To promote health in children with experience of cancer treatment

Eva-Lena Einberg
“Sit there and have a snack... look at the birds that come flying ...then it is the view from the hut”

One child treated for cancer
Abstract

The overall aim of this thesis was to develop knowledge about how to promote health in children treated for cancer and how health promotion interventions based on such knowledge can be evaluated. In this thesis, a descriptive and explorative design has been used, comprising both qualitative (Papers I-III) and quantitative (Papers I and IV) methods. A nationwide cohort of 144 childhood cancer survivors (24-42 years) answered a questionnaire about the support they had received from health care services (Paper I). The analysis was conducted with a mixed method. Fifteen children (8-12 years), with experience of cancer treatment, participated in five focus groups with two sessions per group (Paper II and III). The focus group methodology was combined with participatory and art-based techniques, such as draw and tell and photography. The children discussed what promotes health and what friendship is about. The analysis of focus groups was conducted using inductive content analysis. A methodological design was used to psychometrically test the Swedish version of the Minneapolis-Manchester Quality of Life instrument (MMQL)-Youth form and Adolescent form (Paper IV). The study included 950 pupils in grade 6 and 9 from seven primary schools in western Sweden. In addition to this, a comparison of the MMQL instrument with the health-promoting factors described by children in the focus groups was performed.

The findings showed that there is a need for health-promoting factors, such as knowledge and psychosocial support, from health care services for childhood cancer survivors. Their family and friends may contribute with support and then serve as health-promoting factors. Health-promoting factors, according to children 8-12 years of age and with experience of cancer treatment, are meaningful relationships, recreational activities and a trustful environment. The children expressed a holistic view of what promotes their health. Friendship, from the perspective of the children, is a process of equal and mutual commitment that develops over time and with interactions occurring face-to-face and digitally. The MMQL instrument
may be valid and reliable in a sample of healthy children. However, less than one-third of the items in the MMQL instrument could be linked to the health-promoting factors that the children participating in the focus groups highlighted.

In conclusion, the findings in this thesis contribute knowledge from a participant perspective regarding the needs and the experiences of health-promoting factors for those who have received treatment for cancer. This knowledge could form a basis for development of health promotion interventions aimed at children who have received treatment for cancer. It is suggested that if the MMQL instrument is used to evaluate health promotion among children who have received treatment for cancer, the MMQL should be complemented with items that capture aspects of health that are important to the children.

Keywords: children, cancer, health promotion, nursing, focus group, photography, questionnaire, validity, reliability
Original papers

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

Paper I


Paper II


Paper III


Paper IV


The articles have been reprinted with permission of the respective journals.
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Skäret, Sweden
December 2015

Eva-Lena Einberg
# Abbreviations

<table>
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<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>GRR</td>
<td>General Resistance Resources</td>
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<td>HRQoL</td>
<td>Health Related Quality of Life</td>
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<td>ICC</td>
<td>Intraclass Correlation Coefficient</td>
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<td>MMQL</td>
<td>Minneapolis-Manchester Quality of Life</td>
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<td>QoL</td>
<td>Quality of Life</td>
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<td>SOC</td>
<td>Sense of Coherence</td>
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<td>WHO</td>
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Introduction

During my work as a school nurse, I have met children with experience of cancer treatment, children who no longer have the disease, children who remain affected by the disease and those who struggle with the consequences of the disease and its treatment in their everyday lives. The children sometimes needed support with their schoolwork or friendship relations or needed a person to talk to about their experiences and life.

Health and development are closely related to each other during childhood and may be influenced by experiences of illness (Hwang & Nilsson, 2011; Wolfe & McKee, 2014). Today, the majority of children who get cancer survive; however, cancer is a life-threatening disease. Due to the late effects related to the disease itself or its treatment, cancer may lead to long-term and chronic health conditions (Phillips et al., 2015). The affected children live with uncertainty for an extended time and experience painful medical procedures and limitations in their social life such as at school and with friends (Enskär & von Essen, 2008; Hildenbrand, Clawson, Alderfer, & Marsac, 2011). After completing treatment, several of the children live with late effects such as growth failure, learning problems, hyperactivity and cardiovascular problems and continue to feel uncertain about whether the cancer will return (Phillips et al., 2015). Although research results regarding psychosocial health vary, some results show that childhood cancer survivors may experience lower levels of psychological well-being and difficulties with friendship relations (Mattsson, Lindgren, & Von Essen, 2008; Wakefield et al., 2010). Because children with cancer may experience physical or psychosocial problems but also positive psychosocial outcomes and continue to live a good life after they complete treatment, these children’s health should be promoted.

Health promotion should be based on a salutogenic approach and an ecological approach in which all factors that may contribute to health are taken into account (WHO, 2009). The social environment, including family,
school and friends, is important for children’s health and development (Hwang & Nilsson, 2011). In health promotion activities, it is also important to consider the target group’s view on what promotes health (WHO, 1986). Knowledge of how those who are targets of these activities (in this case, those who have experience of childhood cancer treatment) view their needs and experiences of health-promoting factors is essential to health promotion. In addition, there is a need for relevant and valid instruments that capture the target group’s view when evaluating health promotion interventions. This thesis contributes knowledge based on the target group’s view on health-promoting factors that could be considered in health-promoting interventions for children with experience of cancer treatment. Furthermore, this thesis discusses how health promotion interventions based on this knowledge can be evaluated.

Background

Child health

For children, health and development are closely related to each other. Thus, both of these factors have to be taken into account in promoting children’s health. Experiences of an illness, such as cancer, during childhood may affect the child’s health and development (Wolfe & McKee, 2014). In addition to sufficient food and access to qualified health and medical care, the environment that surrounds the child is of major importance for their health and development (Bronfenbrenner, 1977; Wadsworth & Butterworth, 2006). The child’s immediate and most important environment is the family (Evenshaug & Hallen, 2001). In addition to the family, school and friends are of importance for children’s health and development (Bergmark & Kostenius, 2012; Hwang & Nilsson, 2011; Modin & Östberg, 2009). During the school-age years, children’s thinking becomes more logical, less
egocentric and more flexible. The social world expands, and children start to appreciate others’ viewpoints. Children aged 8-9 years can understand how another person experiences a situation. The peer group plays an important role in children’s level of self-esteem. Children’s dependence on parents decreases, while their dependence on friends increases (Hwang & Nilsson, 2011). Children serve as models for each other. They learn rules, conflict management and how other people think and feel from each other. Friends serve as cognitive and social resources in children’s everyday lives (Hartup, 1996; Hwang & Nilsson, 2011).

There has been a shift regarding the epidemiology of children’s health from acute illness to long-term or chronic health conditions (Halfon & Newacheck, 2010; Wolfe & McKee, 2014). International studies indicate that 12-20% of children live with some kind of long-term or chronic health condition (Halfon & Newacheck, 2010; Sawyer, Drew, Yeo, & Britto, 2007; Svavarsdóttir & Örlygsdóttir, 2006; van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007). The increasing prevalence of chronic health conditions among children can be partly attributed to improvements in diagnosis, treatment and care (Halfon & Newacheck, 2010), such as improvements in paediatric oncology.

**Childhood cancer**

Every year, more than 300 children in Sweden are affected by cancer (Gustafsson, Kogner, & Heyman, 2013). The causes of childhood cancer are mainly unknown (Haddy & Haddy, 2010), and among children up to 14 years of age, the number of children who die from cancer has remained unchanged since the beginning of the 1990s (Gustavsson et al., 2013; Pritchard-Jones et al., 2013). According to international studies, the incidence of cancer among children is increasing, and this can be partly explained by improved diagnostic methods and registration of childhood cancers (Haddy & Haddy, 2010; Pritchard-Jones et al., 2013). In Sweden,
the incidence of childhood cancer has been stable for the last 30 years (Gustafsson et al., 2013), and this may be explained by the good registration procedures that Sweden has implemented for several years. The overall 5-year survival rate from childhood cancer is now estimated to be approximately 80%, although there are considerable variations across diagnostic groups and countries (Gatta et al., 2014; Gustavsson et al., 2013).

Childhood cancer does not only imply that the child is affected by a very serious disease and is at risk of dying. Those who survive may also experience late effects related to the cancer disease itself or its treatment later in life (Eilertsen, Rannestad, Indredavik, & Vik, 2011; Phillips et al., 2015). Examples of late effects are growth failure, learning problems, hyperactivity, delayed sexual maturation, bone mineral density deficits, cardiovascular problems and respiratory symptoms (Haddy & Haddy, 2010). Thus, those who survive childhood cancer may have to live with long-term and chronic health conditions. Due to improved treatment and treatment outcome over the last 50 years, the numbers of individuals who have survived childhood cancer and suffered from late effects have increased. There are indications that approximately 70% of childhood cancer survivors have a mild or moderate chronic condition and that approximately one-third have a severe, disabling, or life-threatening condition (Phillips et al., 2015). The prevalence of chronic health conditions also increases with age. Survivors of childhood cancer also have an increased risk of mortality due to the primary cancer, second or subsequent cancer, circulatory diseases and pulmonary diseases (Garwicz et al., 2012; Reulen et al., 2010). Children who have to live with long-term and chronic health conditions might experience problems attending and fully participating in school and activities (Wolfe & McKee, 2014). Their opportunities to socialize with their schoolmates can be constrained due to hospital stays, school absences or physical limitations. Differences in appearance may also complicate the process of making friends (Lambert & Keogh, 2015; McCarroll, Lindsey, MacKinnon-Lewis, Chambers, & Frabutt, 2009; Taylor, Gibson, & Franck, 2008b).

Regarding psychosocial health, studies indicate that childhood cancer survivors are at higher risk of experiencing emotional problems. Childhood
cancer survivors have reported higher levels of depression and anxiety and lower levels of psychological well-being, mood, liveliness and self-esteem (Eilertsen et al., 2011; Li, Lopez, Chung, Ho, & Chiu, 2013; Wakefield et al., 2010; von Essen, Enskar, Kreuger, Larsson, & Sjoden, 2000; Zeltzer et al., 2009). It has been suggested that symptoms of depression are related to the discomfort associated with a chronic health condition (von Essen et al., 2000). Disfigurement and persistent hair loss have been associated with emotional distress and reduced quality of life (QoL) (Kinahan et al., 2012). There are differences in the extent of late effects between certain subgroups of childhood cancer survivors (according to diagnostic groups, age at diagnosis and gender) (Mertens et al., 2014; Zeltzer et al., 2009). In contrast to the above consequences, there are positive consequences of childhood cancer such as a more positive view of life and of self, high self-worth, good behavioural conduct, and improved mental health and social behaviour (Sundberg, Lampic, Bjork, Arvidson, & Wettergren, 2009; Wakefield et al., 2010). Regarding the QoL of survivors of childhood cancer, results from various studies reveal considerable variability in perceived QoL. These children report lower, comparable or higher levels of QoL than comparison groups. The variability in the results may be explained by methodological differences between studies, including type of cancer and timing of assessment (age of respondents and time since remission) (McDougall & Tsonis, 2009). Although it has been found that a majority of survivors feel that they are almost like or like any other person, there is also a group that feels different from others (Jervaeus, Lampic, Johansson, Malmros, & Wettergren, 2014). This result could suggest that certain groups have a greater need for support but also that despite the experiences of cancer treatment and late effects, it is possible for children to move on and lead a good life.
Everyday life with childhood cancer

The everyday life of children affected by cancer changes drastically starting on the day they receive the diagnosis. The cancer diagnosis and its treatment have an impact on their physical, psychological, social and existential health and well-being (Hedstrom, Haglund, Skolin, & von Essen, 2003; Hildenbrand et al., 2011; Wilson, Mazhar, Rojas-Cooley, De Rosa, & Van Cleve, 2011). Treatment can vary depending on the type of cancer the child has and can involve surgery, radiation, chemotherapy, and/or transplantation (Haddy & Haddy, 2010). Furthermore, treatments are often intensive and extended over time and can be painful (Wilson et al., 2011). Children undergoing treatment for cancer have expressed that anxiety, painful medical procedures, fear of pain and fear of the unknown are the worst aspects of having cancer (Enskär, Carlsson, Golsäter, Hamrin, & Kreuger, 1997). They experience changes in their bodies such as fatigue, hair loss, nausea, pain, vomiting, decreased appetite and eating problems (Enskär & von Essen, 2008; Kestler & LoBiondo-Wood, 2012; Miller, Jacob, & Hockenberry, 2011). The list of physical symptoms that the children may experience can be long (Miller et al., 2011). The children may also exhibit changed mood such as aggression, apathy or sadness (Enskär et al., 1997) and may feel afraid, worry and have sleep difficulties (Han et al., 2011; Miller et al., 2011). They have thoughts about why they get sick and about death (Enskär & von Essen, 2008; Han et al., 2011; Hedstrom et al., 2003; Miller et al., 2011). They may get more attention from and be spoiled by family, friends, relatives, school teachers and health care personnel (Enskär et al., 1997). By contrast, they experience alienation, feel confined and isolated and miss friends, play and school (Hedstrom et al., 2003; Hildenbrand et al., 2011). Even young children have these feelings of isolation and loneliness and miss friends and pre-school (Darcy, Knutsson, Huus, & Enskar, 2014). Furthermore, cancer may keep children from doing things that their peers have the opportunity to do such as gaining more independence (Woodgate, 2006). Disease and treatment often lead to decreased pre-school and school attendance (af Sandeberg, Johansson, Björk, & Wettergren, 2008; Darcy et al., 2014; French et al., 2013), and the children may have difficulty in
maintaining contact with friends. Their friends may disappear (Hildenbrand et al., 2011; Wilson et al., 2011), and they may also experience bullying (Fraser, 2003; Lähteenmäki, Huostila, Hinkka, & Salmi, 2002). Friends might also become jealous and tease the child with cancer because he/she gets a substantial amount of attention (Hildenbrand et al., 2011). However, other studies have found that children with cancer report that they have many friends and no problematic relationships in school (af Sandeberg et al., 2008; Enskär & von Essen, 2008). The contrasting results about friendship relations might be due to methodological differences, including differences in study populations or cultural contexts. However, childhood cancer survivors have recently reported that they are less satisfied with their friends at school than peers without a history of cancer (Winterling, Jerveaus, af Sandeberg, Johansson, & Wettergren, 2015). Survivors have also reported that their social bonding is weakened, and they have related this to their different growing experience and the age gap between them and their peers (Li et al., 2013). It has been suggested that the inability to attend school as much as a child wishes may explain why children report that their life is less than satisfying (Enskär & von Essen, 2008). It has been emphasized that friendship relations is an area of concern (Mattsson et al., 2008; Winterling et al., 2015) and that school attendance is related to the QoL of children with cancer (af Sandeberg et al., 2008).

