modified version of the standardized, semi-structured form "Parental Account of Children's Symptoms" (PACS). PACS included questions that were relevant for a psychological assessment of children, and was useful to record socio-demographic factors. The interview also had questions which directly referred to the parents' experiences and concerns regarding their child and his/her siblings, as well as aspects of development from birth to early childhood before the diagnosis of ALL, emotional and practical aspects of treatment procedures, medical follow-up, family climate, accessibility and type of social support and parents' own experiences of the possibility of after-effects of ALL-treatment. Parents also filled out the questionnaires "The Resilience Scales for Adults" (RSA) and "The General Health Questionnaire" (GHQ-30) for information about their own quality of life and mental health. More information about the RSA and GHQ-30 is given in the next section.

Concerning the control group, the educational sections of two municipal districts were contacted in order to discuss the demographics of different schools, and for permission to contact school principals in their county. Written informed consent was given by the sections before four school headmasters were contacted and their informed consent was given. Based on age and gender matches, two headmasters in the city of Trondheim were instructed to make a sample by drawing lots. Another group from the rural county of North-Trøndelag was matched along the lines of gender and age in the nearest age in month. When necessary or when several children matched the age-group, lots were drawn. The different principals sent written information and consent forms to the families, and they also contacted the families by phone to inform them about the project. The assessments with each child were carried out individually at school after informed consent was given by the parents and adolescents. Each child/adolescent received an envelope after the assessments, which contained a questionnaire for their parents. Parents were asked to return the completed questionnaire in a pre-stamped envelope, and they were able to contact the researchers to obtain further information.

2.4 Measures

2.4.1 Instruments

To measure resilience among parents of children surviving leukaemia and parents of healthy children a questionnaire called “Resilience Scale for Adults” (RSA) was used (Appendix 1). The RSA consists of 33 items indicating intrapersonal and interpersonal protective factors presumed to facilitate adaption to psychosocial adversities (Friborg Hjemdal, Rosenvinge, Martinussen 2003). It consists of six factors: positive perception of self (6 items), positive perception of future (4 items), social competence (6 items), structured style (4 items), family cohesion (6 items), and social resources (7 items). The scale uses a semantic differential response format in which each item had positive and negative adjectives to the right for every second item, to reduce acquiescence response biases, as shown in figure 1.

Fig. 1 An excerpt from the RSA

1. When something unexpected happens	I often feel confused	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	I always find a solution
2. My plans for the future are	hard to achieve	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	achievable
5. In my family, the understanding of what is important	is quite different	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	is similar

The short version of the General Health Questionnaire (GHQ-30) was included to assess parents' mental health (Appendix 2). The GHQ is the most commonly used questionnaire to study distress, psychopathology and quality of life in adults, and it includes both positive and negative questions (Goldberg & Williams 1988). The short version, GHQ-30, contains 30 items covering symptoms that may reveal distress, psychopathology and well-being. All items have a 4-point scale scoring system that ranges from a "better/healthier than normal" option, through a "same as usual" and a "worse/more than usual" option. The exact wording will depend upon the particular nature of the item, and that the higher the score, the more severe the condition. In addition, GHQ-30 avoids using physical symptoms as an indication of fatigue.

2.4.2 Analyses

T-test for independent samples was used to analyse the differences in resilience among parents of children surviving cancer and parents of healthy children. Pearson's correlation analysis was used to assess the strength in the relationship between parents' resilience and mental health. PASW Statistics 18 for Windows was used for all the analyses, and in general a p-value of 5 % or less was considered as statistically significant.

2.4.3 Missing data

The final sample included 71.4 % of those eligible. There were more girls (n=13) than boys (n=3) among the 16 families that did not participate. The reasons for non-participation were that the parents were too busy or distressed that they were not willing to participate, not wanting to "relive" previous experiences of illness and hospitalization was also something they did not want to, and practical reasons such as geographical distance were also an issue.

2.5 Ethics

This study uses existing data that has already been approved by the Regional Committees for Medical Research Ethics (REK). The approval was granted June 28th 2002, reference number: 092-02. This study was approved by REK April 1st 2011, reference number: 2011/546 (Appendix 5). Written information about the study was sent by mail to the children and their parents. Informed written content was obtained from the parents of participating children at the age ≥ 12 . Non-responses to the letter were followed up by telephone, and a written reminder was sent when the family could not be reached by phone.

3. Results

Parental and sociodemographic characteristics of the sample are presented in table 1. There were no significant group differences between parents of children surviving cancer and parents in the control group regarding education and economical status, as well as urban and rural living. The resilience scores for mothers and fathers of children surviving ALL and healthy controls are presented in table 2. The only significant differences was found for the category “planned future” among mothers ($p < 0.01$). Mothers of ALL children had a higher score compared to mothers of healthy children, indicating a better resilience. No such differences were found for the other scales regarding mothers. Among fathers we found more significant differences in the following categories: “perception of self” ($p < 0.05$), “social resources” ($p < 0.05$) and “structured style” ($p < 0.05$). Results on mental health are previous presented in the doctoral study by Reinfjell (2007). Pearson’s correlation was used in the analyses of the relationship between resilience and mental health among mothers and fathers (Table 3 and 4).

Table 1: Parental and sociodemographic characteristics for parents of children with ALL and parents with healthy children (control group)

	ALL (n = 40)	Healthy (n = 42)	t score	p-value
Age, median (range)				
Mother	40 (30-55)	40 (31-52)	-.25	.81
Father	43.0 (32-58)	43.5 (34-73)	-.09	.93
Family composition, n (%)				
Both parents	31 (77)	29 (70)	-.75	.46
Single parents	9 (23)	13 (30)		
Education in years, mean (range)				
Mother	14.0 (10-19)	13.0 (9-19)	.07	.95
Father	14.0 (10-20)	13.0 (10-19)	.84	.40
Community, n (%)				
Urban	15 (37)	18 (43)	.69	.49
Rural	25 (63)	24 (57)		
Home, n (%)				
Own house	36 (90)	39 (93)	.72	.48
Own apartment	3 (8)	3 (7)		
Renting apartment	1 (2)	0 (0)		
Economy, n (%)				
Very satisfying	27 (67)	21 (50)	-.04	.96
Good	8 (20)	21 (50)		
Poor	5 (13)	0 (0)		

Table 2: Resiliens among parents of children with ALL, and healthy controls

	ALL			Healthy				
Mother	n	Mean	SD	n	Mean	SD	Difference	p-value
Total score	35	4,08	0,25	38	4,08	0,21	-.00	.409
Perception of self	36	4,29	0,55	36	4,45	0,49	-.16	.532
Planned future	32	4,01	0,54	37	3,89	0,28	.12	.006
Social competence	35	3,88	0,62	38	3,87	0,37	.00	.210
Family cohesion	34	4,97	0,77	38	5,35	0,65	-.38	.375
Social resources	36	3,65	0,53	38	3,50	0,33	.15	.144
Structured style	33	3,49	0,76	33	3,09	0,72	.40	.733
Father								
Total score	20	4,10	0,25	25	4,13	0,18	-.02	.111
Perception of self	20	4,53	0,62	24	4,47	0,41	.06	.049
Planned future	19	4,02	0,60	24	3,98	0,42	.03	.355
Social competence	19	3,84	0,29	25	3,93	0,34	-.08	.216
Family cohesion	19	4,94	0,64	24	5,27	0,59	-.32	.490
Social resources	20	3,60	0,51	25	3,68	0,33	-.07	.041
Structured style	17	3,58	0,81	22	2,98	0,51	.59	.015

