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When children undergo radiotherapy

Exploring care, developing and testing preparation procedures

Jenny Gårdling



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DOCTORAL DISSERTATION

by due permission of the Faculty of Medicine, Lund University, Sweden.

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Title and subtitle. When children undergo radiotherapy. Exploring care, developing and testing preparation procedures		
<p>Abstract</p> <p>Radiotherapy (RT) is a repetitive treatment divided into daily fractions, scheduled five days a week from one up to several weeks depending upon the child's diagnosis. Although RT is painless and non-invasive, children experience anxiety. Depending on the child's age, anxiety or inability to comply, they may require sedation or general anaesthesia (GA), meaning that some children receive GA over 30 times during their RT, which may have a negative effect on the child's health. The overall aim of this thesis was to explore care, develop and test preparation procedures for children with cancer undergoing RT. Radiotherapy nurses' (RTN) perceptions of caring for children undergoing RT and parents' lived experiences while their child underwent RT was explored. Based on the findings, previous research and theoretical framework, age-appropriate information and preparation procedures for children undergoing RT were developed and tested for feasibility and effectiveness in terms of need for GA and anxiety. Furthermore, the impact of age-appropriate information and preparation procedures for children with cancer undergoing RT on parents' and family functioning, parents' anxiety and hospital costs compared to traditional care was evaluated.</p> <p>Semi-structured interviews of RTNs were conducted and the interviews were analysed using a phenomenographical approach. Parents wrote a diary about their lived experience while their child underwent RT and the diaries were analysed with hermeneutic phenomenological methodology. A quasi-experimental controlled clinical trial was conducted. Seventeen children aged 3-18 years and 31 parents receiving age-appropriate preparation procedures were compared with 16 children and 32 parents in a control group. The children and parents in the control group received traditional care and in the intervention group, they received age-appropriate information and preparation procedures. The child's and parents' anxiety was measured and the child's emotional behaviour was observed during the first three fractions, then at every fifth fraction and the last fraction. Furthermore, the parents answered questionnaires about their sense of coherence, and their and the families' functioning.</p> <p>The findings showed that the RTNs perceived that they provided holistic care, created a sense of security and became committed. The RTNs wished to meet the family and child before the treatment began. Continuity with healthcare professionals and routines was a priority and keeping the balance between care, technology and communication were important parts as well as broadening their competence regarding childcare. The analyses of the parents' diaries showed that the parents experienced their child's RT as a balancing act involving coercing and protecting their child, balancing despair and hope, and feelings of powerlessness and trying to gain control. Being close to their child, meeting the same healthcare professionals and finding routines and strategies during treatment was experienced as important. The whole family was in need of support and they wished for help to coordinate the care. To maintain normality in daily life it was important for the parents to gain control. The developed age-appropriate information and preparation procedures, including written information, in advance meeting the RTN, doll-models to play with, pay a visit to the treatment room, watch a movie or listen to music during RT and hold onto a "safety-string", were found feasible and acceptable. No statistically significant differences were found concerning the number of children receiving GA or their and the parents' anxiety. However, three children planned for GA in the intervention group completed their RT without GA, including 73 fractions awake. Children receiving GA, regardless of group, showed significantly higher negative emotional behaviour. Parents whose children received GA showed significantly increased anxiety. Parents of children in the intervention group showed significantly better communication at the first and last fraction and better social function at the child's last fraction. There were no significant differences between the groups concerning hospital costs. However, hospital costs for the three children not receiving GA in the intervention group were reduced by SEK 385 002.</p> <p>In conclusion, this thesis has shown that age-appropriate information and preparation procedures for children with cancer undergoing RT are important for the children, parents and healthcare. If a child is able to undergo RT without receiving GA, it means fewer risks and restrictions for the individual child, and less anxiety for both the child and the parents. Furthermore, healthcare costs are reduced, which makes it possible to prioritize other areas where anaesthetic professionals are needed. To demonstrate effectiveness, a larger study with a more homogeneous group of children is needed.</p>		
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Abstract