The child is not the only person affected by the child’s diagnosis of cancer. The child’s family members feel as though their life has fallen apart and changed forever (Björk, Wiebe, & Hallström, 2005; Woodgate, 2006). They lose daily routines and feel that life will never be the same. There is fear of losing the ill child and of the break-up of the family (Woodgate, 2006). There are feelings of uncertainty, chaos and loneliness (Björk et al., 2005), and the parents feel as though their role as parents is different and unfamiliar (Darcy et al., 2014). They experience a loss of increasing independence (Woodgate, 2006) and may overprotect their child (Enskär et al., 1997; Rivero-Vergne, Berrios, & Romero, 2010). Normally, children become more independent from their parents as they grow and develop. When the child gets cancer, he or she does not become more independent. Rather, the child’s
need for care increases (Woodgate, 2006). The child is submitted to appointments, procedures, treatments, and waiting times, which take up all their time, and the parents become dependent on others (Björk et al., 2005). Siblings put their own needs aside on behalf of their sick sibling (Woodgate, 2006) but also experience divided loyalties between their own interests such as friends and school and their need to support their sick sibling (Nolbris, Enskär, & Hellström, 2007). They are concerned about their sick sibling and feel worry and anxiety (Nolbris et al., 2007). Furthermore, they can feel as though they are not a part of the family when their parents focus on the sick sibling (Woodgate, 2006).

After completing treatment, the children wish to return to school and other activities that children of their age are engaging in (Bjork, Nordstrom, Wiebe, & Hallstrom, 2011; Wakefield et al., 2010). Such activities provide a sense of normality, and many children also have positive experiences when returning to school and seeing their friends (Wakefield et al., 2010). The children want to move on with life and do not wish to discuss their illness with their friends (Sundler, Hallstrom, Hammarlund, & Bjork, 2013; Wakefield et al., 2010). However, physical and mental changes and feelings of being different from peers can be difficult for children even after the treatment is completed (Bjork et al., 2011; Wakefield et al., 2010). Some research shows that children can be more self-confident and develop sympathy for others (Bjork et al., 2011); however, other studies show that they may experience a lower sense of confidence (Wakefield et al., 2010). Even after active treatment, fatigue can remain a problem (Enskär & von Essen, 2008; Kestler & LoBiondo-Wood, 2012), and the children may continue to think about why they get sick (Enskär & von Essen, 2008). They may feel as though they are forgotten because they are now treated more normally and are not as spoiled as before (Bjork et al., 2011). However, parents’ concern that their child might have a relapse may hamper the children’s reintegration into a normal everyday life (Bjork et al., 2011; Rivero-Vergne, Berrios, & Romero, 2010). The children may experience feelings of uncertainty regarding whether they are healthy or whether the disease will return and may feel as though other people do not understand
what they have experienced. The experience of cancer remains (Wakefield et al., 2010), and they carefully choose who they share their thoughts with (Sundler et al., 2013). These factors could explain why childhood cancer survivors have lower satisfaction regarding friendship relations compared to comparison groups (Winterling et al., 2015) and why they have fewer close friends and consult with their friends less often (Barrera, Shaw, Speechley, Maunsell, & Pogany, 2005).

In summary, social relationships, school and friends are important for children’s health and development. For children affected by a disease, such as cancer, the natural contact with school and friends may be hampered due to disease, treatment and late effects, which may compromise the child’s health.

Health

Health is a fundamental human right (WHO, 2005), and an understanding of the concept of health constitutes the basis for health promotion (Naidoo & Wills, 2009; Svedberg, 2011). According to the WHO (2005), health promotion is based on a positive and inclusive concept of health. The WHO defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 1948); thus, health is a holistic and multidimensional concept. The concept has been further developed to be viewed as a resource for everyday life (WHO, 1986). Along with the concepts of person, environment and nursing, health is one of the core concepts in nursing science (Alligood, 2013). Furthermore, health is the goal in caring science, including the discipline of nursing (Alligood, 2013; Dahlberg & Segesten, 2010). In nursing science, health is regarded as a process that human beings create and experience in everyday life (Parse, 1990, 2007; The Swedish Society of Nursing, 2008). Based on this concept, nurses’ overall aim is to support and strengthen a person’s health processes (Dahlberg & Segesten, 2010; The Swedish Society of Nursing, 2008). Health
is related to the whole person, means different things to different people, and consists of both biological aspects and existential experience of health. Health means to experience well-being, feel good and have the ability to carry out activities that are perceived as essential in life (Dahlberg & Segesten, 2010). Bronfenbrenner (1977) and Parse (1990, 2007) highlight the importance of the environment. According to these scholars, the human participates in the creation of her/his reality (or, rather, the experience of her/his own reality) in interaction with the environment. This creation also includes the creation of health (Parse, 1990, 2007). Children (8-11 years of age) express both a biomedical and a holistic view on health. They view health as a resource in life and also consider the importance of the environment (Piko & Bak, 2006). Furthermore, children (10-12 years of age) describe health as the experience of good relationships, togetherness and support. Children also discuss the importance of participating in positive activities. The experience of relationships with others and relationship with oneself is central in children’s description of health (Kostenius & Öhrling, 2006).

The social dimension of health

The dimensions that are frequently found in health models are the physical, social, emotional, intellectual, and spiritual dimensions. The social dimension refers to building relationships that enhance well-being (Hjelm, 2010). The importance of the social environment such as social relationships and social networks has been recognized in health promotion (Green & Tones, 2010). Today, it is well known that the social network, the web of social relationships that surround an individual, has an impact on health (Berkman & Glass, 2000; Christakis & Fowler, 2009). It has been found that individuals with poor health have fewer friends and may have weaker friendships (Barrera et al., 2005; Haas, Schaefer, & Kornienko, 2010; Li et al., 2013). For children, important social relationships are parents and, when applicable, siblings and other relatives in their immediate local environment.
Other important social relationships are those with peers and adults who the children meet at school and during their leisure time (Evenshaug & Hallen, 2001; Hartup, 1996; Wadsworth & Butterworth, 2006). From 8 to 9 years of age, mutual trust and support becomes increasingly important. There is an expectation that friends help each other, cooperate and are loyal to each other (Evenshaug & Hallen, 2001).

In the present thesis, health is viewed as an experience that is constructed in the interaction between individuals and their surroundings and as a continuously ongoing process. The child co-creates the experience of health in interaction with her/his environment, which includes family, friends and other factors.

**Health promotion**

It has been emphasized that the health sector should be more health-oriented (WHO, 1986, 2005). Currently, Swedish public health policy aims to provide a health-promoting health care service. The health-promoting perspective should be a natural aspect of all care and treatment (Proposition, 2002/03:35, 2007/08:110). The definition of health promotion has been discussed extensively in the literature (see for e.g., Green & Tones, 2010; Naidoo & Wills, 2009). There is not an established consensus about the concept of health promotion (Naidoo & Wills, 2009; Piper, 2009). However, the Ottawa Charter for Health Promotion’s definition of health promotion (WHO, 1986) is the most frequently used, and the more recent definitions are often based on this definition (Piper, 2009). The definition has been expanded to include the determinants of health and is now as follows: “Health promotion is the process of enabling people to improve and increase control over their health and its determinants, and thereby improve their health” (WHO, 2005). It is important to clarify that health promotion, disease prevention and health education are different concepts, although they are linked to each other (Dahl, Andrews, & Clancy, 2014; Piper, 2009;
Whitehead, 2009). Disease prevention often targets a specific disease and is based on a pathogenic approach. The purpose of such prevention is to stop, eliminate or postpone ill health, and it often focuses on risk factors and risk behaviours (Nutbeam, 1998; Tengland, 2010). By contrast, health promotion has a wider scope and is based on a salutogenic approach, which is primarily concerned with promoting positive health and well-being (Eriksson & Lindström, 2008; Tengland, 2010). Health can be promoted without preventing disease, but it is not possible to prevent disease without promoting health (Tengland, 2010). Health education is one of several components of health promotion, but it is not equivalent to health promotion. Health promotion has a broader meaning and does not necessarily include health education (Piper, 2009; Whitehead, 2004, 2008; WHO, 2009). The focus of health promotion is to utilize, enable, enhance and improve people's own resources and the environmental resources that may contribute to health (Green & Tones, 2010).

Nurses have a responsibility to promote health (International Council of Nurses, 2012; The Swedish Society of Nursing, 2008). Because nurses are the largest group of health professionals and have close contact with patients, they play a key role in health promotion (Piper, 2009; Whitehead, 2009). Although the holistic philosophical underpinnings of nursing correspond well with the goals of health promotion (Berg & Sarvimäki, 2003; Whitehead, 2011b), it appears as though nurses have a greater focus on health prevention and health education than health promotion (Dahl et al., 2014; Whitehead, 2006, 2009). It has been argued that nurses need to go beyond the current focus on health prevention and practice broader health promotion (Whitehead, 2006). According to Berg and Sarvimäki (2003), health promotion nursing is based on a holistic-existential approach and a humanistic view of the human being. Rather than entirely focusing on disease and problems, health promotion nursing focuses on understanding the person’s lifeworld in relation to health, illness and suffering (Berg & Sarvimäki, 2003). Health promotion nursing involves partnership with the patient such that the individual’s needs and preferences are taken into account to promote the individual’s health processes (Berg & Sarvimäki,
This empowerment approach gives authority to individuals and enables them to increase their control over and improve their own health. Furthermore, it is in line with enablement, one of the three strategies in the Ottawa Charter for Health Promotion (Nutbeam, 1998; WHO, 1986). The two other strategies are advocacy and mediation. Through their close work with children and their families, both within hospitals and child and school health services, nurses have the opportunity to enable, strengthen and enhance the resources of the child and resources in the child’s environment that may contribute to improved health (Hean, Hewitt-Taylor, Cash, Buckley, & van Teijlingen, 2013; Whitehead, 2011a). According to Roden and Jarvis (2012), paediatric nurses may have a limited understanding of the Ottawa Charter’s relevance to nursing; however, they argue that there is support for the advocacy role of paediatric nurses. The advocacy role might include developing personal skills and strengthening community actions, two of the action areas in the Ottawa Charter for Health Promotion. Roden and Jarvis (Roden & Jarvis, 2012) also found that building healthy public policy and creating a supportive environment are important action areas within paediatric nursing practice. Hean and colleagues (2013) emphasize nurses’ role in enabling children to maintain contact with friends and other significant people in their lives when they are sick to promote their health. This role can be related to the strategy of enablement (WHO, 1986).

An individual's health is affected by several factors that influence each other (Green & Tones, 2010). Health-promoting factors include an individual’s own inner resources and environmental factors such as family, friends and neighbourhood as well as access to health care services (Antonovsky, 1987; Green & Tones, 2010). These factors illustrate the need to adopt an ecological approach in health promotion in which all aspects of an individual's environment are taken into consideration as possible targets for intervention (Crosby & Noar, 2011). In the context of childhood cancer, the following health-promoting factors have been found: family togetherness, coping strategies and engagement in activities of normal life. Quality of care such as emotional support, information and family participation in care are also factors that promote health (Enskär et al., 2014). However, in health
promotion, it is important to consider the target group’s view on health and what promotes health (WHO, 1986) because this view has an impact on the health promotion intervention that is selected. The target group’s participation is essential for sustaining the effects of health-promoting activities (Nutbeam, 1998). Today, our knowledge about factors that promote the health of children with experience of cancer treatment is mainly based on the perspective of adults, particularly health care professionals and parents, and less based on children’s own views (Enskär et al., 2014). Thus, knowledge about children’s perspective regarding what promotes health is needed. Furthermore, today, when health promotion is mentioned in the paediatric oncology literature, the focus is behavioural risk factors and health prevention such as physical activity, smoking, sun protection etc. (see for e.g., Brier, Schwartz, & Kazak, 2014; Elliot, Lindemulder, Goldberg, Stadler, & Smith, 2013). Because of this confusion of concepts, the focus is negative health rather than resources and a process towards positive health. A potential consequence is that health-promoting activities are neglected.

In conclusion, health promotion, which is a responsibility for nurses, is based on a salutogenic perspective. Furthermore, important principles of health promotion include participation and a holistic and ecological approach. The definition of health and the target group’s view (in this case, the children’s perspective) on what promotes health are essential to health promotion. The salutogenic approach, the ecological approach, and the children’s perspective (Figure 1.) will be further described below because they are relevant to this thesis.
The salutogenic approach

A salutogenic perspective and empowerment is the foundation of health promotion, and the focus of this perspective is strengthening and supporting the resources that promote health (WHO, 1986). According to the salutogenic model (Antonovsky, 1987), health and disease can be viewed on a continuum where the individual moves between health and ill-health. It is possible for an individual to experience health even when he or she has a disease. The salutogenic model focuses on the resources that are available for a person to move towards health (Antonovsky, 1987). These resources are also termed General Resistance Resources (GRR). The salutogenic model includes the concept of Sense of Coherence (SOC), a person’s view of life and capacity to manage stress. Antonovsky (1987) argues that health arises from a sense of coherence. SOC consists of three components: comprehensibility, manageability and meaningfulness. Comprehensibility refers to the feeling that things are predictable and understandable, and manageability concerns the feeling that there are resources that one can use
to meet demands. *Meaningfulness* refers to participation and the notion that some things in life are emotionally important. The salutogenic model also considers the interaction between the individual and the environment. The environment influences the individual’s life experiences and, thus, the individual’s SOC (Antonovsky, 1987). This interaction between the individual and the environment is important for health promotion.

**The ecological approach**

The need for an ecological perspective in health promotion has been emphasized because health is determined by several interconnected individual and environmental factors (Crosby & Noar, 2011; Green & Tones, 2010). The Ottawa Charter for Health Promotion adopts the ecological perspective in the action areas of supportive environments and the reorientation of health services (WHO, 1986). Although it has been argued that health promotion interventions should focus on several factors, it has also been discussed that this goal might be unrealistic due to practical or financial issues (Golden & Earp, 2012). However, an ecological approach may reveal additional aspects that can be considered in health promotion interventions (Golden & Earp, 2012). The ecological approach is not unique to health promotion; rather, it can be found in several fields. In paediatric oncology care, the ecological approach has been emphasized (Labay, Mayans, & Harris, 2004; Schwartz, Tuchman, Hobbie, & Ginsberg, 2011) to take into account the various factors and contexts (not only disease and treatment) that have an impact on the individual. One of the primary contributors to the ecological approach is Urie Bronfenbrenner (1977), whose ecological model is related to children’s health and development and, therefore, is useful in promoting children’s health. Bronfenbrenner’s ecological model of human development (1977) illustrates the individual’s exposure to environmental influences. The ecological environment is conceived as a set of nested structures, each inside the next. Furthermore, the forces at different levels mutually affect each other. The model consists of
four system levels and the time factor, called the chronosystem. The four system levels are: the microsystem, which includes the environments that the child is included in such as family, school and friends; the mesosystem, which is a system of microsystems and the overall effect of these microsystems; the exosystem, which can include, for example, the parent’s workplace and neighbours; and the macrosystem, which includes, for example, cultural values and laws. Over time, the individual and the environment will change. Change is more pronounced in the child’s development when several changes occur over a short time (Bronfenbrenner, 1977; Hwang & Nilsson, 2011).