Table 3: Correlation between mental health (GHQ) and resilience among mothers

MOTHER	GHQ anxiety	GHQ coping	GHQ depression	GHQ social	GHQ well-being	Resilience total score	Resilience perception of self	Resilience planned future	Resilience social competence	Resilience family cohesion	Resilience social resources	Resilience structured style
GHQ anxiety	-											
GHQ coping	.918**	-										
GHQ depression	.820**	.866**	-									
GHQ social	.738**	.855**	.741**	-								
GHQ well-being	.466**	.424*	.540**	.268	-							
Resilience total score	-.148	-.276	-.117	-.275	.269	-						
Resilience perception of self	-.163	-.220	-.154	-.157	.141	.602**	-					
Resilience planned future	.345	.287	.207	.169	.319	-.040	-.218	-				
Resilience social competence	-.070	-.172	-.016	-.154	.234	.585**	.109	.402*	-			
Resilience family cohesion	-.464**	-.524**	-.445*	-.401*	-.336	.400*	.265	-.178	.108	-		
Resilience social resources	.042	.003	.053	-.170	.230	.595**	.478**	-.406*	.128	-.182	-	
Resilience structured style	.262	.283	.372*	.306	.266	.127	-.265	-.192	-.200	-.368*	-.417*	-

** Correlation is significant at the 0,01 level (2-tailed)

* Correlation is significant at the 0,05 level (2-tailed)

Table 4: Correlation between mental health (GHQ) and resilience among fathers

FATHER	GHQ anxiety	GHQ coping	GHQ depression	GHQ social	GHQ well-being	Resilience total score	Resilience perception of self	Resilience planned future	Resilience social competence	Resilience family cohesion	Resilience social resources	Resilience structured style
GHQ anxiety	-											
GHQ coping	.577*	-										
GHQ depression	.606**	.622*	-									
GHQ social	.371	.679**	.310	-								
GHQ well-being	.251	.589*	.115	.593**	-							
Resilience total score	-.237	-.216	-.234	-.445*	-.485*	-						
Resilience perception of self	-.125	-.387	-.496*	-.308*	-.314	.765**	-					
Resilience planned future	-.055	-.030	.128	-.297	-.451	.615**	.391	-				
Resilience social competence	.020	.181	.390	-.207	-.529*	.535*	.158	.577*	-			
Resilience family cohesion	-.388	-.376	-.624**	-.446	-.323	.671**	.595**	.210	-.061	-		
Resilience social resources	-.028	-.013	-.155	.065	.036	.325	.188	-.095	-.036	-.129	-	
Resilience structured style	.106	.373	.584*	.099	.055	-.417	-.671**	-.154	.275	-.442	-.598*	-

** Correlation is significant at the 0,01 level (2-tailed)

* Correlation is significant at the 0,05 level (2-tailed)

4. Discussion

This study presents descriptive data regarding resilience and mental health in parents of children surviving ALL and parents of healthy children. The results indicate that parents of children surviving ALL and parents of healthy children are equal in resilience. Also, the results show no significant group differences between parents of children surviving ALL and parents in the control group regarding education and economical status, as well as urban and rural living. As presented in the study of Reinfjell et al. (2009) fathers of children surviving ALL showed significantly more anxiety and depression compared to fathers of healthy children, while no such differences were found for mothers. Furthermore, the correlation between resilience and mental health among parents are not as strong as expected.

Resilience

The results regarding resilience (Table 2) reveal that mothers of children surviving cancer and mothers of healthy children are comparable in resilience. Only one significant difference was found, in the category “planned future” ($p < 0.01$). Mothers with sick children appeared to be better at planning their future than mothers with healthy children, something which might be explained by the fact that treatment for acute lymphoblastic leukaemia (without sign of setback) last up to 2-3 years (NHI 2011). As a result, mothers are used to coordinating the everyday life with a child surviving leukaemia; meeting health professionals, treatment sessions, work, school, spare time activities and other everyday chores. Many activities have to be done at the same time, something which requires a great deal of coordinating. Furthermore, the same tendency is seen for the rest of the categories except “perception of self”, but these are not significant differences. The fathers’ resilience results showed more significant differences, for the following categories: “perception of self”, “social resources” and “structured style”, all at the level $p < 0.05$. Fathers of ALL children seem to have a better perception of themselves and structured style compared to fathers of healthy children.

Mental health

Results from Reinfjell et al. (2009) showed that fathers of children surviving ALL had more symptoms related to mental health, with significant differences for the categories “depression” and “anxiety”. For mothers there were no significant differences. According to Eiser, Eiser & Stride (2005) fathers tend to remain more involved in the everyday life despite the child’s

illness. Staying at home or at work during the treatment period of the child may prevent fathers from getting adequate help for their emotional needs. This may result in later adjustment problems.

Resilience and mental health

The results of the correlation analyses indicate that there are several significant correlations between mental health and resilience for all mothers, even though all of the correlations are rather weak to moderate. There are four significant correlations: “GHQ anxiety” and “resilience family cohesion” ($r = -.464, p < 0.01$), “GHQ coping” and “resilience family cohesion” ($r = -.524, p < 0.01$), “GHQ depression” and “resilience family cohesion” ($r = -.445, p < 0.05$) and “GHQ social” and “resilience family cohesion” ($r = -.401, p < 0.05$). Note that all four significant correlations are related to family cohesion. Among fathers there are more varieties in significant categories compared to mothers, but similar to mothers most of the correlations are weak to moderate. There are seven significant correlations, for the following categories: “GHQ depression” and “resilience perception of self” ($r = -.496, p < 0.05$), “GHQ depression” and “resilience family cohesion” ($r = -.624, p < 0.01$), “GHQ depression” and “resilience structured style” ($r = .584, p < 0.05$), “GHQ social” and “resilience total score” ($r = -.445, p < 0.05$), “GHQ social” and “resilience perception of self” ($r = -.308, p < 0.05$), “GHQ well-being” and “resilience total score” ($r = -.485, p < 0.05$) and “GHQ well-being” and “resilience social competence” ($r = -.529, p < 0.05$).

Previous research show that it is normal that the levels of anxiety and depression are elevated in caregivers when they're caring for a cancer patient in a palliative setting (Higginson, Wade & McCarthy 1990; Given, Stommel, Given, Osuch, Kurtz & Kurtz 1993; Payne, Smith & Dean 1999; Grunfeld, Coyle, Whelan, Clinch, Reyno, Earle et al. 2004; Grov, Dahl, Moum & Fosså 2005). Cancer is a crisis which can be characterized by insecurity, fear and anxiety related to worries concerning the fear of a potential relapse after end treatment. One also struggles to be a part of the civilized society again after prolonged stays at the hospital. Related to this study, it is the parents who are the ones that have to return to the normal daily life, and fathers struggle the most. This might be an explanation for why some parents still experience anxiety and depression, despite a good family cohesion. In this case, it is the fathers that showed more symptoms for depression and anxiety.