The perspective of children – as the target group

Both the Ottawa Charter’s (WHO, 1986) perspective of enablement and the participatory rights of the Convention on the Rights of the Child (United Nations, 1989) demonstrate the importance of talking with children about matters that affect them. The Convention on the Rights of the Child (United Nations, 1989) addresses the child's right to development and to the highest attainable standard of health and further emphasizes children’s right to participate in matters that affect them. Children should be allowed to comment on and influence their situation, and their views should be considered (United Nations, 1989), such as in the case of health promotion targeted at them. The Convention on the Rights of the Child includes both a child perspective and the child’s perspective. The child perspective refers to adults’ outside perspective on children's needs and circumstances and is a reconstruction of the child’s perspective. The intention is to do what is best for the child, but this does not necessarily mean that the children are involved. The child's perspective is understood as the child's own perspective on her/his lifeworld; it is an inside perspective on what is important (Pramling Samuelsson, Sommer, & Hundeide, 2011). The two perspectives complement each other (Soderback, Coyne, & Harder, 2011), and it has been proposed that they can be viewed as two ends on a
continuum (Nilsson et al., 2013). Previously, research viewed children as merely vulnerable and dependent, resulting in the marginalization of children (Carter, 2009). Today, it is recognized that children are experts on their own lives (Hill, 2005). They are viewed as competent, social actors and active participants who create their own lifeworld. Thus, the best way to understand children’s experiences is to ask them about those experiences (Soderback et al., 2011; Thomas & O’Kane, 1998). Researchers have a responsibility to enable children to participate on their own terms, e.g., by using research methods adapted for children (Johansson, 2003; Thomas & O’Kane, 1998), and to ensure that the child’s perspective is expressed (Johansson, 2003). By asking the children about their perspective, the chances that we learn more about how to support the children increases (Carter, 2009). However, there must be an awareness that when approaching the child’s perspective, there are always some aspects that one does not obtain access to, as is always the case when approaching another person’s perspective (Johansson, 2003). Furthermore, there is not one child’s perspective; rather, there are several perspectives. There might be differences according to the child’s age, life situation and the context (Carter, 2009; Hill, 2005; Johansson, 2003). To the author’s knowledge, children with experience of cancer treatment have not been asked their opinion on what promotes their health.

**Evaluation in health promotion**

New health-promoting interventions must be evaluated to justify their inclusion in clinical practice (Naidoo & Wills, 2009). Evaluation has more than one purpose, including to measure the degree to which the goal of the intervention is achieved, to take responsibility for the resources used and to ensure that there are no harmful consequences of the intervention (Green & Tones, 2010). It has been argued that both the process and outcomes of health promotion interventions should be evaluated (Green & Tones, 2010). Process evaluation refers to the assessment of how the intervention was
carried out, and outcome evaluation refers to the assessment of the effect of the intervention (Naidoo & Wills, 2009). The overall goal of health promotion is to improve health (WHO, 1986), and depending on the definition of health, this goal leads to different activities. Consequently, the definition employed also determines what objectives to measure when evaluating health promotion (Naidoo & Wills, 2009). However, it has been argued that health-related quality of life (HRQoL) is the general goal of all kinds of health work, including health promotion (Tengland, 2006). The WHO (2005) also states that health, as a positive and inclusive concept, is a determinant of QoL. Given this background, HRQoL can be regarded as a useful objective to measure in the outcome evaluation of health promotion.

**Health-related quality of life**

Although there is no agreement in the literature regarding the concepts of QoL and HRQoL, there is a distinction between these two concepts. The WHO (WHO, 1998) defines QoL as “the individuals’ perceptions of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns”. A simplified definition of QoL that has been proposed is satisfaction with life (Moons, Budts, & De Geest, 2006). QoL is a broad concept of general well-being. By contrast, HRQoL is more specific and refers to the impact of health and illness on an individual’s QoL (Eiser & Morse, 2001; Spieth & Harris, 1996). HRQoL may be interpreted as a sub-component of QoL (Fayed et al., 2012) and is generally defined as a dynamic, subjective and multidimensional construct encompassing dimensions such as physical, mental, social and emotional aspects of life (Eiser, 2007; Spieth & Harris, 1996; Taylor, Gibson, & Franck, 2008a). These dimensions reflect the WHO’s definition of health (WHO, 1948).

Children’s perceptions of health and QoL differ from those of adults, and it has been found that children’s and parents’ reports of the child’s HRQoL differ (Eiser & Jenney, 2007; Taylor et al., 2008a). The definition of HRQoL
(Taylor et al., 2008a) emphasizes the subjective perspective; thus, as far as possible, children should self-report their own HRQoL. Furthermore, developmental stage and relationships with friends and family are important factors in children’s health and QoL (Eiser & Jenney, 2007; Taylor et al., 2008a; Webb et al., 2013). These factors, as well as children’s cognitive function, should be considered when assessing the HRQoL of children (Savage, Riordan, & Hughes, 2009; Taylor et al., 2008a). It has been found that the contents of different HRQoL instruments developed for children substantively differ, for example, regarding areas the questions cover (Petersson, Simeonsson, Enskar, & Huus, 2013). In comparison with other health status and QoL instruments developed for children, the Minneapolis-Manchester Quality of Life (MMQL) instrument has proved to better capture the QoL perspective of health (Fayed, Schiariti, Bostan, Cieza, & Klassen, 2011). Children participated in the development of the MMQL instrument (Bhatia et al., 2002; Bhatia et al., 2004). It has been emphasized that the involvement of those targeted by an instrument increases the instrument’s validity as well as its relevance and appropriate language (Matza, Swensen, Flood, Secnik, & Leidy, 2004; Streiner & Norman, 2008). The items used in the MMQL instrument also have a mainly positive phrasing, which is important for how each item is perceived and may be important for the child’s experience of completing the questionnaire (Fayed et al., 2011). However, when instruments developed in another context are used, they need to be evaluated in the new context, as perceptions about, e.g., health and QoL may differ across groups in different contexts (Streiner & Norman, 2008).
Rationale for the study

Previous research has shown that childhood cancer can lead to late effects with long-term conditions and emotional problems after children complete treatment. It has been found that childhood cancer survivors may experience limitations in activities and participation, and it has been recognized that survivors of childhood cancer are less satisfied with their friendship relations and may have a smaller social network and fewer close friends than their peers.

Given the risk of later adverse consequences for children with cancer, it is important to enable, enhance and strengthen factors that promote health to support children’s process towards health. Consequently, there is reason to identify health-promoting factors for these children. However, it is important to begin by asking children about their perspective on what promotes health. In health promotion, the target group’s view and participation are considered important for sustainable interventions. Today, there is limited knowledge about health promotion and friendship relations from the perspective of children with experience of cancer treatment. Furthermore, previous studies have often employed a pathogenic approach. A limited number of studies have focused on the child’s perspective and have applied a salutogenic approach.

To support health-promoting factors among children treated for cancer, instruments that can evaluate the health promotion interventions offered to these children are needed. When evaluating health promotion, instruments that capture the target group’s view of important health-promoting factors are needed. This thesis will provide knowledge from a participant perspective regarding the needs and experiences of health-promoting factors of those with experience of childhood cancer treatment. Furthermore, it will discuss how health promotion interventions based on this knowledge may be evaluated.
The overall aim of this thesis was to develop knowledge about how to promote health in children treated for cancer and how health promotion interventions based on such knowledge can be evaluated.

The specific aims were as follows:

- To explore needs and experiences of health-promoting factors from the perspective of childhood cancer survivors (Papers I and II)

- To explore experiences of friendship relations, a social dimension of health, from the perspective of children 8-12 years of age with experience of cancer treatment (Papers II and III)

- To, in addition to conducting psychometric evaluation, compare the MMQL instrument with the children’s description of health-promoting factors to explore the possibility of using the MMQL instrument to evaluate health promotion interventions for children with experience of cancer treatment (Papers II and IV)
Methodological framework

In this thesis, the ontological and epistemological framework is applied to nursing science. Nursing research has been performed primarily within two paradigms, the positivist paradigm and the constructivist paradigm, the latter of which is also referred to as the naturalistic paradigm (Polit & Beck, 2013). The research question is the starting point for the choice of method, but assumptions about reality based on theoretical perspectives will also affect the method selection (Crotty, 1998). Qualitative and quantitative approaches may be observed as different ends of a continuum and can serve as both the positivist and constructivist paradigm (Creswell, 2009; Crotty, 1998). Different methods complement each other and generate different types of knowledge, which is useful in nursing practice. Qualitative research methods may contribute to an increased understanding of how individuals experience a phenomenon and create meaning in their lives. Quantitative methods may contribute to an understanding of underlying causes of natural phenomena (Polit & Beck, 2013). Taken together, these methods contribute to a broader knowledge of the research field.

In this thesis, the dominant theoretical perspective is within the constructivist paradigm, i.e., the naturalistic paradigm. The assumption of reality is that every truth can be seen as one perspective among many because every culture or society creates its own version of reality. The creation of knowledge occurs through interaction with one another, and it is through common language that we obtain our understanding of the world and its construct (Burr, 2003). Nursing science is grounded in humanistic science and is based on the holistic perspective that the human being is seen as a whole person, an indivisible entity of the body, soul and spirit; the person is an ever-changing active co-creator of meaning and health (Dahlberg & Segesten, 2010; Parse, 1990, 2007). The world around us possesses terms for the human conditions to create health (Dahlberg & Segesten, 2010; Nightingale, 1969).
Methods

Design

The design of this thesis was descriptive and explorative. Furthermore, to respond to the aims of the thesis, both qualitative and quantitative methodological approaches were used. A nationwide cohort study with a cross-sectional retrospective design (Paper I) was performed to explore childhood cancer survivors’ experience of support from health care during the transition to adulthood. The participants answered a study-specific questionnaire that included questions about their experiences of support. Experiences of support may disclose unmet needs related to health-promoting factors. To explore health-promoting factors (Paper II) and friendship relations (Paper III) from the perspective of children with experience of cancer treatment, focus groups combined with participatory and art-based techniques were performed. Because health promotion factors and friendship relations from the perspective of children with experience of cancer treatment are research areas that are rarely explored, a qualitative design with an inductive approach was employed (Polit & Beck, 2013). A methodological design (Grove, Burns, & Gray, 2013) was used to psychometrically test the Swedish version of the Minneapolis-Manchester Quality of Life instrument (MMQL)-Youth Form and MMQL-Adolescent Form (Paper IV). This thesis also compared the MMQL instrument and the health-promoting factors described by the children (Papers II and IV). The intention was to explore whether the MMQL instrument could be useful in evaluating future health promotion interventions for children with experience of cancer treatment. An overview of the studies’ (Papers I-IV) design, participants, data collection and data analysis is presented in Table 1.
Table 1. Overview over Paper I-IV.

<table>
<thead>
<tr>
<th>Paper</th>
<th>Design</th>
<th>Participants</th>
<th>Data collection</th>
<th>Data analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Cross-sectional retrospective design</td>
<td>A nationwide cohort of 144 childhood cancer survivors (24-42 years)</td>
<td>Study specific questionnaire</td>
<td>Mixed method with a convergent parallel design</td>
</tr>
<tr>
<td>II and III</td>
<td>Qualitative design with an inductive approach</td>
<td>15 children with experience of cancer treatment (8-12 years)</td>
<td>Five focus groups combined with participatory and art-based techniques</td>
<td>Qualitative content analysis</td>
</tr>
<tr>
<td>IV</td>
<td>Methodological design</td>
<td>950 children from 7 schools (11-16 years)</td>
<td>MMQL-instrument Youth Form and Adolescent Form</td>
<td>Statistical analysis</td>
</tr>
</tbody>
</table>

Participants

This thesis is comprised of three samples: a nationwide cohort of 144 patients treated for acute lymphoblastic leukaemia (ALL) in Sweden (Paper I), a purposive sample of 15 children with experience of cancer treatment from the southern part of Sweden (Papers II and III), and 950 pupils from 7 schools in western Sweden (Paper IV).

Paper I

Paper I included 144 participants, aged 24-42 years, who were treated for ALL in their childhood. Recruitment was done through the Swedish Children’s Cancer Registry, and all individuals who were diagnosed with paediatric cancer during the period of 1985-1997 were invited to participate in the study. The inclusion criteria were individuals with a history of ALL in childhood who were treated more than 10 years ago. The time range was selected to exclude individuals who received radiation treatment, which was used in some treatment protocols before 1985. Based on the inclusion
criteria, a total of 416 people in the registry were eligible. Out of these people, 42 were excluded due to mental health problems, disability, long-term stay abroad or unknown addresses. A total of 224 respondents answered the questionnaire. Of these respondents, 80 did not complete the questions that were the subject of Paper I, resulting in 144 participants. The mean age of the participants was 30 years (range 24-42), and 53% were female. Age at diagnosis ranged from 1 to 16 years, with a mean age of 7 years. The demographic characteristics of the participants are shown in Table 2. There were no differences in age, sex and age at diagnosis between eligible participants who did not take part in the study and the participants who answered the questionnaire.

Table 2. Demographic characteristics of the participants in Paper I (n=144).

<table>
<thead>
<tr>
<th>Participants</th>
<th>Age at data collection Mean (range)</th>
<th>29.6 (24-42)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at diagnosis Mean (range)</td>
<td>7.1 (1-16)</td>
<td></td>
</tr>
<tr>
<td>Gender Female</td>
<td>76 (53%)</td>
<td></td>
</tr>
<tr>
<td>Civil status Single</td>
<td>59 (41%)</td>
<td></td>
</tr>
<tr>
<td>Married/co-habiting</td>
<td>82 (57%)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>3 (2%)</td>
<td></td>
</tr>
<tr>
<td>Education Compulsory comprehensive school</td>
<td>66 (46%)</td>
<td></td>
</tr>
<tr>
<td>Upper secondary school</td>
<td>68 (47%)</td>
<td></td>
</tr>
<tr>
<td>Undergraduate studies</td>
<td>9 (6%)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>1 (1%)</td>
<td></td>
</tr>
</tbody>
</table>
Papers II and III

Papers II and III included 15 children, aged 8-12 years, with experience of cancer treatment. Initially, the intention was to include only children diagnosed with ALL. When it became difficult to create focus groups and to ensure that children and their families would not have to travel too far, the inclusion criteria was extended to children with experience of chemotherapy treatment. The inclusion criteria then became children with experience of chemotherapy treatment, 8-12 years of age, under maintenance treatment or under routine clinical monitoring following treatment at a paediatric oncology department in Sweden declared healthy. The exclusion criteria were as follows: the child was in an acute stage of treatment or undergoing radiation therapy or surgery alone. These criteria were considered to reflect homogeneous groups with experiences of chemotherapy treatment. Recruitment was done in collaboration with one university hospital and one county hospital in southern Sweden. Based on the inclusion criteria and knowledge of the children, nurses at the hospitals selected children. These children were then contacted and asked to participate. Out of 29 children, 15 were willing to participate in the study. The demographic characteristics of the participants are shown in Table 3.

Pilot focus groups were carried out before the recruitment and focus groups for Papers II-III started. Schoolchildren aged 8-12 years with no previous cancer diagnosis took part in four pilot focus groups. School-aged children were recruited because of the limited number of children with experience of cancer. Overall, 16 children, 8 girls and 8 boys, participated in the pilot focus groups. The children were from a municipal compulsory school located in a suburban area in a municipality of 25 000 inhabitants in southern Sweden.
Table 3. Demographic characteristics of the participants in Paper II and III (n=15).