Another possible reason involves a family cohesion that is too close, and therefore might not act as a protective factor (Hjemdal 2011). A family cohesion that is too close can involve parents and family members overcompensating or being overprotective towards one

another. E.g. mothers can be overprotective towards their sick child or his/hers siblings (afraid that the siblings will be diagnosed with cancer as well), and fathers can be more supportive towards their wife more than they usually are, both to the extent of what is (expected to be) normal. It is common to take care of each other during adversities, but parents might feel a pressure to behave in a certain way or give a certain amount of support, so that the attempt to establish a close family cohesion becomes too eagerly, and strike out wrong. This, in addition to their life situation forms a possible third variable explaining the correlation results. The ALL parents are in a special situation, not only do they have to deal with cancer, but they also have to live with their child having the life-threatening disease up to several years. This unique circumstance might have lead to a family cohesion that is too closed, something which may have affected the results.

The present findings regarding resilience and mental health among parents with ALL children suggest that most mothers and fathers with a child surviving leukaemia have a relatively good resilience. Compared to healthy control parents, parents with a child surviving leukaemia appear to be able to manage their life well. Mothers of children surviving cancer are better to plan their future compared to mothers in the control group, the results are also similar for fathers in regards to structuring and organizing compared to fathers in the healthy group. As mentioned earlier, parents of children surviving leukaemia may have become resilient in certain ways, such as when it comes to future planning and everyday structuring because of their experience of having a child with cancer. Another cause to explain the ALL parents' good resilience (compared to healthy controls) may be their socioeconomic background. Most parents had a higher education, a good economy and are quite satisfied with their work situation. All of this has been proved to be protective factors in situations involving a child being life-threatening sick; e.g. parents are better able to deal with their child's illness when they are supported by their workplaces (McCubbin Balling, Possin, Frierdich & Bryne 2002). Moreover, a study from 2007 showed that a number of demographic variables appear to be protective factors related to strengthening resilience (Bonnano, Galea Bucciarelli & Vlahov 2007).

In general, research show that family cohesion is normally a positive thing (Cooper, Holman & Braithwaite 1983; Farrell, Barnes & Banerjee 1995; Lucia & Breslau 2006; Franko, Thompson, Bauserman, Affenito, Striegel-Moore 2008), but this is not the case in the present study. Protective factors, such as social support, professional help and family cohesion, are not necessarily a positive factor in all situations (Hjemdal 2011). Mothers and fathers cope in different ways with different factors. For instance, research on family cohesion related to

childhood cancer demonstrates that fathers tend to be more positive compared to mothers concerning their marital relationship (Katz 2002). At the same time fathers are often expected to provide emotional support to their wives in difficult times (Katz 2002), they may have to bring their children to medical procedures that are too difficult for mothers to cope with (McGrath 2001). Fathers also see the marriage as their primary source of support compared to mothers who tend to have more sources of support outside their marriage, such as extended family, community and workplace (Dahlquist, Czywevski & Jones 1996). Other differences between parents are for instance that fathers are better able to keep their focus on the task at hand, while mothers often experience mental and emotional strains of the child's cancer in all aspects of their life (Reay, Bignold, Ball & Cribb 1998). Another difference in parental coping is related to gender-acceptance; many fathers suppress or do not want to reveal their emotions because they're afraid it will be seen as a sign of weakness. Additionally, fathers' emotions may be just as strong as the mothers, but they often struggle to find a gender-accepted way of expressing themselves (Brody & Simmons 2007). Or they might express their psychological problems in less noticeable ways (Silver, Westbook & Stein 1998).

These factors, as well as the fact that fathers' perspective is something which may have been overlooked compared to mothers (Brody & Simmons 2007), support the importance of including more fathers in future research. How fathers react and manage the child's cancer is particularly essential for professionals and health care. In order to help fathers manage the situation while trying to improve their resilience, it is necessary for researchers, doctors and other health professionals to have knowledge of what is important.

4.1 Limitations of the study

A high percentage of parents in the present study have higher education, and the majority is quite satisfied with their economy and work. This might have had an influence on our findings, since earlier research shows that certain sociodemographic characteristics function as protective factors. It might be interesting to carry out a similar study with samples consisting of parents with different sociodemographic background, e.g. lower education or poor income.

The study was based on a cross-sectional design, which means that it was done in one moment in time, and only suitable to present at-the-moment-picture, and cannot be used to make conclusions about processes that develop over a period of time (Ringdal 2007). It means that the present study with a cross-sectional design cannot determine causal relations, and implies that the results should be treated with some caution. A longitudinal design might have

been a better choice, in order to describe and explain stability and changes because it is based on repeated measurements of a case over time (Ringdal 2007).

Another limitation concerns proxy-report. In this study, the parents' resilience were assessed by the RSA, which is based on their own subjective evaluation. Including proxy-report may result differently, and give the researchers another perspective regarding parental resilience.

The findings based on 21 fathers of ALL patients who participated in the present study should be treated with caution. However, the results may indicate the need to pay special attention to the mental health and adjustment of fathers during the time of the child's treatment, as well as the rehabilitation phase. The fact that only 21 fathers participated indicates a common problem in clinical research, and the importance that more fathers should be included in future research (Brody & Simmons 2007). Means in recruiting fathers in future research need to be established and implemented.

Finally, the present study was carried out a relatively long time after diagnosis (mean=7.9 years, range=4.2-12.5), findings may therefore not apply to newly diagnosed parents. In the future, studies may benefit studying resilience-related determinants at an early age.

4.2 Implications for practice and research

Issues related to gender-acceptance are important to take into consideration. In particular, this concerns the fathers who have expressed that they find it hard to find an appropriate way to express their emotions. At the same time, fathers appear to be underrepresented in paediatric research samples, something future practice and research can take into consideration.

The importance of similarity in parents' coping style is understandable; however, the importance of dissimilarity may also be essential. A great deal of previous research has focused on how to maintain parental coping and adaption style, similar (Frank, Blount & Brown 1997; Goldbeck 2001; McCubbin Balling, Possin, Friedrich & Bryne 2002). Parental dissimilarity in information seeking is correlated with a decrease in the child's quality of life (Goldbeck 2001), while symmetry between parents' coping style is associated with higher marital quality in childhood cancer (Hoekstra-Weebers et al. 1998 in McCubbin et al. 2002). Every individual reacts differently to different factors, an example in the present study are the results for family cohesion, where family cohesion did not function as a positive factor. Therefore it is beneficial to gain more knowledge about parental dissimilarity in coping. A huge challenge within resilience research is to find out why factors that are protective in one context are not

necessarily in another. Further implications for research and practice, in particular psychosocial interventions, need to support dissimilarity when it appears adaptive, and help parents overcome the differences that affect their child in a negative way.

This presents several challenges for health care systems: how to keep focus on providing appropriate care for mothers and fathers of ALL children, as well as providing an after treatment follow up programs or check-ups for parents. This study shows that problems can be seen several years after diagnosis and treatment, and demonstrates the need for detecting and addressing potential late effects related to mental health among parents in future research. Along with researchers and health care professionals, other parents in the same situation will also gain from new information about protective factors and other factors that might lead to or strengthening individuals' resiliency and mental health.

5. Conclusion

Our main findings in the present study are that parents of children surviving leukaemia have in general an average level of resilience. Regarding mental health, fathers show more mental health symptoms. Fathers struggle with depression and anxiety, while mothers show no such symptoms. Despite showing symptoms for depression and anxiety, fathers are still capable of being structured and having social competence in the daily life. The same goes for mothers who manage future planning well. As a result, the first hypothesis which stated that parents of ALL children had weaker resilience, as well as the second hypothesis about the relationship between high resilience and good mental health can be rejected.