<table>
<thead>
<tr>
<th>Age (yrs) Mean = 10.4 (SD 1.3)</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>11</td>
<td>3</td>
</tr>
<tr>
<td>12</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Girl</td>
<td>5</td>
</tr>
<tr>
<td>Boy</td>
<td>10</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute lymphoblastic leukemia</td>
<td>13</td>
</tr>
<tr>
<td>Acute myeloid leukemia (AML)</td>
<td>1</td>
</tr>
<tr>
<td>Non Hodgkin’s Lymphoma</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Time since diagnosis</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 4 years ago</td>
<td>0</td>
</tr>
<tr>
<td>4-8 years ago</td>
<td>8</td>
</tr>
<tr>
<td>&gt;8 years ago</td>
<td>7</td>
</tr>
</tbody>
</table>

**Paper IV**

Paper IV included 950 children, aged 11-16 years (469 children in grade 6 and 478 children in grade 9). The children were recruited from 7 primary schools out of the 42 schools in a municipality of 92,000 inhabitants in western Sweden. The schools were located in both central and suburban areas of the municipality and represented different socio-demographic areas in the municipality (low- and high-income earners, a variety of housing...
situations and domestic- and foreign-born inhabitants). Inclusion criteria were schools with children in both grade 6 and grade 9 and with more than 100 children in total. A total of 49 classes were included, 24 classes in grade 6 (n = 536) and 25 classes in grade 9 (n = 576). For the test-retest 13 classes (n = 127) out of the 49 were included. The demographic characteristics of the participants are shown in Table 4.
Table 4. Demographic characteristics of the participants in Paper IV (n=950).

<table>
<thead>
<tr>
<th></th>
<th>Grade 6</th>
<th>Grade 9</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>n</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 or younger</td>
<td>469</td>
<td>478 (missing n=3)</td>
</tr>
<tr>
<td>12</td>
<td>440 (93.4 %)</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>16 (3.4 %)</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>4 (.9 %)</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>375 (78 %)</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>19 (4 %)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>232 (49.5 %)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>235 (50.1 %)</td>
<td></td>
</tr>
<tr>
<td>Country of birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sweden</td>
<td>409 (87.2 %)</td>
<td></td>
</tr>
<tr>
<td>Foreign born</td>
<td>56 (11.9 %)</td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td>3 (.6 %)</td>
<td></td>
</tr>
<tr>
<td>Parents’s country of birth</td>
<td>455 (missing n=14)</td>
<td>472 (missing n=9)</td>
</tr>
<tr>
<td>Both parents in Sweden</td>
<td>282 (60.1 %)</td>
<td>298 (62 %)</td>
</tr>
<tr>
<td>One parent born abroad</td>
<td>59 (12.6 %)</td>
<td>60 (12.5 %)</td>
</tr>
<tr>
<td>Both parents born abroad</td>
<td>114 (24.3 %)</td>
<td>114 (23.7 %)</td>
</tr>
<tr>
<td>Siblings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>23 (4.9 %)</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>192 (40.8 %)</td>
<td></td>
</tr>
<tr>
<td>2-3</td>
<td>202 (43.1 %)</td>
<td></td>
</tr>
<tr>
<td>4 or more</td>
<td>72 (11.1 %)</td>
<td>47 (9.7 %)</td>
</tr>
</tbody>
</table>
Data collection

The data collection for Papers I, II and III was carried out in 2012 and for Paper IV in 2011. Two different questionnaires were used in Papers I and IV. Focus groups with a semi-structured approach and combined with different participatory and art-based techniques were utilized in Papers II and III.

Questionnaire (Paper I)

In Paper I, participants’ addresses were retrieved from the Swedish population register (SPAR, Statistics Sweden). The participants received a letter containing information about the study, a consent form, a questionnaire and a prepaid response envelope as well as information about a website. The website contained the same information as the letter as well as a frequently asked questions section and an interactive section where participants could submit their questions about the study. A reminder was sent to those who had not responded after three weeks and was repeated once.

A 13-item study-specific questionnaire developed for the current study was used. The questionnaire was based on the definition of cancer rehabilitation used by The Nordic Cancer Union (Byrgesen Jensen, Bruun Piester, Nissen, & Evan Pedersen, 2004), and experts in the field reviewed the items to ensure that they conformed to the aim of the questionnaire. Three items were about the frequency of and satisfaction with follow-up care. Nine items were about experiences of support from health care, specifically, whether health care had given them knowledge about and supported them in continuing life after the disease. The response options for these 12 questions were yes, partially, no, and don’t know. The last item was an open-ended question where the participants were allowed to describe how they experience their contacts with health services in their own words. The internal consistency reliability of the study-specific questionnaire was tested by means of Cronbach’s coefficient alpha and was found to be 0.864.
Questionnaire (Paper IV)

In Paper IV, the MMQL-Youth Form and MMQL-Adolescent Form were translated and psychometrically tested. The MMQL instrument was created to evaluate HRQoL of individuals surviving from cancer, and there are three versions of the instrument to meet the developmental needs of different age groups (Bhatia et al., 2002; Shankar et al., 2005). Two of these versions were used in paper IV, the Youth Form for children 8-12 years of age and the Adolescent Form for adolescents 13-20 years of age. The MMQL-Youth Form is a 32-item, self-rating instrument that consists of four subscales: physical symptoms, physical functioning, psychological functioning and outlook on life (Bhatia et al., 2004). The MMQL-Adolescent Form is a 45-item, self-rating instrument that consists of seven subscales: physical functioning, cognitive functioning, psychological functioning, body image, social functioning, intimate relations and outlook on life (Bhatia et al., 2002). The items of these two instruments are rated on a 4- or 5-point Likert scale, and higher scores indicate greater HRQoL (Bhatia et al., 2002; Bhatia et al., 2004). Previous studies have shown that the MMQL-Youth Form and MMQL-Adolescent Form display good reliability and validity (Bhatia et al., 2002; Bhatia et al., 2004). The Swedish versions of the MMQL-Youth Form and MMQL-Adolescent Form are found in Appendices A-B.

Using forward-backward methodology (Brislin, 1970; Cha, Kim, & Erlen, 2007), the original versions of the MMQL-Youth Form and MMQL-Adolescent Form were translated into Swedish. The translation from English to Swedish was performed by two researchers, both native Swedish speakers who are fluent in English. A third researcher, a native English speaker who is fluent in Swedish, retranslated the questionnaires into English. Then, the three researchers discussed the small differences between the original version and the retranslated version to improve the quality of the Swedish translation and to reach consensus. The items in the Swedish version were also discussed in the research group and with 20 children between 8 and 15 years of age. These discussions resulted in the further adaptation of some of the items of the questionnaires.
Because the MMQL instrument was developed in the USA, it was important to test the reliability and validity of the Swedish version in a Swedish context. The validity and reliability were investigated in terms of face and content validity and internal consistency and test-retest reliability. The Swedish versions of the MMQL-Youth Form and MMQL-Adolescent Form were distributed to the participating schoolchildren after information concerning the study was provided in the classroom. In five of the seven schools, the questionnaire was completed directly following its distribution and collected by the researchers, and in two schools, the teachers distributed and collected the questionnaires in return envelopes. Two weeks later, the test-retest evaluation was carried out. The questionnaires were then distributed to the children in the classes and collected by the teachers.

**Focus groups (Papers II and III)**

In Papers II and III, data collection was conducted through focus group interviews using a semi-structured approach. Each group had two focus group sessions. In a focus group, the interaction between the participants is utilized to stimulate thoughts and to deepen the discussion regarding the phenomenon of interest. The participants have shared experiences of the phenomenon, and the discussion is guided and encouraged by a moderator (Ivanoff & Hultberg, 2006). The focus group methodology has proved to be useful in research with children (Coyne, Hayes, & Gallagher, 2009; Heary & Hennessy, 2002) and can be combined with other methods (Darbyshire, MacDougall, & Schiller, 2005; Heary & Hennessy, 2002). In this thesis, the focus group methodology was combined with participatory and art-based techniques (Colucci, 2007; Fargas-Malet, McSherry, Larkin, & Robinson, 2010) in the first session (Paper II) and with photography (Coad, 2007; Stegenga & Burks, 2013) in the second session (Paper III).

Four pilot focus groups with healthy children were first conducted at a municipal compulsory school to test the structure and content of the focus groups. Based on the pilot focus groups, changes were made to make it
easier for children in the target age group to express themselves. Tasks that were perceived as time consuming or overly difficult were simplified. After the refinement of the focus group arrangement, the focus groups involving children with experience of cancer treatment took place. The groups were conducted in different locations, depending on where the children lived and the families’ requests. Three focus groups were carried out in a child-friendly room at a paediatric oncology ward, one focus group was carried out at the children’s department at a local library and one focus group was conducted in a conference room at a hotel. These different locations were selected to shorten the travel time and, thus, make it easier for children and their families to participate in the study.

All focus groups were carried out by the same researcher over a 3-month period, and each focus group took approximately 90 minutes. The focus groups were video- and tape-recorded to minimize missed recordings due to errors. The children participated in one focus group, with each group having two sessions. The focus groups consisted of an icebreaking phase, theme phase and concluding phase. In the icebreaking phase, the researcher gave information about the study and about the tasks and topics to be discussed. This information was also included in a written agenda to provide the children with security. The request for participation was repeated to give children the opportunity to drop out. The main purpose of the icebreaking phase was to perform exercises to get to know each other. For example, the children and researcher tell each other what they like to do as leisure activities (Horstman, Aldiss, Richardson, & Gibson, 2008). In the theme phase, topics relevant to the study were discussed. In the first session, the children discussed what friendship is about, why friends want to hang out, and how friends can help and support each other. In the second session, the children discussed what promotes their health based on their photographs. During the theme phase, the children had a break and were offered fruits and refreshments. In the concluding phase, the discussions were summarized and the children were given the opportunity to discuss their participation. The methods that were combined with the focus groups and used in the theme phase, participatory and art-based techniques as well as photography, are described below.
Participatory and art-based techniques

Informative and creative techniques such as brainstorming, draw and tell, listing, and open questions were used in the first focus group session (Paper II). These techniques are considered to help children express themselves and to avoid young participants’ boredom and loss of attention (Colucci, 2007; Driessnack, 2006; Fargas-Malet et al., 2010). By using multiple techniques, all participants are given the opportunity to express themselves in a way that suits them (written, oral or visual). Answering questions in a more active way can be more enjoyable and take the discussion to greater depths (Colucci, 2007). Furthermore, it can give the children time to reflect and to gain more control over the situation (Fargas-Malet et al., 2010). In the current study, a listing technique was used. Specifically, the children listed words related to what makes a good friend and then discussed what they had listed. The draw and tell method was also used. The children drew pictures of situations when they were with their friends, talked about their pictures and discussed the pictures with each other in the focus group. Photography, also a participatory and art-based technique, was used in the second focus group session. The use of photography is described in more detail below.

Photography

Photography was used in the second focus group session (Paper III) because it can make it easier for children to express themselves and, thereby, grant us access to children’s interpretation of their world (Coad, 2007; Fargas-Malet et al., 2010). Photography is considered to engage and empower the participants and has been applied in different research approaches, such as photo elicitation, photo novella and photovoice (Riley & Manias, 2004). The purpose is to engage participants in taking photographs of aspects that symbolize the phenomenon of interest. The photographs stimulate reflection and provide a basis for discussion on what the photographs illustrate. Even objects not included in the photographs and underlying meanings can be discussed (Coad, 2007; Riley & Manias, 2004). Furthermore, photographs can provide structure and focus to the discussion and present both relevant, detailed information and rich in-depth knowledge (Coad, 2007; Fargas-Malet
et al., 2010). An adapted photovoice methodology has been found to be useful in research with children aged 6 to 14 years (Stegenga & Burks, 2013). In the adjusted photovoice methodology, the children complete a qualitative interview rather than keeping a journal of their photographs.

In the current study and at the end of the first session of the focus groups, the children received a digital camera. The children were given oral and written information concerning the task, i.e., to take photographs of subjects or situations that the children believe promote their health for 1 week. Their parents were also informed of the task so that they could assist the children if needed. The children were allowed to take as many photographs as they wished, and they were informed that they would receive the memory card with the photographs after the second focus group session. They were asked to choose approximately 10 photographs to show and talk about in the second session. Before the second session, the children mailed the camera’s memory card in a pre-paid envelope to the researcher, who collected the photographs on a computer for the next focus group meeting. The photographs functioned as a starting and reference point in the focus group discussions regarding what promotes health.

The researcher asked questions during the focus group discussions for clarification and to avoid misunderstandings and misinterpretations of what had been said. Such questions were also asked in regards to drawings, listings and photographs.

**Data analysis**

The data analysis in this thesis will be presented under the headings quantitative method (Papers I and IV), qualitative method (Papers I-III) and mixed methods (Paper I). When the mixed methods approach implies that the qualitative and quantitative data are first analysed separately, the analysis for each data set is first described in the appropriate method section and then described in the mixed methods section.
Quantitative method (Papers I and IV)

A quantitative method was used as part of a mixed methods approach in Paper I and independently in Paper IV. Statistical analyses were performed using the SPSS software 20.0 (SPSS Inc. Chicago, IL, USA).

In Paper I, descriptive statistics were used to describe the participants’ experiences of knowledge, treatment strategies and guidance from healthcare on how to best continue life after the disease in relation to physical, mental and social changes. The response options of the items concerning provided support (nine items) were dichotomized into yes/partially and no/don’t know. Chi-square tests were carried out to assess differences between gender, regular medical check-up, satisfaction with the extent of care and experience of knowledge, treatment strategies and guidance from health care. A significance level of \( p<0.05 \) was applied.

In Paper IV, statistical analyses were used to examine the reliability of the Swedish version of the MMQL-Youth Form and MMQL-Adolescent Form. Reliability was examined by testing the questionnaires’ internal consistency and test-retest reliability. Cronbach’s alpha coefficient was used to calculate the internal consistency of the two questionnaires and the subscales, and a Cronbach’s alpha value of \( \geq 0.70 \) was considered acceptable (Grove et al., 2013; Streiner & Norman, 2008). Internal consistency is tested to determine how well the items on a scale correlate with each other, i.e., the scale’s homogeneity. If the scale measures one concept, each item should relate to the concept and, consequently, all the items should be consistent with each other (Streiner & Norman, 2008). Intraclass Correlation Coefficient (ICC) was used to investigate the test-retest reliability of the questionnaires. ICC measures the stability of the questionnaires. Stability refers to the degree to which an instrument obtains similar results on different occasions (Streiner & Norman, 2008). When the scores on the first occasion are exactly the same as those on the second occasion, ICC produces a value of 1.0. The reference values for the levels of agreement consider < 0.20 as poor agreement, 0.21-0.40 as fair, 0.41-0.60 as moderate, 0.61-0.80 as good and 0.81-1.00 as very good agreement (Streiner & Norman, 2008).
Face and content validity were examined by asking the participants to evaluate the questions for clarity and readability. Face validity is a subjective evaluation and concerns the users’ perception of the questionnaire. Although it is considered to be a weak form of validity, it is important because it can affect participants’ willingness to complete the questionnaire (Grove et al., 2013). Thus, face validity should be judged by those who answer the questionnaire (Streiner & Norman, 2008). Content validity is closely related to face validity and evaluates whether the content of the questions measure the construct or phenomenon of interest that it is expected to measure (Streiner & Norman, 2008).