The course of childhood cancer is not predictable for either children or parents. Some children respond rapidly to treatment, and have a relatively smooth course, while others go through a tough time and experience more difficulties. Parents' physical and mental health also fluctuates during the active cancer period. The child and the parents affect each other by their adaption and coping style. Besides researchers and health care professionals, other parents and family members in the same situation, will also gain from new knowledge about protective factors and other factors that might lead to or strengthening ones' resiliency and mental health.

6. References

- Bonnano, G. A., Galea, S. & Bucchiarelli, A. & Vlahov, D. (2007). What Predicts Psychological Resilience After Disaster? The Role of Demographics, Resources, and Life Stress. *Journal of Consulting and Clinical Psychology, 75* (5), 671-682
- Bringager, H., Hellebostad, M. & Sæter, R. (2005). *Barn med kreft. En medisinsk og sykepleiefaglig utfordring*. Oslo: Gyldendal Akademisk.
- Brody, A. C. & Simmons, L. A. (2007). Family Resiliency During Childhood Cancer: The Father's Perspective. *Journal of Pediatric Oncology Nursing, 24*, 152-165.
- Cooper, J. E., Holman, J. & Braithwaite, V. A. (1983). Self-Esteem and Family Cohesion: The Child's Perspective and Adjustment. *Journal of Marriage and Family, 45* (1), 153-159.
- Dahlquist L. M., Czywevski, D. I. & Jones, C. L. (1996). Parents of children with cancer: A longitudinal study of emotional distress, coping style and marital adjustment two and twenty months after diagnosis. *Journal of Pediatric Psychology, 21*, 541-554.
- Drotar, D. (1997). Relating parent and family functioning to the psychological adjustment of children with chronic health conditions: What have we learned? What do we need to know? *J Pediatr Psychol. 22* (2), 49-65.
- Eiser, C., Eiser, R. J. & Stride, C. B. (2005). Quality of life in children newly diagnosed with cancer and their mothers. *Health and Quality of Life Outcomes, 3*: 29.
- Farrell, M. P., Marnes, G. M. & Banerjee, S. (1995). Family Cohesion as a Buffer Against the Effects of Problem-Drinking Fathers on Psychological Distress, Deviant Behavior and Heavy Drinking in Adolescents. *Journal of Health and Social Behaviour, 36* (4), 377-385.
- Frank, N. C., Blount, R. L. & Brown, R. T (1997) Attributions, Coping, And Adjustment in Children with Cancer. *Journal of Pediatric Psychology, 22* (4), 563-576.

- Franko, D. L., Thompson, D., Bauserman, R., Affenito, S. G. & Striefel, R. H. (2008). What's Love Got to Do with It? Family Cohesion and Healthy Eating Behaviours in Adolescent Girls. *Journal of Eating Disorders* 41 (4), 360-367.
- Friborg, O., Hjemdal, O., Rosenvinge, J. H. & Martinussen (2003). A new rating scale for adult resilience: What are the central protective resources behind healthy adjustment? *International Journal of Methods in Psychiatric Research*, 12, 65-76.
- Gatta G., Capocaccia R., De Angelis R., Stiller, C., Coebergh, J. W., & the EUROCORE Working Group (2003). Cancer survival in European adolescents and young adults. *European Journal of Cancer*, 39: 2006-2610.
- Given, C. W., Stommel, M., Given, B., Osuch, J., Kurtz, M. E. & Kurtz, J. C. (1993). The influence of cancer patients' symptoms and functional states on patients' depression and family caregivers' reaction and depression. *Health Psychology*, 12 (4), 277-285.
- Goldbeck, L. (2001). Parental coping with the diagnosis of childhood cancer: Gender effects, dissimilarity within couples, and quality of life. *Psycho-Oncology*, 10, 325-335.
- Goldberg, D. & Williams, P. (1988). A user's guide to the General Health Questionnaire GHQ. NFER-Nelson, Windsor.
- Grov, E. K., Dahl, A. A., Moum, T. & Fosså, S. D. (2005). Anxiety, depression and quality of life in caregivers of patients with cancer in late palliative phase. *Annals of Oncology*, 16 (7), 1185-1191.
- Grov, E. K., Fosså, S. D., Sørebo, Ø. & Dahl, A. A. (2006). Primary caregivers of cancer patients in the palliative phase: A path analysis of variables influencing their burden. *Social Science & Medicine*, 63, 2429-2439.
- Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C. C. et al. (2004). Family caregiver burden: Results of a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal*, 170 (12), 1795-1801.

- Gudmundsdottir, E., Schirren, M., Boman, K. K. (2010). Psychological resilience and long-term distress in Swedish and Icelandic parents' adjustment to childhood cancer. *Acta Oncologica*, 1-8.
- Higginson, I., Wade, A. & McCarthy, M. (1990). Palliative care: Views of patients and their families. *British Medical Journal*, 301 (6746), 277-281.
- Hjemdal, O. (2007). The Protective Factors: The Development of Two Resilience Scales in Norway. *Child Adolesc Psychiatric Clin N Am*, 16, 303-321.
- Hjemdal, O. (2011). Informal meeting, 03/05/2011, Dragvoll NTNU.
- Hoekstra-Weebers, J. Jaspers, J., Kamps, W. & Klip, E. (1998). Marital dissatisfaction, psychological distress and the coping of parents of pediatric cancer patients. *Journal of Marriage and the Family*, 60, 1012-1021.
- Katz, S. (2002). Gender differences in adapting to a child's chronic illness. A causal model. *Journal of Pediatric Nursing*, 17, 257-268.
- Last, B. F., Grootenhuis, M. A. & Eiser, C (2005). International comparisons of contributions to psychosocial research on survivors of childhood cancer: Past and future considerations. *J Pediatr Psychol.*, 30 (1), 99-113.
- Lucia, V. C. & Breslau, N. (2006). Family cohesion and children's behavior problems: A longitudinal investigation. *Psychiatry Research*, 141, 141-149.
- Masten, A. S. & Shaffer, A. (2006). *How Families Matter in Child Development: Reflections from Research on Risk and Resilience*. New York: Cambridge University Press.
- Maurice-Stam, H., Oort, F. J., Last, B. F. & Grootenhuis, M. A. (2008). Emotional functioning of parents of children with cancer: the first five years of continuous remission after the end of treatment. *Psycho-Oncology*, 17, 448-459.

- McCubbin, M., Balling, K., Possin, P., Friedrich, S. & Bryne, B. (2002). Family Resiliency in Childhood Cancer. *Family Relations*, 51 (2), 103-111.
- McGrath, P. (2001). Identifying support issues of parents of children with leukaemia. *Cancer Practice*, 9 (4), 198-205.
- NHI (2010) "De fleste barn med kreft blir friske", Norsk helseinformatikk. Retrieved 15/09/2010 from <http://nhi.no/foreldre-og-barn/barn/sykdommer/intervju-om-barn-og-kreft-26617.html>
- NHI (2011). "Leukemi hos barn", Norsk helseinformatikk. Retrived 15/09/2010 from <http://nhi.no/foreldre-og-barn/barn/sykdommer/barneleukemi-2865.html>
- Payne, S., Smith, P. & Dean, S. (1999). Identifying the concerns of informal carers in palliative care. *Palliative Medicine*, 13 (1), 37-44.
- Reay, D., Bignold, S., Ball, S. J., & Cribb, A. (1998). "He just had a different way of showing it": Gender dynamics in families coping with childhood cancer. *Journal of Gender Studies*, 7 (1), 39-52.
- Reinfjell, T. (2007). *Children with acute lymphoblastic leukaemia: A study of health-related quality of life, mental health and intellectual aspects*. Doctoral thesis, NTNU, 2007:189.
- Reinfjell, T., Lofstad, G. E, Nordahl, H. M, Vikan, A. & Diseth, T. H. (2009). Children in remission from acute lymphoblastic leukaemia: mental health, psychosocial adjustment and parental functioning. *European journal of Cancer Care*, 18, 364-370.
- Ringdal, K. (2007). *Enhet og mangfold*. 2. utgave. Bergen: Fagbokforlaget
- Silver, E. J., Westbrook, L. E., & Stein, R. E. K. (1998). Relationship of parental psychological distress to consequences of chronic health conditions in children. *Journal of Pediatric Psychology*, 23, 5-15.

von Essen, L., Enskår, K., Kreuger, A., Larsson, B. & Sjøden, P. O. (2000) Self-esteem, depression and anxiety among Swedish children and adolescents on and off treatment. *Acta Paediatr*, 89, 229-236.

Zebrack, B. J. & Chesler, M. (2001) Health-related worries, self-image, and life outlooks of longterm survivors of childhood cancer. *Health Soc Work*, 26 (4), 245-256.

Appendices

Appendix 1: The Resilience Scale for Adults

Appendix 2: The General Health Questionnaire

Appendix 3: Information letter for children and adolescents

Appendix 4: Information letter for parents, and informed consent

Appendix 5: Approval letter from REK

Appendix 1: The Resilience Scale for Adults

Resilience skala for voksne

Vennligst angi hvordan du i løpet av den siste måneden har tenkt og følt om deg selv, og om betydningsfulle mennesker omkring deg. Vennligst kryss av i boksen som er nærmest det utsagnet som best beskriver deg.

(Utviklet av Odin Hjemdal & Oddgeir Friborg)

1. Når noe uforutsett skjer	<i>føler jeg meg ofte rådvill</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>finner jeg alltid en løsning</i>
2. Planene mine for fremtiden er	<i>vanskelige å gjennomføre</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>gjennomførbare</i>
3. Jeg trives best	<i>sammen med andre mennesker</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>for meg selv</i>
4. I familien min er forståelsen av hva som er viktig i livet	<i>ganske forskjellig</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>lik</i>
5. Personlige tema kan jeg	<i>ikke ta opp med noen</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>ta opp med venner/familie-medlemmer</i>
6. Jeg fungerer best når jeg	<i>har et mål å strekke meg mot</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>får ta en dag av gangen</i>
7. Mine personlige problemer	<i>vet jeg hvordan jeg kan løse</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>finner jeg ingen løsning på</i>
8. Jeg føler at fremtiden min	<i>ser lovende ut</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>er usikker</i>
9. Å kunne være fleksibel i sosiale sammenhenger	<i>er jeg mindre opptatt av</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>er viktig for meg</i>
10. Jeg trives	<i>svært godt i familien min</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>dårlig i familien min</i>
11. De som er flinke til å oppmuntre meg	<i>er noen nære venner/familie-medlemmer</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>finnes ikke</i>
12. Når jeg skal gjøre noe	<i>planlegger jeg sjelden og hopper bare i det</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>foretrekker jeg å ha en plan</i>
13. Mine vurderinger og avgjørelser	<i>tviler jeg ofte på</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>stoler jeg fullt ut på</i>
14. Målene mine	<i>vet jeg hvordan jeg skal nå</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>er jeg usikker på hvordan jeg skal nå</i>
15. Nye vennskap	<i>knytter jeg lett</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>har jeg vansker med å knytte</i>
16. Familien min preges av	<i>splittelser</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>godt samhold</i>
17. Samholdet mellom vennene mine	<i>er dårlig</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>er godt</i>

18. Jeg er flink til å	<i>organisere tiden min</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>rote bort tiden min</i>
19. Troen på meg selv	<i>får meg gjennom vanskelige perioder</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>hjelper meg lite i vanskelige perioder</i>
20. Målene mine for fremtiden er	<i>uklare</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>godt gjennomtenkte</i>
21. Å komme i kontakt med nye folk	<i>er vanskelig for meg</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>er jeg flink til</i>
22. I vanskelige perioder	<i>beholder familien min et positivt syn på fremtiden</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>ser familien min mørkt på fremtiden</i>
23. Når noen familiemedlemmer kommer i en krise	<i>får jeg raskt beskjed</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>får jeg sent beskjed</i>
24. Regler og faste rutiner	<i>mangler i hverdagen min</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>er en del av hverdagen min</i>
25. I motgang har jeg en tendens til	<i>å se mørkt på tingene</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>finne noe bra jeg kan vokse på</i>
26. Når jeg er sammen med andre	<i>sitter latteren min løst</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>sitter latteren langt inne</i>
27. Overfor andre mennesker, er vi i vår familie	<i>lite støttende overfor hverandre</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>lojale overfor hverandre</i>
28. Jeg får støtte fra	<i>venner/familiemedlemmer</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>ingen</i>
29. Hendelser i livet som jeg vanskelig kan gjøre noe med	<i>klarer jeg å innfinne meg med</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>er en stadig kilde til bekymring</i>
30. Å komme på gode samtaleemner synes jeg er	<i>vanskelig</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>enkelt</i>
31. I familien min liker vi å	<i>finne på fellesaktiviteter</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>gjøre ting hver for oss</i>
32. Når det trengs, har jeg	<i>aldri noen som kan hjelpe meg</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>alltid noen som kan hjelpe meg</i>
33. Mine nære venner/familiemedlemmer	<i>verdsetter egenskapene mine</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<i>misliker egenskapene mine</i>

Appendix 2: The General Health Questionnaire

*FORESATTES NAVN: _____ Dato: ___/___/19__

Vi vil gjerne vite hvordan din helse har vært de siste 2 ukene.

Vær vennlig å besvare alle spørsmålene ved å streke under det svaret du vurderer som den beste beskrivelsen av deg selv.

Husk at vi ønsker å vite om de eventuelle besvær du har nå eller har hatt gjennom de siste par ukene før innleggelsen/ denne undersøkelsen.

Det er viktig at du besvarer alle spørsmålene.