The comparison between the health-promoting factors described by the children (Paper II) and the items in the MMQL instrument (Paper IV) was carried out by reviewing the MMQL-Youth Form item by item to determine whether the items capture any of the health-promoting factors described by the children. This method was repeated for the MMQL-Adolescent Form.

Qualitative method (Papers I-III)

Qualitative content analysis was used in Papers II and III, and in Paper I, it was used as part of a mixed methods design. Content analysis has a long history dating back to theological texts and media and communication research (Krippendorff, 2004). Today, it is an established method in nursing research (Elo & Kyngas, 2008). It is a method used to systematically analyse texts, images or verbal communications (Krippendorff, 2004), and its purpose is to describe the phenomenon of interest. The method can be used with either quantitative or qualitative data, and depending on the purpose, with either an inductive or a deductive approach (Elo & Kyngas, 2008). In this thesis, a qualitative content analysis with an inductive approach was used to explore an area for which we have limited knowledge.

The qualitative content analysis occurs within the hermeneutic circle (Krippendorff, 2004), which means that a certain pre-understanding is required and that every time a text is re-read, it is read on the basis of the
previous reading and with a new pre-understanding. To understand the different parts, an understanding of the whole is necessary. An understanding of the whole, in turn, requires an understanding of the parts (Polit & Beck, 2013). The researchers’ pre-understanding essentially impacts the analysis (Krippendorff, 2004). Qualitative content analysis involves a search for common patterns and starts with reading or looking through the data several times to make sense of the data and the whole story (Elo & Kyngas, 2008). Thereafter, the data are processed to identify and extract meaning units that address the purpose of the study. Each meaning unit is condensed into a code, codes are grouped into subcategories and subcategories are grouped into categories. The analysis is an ongoing process with repeated revisions and modifications of the categories. The creation of categories and the abstraction process result either in separated categories or, if possible, in a main category (Elo & Kyngas, 2008).

In Paper I, the responses to the open-ended question (Please describe how you experience your contacts with health services in your own words) was analysed using qualitative content analysis. The responses were read several times. In Papers II and III, the transcribed focus group discussions were read several times to grasp a sense of the whole. This process included comparing the transcribed text with the recorded material, and in Paper III, it also included examinations of the photographs that served as the basis for the group discussions. It is difficult for adults to understand and interpret photographs that children have taken unless the children are given the opportunity to talk about the photographs (Darbyshire et al., 2005). In Paper III, the children were asked to talk about and discuss their photographs, which can be seen as an initial interpretation involving the children. After the initial reading and comparison of the data materials, the open coding was carried out and followed by creating a code scheme with meaning units and their codes. Similar codes were clustered into subcategories, and these were abstracted into categories. In Paper III, the analysis resulted in one main category. By contrast, in Paper II, the analysis resulted in three categories. The analysis conducted in Paper I also resulted in three categories. The categories in Paper I were further analysed together with the quantitative results in Paper I according to a mixed methods approach; see below.
Mixed methods (Paper I)

A mixed methods, convergent parallel design (Creswell & Plano Clark, 2011) was used in Paper I. The collection of quantitative and qualitative data was conducted at the same time, followed by separate analysis. The data are compared and contrasted during the discussion (Creswell & Plano Clark, 2011). The quantitative and qualitative data in Paper I were first analysed separately, as described above and previously in the sections of quantitative and qualitative methods. Then, the results were compared and synthesized in the discussion section of Paper I.

The author’s pre-understanding

As a paediatric nurse with over 10 years of experience working as a school nurse, I have extensive experience with professional consultation with children. The resulting pre-understanding was a requirement for performing the focus group studies with the children (Paper II and III), as I have knowledge of communicating with children about health issues and issues related to friendship relations. I have no pre-understanding of paediatric oncology. However, because the focus of this thesis is health promotion and the thesis employs a salutogenic approach, this lack of pre-understanding may be an advantage in that it may be easier to focus on children’s health and well-being rather than disease. Furthermore, when collecting the data for the methodological study (Paper IV), my familiarity with the school environment was an advantage. Although a pre-understanding may be an asset, awareness of one’s pre-understanding is important to ensure that one remains open to and sees what emerges when analysing the material.
Ethical considerations

The studies included in this thesis have followed the international ethical principles for medical research on human beings as established in the Declaration of Helsinki (WMA, 2013), the Swedish law regarding research (SFS, 2003:460) and the ethical principles for nursing research established by the Northern Nurses’ Federation (Northern Nurses' Federation, 2003). The cohort study (Paper I) (Dnr 2010/579) and focus group study (Papers II-III) (Dnr 2011/307) were approved by the Regional Ethical Review Board. The methodological study (Paper IV) was approved by the local ethical review board at Halmstad University (Dnr 90-2011-2863) and by the principals at the participating schools. All data materials are stored at Halmstad University and are only available for authorized use (Swedish Research Council, 2011).

The participants in the cohort study (Paper I) received written information about the aim of the research, including the fact that participation was voluntary, that they the right to withdraw from the research at any time without any explanation, and that confidentiality was guaranteed. The questionnaires were coded to protect the confidentiality of the participants. Survey questions can raise concerns and questions among the participants (Polit & Beck, 2013; Streiner & Norman, 2008); this occurred for the questionnaire in Paper I. One participant stated the following: “the questionnaire raises many questions”. It is important to be aware of this and to take this into consideration before sending out surveys. In Paper I, participants had the opportunity to contact a researcher via telephone or a website. Difficulty arises when the questions are related to the participants’ personal health and appropriate contact with health services but participants feel that such contact is not available. When planning questionnaire studies, it is important to consider whether the participants have unanswered questions of concern and the consequences that this may have for individuals. Participation may result in suffering; however, the answers may
lead to better support for others in the future. In this study, several of the participants expressed that they had positive attitudes towards the survey.

When children participate in research (Papers II and III), the power balance between the adult and the child, differences in communication and differences in the understanding and experience of the world must be taken into account (Hill, 2005; Thomas & O'Kane, 1998). The focus group methodology was chosen because it is proposed that by participating in a group, the children can be strengthened in relation to the researcher (Coyne et al., 2009). In addition to the ethical principles of autonomy, beneficence, justice and non-maleficence (Northern Nurses’ Federation, 2003), the components of comprehensibility, manageability and meaningfulness (Antonovsky, 1987) will be discussed because the salutogenic approach interacts with the ethical considerations in the focus group studies (Papers II and III). In consideration of the principle of non-maleficence, children in an acute stage of illness were not asked to participate. The principle of justice may have been neglected because not all children were invited. However, it was considered that the children who participated represent those who did not participate because they all have experience of cancer treatment.

The children’s participation was discussed with both the parents and the children, and such discussions were repeated during data collection. A postcard with information regarding the study was mailed in sealed envelope before the families were contacted by phone. Written information and a consent form were mailed to those who showed an interest in participating. The information included information about the voluntary nature of participation, the right to withdraw from the research at any time without any explanation and with no consequences for their continued contact with the health care, and the confidentially with which all material are treated (SFS, 2003:460). The families were given the opportunity to have repeated phone calls with the researcher so that parents and children would have time to discuss whether they would participate and then contact the researcher regarding participation and questions. This procedure was used to ensure the principle of autonomy. Informed consent requires that the invited person receives adequate and understandable information (Hill, 2005; SFS,
The information needs to be designed so that comprehensibility is achieved for the children. The written information about the research was created in two versions, one version for parents and one easier and more concrete version for children. The children were allowed to choose whether they signed the consent form or merely provided their assent verbally. Thus, each child received the opportunity to receive information and assent to participate according to their own needs and wishes. However, parents’ written consent was always required for participation (SFS, 2003:460). Parents were encouraged to read the information with the children and to discuss consent with the children. There is always a risk that the parents desire to participate and that the children’s willingness to participate in research is overlooked (Coyne, 2010). It is important to be sensitive to situations in which children do not wish to participate but parents have convinced the children to participate. The power balance between children and adults is, therefore, not only between the child and the researcher but also between the child and the parents (Coyne, 2010). In addition to emphasizing to the parents that the children themselves must wish to participate, during the focus groups, the researcher listened to the children’s thoughts about participating and informed the children that they can withdraw at any time. It is important to help children withdraw if they wish to do so (Coyne, 2010). The researcher then ensures that the principle of autonomy is followed.

There might be a risk of stigmatization when persons are invited to participate in research related to a diagnosis or disease. The focus groups were not designed to discuss experiences related to care and treatment. Rather, related to the salutogenic approach, the focus was on the children’s current everyday life. When the children brought up the fact that they had cancer treatment in common, the researcher had to be responsive to whether some of the children did not wish to talk about this topic. However, the children showed an interest in sharing their experiences, albeit in varying degrees in the different focus groups. One focus group received extra time to share experiences, although this was beyond the research question. This could be seen through the lens that the principles of beneficence and justice
were evident when the children’s interest was respected and they had opportunity to discuss this interest. Participation in research takes time, and during this time, the children may have been able to engage in a different activity. The risk of stigmatization and the time required to participate have to be balanced against the beneficence of the research (Helgesson, 2006; Nygren, 2012). Beneficence is evident when children are listened to and have the opportunity to influence future health promotion interventions directed to them, which increases the probability that the interventions are adapted to the children’s needs and requirements. If children who participate in research feel as though they have contributed to something important or feel as though they have received something in return, such as the opportunity to meet others with the same history, engage in fun activities or make new friends, their participation in research may be meaningfully. The children stated that they thought it was fun to participate in the focus groups. They appreciated the creative techniques that were used, and they wanted to continue to participate because of these techniques. The methodology with the salutogenic approach facilitated the children’s experience of manageability and meaningfulness in their participation in the research and, thus, the principle of beneficence.

In Paper IV, after the principals approved of the study, the parents of the schoolchildren were informed about the research through written communication and had the option to deny their child’s participation. The children also received verbal information about the research and the voluntary nature of participation in conjunction with the distribution of the questionnaires in the classroom. Informed consent should be viewed as a process. Furthermore, parents and children may not be of the same opinion regarding participation in research (Coyne, 2010; Helgesson, 2006). Thus, the children were given an opportunity to decide to not complete the questionnaire without having to explain their decision; this method ensured that the principle of autonomy was followed. To ensure the participants’ confidentiality, the questionnaires were coded and returned without names in a return envelope. The principle of beneficence may be seen as fulfilled because both the principals and the participating children expressed that it
felt good to be able to contribute to research. When children are given the opportunity to speak in research that concerns them (Papers II, III and IV), the principle of *justice* has been taken into account.

**The author’s contribution**

The author of this thesis is the first author of Papers II-IV. In Paper I, served as a contact person who addressed participants’ questions, participated in the qualitative content analysis and discussed the interpretation of data with four of the co-authors. Furthermore, contributed to the drafting of the manuscript and supplied constructive criticism.
Results

The results are presented based on the three specific aims of this thesis.

- Needs and experiences of health-promoting factors
- Experiences of friendship relations, a social dimension of health
- Psychometric evaluation of the Swedish version of the MMQL instrument and comparison of health-promoting factors and the MMQL instrument

Needs and experiences of health-promoting factors

The results in this section will be divided into the topics of needs and experiences of health-promoting factors. First, the needs of health-promoting factors are presented; then, the experiences of health-promoting factors are presented.

Needs of health-promoting factors

Childhood cancer survivors (Paper I) expressed satisfaction with the care they had received, and some of them were also satisfied with their current health care contacts. Even when they did not have a contact, they could be satisfied. However, several survivors expressed dissatisfaction with their health care contacts, in terms of both continuity and treatment provided in their contacts with health care professionals. One participant expressed the following: ‘I am disappointed with the health care because no one listens and understands’. They expressed a need for a long-lasting health care
contact who meets their personal needs related to their medical history and their need for psychosocial support. The participants lacked information and knowledge regarding the long-term effects of the disease and treatment and where to turn with their questions. One participant made the following statement: ‘... now other questions have appeared and you wonder if these are linked with the disease and treatment and where to turn to for help...’. These factors also apply when they needed psychosocial support. As one participant said, ‘What I’ve felt has been missing is a follow up on how you feel mentally, even if you survive there are a lot of thoughts in your head’. The childhood cancer survivors expressed an imbalance between the support offered for physical and psychosocial health problems, with a lack of support for psychosocial questions. The picture that emerged from the participants’ responses describes a continuum of experiences of health care contacts related to the participants’ health. The continuum extends from those who are satisfied and feel well to those who suffer from various symptoms and lack information and knowledge as well as positive contact with the health care services. In some cases, the differences depended on where they sought health care, but many of the participants had an expressed need of support from the health care that was not answered. The participants expressed that they had not received information and support regarding how to best continue life as childhood cancer survivors. There is a need for regular contact with the same health care professional; specifically, a provider who has knowledge of childhood cancer and can answer their questions regarding long-term effects. One participant expressed: ‘It would be nice to have a cancer contact that understands the problems’. Some participants were satisfied with their health care and had regular follow-ups but still wish for more frequent contacts and more information. In conclusion, there was a need for health-promoting factors such as information, knowledge and support, including both physical and psychosocial perspectives.
Experiences of health-promoting factors

Childhood cancer survivors (Paper I) who expressed that they receive support from their family and friends described fewer complaints. Instead, they felt well; as one participant stated, ‘I have support from my family and I feel well’. Support in the form of a regular contact with a health care professional who listens to all kinds of questions (from medical questions to questions related to general aspects of life) was important. One participant expressed this as follows; ‘...with her (the nurse), I was able to talk about everything’. A positive experience of the contact with health care professionals, such as continuity and support, as well as support from family and friends emerged as potential health-promoting factors (Paper I).

Children aged 8-12 years and with experience of cancer treatment highlighted meaningful relationships, recreational activities and trustful environment as health-promoting factors (Paper II). These health-promoting factors are presented as generic categories and related subcategories in Table 5. Meaningful relationships include togetherness within family, affection for pets and friendship with peers. The children expressed that the family is important for them and that they enjoy engaging in activities with their parents and siblings, such as playing games and watching movies. One child said, “My older brother makes me happy, like when we fish and stuff like that...” The children have fun and relax with their family. According to the children, this promotes their health. Furthermore, the children report that their family members are able to help and support them. The family members are there for each other and make the children happy. Affection for pets emerged as another important health-promoting factor. The children expressed that their pets make them happy and can provide comfort if they are sad. As one child said, “It’s my cat... They are kind; if you are sad, you can have them on your lap and you became happy again...”. The pets provided companionship and closeness, and the children also expressed that they make the pets happy. Similar to togetherness within family and affection for pets, friendship with peers was meaningful for the children. Friends are people who are kind and who the children can play with. One child expressed this as follows: “They are my friends... we are at the playground... It makes me feel good when I am with my friends”. According
to the children, having someone to spend time with as well as having someone to have fun with are health-promoting factors. Friends can also be people who can comfort the children when they are sad. Meaningful relationships involve a mutual exchange of care and consideration as well as to having fun together. These relationships lead to children’s experience of positive feelings, which promotes their health.