Har du i løpet av de siste par ukene:

1. Vært i stand til å konsentrere deg (fullt ut) om alt du har gjort?	Bedre enn vanlig	Samme som vanlig	Mindre enn vanlig	Mye mindre enn vanlig
2. Ligget våken på grunn av bekymringer?	Ikke i det hele tatt	Ikke mer enn vanlig	Heller mer enn vanlig	Mye mer enn vanlig
3. Hatt lett for å våkne etter at du har sovnet?	Ikke i det hele tatt	Ikke mer enn vanlig	Heller mer enn vanlig	Mye mer enn vanlig
4. Vært i stand til å holde deg selv engasjert og i virksomhet?	Bedre enn vanlig	Samme som vanlig	Mindre enn vanlig	Mye mindre enn vanlig
5. Vært ute blant andre så mye som du pleier?	Mer enn vanlig	Samme som vanlig	Mindre enn vanlig	Mye mindre enn vanlig
6. Klart deg like bra som folk flest i samme situasjon?	Bedre enn de fleste	Omtrent som vanlig	Heller mindre enn vanlig	Mye mindre enn vanlig
7. Føler du at du i det store og hele greier deg bra?	Bedre enn vanlig	Omtrent som vanlig	Mindre bra enn vanlig	Mye mindre bra
8. Vært fornøyd med den måten du fungerer på?	Mer fornøyd	Omtrent som vanlig	Mindre enn vanlig	Mye mindre fornøyd
9. Vært i stand til å føle varme og hengivenhet for dine nærmeste?	Bedre enn vanlig	Samme som vanlig	Mindre enn vanlig	Mye mindre enn vanlig
10. Funnet det lett å komme ut av det det med andre mennesker?	Bedre enn vanlig	Omtrent som vanlig	Mindre bra enn vanlig	Mye mindre enn vanlig
11. Brukt mye tid på å hygge deg med andre?	Mer tid enn vanlig	Omtrent som vanlig	Mindre enn vanlig	Mye mindre enn vanlig
12. Følt at du tar del i ting på en nyttig måte?	Mer enn vanlig	Som vanlig	Mindre enn vanlig	Mye mindre brukbart

1/GH01

13. Følt at du er i stand til å ta bestemmelser?	Mer enn vanlig	Som vanlig	Mindre enn vanlig	Mye mindre enn vanlig
14. Følt deg stadig under press?	Ikke i det hele tatt	Ikke mer enn vanlig	Heller mer enn vanlig	Mye mer enn vanlig
15. Følt deg ute av stand til å mestre dine vanskeligheter?	Ikke i det hele tatt	Ikke mer enn vanlig	Heller mer enn vanlig	Mye mer enn vanlig
16. Følt livet som en kamp hele tiden?	Ikke i det hele tatt	Ikke mer enn vanlig	Heller mer enn vanlig	Mye mer enn vanlig
17. Vært i stand til å glede deg over dine daglige gjøremål?	Mer enn vanlig	Samme som vanlig	Mindre enn vanlig	Mye mindre enn vanlig
18. Tatt tingene tungt?	Ikke i det hele tatt	Ikke mer enn vanlig	Heller mer enn vanlig	Mye mer enn vanlig
19. Blitt engstelig eller panisk uten grunn?	Ikke i det hele tatt	Ikke mer enn vanlig	Heller mer enn vanlig	Mye mer enn vanlig
20. Vært i stand til å møte dine problemer?	Mer enn vanlig	Samme som vanlig	Mindre enn vanlig	Mye mindre enn vanlig
21. Synes at alt vokser over hodet på deg?	Ikke i det hele tatt	Ikke mer enn vanlig	Heller mer enn vanlig	Mye mer enn vanlig
22. Følt deg ulykkelig og nedtrykt (deprimert)?	Ikke i det hele tatt	Ikke mer enn vanlig	Heller mer enn vanlig	Mye mer enn vanlig
23. Mistet selvtilliten?	Ikke i det hele tatt	Ikke mer enn vanlig	Heller mer enn vanlig	Mye mer enn vanlig
24. Tenkt på deg selv som en verdiløs person?	Ikke i det hele tatt	Ikke mer enn vanlig	Heller mer enn vanlig	Mye mer enn vanlig
25. Følt at livet er helt håpløst?	Ikke i det hele tatt	Ikke mer enn vanlig	Heller mer enn vanlig	Mye mer enn vanlig
26. Sett lyst på din framtid?	Bedre enn vanlig	Omtrent som vanlig	Mindre enn vanlig	Mye mindre enn vanlig
27. Stort sett følt deg tilfreds, alt tatt i betraktning?	Mer enn vanlig	Som vanlig	Heller mindre enn vanlig	Mye mindre enn vanlig
28. Stadig følt deg nervøs og anspent/ oppjaget?	Ikke i det hele tatt	Ikke mer enn vanlig	Heller mer enn vanlig	Mye mer enn vanlig
29. Følt at livet ikke er verdt å leve?	Ikke i det hele tatt	Ikke mer enn vanlig	Heller mer enn vanlig	Mye mer enn vanlig
30. Følt at du til tider ikke var i stand til å gjøre det minste fordi nervene dine var i ulage?	Ikke i det hele tatt	Ikke mer enn vanlig	Heller mer enn vanlig	Mye mer enn vanlig

1/GHQ2

NTNU
Norges teknisk-naturvitenskapelige
universitet

Fakultet for samfunnsvitenskap
og teknologiledelse
Psykologiske poliklinikker



Til barn og ungdom som fikk diagnosen Akutt Lymfatisk Leukemi (ALL) i tidsperioden 1992 – 1999 ved Rikshospitalet og St. Olavs hospital.

Vi ønsker å komme i kontakt med deg som fikk sykdommen ALL for minst fire år siden.

Psykolog Trude Reinfjell og spesialist i klinisk nevropsykologi G. Elisabeth Lofstad ved Psykologisk institutt, NTNU (Trondheim) gjennomfører studien:

”Livskvalitet hos barn og ungdom med Akutt Lymfatisk Leukemi; En oppfølgingsstudie av psykososiale, kognitive og nevropsykologiske aspekter etter avsluttet behandling”.

Studien gjennomføres i samarbeid med Barneklippene v/ Rikshospitalet og St. Olavs Hospital. Studien er vurdert og akseptert av Regional komite for medisinsk forskningsetikk, Midt-Norge og godkjent av datatilsynet.

Vi er opptatt av hvordan det å ha hatt en alvorlig sykdom som kreft virket inn på hverdagen din. Noen barn og ungdommer opplever at de blir fort trøtte og slitne. De kan derfor ha vansker med å konsentrere seg og kan føle seg uopplagt i skole, jobb og sosiale sammenhenger. Dette er noe vi ønsker å undersøke nærmere og få mer kunnskap om.

Hvorfor vil vi vite noe om dette?

Hvis vi får vite mer om hvordan barn og ungdom med kreft har det, så vil det sette oss bedre i stand til å hjelpe de som har fått vansker etter at de er ferdigbehandlet. Samtidig vil vi bli i stand til å hjelpe nye barn som er under behandling, og best mulig prøve å hindre at de nye pasientene får samme vansker. Det blir lettere å hjelpe, når vi vet litt om hva som kan være vanskelig for deg og hva som faktisk hjelper.

Hva innebærer din deltakelse?

For å finne ut hva dere tenker om dette, vil vi be hver av dere og foreldrene deres om å svare på spørsmål og be dere utføre noen psykologiske og nevropsykologiske tester. Dette for å få bedre forståelse for de vanskene som noen barn har fortalt om etter at de er ferdigbehandlet. Det er spørsmål om hvordan du har det, hvordan det er med familie, skole og venner, om det er noe som hjelper deg i din situasjon og om det er noe som er vanskelig for deg.

Vi vil spørre deg og foreldrene dine om å være med på en del undersøkelser. Om du deltar i denne undersøkelsen eller ikke, har ingen betydning for den vanlige oppfølging og behandling ved sykehuset.

Postadresse
Postboks 1826
N-7440 Trondheim

Besøksadresse
H. Magnussons gt. 1a

Telefon 73 59 74 06/07
Telefaks 73 59 76 94
Org.nr. 974 767 880

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Vi har taushetsplikt og alle svarene blir brukt anonymt. Det betyr at ingen andre får vite hva akkurat du svarer på spørsmålene vi stiller. Snakk med foreldrene dine og les også brevet som foreldrene dine har fått hvis du har flere spørsmål om undersøkelsen.

Ring gjerne Trude Reinfjell på tlf. 73 59 78 91 dersom dere har spørsmål om undersøkelsen. Dersom det er vanskelig å nå meg på 73 59 78 91 direkte, så ring 73 59 19 60 og legg beskjed i ekspedisjonen på Psykologisk institutt, NTNU, så ringer jeg tilbake. Hvis noen har spørsmål om de nevropsykologiske testene kan dere ringe G. Elisabeth Lofstad på 73590992. Vi takker på forhånd for hjelpen!

Vi takker på forhånd for hjelpen!

Vennlig hilsen

Trude Reinfjell
Psykolog
Psykologisk institutt, NTNU

Elisabeth Lofstad
Spesialist i klinisk nevropsykologi
Psykologisk institutt, NTNU

NTNU
Norges teknisk-naturvitenskapelige
universitet

Fakultet for samfunnsvitenskap
og teknologiledelse
Psykologisk institutt



Til

foreldre til barn og ungdom som fikk diagnosen Akutt Lymfatisk Leukemi (ALL) i tidsperioden 1992 – 1999 ved Rikshospitalet og St. Olavs Hospital, og hvor barnet var i alderen 1 – 10 år.

Psykolog/stipendiat Trude Reinjfjell og spesialist i klinisk nevropsykologi G. Elisabeth Lofstad (daglig leder v/ nevropsykologisk poliklinikk), begge ansatt ved Psykologisk institutt, NTNU (Trondheim) gjennomfører studien:

”Livskvalitet hos barn og ungdom med Akutt Lymfatisk Leukemi; En oppfølgingsstudie av psykososiale, kognitive og nevropsykologiske aspekter etter avsluttet behandling”.

Studien gjennomføres i samarbeid med leger fra Barneklinikkene v/ St. Olavs Hospital i Trondheim og Rikshospitalet i Oslo. Studien er vurdert og akseptert av Regional komite for medisinsk forskningsetikk, Midt-Norge og godkjent av datatilsynet.

Diagnosen kreft hos barn og ungdom gir mange og nye utfordringer for hele familien, både når det gjelder en intens medisinsk behandling, etterfulgte bivirkninger og alle de praktiske forandringene i hverdagen. Dette kan for de fleste familier gi økt stress og følelsesmessige bekymringer. Store medisinske fremskritt har bidratt til at prognosen for kreft hos barn har bedret seg radikalt i løpet av de siste ti årene, mens det fremdeles foreligger liten kunnskap om barnas og foreldrenes sosiale og psykologiske situasjon etter avsluttet behandling.

Formålet med planlagte undersøkelser er å studere effekter en kreftsykdom og behandling kan ha på barn og ungdoms livssituasjon over tid. Har det å leve med en kreftsykdom noen innvirkning på barnas og ungdommenes psykososiale og nevropsykologiske utvikling og tilpasning etter avsluttet behandling. Dette kan videre gi bedre grunnlag for vurdering og behandling av barnas totale situasjon og dermed styrke muligheten til å forebygge eventuelle vansker for barn og ungdom med kreft.

Med denne undersøkelsen er vi spesielt opptatt av følgende spørsmål:

- Hvordan reagerer barn og ungdom i ulike aldre på fysiske og psykiske påkjenninger som en kreftsykdom kan gi? Dette er viktig for å kunne vite om noen barn er spesielt sårbare i forhold til utvikling av eventuelle tilpasningsvansker. Samtidig ønsker vi også kunnskap om hva som kjennetegner barn som viser god mestring og tilpasning i forhold til sykdommen ALL.
- Er det spesielle livssituasjoner som gjør at en er mer sårbar? Gjennom å vite noe om dette, blir man mer oppmerksom på barn, ungdom og familier som kan trenge ekstra hjelp og støtte i forbindelse med undersøkelser og oppfølginger i både sykehus og i hjemmemiljøet.
- Hvordan opplever dere som foreldre og barna selv sin nåværende fungering i barnehage, skole og jobb? Kunnskap om dette kan bidra til økt bevissthet om behov for støtte og hjelp hos barn og ungdom ferdigbehandlet for kreft. Studiet gir også mulighet til å se barnas psykososiale og nevropsykologiske fungering i sammenheng med faktorer relatert til behandling.

Postadresse
N-7491 Trondheim

Besøksadresse
H. Magnussons gt. 1b

Telefon +47 73 59 19 60
Telefaks +47 73 59 19 20
Org. nr. 974 767 880

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Kreftsykdom hos barn vil påvirke hele familiens livssituasjon, det blir derfor betydningsfullt å kunne undersøke situasjon og behov også for foreldre til barn og ungdom med kreft. Foreldrenes erfaringer og opplevelser vil være av stor betydning for undersøkelsen, og en nødvendig kunnskap for å kunne forstå hvordan barna har det.

Hva innebærer deres deltakelse?

Deres deltakelse vil innebære at vi gjennom intervju og spørreskjemaer ber dere om å beskrive barnas fungering ut fra slik som dere opplever det. Intervjuet har spørsmål om barnas og familiens sykehistorie og om sosial og følelsesmessig tilpasning. I tillegg er det viktig at dere kan gi litt informasjon om egen helse, både fysisk og psykisk, samt praktiske forhold. Vi ønsker informasjon om dette ut fra at det er viktig å ivareta den helhetlige situasjonen, mange faktorer vil påvirke hvordan man lever med og tilpasser seg alvorlig sykdom.

Vi vil snakke med barn/ungdom og foreldre dels sammen og dels hver for seg. Gjennom samtale og psykologiske spørreskjemaer vil vi undersøke barnas psykososiale og kognitive fungering. Det vil også bli utført en bredere nevropsykologisk testing for å utrede barnas fungering mht blant annet konsentrasjon, problemløsning og generell mestring. Opplysninger om sykehistorie og behandling for den enkelte vil også innhentes fra medisinsk journal.

Praktiske opplysninger:

Undersøkelsene vil foregå i forbindelse med barnets medisinske kontroll ved Rikshospitalet og St.Olavs hospital. Den psykososiale og nevropsykologiske undersøkelsen vil fordeles over to dager. I Trondheim vil den nevropsykologiske utredningen foregå ved Nevropsykologisk poliklinikk, Psykologisk institutt, NTNU.

Deltagelse er frivillig, og dere som deltar kan velge å trekke dere på et hvilket som helst tidspunkt uten å oppgi grunn. Hvorvidt dere deltar i denne studien eller ikke, har ingen betydning for den vanlige oppfølging og behandling ved sykehuset.

Vi ber alle om skriftlig svar på samtykkeerklæringen og at denne returneres så snart som mulig i vedlagte frankerte konvolutt som returneres direkte til undertegnede innen en uke.

For dere som samtykker i deltagelse, vil Trude Reinfjell og G. Elisabeth Lofstad ta kontakt for nærmere avtaler.

All informasjon behandles fortrolig.