Table 5. Health-promoting factors according to the children.

<table>
<thead>
<tr>
<th>Subcategory</th>
<th>Generic category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Togetherness within the family</td>
<td>Meaningful relationships</td>
</tr>
<tr>
<td>Affection for pets</td>
<td></td>
</tr>
<tr>
<td>Friendship with peers</td>
<td>Recreational activities</td>
</tr>
<tr>
<td>Engagement in play and leisure</td>
<td></td>
</tr>
<tr>
<td>Withdrawal for relaxation</td>
<td></td>
</tr>
<tr>
<td>Feeling enjoyment</td>
<td></td>
</tr>
<tr>
<td>Feeling safe</td>
<td>Trustful environment</td>
</tr>
<tr>
<td>Confidence in significant others</td>
<td></td>
</tr>
</tbody>
</table>

According to the children, **recreational activities** promote their health, and such activities include **engagement in play and leisure, withdrawal for relaxation and feeling enjoyment**. The activities can be fun or activities that the children enjoy engaging in. The children talked about both physical activities such as horse riding and playing floor ball and quieter activities such as reading a book or listening to music. The children expressed that they felt good when doing or creating something. One child said, “*I painted because it was fun and good to have something to do when you have nothing else*”. It felt good to have something to do because it helped to pass the time. Creating something such as a cake or painting elicits satisfaction. It also emerged that it was important for the children to have the opportunity to withdraw to a private or quiet place to relax or to be alone. One child said, “*Sit there and have a snack... look at the birds that come flying ...then it is the view from the hut*”. The children talked about their own room or a hut
where they can sit or lay down and be with their own thoughts. The ability to withdrawal made them feel well and helped them to calm down if they were upset or angry. The children appeared to associate their photographs illustrating candy, fruits, flowers and holidays with enjoyment. One boy described his photographs in the following manner: “It is the flowers... it’s nice when spring comes... it feels good when the bees come out and there are so many flowers”. The children expressed a sense of enjoying things that are beautiful or good and enjoying the moment. The children related these objects to moments when it is beneficial to enjoy the good things in themselves. The photographs represented moments that were cozy and relaxed, causing the child to experience positive feelings and wellness.

The health-promoting factor of trustful environment includes confidence in significant others and feeling safe. The children had taken photographs of people, surroundings and their own mobile phone. When looking at the photographs, the children talked about feeling safe in their environment and the security their mobile phone provides them. One child said, “Yes, it’s my mobile... if you are out late or get lost, you can call home”. Through the mobile phone, they can always get in touch with their parents, regardless of where they are located. They also expressed that their home is a safe place and that makes them feel well. Thus, feeling safe emerged as a health-promoting factor. They also talked about their school, classmates and neighbours. One child said, “Yes it’s my class... they all make me feel good... everyone in my class is really kind”. They had taken photographs of these people and when they talked about them, it was clear that the children have confidence in them. The children perceived these people as kind, nice and brave and people who would not hurt them. Rather, these people cared for them. The children stated that the neighbours had time to listen to them and talk to them and their schoolmates were in their everyday life. When the children talked about their photographs, representing subjects that promote health, it emerged that it was about to be and to do in a context that is positive and trustful and, therefore, meaningful in everyday life. Relations, activities and environments that are meaningful in their everyday lives promote their health.

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In conclusion, children expressed that health-promoting factors are meaningful relationships, including togetherness within the family, affection for pets and friendship with peers; recreational activities, including engagement in play and leisure, withdrawal for relaxation and feeling enjoyment; and a trustful environment, including feeling safe and having confidence in significant others. It emerged that for childhood cancer survivors, a long-lasting health care contact to provide information, knowledge and psychosocial support as well as support from family and friends are potential health-promoting factors.

Friendship relations, a social dimension of health

Friends were common subjects of the children’s photographs of subjects that promote health (Paper II). When the children talked about their friends, it became evident that friendship relations developed over time (Paper III); see Table 6. Being with friends made the children feel well because they had someone to play with and they had fun (Paper II). In the children’s discussions regarding friendship relations, it appeared that the development of friendship relations is a process. This process requires certain prerequisites, which are described as the subcategories in Table 6. The process starts with common interests and experiences, which includes do things together and like to be together. When the children do things together and find that they like to be together, the first step in the process of friendship relation has occurred (Paper III). When the children talked about their friends, it was found that socializing was the primary focus and that the activities that they did together were less important (Papers II and III). One child said, ‘...we’re usually at the computer and then are together outside and can walk around almost anywhere...’. Enjoying the same things or having similar interests facilitate the friendship relation, but common interests are not an absolute requirement. It is more important for the children to have fun together and to put each other in a good mood (Papers II and III). Common interests represent more than having the same interests;
the children also have an interest in getting to know each other. One child expressed this as follows: ‘that you can think of being with that person, and think it’s fun’. The friendship relation begins with the children meeting each other at school, in the neighbourhood or in organized activities and discovering that they like to be together. The children stated that it is important that they both can propose activities or play when they are together (Paper III). Friendship is about wanting to be with each other, listening to each other and experiencing happiness together.

Table 6. Friendship relations.

<table>
<thead>
<tr>
<th>Main category</th>
<th>An equal and mutual commitment that evolves over time and with interaction face-to-face and digitally</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generic category</td>
<td>Common interests and experiences</td>
</tr>
<tr>
<td>Subcategory</td>
<td>Do things together</td>
</tr>
</tbody>
</table>

The second step in the friendship process is mutual empathic actions, which includes respecting each other and helping each other (Paper III). The children expressed that a friend is a person who is kind (Papers II and III). According to the children, friends care for each other and a friend can take turns when playing together. Respecting each other as friends refers to showing appreciation and being kind to each other. It involves saying positive things to each other and inviting the other to engage in activities. Helping each other can include, for example, waiting for each other, explaining difficult things when doing schoolwork or playing a game. One child said, ‘yes, I think more about helping another person to get around the track (in a computer game) that he has’. It can also be about receiving help from an adult if the friend is injured or simply carrying something for the friend. Friends support each other when needed, regardless of whether the issue concerns major or minor things in their everyday lives.
The third step in the friendship process, *mutual trust and understanding*, includes *having a shared history, trusting each other and being there for each other* (Paper III). Now, the relationship has evolved to a level at which the friends understand and have confidence in each other. To reach this level in the friendship relation, the two people must spend time together. The children expressed that they have known their close friends for a long time, sometimes because they went to preschool or they spent time together because their parents know each other. Furthermore, they may have spent time together at school or during their leisure time in their everyday lives. One child said, ‘*you’re together with that person a lot … you start being together a lot, that’s what it was like for me and my best friend*’. However, time together can also mean that the children have spent time together during a holiday, with the time together being intense rather than over a long period. Through this experience, the children gain a shared history. The friendship relation now involves sharing everything with each other and a feeling that the friend is always there. The children talked about trusting each other, which involves keeping promises and secrets. They also talked about having trust in each other such that they can tell each other everything without being afraid that the other will snitch on them. It was important that the friend also tell them everything; there must be a mutual trust, with both friends sharing stories and listening to each other. As one child stated, ‘*that they, for example, tell you everything*’. Being there for each other has a double meaning (or more than one meaning). The other one is there both physically, a person to spend time with, and emotionally, a person who understands and can provide comfort. The children expressed that friends can comfort you if you are sad and improve your mood (Papers II and III). Furthermore, friends can talk to you and help you to focus on other thoughts by joking or by proposing a fun activity to do together. According to the children, friends can provide support because they know and understand you.

In conclusion, from the children’s perspective and with a salutogenic perspective, a friendship relation refers to an equal and mutual commitment that evolves over time and includes both face-to-face and digital interactions.
The Swedish version of the MMQL instrument

The results provided in this section will be divided according to the result of the psychometric evaluation of the Swedish version of the MMQL-Youth Form and MMQL-Adolescent Form and the comparison between the MMQL-instrument and the health-promoting factors. First, the results of the psychometric evaluation of the MMQL instrument are presented. Then, the results of the comparison of the MMQL instrument with the health-promoting factors are presented.

Psychometric evaluation of the Swedish version of the MMQL instrument

The children who completed the Swedish version of the MMQL-Youth Form and MMQL-Adolescent Form expressed that the items were relevant to the purpose of the instrument. The statements in the questionnaire were considered as understandable and as having sufficient clarity and readability. The internal consistency was found to be acceptable for the total scale for both the MMQL-Youth Form and the MMQL-Adolescent Form. The Cronbach’s alpha coefficient for the total scale was 0.88 for the Youth Form and 0.92 for the Adolescent Form. In Table 7, the Cronbach’s alphas for the subscales are shown.

The test-retest reliability, according to ICC, ranged from 0.43-0.78 for the MMQL-Youth Form (Table 3 Paper IV) and from 0.24-0.76 for the MMQL-Adolescent Form (Table 4 Paper IV). The test-retest reliability was good for 16 of the items and moderate for the remaining 16 items of the MMQL-Youth Form. For the MMQL-Adolescent Form, the test-retest reliability showed good agreement for 10 of the items, moderate agreement for 26 items and fair agreement for 9 of the items.
Table 7. Cronbach’s Alpha Coefficient for the MMQL-Youth form and Adolescent form.

<table>
<thead>
<tr>
<th>Sub-scales of the scale</th>
<th>Youth form Cronbach’s Coefficient</th>
<th>Adolescent form Cronbach’s Coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Functioning (6 items)</td>
<td>.66</td>
<td></td>
</tr>
<tr>
<td>Psychological Functioning (8 items)</td>
<td>.81</td>
<td></td>
</tr>
<tr>
<td>Physical Symptoms (10 items)</td>
<td>.68</td>
<td></td>
</tr>
<tr>
<td>Outlook on Life/ Family Dynamics (8 items)</td>
<td>.78</td>
<td></td>
</tr>
<tr>
<td>Physical Functioning (8 items)</td>
<td></td>
<td>.69</td>
</tr>
<tr>
<td>Cognitive Functioning (9 items)</td>
<td></td>
<td>.86</td>
</tr>
<tr>
<td>Psychological Functioning (9 items)</td>
<td></td>
<td>.83</td>
</tr>
<tr>
<td>Body Image (6 items)</td>
<td></td>
<td>.78</td>
</tr>
<tr>
<td>Social Functioning (6 items)</td>
<td></td>
<td>.85</td>
</tr>
<tr>
<td>Outlook on Life (3 items)</td>
<td></td>
<td>.91</td>
</tr>
<tr>
<td>Intimate Relations (4 items)</td>
<td></td>
<td>.75</td>
</tr>
<tr>
<td><strong>MMQL overall scale</strong></td>
<td><strong>.88</strong></td>
<td><strong>.92</strong></td>
</tr>
</tbody>
</table>

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Comparison of the MMQL instrument and the health-promoting factors

The comparison of the items in the MMQL-Youth Form (Paper IV) and the health-promoting factors described by the children (Paper II) showed that five (16%) of the 32 items can be linked to a health-promoting factor. Four items on the physical functioning subscale can be linked to the health-promoting factor *engagement in play and leisure*. One item on the psychological functioning subscale, *feeling lonely*, captures the opposite concept of the health-promoting factor *friendship with peers*. Except for this item, none of the items of the MMQL-Youth Form capture *friendship with peers*, a health-promoting factor according to the children. None of the items capture *togetherness within the family* or *affection for pets*, which the children reported as health-promoting factors. The comparison of the items in the MMQL-Adolescent Form (Paper IV) and the health-promoting factors described by the children (Paper II) showed that 13 (29%) of the 45 items can be linked to a health-promoting factor. The items on the social functioning subscale and two items on the intimate relations subscale can be linked to the health-promoting factor *friendship with peer*. Four of the items on the physical functioning subscale can be linked to the health-promoting factor *engagement in play and leisure*, and the item *feeling lonely* on the psychological functioning subscale captures the opposite concept of the health-promoting factor *friendship with peers*. Like the MMQL-Youth Form, none of the items on the MMQL-Adolescent Form capture the health-promoting factor *togetherness within the family* or *affection for pets*.

In conclusion, the psychometric evaluation of the Swedish versions of the MMQL-Youth Form and MMQL-Adolescent Form indicated that the instruments are valid and reliable for use in a sample of healthy schoolchildren. The comparison of the MMQL instrument and the health-promoting factors showed that 16% of the items of the MMQL-Youth Form and 29% of the items of the MMQL-Adolescent Form can be linked to a health-promoting factor described by the children.
Discussion

Methodological discussion

A limitation and threat to the *internal validity* (Polit & Beck, 2013), as noted in the retrospective study (Paper I), is the internal dropout rate of 36%. It is not known why participants did not complete the questions included in the study. Although there were no sociodemographic differences between those who completed the questions and those who did not complete the questions, there still may be differences between these two groups, which may have affected the results. It could be that the non-participants want to move on with their life or that they choose to not participate because they feel well. However, it may be in the contrary, and they may have a more troublesome life situation, which caused them to decline to participate. In retrospective studies, caution should also be exercised regarding what the respondents remember; for example, regarding the information and support that they gained from the health care services. Participants who responded with "do not know" might potentially have been informed but do not remember it. However, the participants who responded with “do not know” were few compared to those who answered “yes” and “no.” Another limitation and threat to the *external validity* (Polit & Beck, 2013) is that the study examines the care that survivors of childhood cancer had received and not the care given today to childhood cancer patients. Although the Cronbach’s alpha value was acceptable for the questionnaire, it has not been tested before; thus, the result should be considered with caution. Regarding the *trustworthiness* (Polit & Beck, 2013) of the qualitative component of the study, *credibility and dependability* were strengthened due to discussions of the findings between the researchers. Quotations may strengthen the *authenticity of the study*. Despite the limitations, the result provides insight into what may be considered in the development of follow-up care, including health promotion for these patients.
Recruitment is not only dependent on the child's own will to participate, but it is also dependent on the adults' perception of the children's ability to participate in research and their desire to protect their children (Carter, 2009; Coyne et al., 2009). The parents (Paper II and III) expressed that they did not want their children to have to talk about subjects that could upset them, such as negative memories related to disease and treatment. The salutogenic approach (Antonovsky, 1987), which focuses on resources and the children’s current everyday life, was perceived as positive and more relevant to the parents and thus facilitated the recruitment. However, there were families that declined to have their children participate in the focus groups. The reason to not participate is not entirely known, but some of the families said that they did not have time to participate. Another reason for the decision to decline to participate was that they wanted to move on with their life and leave the period with cancer behind them.

To increase the trustworthiness, including credibility, dependability, confirmability, transferability and authenticity (Polit & Beck, 2013), different steps were considered throughout the focus group studies (Paper II and III). Previous studies have highlighted the importance of planning carefully the types of methods and when to use the methods during the data collection, the goal of which is to prevent the procedure from becoming chaotic for the children (Coad, 2007). The pilot focus groups made it possible to refine the arrangement and tasks to suit the children in the selected age group, which also increased the credibility of the studies (Paper I and II). By starting the focus groups with a written agenda, clarity and security were created for the children who had participated. It has been argued that the environment where the focus groups were asked to perform may influence the experience of comfort (Gibson, 2007; Kreuger & Casey, 2009). Despite the use of different facilities for the focus groups, it did not seem to affect the children’s participation. The premises seemed to play less of a role, which may be explained by the fact that the parents were close at hand to their children. The researcher has extensive experience working with children. Because the arrangement of the focus groups was adapted to the age group with elements that the children appreciated, such as the use of
visual art-based techniques and refreshment breaks, also facilitated this process. The latter also created an open climate and promoted communication within the group, which has also been previously reported (Gibson, 2007; Kreuger & Casey, 2009). It has been argued that focus groups with children should be homogeneous (Heary & Hennessy, 2002). In this thesis, one of the focus groups were mixed based on gender, but this did not generate any problems or differences regarding communication or the amount of data material compared to the other groups. Most likely, the need of homogeneity is dependent on the theme that is the subject of the discussion. A limitation of focus groups with children may be that children do not feel comfortable talking in groups (Coyne et al., 2009). This could therefore be a threat to the credibility of the study. During the recruitment, there was also a parent who had declined to participate in the study due to this reason. However, it is not known whether there were more children who had declined to participate related to shyness. One reflection is that if there are time and resources available when performing research with children, the best option would be to perform both individual interviews and focus groups.

Visual art-based techniques, such as drawing and show-and-tell and photography, proved to be useful methods. These methods provide child-centred structure that enabled the children to describe their experiences (Coad, 2007). However, it is important to discuss how satisfactory particular techniques are and if any of the used techniques were less satisfactory (Fargas-Malet et al., 2010). It was revealed that drawings were not always popular among the children when some of the children expressed that they were not comfortable with drawing. When they learned that their drawings would only be used in the focus group as a basis for discussion, the children relaxed and it became easier for them to draw. However, it may be further discussed whether drawing is a suitable method to interact with children. In research with children, the power imbalance is often discussed (Coyne et al., 2009). When the children are allowed to choose what to take photographs of and are allowed to choose which of these photographs they want to show in the focus group, their power is increased in relation to the researcher. To
entrust the children with a camera is a way to empower the children. The researcher shows confidence in the children’s ability, which may in turn strengthen them.

The children’s statements are often short (Paper II and III) and may therefore be perceived as less rich material compared with qualitative data obtained from adults. However, even if the data consisted of short statements, they were still rich; this has also been previously recognized upon closer analysis (Irwin & Johnson, 2005; Pelander & Leino-Kilpi, 2010). The author of this thesis was responsible for the initial analysis of the focus group studies (Paper II and III). The analysis was discussed with the co-researchers to strengthen confirmability and credibility. This may also have increased the dependability of the studies. Furthermore, the credibility was ensured by the fact that the children themselves explained and discussed the photographs and the photographs that the children did not want to talk about were excluded from the analysis (Paper II). By including quotes in the description (Paper II and III), authenticity may be achieved. The quotes allowed the description to become more vivid; thus, a sense of the participants’ experiences is reported (Polit & Beck, 2013).

The transferability (Polit & Beck, 2013) of the results (Paper II and III) may be discussed according to the context and participants. There were few participants, and no one of foreign origin participated, which may limit the transferability of the results. The reasons for why those with a foreign background declined to participate are not known. Furthermore, the findings in paper II and III may also be discussed from the view that the meaning of the phenomenon under discussion in the focus groups is constructed (Burr, 2003) by the participants and may have been seen as one of several truths about the phenomenon. The children’s experiences of the phenomenon are influenced by the context and time that they are living. However, these results (Paper II and III) are consistent with previous research performed in other parts of Sweden, as well as internationally (Hartup, 1996; Ihrskog, 2006; Kostenius & Öhrling, 2006; Nic Gabhainn & Sixsmith, 2006). The transferability of the results is also dependent on the description of the participants, data collection, data analysis and results. Carefully crafted
descriptions enable those of interest to determine if the findings can be transferred to similar groups (Polit & Beck, 2013). However, considering that the results are consistent with previous research, it is conceivable that they may be transferred to other groups of children in similar contexts.

Regarding the test of the psychometric properties of the Swedish version of the MMQL-Youth form and Adolescent form (Paper IV), there are some methodological considerations to be discussed. There are limitations in the evaluation of the content validity when it is limited to what the children considered about the existing items in the instrument. Although there are no completely objective methods to ensure instrument content validity (Polit & Beck, 2013), the content validity may be judged by a panel of experts to strengthen the evaluation of the instrument. However, development of the original MMQL instrument was performed in several steps to identify which questions should be included in the instruments. An assessment of construct validity was also performed (Bhatia et al., 2002; Bhatia et al., 2004). In the MMQL-Adolescent form, the ICC values were only fair for 20% of the items (Paper IV). If the ICC values depend on whether the instrument is unstable (stability) or if the instrument is sensitive to changes, then it is not possible to know based on this study. If the participating children were asked whether they felt better, the same or worse, then the test-retest could have been based on the children reporting the same well-being; in this case, the findings of the study have been strengthened.
Discussion of the findings

The salutogenic approach, what promotes health (Antonovsky, 1987), is the starting point and focus of the present thesis. Although there is no consensus about the definition of concept health promotion, proposed definitions in recent years are mostly based on the Ottawa Charter’s definition (WHO, 1986), and the salutogenic approach is emphasized in addition to the target group’s perspective. The overall aim for this thesis was to develop knowledge about how to promote health in children treated for cancer, as well as how health promotion interventions based on such knowledge can be evaluated.

The result showed that from the children’s perspective, health-promoting factors are meaningful relationships, recreational activities and a trustful environment (Paper II), which include family, friends and pets to engage in, play and leisure, relaxation and the feeling of enjoyment, as well as having confidence in others and feeling safe. Friendship relations, a social dimension of health, are an equal and mutual commitment that evolves over time and with face-to-face and digital interactions (Paper III). Support from family and friends as well as long-lasting health care contact, including information, knowledge and psychosocial support emerged as potential health-promoting factors for childhood cancer survivors (Paper I). Furthermore, these results indicated that the Swedish version of the MMQL-instrument is valid and reliable in a sample of healthy school children (Paper IV). However, less than a third of the items in the MMQL-instruments can be linked to a health-promoting factor described by children with experience with cancer treatment.

Health-promoting factors

The results showed that the children’s photographs (Paper II) were about meaningful relationships and recreational activities in a context that is
positive and trustful and thus promotes their health. The children expressed a holistic view of what promotes their health. They highlighted the importance of relationships to others for their health, as well as various forms of activities. In addition, they indicated that not just physical activities, but also quiet or creative activities, promoted their health. The children showed that they understood that the environment affects their health, particularly when it is perceived to be safe and when it is possible to have trust in others. Interestingly, the children do not focus on physical health, such as diet and physical activities; the current society tends to focus on such subjects. It can be discussed if the children’s view of health-promoting factors is dependent on the arrangement of the focus groups or if it may be explained by their experience of having a severe disease. However, the children’s holistic view of health has also been found in earlier studies with healthy children (Nic Gabhainn & Sixsmith, 2006; Piko & Bak, 2006). Children are aware of the importance of good relationships for their health, and access to emotional resources and support are as important as material resources (Backett-Milburn, Cunningham-Burley, & Davis, 2003). This explanation may be related to their age and developmental level. During school age, the children’s world expands and their social relations become more important (Hwang & Nilsson, 2011). Several of the children’s photographs (Paper II) were about being together with their family, pets and friends. The value of social relations for health is well known (Berkman & Glass, 2000), and research with school children has yielded similar results (Kostenius & Öhrling, 2006). Regarding the salutogenic model and the key constituent meaningfulness in the concept SOC (Antonovsky, 1987), togetherness within the family, affection for pets and friendship with peers (Paper II) may contribute to participation and may be things that are valuable investments. It has also been found that families with a child with cancer develop closer family bonds (Bjork et al., 2011; Sundler et al., 2013), which can explain why many of the children’s photographs are about their parents and siblings. The family was also emphasized as an important resource during and after treatment by the childhood cancer survivors (Paper I). These results show that interventions targeting families with a child with cancer, such as hospital-based home care and camp activities, are also desirable from the child’s perspective (Hansson, Kjaergaard, Schmiegelow, & Hallström, 2012;
Martiniuk, Silva, Amylon, & Barr, 2014; Wu, Prout, Roberts, Parikshak, & Amylon, 2011). The children emphasized pets as beings that can give closeness, comfort and fun. The importance of pets for children is not prominent in research (Tipper, 2011). However, children have highlighted pets as a form of social support (Kyngäs, 2004), and it has been found that animal-facilitated therapy may increase the QoL of paediatric patients (Urbanski & Lazenby, 2012). It is proposed that children’s relationships with pets provide specific types of interaction that may not be obtained from adults and that these relationships are complex and crucial for understanding the children’s perspective of their own lives (Tipper, 2011). Attachment and social support may underlie the ability of pets to promote health (Casciotti, 2014). Furthermore, it could be discussed from the perspective of SOC (Antonovsky, 1987) that if pets make life more manageable and meaningful, they can contribute to a movement towards health. Based on the above description, pets should be highlighted more in research and health promotion interventions targeting children. Nurses can support the children by stressing pets as important in the children’s social network and to consider if it is possible for children at the hospital to have contact with their pets.

During school age, friends become more important for children (Hwang & Nilsson, 2011). Friends were also represented in several of the children’s photographs (Paper II) and were listed as a resource by childhood cancer survivors (Paper I). It was revealed that it was more important to meet with friends than to take part in the activity (Paper II and III). According to the children, friendship relations promote health because they give the children a positive feeling because friends have fun and put each other in a good mood (Paper II). Friendship relations develop over time, and the development of friendship requires specific aspects, such as doing things together, respect for each other and trusting each other (Paper III). The school is an important arena where children can develop friendship relations over time, but for children with cancer during the treatment period, it might be difficult to maintain contact with their friends (Enskär & von Essen, 2008; Griffiths, Schweitzer, & Yates, 2011). After the treatment period, when the children return to school, it may be difficult to integrate with a peer group and to follow social rules at school (McLoone, Wakefield, & Cohn, 2013). Today,
there is limited research regarding interventions that focus on children’s return to school and their peer relationships (Helms et al., 2014). However, programmes with school-related social networking for children in paediatric care have shown promising results. Continued contact with the school-class during hospitalization resulted in a retained connection to classmates as well as a facilitated return to school (Dunlap, Kagan, Arnold, & Gottschlich, 2013). Nurses should engage in helping sick children to maintain their social networks because it is important for their health and recovery (Hean et al., 2013). This can be achieved by enabling contact with friends or other important persons in the child’s social network when staying at the hospital and by considering social networks in which the child might be involved (Hean et al., 2013; Olsen & Harder, 2011). Classmates may be involved as ambassadors that can create a bridge between the child’s everyday life at home and at the hospital, with the aim of recreating a normal everyday life for the child at the hospital (Thorsteinsson et al., 2013). The results in this thesis showed that friendship relations developed both face-to-face and digitally (Paper III). New methods for children to maintain and develop their friendship relations during hospitalization have been introduced. A nurse-led intervention using videoconferencing technology resulted in decreased isolation, maintenance of contact with classmates, improved peer acceptance, and a sense of normalcy for children during their cancer treatment (Ellis et al., 2013). Nurses working with children during treatment periods have an important role in supporting the children to maintain their contact with friends and classmates so that the children’s friendship relations can continue to develop. Consistent with this finding, cooperation between school and health care is important and may be possibly maintained through Swedish outreach nurses. However, the responsibility for children with cancer, both during and after treatment, lies both with the personnel at the hospital and also the school personnel, particularly the school personnel group with the task of supporting its pupils’ learning, development and health, including the psychologist, school nurse, special educator and social worker (SFS, 2010:800). Nurses at paediatric clinics and school nurses have different perspectives related to their work inside and outside of the hospital and school, and together with the child and parents, they may create a broader view of the child’s school and friendship situation. A cooperation of
this type may bridge the need of information and knowledge for the children, parents and school personnel.

Recreational activities, including engagement in play and leisure, withdrawal for relaxation and feeling enjoyment, were revealed as significant health-promoting factors from the children’s perspective (Paper II). Engagement in play and leisure comprised of both being with friends and doing things on their own to have fun and to have something to do (Paper II). It is well known that play is important for children’s physical, emotional and social health and well-being. Children’s play provides opportunities to develop physical function, social abilities, and creativity (Alexander, Frohlich, & Fusco, 2014; Ginsburg, 2007). Play and friendship relations are intertwined and provide the child with experience of social relationships, e.g., how to manage conflicts (Ginsburg, 2007; Hwang & Nilsson, 2011). From the perspective of the SOC (Antonovsky, 1987), recreational activities may contribute to manageability. Furthermore, recreational activities involve engagement and enjoyment, which may contribute to meaningfulness. The importance of play for children is also emphasized in the Convention on the Rights of the Child, article 31 (United Nations, 1989), which also addresses the children’s right to rest and leisure. The children described a need of both movement and stillness (Paper II), which can be compared to the view of health as a rhythm of life (Dahlberg & Segesten, 2010). Health and well-being demand rhythm, including physical activity and rest. Currently, the need for movement, such as physical activity to prevent ill-health, is well known (see for e.g., Feeny et al., 2014; Ortega, Ruiz, Castillo, & Sjöström, 2008), and it has been found that physical activity may improve HRQoL in childhood cancer survivors (Mishra, Scherer, Snyder, Geigle, & Gotay, 2014). The children stressed the opportunities to withdraw for relaxation, to be alone for a while, take it easy and relax or to be with their own thoughts (Paper II). This can be related to the need of rest to experience health as a rhythm of life (Dahlberg & Segesten, 2010). Stillness is not to be confused with not moving (the body), but rather it refers to tranquillity, which is possible even when walking or running (Dahlberg & Segesten, 2010). The children also expressed this need when they talked about activities in which they were able to withdraw and be by themselves with their own thoughts (for example, to calm down if they were upset) (Paper II). The children
expressed an understanding for the need of movement as something that provides pleasure and well-being, and they understood stillness as something that provides tranquillity. They understood that the first did not exclude the second. Children’s understanding of the need for both movement and stillness should be encouraged. Nurses have a key role to support and encourage this knowledge in children because nurses often have close contact with children and parents in health care and school.