Intervjuet, spørreskjemaene og testdataene blir underlagt taushetsplikt og arkivert i eget arkiv. Under behandlingen av disse opplysningene vil de kun bli identifisert med et kodenummer og dataene vil behandles konfidensielt. Hvis det blir avdekket psykososiale problemer som barna, ungdommene eller foreldrene ønsker hjelp med, vil vi være behjelpelig med henvisning til relevant instans. For de foresatte som ønsker det kan vi gi tilbakemeldinger om resultater fra undersøkelsen for deres barn.

Dere kan ringe Trude Reinfjell dersom dere har spørsmål om undersøkelsen. Dersom det er vanskelig å nå meg på 73 59 78 91 direkte, så ring 73 59 19 60 og legg beskjed i ekspedisjonen på Psykologisk institutt, NTNU, så ringer jeg tilbake. Hvis noen har spørsmål om de nevropsykologiske testene kan dere ringe G. Elisabeth Lofstad på 73 59 09 92.

Vi takker på forhånd for hjelpen!

Vennlig hilsen

Trude Reinfjell
Stipendiat
Psykologisk institutt, NTNU

Elisabeth Lofstad
Spes. i klinisk nevropsykologi
Psykologisk institutt, NTNU



**SAMTYKKEERKLÆRING FRA BARN/UNGDOM/FORELDRE VED INNSAMLING OG BRUK AV
PERSONOPPLYSNINGER TIL FORSKNINGSFORMÅL.**

Prosjektittel:

**Livskvalitet hos barn og ungdom med Akutt Lymfatisk Leukemi; En oppfølgingsstudie av
psykososiale, kognitive og nevropsykologiske aspekter etter avsluttet behandling.**

Prosjektleder: Psykolog Trude Reinfjell

Prosjektansvarlige:

Spes.i klinisk nevropsykologi G.Elisabeth Lofstad

Psykolog Trude Reinfjell

Vi har lest det tilsendte informasjonsbrevet vedrørende undersøkelse av effekter en kreftsykdom kan ha for barn og ungdoms livssituasjon over tid.

Vi/jeg er også kjent med at deltagelse i prosjektet er frivillig, og at jeg når som helst kan be om å få slettet mitt navn og identifikasjonsnummer fra undersøkelsen. Dette gjelder også etter at prosjektet er avsluttet.

Denne samtykkeerklæringen fylles ut og sendes psykolog og stipendiat Trude Reinfjell, Psykologisk institutt, NTNU, i egen vedlagt svarkonvolutt innen 10 dager.

Vi/ jeg samtykker i at mitt barn kan delta i undersøkelsen

Sted Dato Underskrift av foreldre/foresatte

Appendix 5: Approval letter from REK

Fra: Regional komite for medisinsk og helsefaglig forskningsetikk REK midt

Til:
Trude Reinfiell
trude.reinfiell@stolav.no

Dokumentreferanse: 2011/546-5
Dokumentdato: 01.04.2011

RESILIENS (MOTSTANDSDYKTIGHET) HOS FORELDRE TIL BARN MED KREFT
INFORMASJON OM VEDTAK



Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK midt	Siv Tone Natland	73598916	01.04.2011	2011/546
			Deres dato:	Deres referanse:
			22.02.2011	

Vår referanse må oppgis ved alle henvendelser

Trude Reinfiell
BUP poliklinikk

2011/546 Resiliens (motstandsdyktighet) hos foreldre til barn med kreft

Prosjektomtale (revidert av REK):

I Norge får ca 130 barn under 15 år en kreftdiagnose hvert år, hvorav 1/3 er leukemi. Behandlingen av akutt lymfatisk leukemi varer opptil 2-2,5 år. Fra før av kjenner vi mye til de negative aspektene ved opplevelsen av kreft, som stress og angst, men det finnes fremdeles lite kunnskaper om de positive aspektene, det vil si de beskyttende faktorene. Formålet med studien er å studere resiliens (motstandsdyktighet) hos foreldre til barn med ALL, sammenlignet med foreldre til friske barn. Det er et kvantitativt forskningsprosjekt som skal bruke spørreskjema-data som allerede er samlet inn fra foreldre til 40 barn med leukemi. Foreldre til friske barn brukes som kontroller. Samtykke for alle deltakere foreligger fra hovedprosjektet, som ble godkjent av REK i 2002. Studien inngår i en masteroppgave.

Forskningsetisk vurdering

Med hjemmel i lov om behandling av etikk og redelighet i forskning § 4 og helseforskningsloven (hfl.) § 10 har Regional komite for medisinsk og helsefaglig forskningsetikk Midt-Norge vurdert prosjektet i sitt møte 18. mars 2011. Komiteen viser til prosjektprotokoll, målsetting og plan for gjennomføring, og finner at prosjektet har et forsvarlig opplegg som kan gjennomføres under henvisning til evt. merknader og vilkår for godkjenning, jf. hfl. § 5.

Merknader og vilkår:

Komiteen har ingen merknader til prosjektet som er beskrevet, og finner at det ligger innenfor det samtykke som deltakerne har gitt til bruk av dette materialet.

Komiteen vil presisere at prosjektmedarbeiderne har taushetsplikt i henhold til hfl. § 7. Personopplysninger skal behandles konfidensielt, og undersøkelsesresultater inkludert evt. navnelister, oppbevares forskriftsmessig.

Komiteen ber om at grunnlagsdata ikke blir anonymisert, slettet eller destruert, men blir oppbevart på en betryggende måte i minimum 5 år etter prosjektslutt av kontrollensyn.

Prosjektleder skal sende sluttmelding til den regionale komiteen for medisinsk og helsefaglig forskningsetikk når forskningsprosjektet avsluttes. I sluttmeldingen skal resultatene presenteres på en

objektiv og etterrettelig måte, som sikrer at både positive og negative funn fremgår, jf. hfl. § 12.

Vedtak

"Regional komité for medisinsk og helsefaglig forskningsetikk, Midt-Norge godkjenner at prosjektet gjennomføres med de vilkår som er gitt."

Vedtaket kan påklages og klagefristen er tre uker fra mottagelsen av dette brev, jf. hfl. § 10 og fvl. §§ 28 og 29. Klageinstans er Den nasjonale forskningsetiske komité for medisin og helsefag (NEM), men en eventuell klage skal rettes til REK Midt-Norge. Avgjørelsen i NEM er endelig. Det følger av fvl. § 18 at en part har rett til å gjøre seg kjent med sakens dokumenter, med mindre annet følger av de unntak loven oppstiller i §§ 18 og 19.

Vi ber om at alle henvendelser sendes inn via vår saksportal: <http://helseforskning.etikkom.no> eller på e-post til: post@helseforskning.etikkom.no.

Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen,

Sven Erik Gisvold
Professor dr.med.
Leder REK Midt

Siv Tone Natland
Rådgiver

Kopi til: Leif.Edward.Kennair@svt.ntnu.no

Besøksadresse:
Det medisinske fakultet Medisinsk teknisk
forskningscenter 7489 Trondheim

Telefon: 73598916
E-post: rek-4@medisin.ntnu.no
Web: <http://helseforskning.etikkom.no/>

All post og e-post som inngår i saksbehandlingen,
bes adressert til REK midt og ikke til enkelte
personer Kindly address all mail and e-mails to the
Regional Ethics Committee, REK midt, not to
individual staff