Well-meaning parents may overprotect their children and prevent them from taking part in school and leisure activities (Earle, Clarke, Eiser, & Sheppard, 2007; Enskär et al., 1997; Rivero-Vergne et al., 2010). This can limit the possibilities for the children to perform recreational activities where they can move, have fun and maintain and develop their friendship relations. Parents may be uncertain of what their children are capable of and may want to protect their children from infections and injuries (Earle et al., 2007; Rivero-Vergne et al., 2010). However, it has been shown that children undergoing cancer treatment do not have an increased risk for starting antimicrobial treatment when attending school compared to those who are absent from school (af Sandeberg, Wettergren, Björk, Arvidson, & Johansson, 2013). There are national guidelines for children undergoing cancer treatment that convey that it is the child’s general condition that will determine if the child can, for example, go to school (National recommendations on social life when children are being treated for cancer, 2008 [revised 2015]). Currently, information is provided to school personnel, but there are indications that the information provided is too limited and insufficient (Selwood, Hemsworth, & Rigg, 2013). This also applies to information given to parents, who have expressed that they are dissatisfied with the availability of information, particularly in the later stages of the child’s treatment (Kästel, Enskär, & Björk, 2011; Ringnér, Jansson, & Graneheim, 2011). Nurses have an important role in providing information and advocacy for the children’s need for contact with friends and need for movement and stillness. This may be achieved via information provided at several occasions to parents and school personnel so that they feel secure with the idea of children going to school, socializing with their friends, playing and participating in leisure activities. If the contact between school personnel, health care professionals and family were regular, information could be repeated, deepened and updated as
needed. Health care professionals need to develop their health promotion work to support the children to maintain their contact with school and friends. School personnel need to maintain their contact with the child and her/his family and not place all of the responsibility on health care professionals during treatment periods. There is a need for a formalised cooperation, including children themselves, parents, school personnel and health care professionals. This formalised cooperation could be based on the existing organization in schools, which would work with outreach nurses with regards to the children’s development and health.

Childhood cancer survivors desire a health care contact who can meet their personal needs, including one who has knowledge related to their medical history and may provide psychosocial support (Paper I). The result is consistent with previous research that describes an unmet need for information and psychosocial support after childhood cancer treatment (Olsson, Jarfelt, Pergert, & Enskär, 2015). Although a request for psychosocial support (Goodall, King, Ewing, Smith, & Kenny, 2012) has been recommended, psychosocial issues appear to be deficient in the encounter between childhood cancer survivors and healthcare personnel (Lamanna, Trapp, Russell, & Stern, 2014). Knowledge and support can be viewed as health-promoting factors because they represent resources for the individual to understand and manage their life situation, including during and after cancer treatment. Together with other resources, knowledge and support may contribute to the GRR (Antonovsky, 1987). This could further be explained by the components comprehensibility, manageability and meaningfulness in the SOC (Antonovsky, 1987). Psychosocial support, including expertise and continuity, can enable childhood cancer survivors to take control over their health situation. Knowledge and support may result in comprehensibility and manageability in everyday life for childhood cancer survivors. Furthermore, meaningful relationships, such as family and friends, may contribute to meaningfulness. Available resources, such as meaningful relationships, recreational activities, knowledge and support, can contribute to a movement towards health for the child with cancer or later in life as a childhood cancer survivor.
In health promotion, there is a need for a salutogenic approach that includes a focus on resources; there is also a need for an ecological approach in which referrers can take into account various aspects and contexts that may be considered in health promotion interventions (Golden & Earp, 2012; Green & Tones, 2010). Health-promoting factors that have emerged in this thesis (Paper I and II) could be viewed from an ecological perspective. Meaningful relationships, including togetherness within family, affection for pets and friendship with peers, belong to the microsystem, according to Bronfenbrenner's ecological model (1977). Recreational activities may also be placed within the microsystem, i.e., the system where the children have first-hand contact with individuals that they are interacting. A trustful environment (in which the child has confidence in significant others and feels safe), the school and the health care service, can be placed in the exosystem. The macrosystem may be discussed based on the view of society, including parents and school personnel, such that the children must be protected and therefore they may be limited in their social life and recreational activities. Nurses encountering children during or after treatment for cancer need to be aware of these systems, which have an effect on the child. Nurses should also be aware that each system may consist of resources that could be useful in promoting the children's health. By being aware of the context that surrounds the child, nurses can work with health promotion strategies, i.e., advocacy, enablement and mediation (WHO, 1986). Advocacy may be achieved by emphasising the need of a formalised cooperation between the school and health care service. Nurses may advocate for available resources, such as meaningful relationships and recreational activities. Enablement may be achieved through interventions that support the children to maintain their contact with school, their friends, and their pets during treatment periods and by further providing knowledge and psychosocial support after treatment and later in life. Mediation may be achieved through information to school personnel and parents about the children's need of contact with school and friends.
**The MMQL instrument and evaluation of health promotion interventions**

The result indicated that the Swedish version of the MMQL-Youth form and Adolescent form could be considered as valid and reliable instruments in a sample of healthy school children (Paper IV). However, the subscale physical functioning in the MMQL-Youth form obtained an alpha coefficient of 0.66, which is below the acceptable alpha of 0.70. The subscale physical symptoms received an alpha of 0.68. In the MMQL-Adolescent form, the subscale physical functioning received a coefficient alpha value of 0.69. An explanation for the low alpha coefficient value could be that the items in the subscales are not valid for healthy children. Other studies have also found a low internal consistency value on physical functioning (Raat, Landgraf, Bonsel, Gemke, & Essink-Bot, 2002). However, it has been found that physical health items are less important than social and psychological determinants of QoL in a sample of children with chronic somatic diseases. Relationships with friends and parents were the most important for these children (Webb et al., 2013). In the focus groups, and in the discussions with children about what promotes health (Paper II), factors related to physical health were not highlighted as important. This finding could suggest that regardless of whether or not children have a disease, social and emotional aspects are of greater importance for children than aspects related to physical health. Consistent with this finding, it is important to further evaluate the Swedish version of the MMQL instruments in a sample of children with different conditions, including experiences of cancer treatment. Furthermore, the stability for 20% of the items in the MMQL- Adolescent form showed a fair agreement between the test and retest. It should be further discussed if the fair agreement is dependent on the sensitivity of the instrument for changes rather than the possibility of the instrument being unstable. The actual items represent issues that may change over short intervals; for example, anxiety, mood, pain (Grove et al., 2013), and other feelings of adolescents may change quickly. These findings could suggest that the test-retest should be measured with a shorter interval.
In evaluating health-promoting interventions, there is a need of valid instruments that can assess the expected outcome. According to the psychometric properties (Paper IV) for the MMQL instrument, the MMQL instrument may be useful as an outcome measurement in the evaluation of health promotion interventions. However, when comparing the items in the MMQL instrument with the health-promoting factors that the children highlighted, it was found that less than one-third of the items could be linked to the health-promoting factors (this thesis). When targeting children, it is important to use instruments that capture aspects of health and QoL, which are important to children (Anthony et al., 2014), particularly if the intervention aims to be based on the children’s perspective. It should be further discussed if the MMQL instrument captures important dimensions of health for children, such as meaningful relationships, including family, friends and pets. Previous studies have emphasized the importance of clarification, including subdomains, that are considered most important by children with cancer, as well as how these domains should be measured (Anthony et al., 2014). Qualitative research, such as this thesis (Paper II and III), can provide important knowledge from the perspective of children with experience of cancer treatment to provide insight towards the development of instruments for measurement of QoL/HRQoL in this population. There could be a need to complement available instruments, such as the MMQL instruments, with items that capture aspects of importance for children, such as meaningful relationships. Another consideration is that instruments provide only a limited view of how the person, or in this case, the child, experiences her/his health and QoL (Parse, 2013). Why there might be a reason to add qualitative approaches to the evaluation should also be considered. Furthermore, the evaluation should address important principles for health promotion, such as participation (Green & Tones, 2010). Why health promotion interventions targeted at children should be evaluated of the participating children. This could be achieved using valid self-report instruments consisting of subdomains that are important for children and are complemented with qualitative methods, such as focus groups with participatory and art-based techniques, which are useful methods when the children’s experiences are requested.
Conclusions

The results in this thesis provide knowledge from a participant perspective regarding needs and experiences of health-promoting factors for those with experience of childhood cancer treatment. Childhood cancer survivors expressed a need for health-promoting factors in terms of knowledge and psychosocial support, which, from the perspective of SOC, may contribute to comprehensibility and manageability. Their family and friends may, from the perspective of SOC, contribute to meaningfulness. Children with experience of cancer treatment expressed a holistic view of health-promoting factors. According to the children, health-promoting factors are meaningful relationships including togetherness within the family, affection for pets, friendship with peers; recreational activities including engagement in play and leisure, withdrawal for relaxation, and feeling enjoyment; and a trustful environment including confidence in significant others and feeling safe. From the perspective of SOC, these health-promoting factors may contribute to manageability and meaningfulness. Friendship relations, a social dimension of health, is a process of equal and mutual commitment that develops over time and with interactions occurring face-to-face and digitally. The results show that for friendship to develop, there is a need for certain prerequisites, such as doing things together, helping each other and having a shared history. The findings contribute to the field with useful insights on how the children’s friendships may be supported.

The results indicate that the MMQL instrument is valid and reliable in a sample of healthy children. In comparison with the health-promoting factors that the children highlighted, it was found that less than one-third of the items in the MMQL instrument could be linked to a health-promoting factor. If the MMQL instrument is used for evaluation of health promotion among children who have received treatment for cancer, there is a need to complement it with aspects of health important to the children.
Clinical implications

By listening to the children, suggestions were obtained as to the resources that health care professionals may utilize, enable, enhance or improve to promote the health of the children. Nurses encountering children with cancer need to see their role as health promoters regardless of if they work at hospitals or at schools. It is suggested that health promotion for children with experience of cancer treatment needs formalised cooperation, including the children themselves, parents, school personnel and health care professionals. This cooperation could uphold regular contact with updates regarding information to enable the children to maintain their contact with school and friends. The formalised cooperation could be based on the existing organization in schools, which would work with outreach nurses.

Nurses may advocate for available resources, such as meaningful relationships and recreational activities; this includes providing information about children’s need to maintain contact with the school, friends and pets. It is suggested that nurses should enable the children to maintain their contact with school and friends through new technology available today, such as digital and mobile services. Nurses may explore the possibilities to enable children at the hospital to have contact with their pets. They should also encourage the children to engage in recreational activities, including both movement and stillness. As the children age there is a need for health care professionals, including nurses, to enable them to obtain knowledge and psychosocial support to promote movement towards health.

This thesis illustrates the importance for those healthcare professionals encountering children to be alert to the fact that children have the answers on what promotes their health; all it takes is asking the children.
Research implications

The findings in this thesis note that there is a need for intervention studies that explore health promotion interventions with the aim of supporting children by maintaining their contact with school and friends. The need for formalised cooperation, including children themselves, parents, health care professionals and school personnel, requires evaluation studies to explore the effects of new approaches.

It is suggested that research should explore how children’s contact with their own pets may be supported when they are staying at a hospital and how pets can promote movement towards health for children.

There is a need to further explore how the evaluation of health promotion interventions targeting children who have received treatment for cancer can be performed. It is suggested that the Swedish version of the MMQL instrument be further evaluated in groups of children with different conditions, including those who received treatment for cancer. There is also a need to explore how instruments used in the evaluation of health promotion may be complemented to capture aspects of importance to the children, such as meaningful relationships.

Children’s participation in research that effects them should ensure that the child’s perspective is included. Using focus groups in combination with art-based techniques can be recommended in future research with children. In particular, the combination of focus groups and photography turned out to be a successful method as it contributed rich information to this thesis. Research with children as the subjects needs to be explored from the children’s perspective to develop knowledge about their experience of taking part in research and about their preferred methods. Children should also, to a greater extent, be active participants when planning research. Children have knowledge about their life situation and about what is interesting to explore from their perspective.

Hälsofrämjande insatser bör grundas på en salutogen ansats och en ekologisk ansats. Den salutogena ansatsen har i fokus vad som leder till hälsa i motsats till en patogen ansats där fokus är vad som orsakar ohälsa. Med en ekologisk ansats tas alla resurser i beaktande, både hos personen och i omgivningen. Utöver dessa ansatser är det av betydelse att de personer insatserna vänder sig till får komma till tals, som att barnen tillfrågas i det som berör dem. Sjuksköterskor har ett ansvar för och en särskild roll i det hälsofrämjande arbetet, då de ofta finns nära personen i vården. Hälsofrämjande insatser behöver också utvärderas för att se om de har effekt, vilket delvis kan göras genom att mäta hälsorelaterad livskvalitet. För att kunna utveckla hälsofrämjande interventioner för barn med erfarenhet av cancerbehandling behöver kunskap utvecklas med barnens perspektiv på vad som främjar deras hälsa, samt med ett salutogent perspektiv. Idag är forskningen mycket begränsad avseende hälsofrämjande insatser utifrån perspektivet barn med
erfarenhet av cancerbehandling och med en salutogen ansats. För att sedan kunna utvärdera de hälsofrämjande insatserna behöver det finnas tillförlitliga instrument som fångar de aspekter barnen upplever är viktiga för deras hälsa.

Det övergripande syftet med denna avhandling var att utveckla kunskap om hur hälsa kan främjas hos barn med erfarenhet av cancerbehandling och hur hälsofrämjande interventioner baserad på denna kunskap kan utvärderas. En beskrivande och utforskande design har använts med både kvalitativa och kvantitativa metoder. I delstudie I deltog 144 personer (24-42 år) från en svensk kohort med personer som behandlats för akut lymfatisk leukemi under barndomen. De besvarade ett frågeformulär om stöd från hälso- och sjukvården. I delstudie II och III deltog femton barn (8-12 år) med erfarenhet av cancerbehandling i fem fokusgrupper med två träffar per grupp. Fokusgrupps-metodiken kombinerades med metoder som att rita och berätta och att fotografera och berätta. Barnen diskuterade vad som främjar deras hälsa och vad vänskap är. I delstudie IV användes en metodologisk design för att utvärdera mätegenskaperna och användarbarheten hos den svenska versionen av frågeformuläret Minneapolis-Manchester Quality of life (MMQL), barn och ungdomsvarianterna. I delstuden deltog 950 skolbarn i årskurs 6 och 9 från 7 skolor i en kommun i västra Sverige. I tillägg till utvärderingen av frågeformuläret gjordes en jämförelse mellan frågeformuläret och de hälsofrämjande faktorer som framkom i fokusgrupperna med barnen.

I resultatet framkom att hos de som behandlats för cancer i barndomen finns behov av hälsofrämjande faktorer i form av kunskap och psykosocialt stöd från hälso- och sjukvården. Familj och vänner kan vara ett stöd och därmed vara en hälsofrämjande faktor. I fokusgrupperna med barn framkom att barnen hade en holistisk syn på vad som främjar deras hälsa. Hälsofrämjande faktorer var meningsfulla relationer, rekreativa aktiviteter och en tillitsfull omgivning. I dessa faktorer ingår gemenskap med familjen, tillgivenhet till husdjur, vänskap med kompisar, engagemang i lek och fritid, att dra sig tillbaka för avkoppling, njuta av det goda, tillit till viktiga personer och att känna sig trygg. Utifrån barnens perspektiv är vänskapsrelationer en process med jämlikt och ömsesidigt engagemang som utvecklas över tid och med

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