Radiotherapy (RT) is a repetitive treatment divided into daily fractions, scheduled five days a week from one up to several weeks depending upon the child's diagnosis. Although RT is painless and non-invasive, children experience anxiety. Depending on the child's age, anxiety or inability to comply, they may require sedation or general anaesthesia (GA), meaning that some children receive GA over 30 times during their RT, which may have a negative effect on the child's health. The overall aim of this thesis was to explore care, develop and test preparation procedures for children with cancer undergoing RT. Radiotherapy nurses' (RTN) perceptions of caring for children undergoing RT and parents' lived experiences while their child underwent RT was explored. Based on the findings, previous research and theoretical framework, age-appropriate information and preparation procedures for children undergoing RT were developed and tested for feasibility and effectiveness in terms of need for GA and anxiety. Furthermore, the impact of age-appropriate information and preparation procedures for children with cancer undergoing RT on parents' and family functioning, parents' anxiety and hospital costs compared to traditional care was evaluated.

Semi-structured interviews of RTNs were conducted and the interviews were analysed using a phenomenographical approach. Parents wrote a diary about their lived experience while their child underwent RT and the diaries were analysed with hermeneutic phenomenological methodology. A quasi-experimental controlled clinical trial was conducted. Seventeen children aged 3-18 years and 31 parents receiving age-appropriate preparation procedures were compared with 16 children and 32 parents in a control group. The children and parents in the control group received traditional care and in the intervention group, they received age-appropriate information and preparation procedures. The child's and parents' anxiety was measured and the child's emotional behaviour was observed during the first three fractions, then at every fifth fraction and the last fraction. Furthermore, the parents answered questionnaires about their sense of coherence, and their and the families' functioning.

The findings showed that the RTNs perceived that they provided holistic care, created a sense of security and became committed. The RTNs wished to meet the family and child before the treatment began. Continuity with healthcare professionals and routines was a priority and keeping the balance between care, technology and communication were important parts as well as broadening their competence regarding childcare. The analyses of the parents' diaries showed that the parents experienced their child's RT as a

balancing act involving coercing and protecting their child, balancing despair and hope, and feelings of powerlessness and trying to gain control. Being close to their child, meeting the same healthcare professionals and finding routines and strategies during treatment was experienced as important. The whole family was in need of support and they wished for help to coordinate the care. To maintain normality in daily life it was important for the parents to gain control. The developed age-appropriate information and preparation procedures, including written information, in advance meeting the RTN, doll-models to play with, pay a visit to the treatment room, watch a movie or listen to music during RT and hold onto a “safety-string”, were found feasible and acceptable. No statistically significant differences were found concerning the number of children receiving GA or their and the parents’ anxiety. However, three children planned for GA in the intervention group completed their RT without GA, including 73 fractions awake. Children receiving GA, regardless of group, showed significantly higher negative emotional behaviour. Parents whose children received GA showed significantly increased anxiety. Parents of children in the intervention group showed significantly better communication at the first and last fraction and better social function at the child's last fraction. There were no significant differences between the groups concerning hospital costs. However, hospital costs for the three children not receiving GA in the intervention group were reduced by SEK 385002.

In conclusion, this thesis has shown that age-appropriate information and preparation procedures for children with cancer undergoing RT are important for the children, parents and healthcare. If a child is able to undergo RT without receiving GA, it means fewer risks and restrictions for the individual child, and less anxiety for both the child and the parents. Furthermore, healthcare costs are reduced, which makes it possible to prioritize other areas where anaesthetic professionals are needed. To demonstrate effectiveness, a larger study with a more homogeneous group of children is needed.

Original papers

The thesis for the doctoral degree is based on the following papers:

- I Gårdling, J., Edwinston Månsson, M., Törnqvist, E. & Hallström, I. (2015). Caring for children undergoing radiotherapy treatment: Swedish radiotherapy nurses' perceptions. *European Journal of Oncology Nursing*, 9(6), 660-666. doi: 10.1016/j.ejon.2015.04.004. Epub 2015 May 21.
- II Gårdling, J., Törnqvist, E., Edwinston Månsson, M. & Hallström, I. (2016). Parents' lived experiences during their child's radiotherapy. *Journal of Pediatric Oncology Nursing*, 34(2), 140-147. doi: 10.1177/1043454216646540. Epub 2016 Jul 7.
- III Gårdling, J., Törnqvist, E., Edwinston Månsson, M. & Kristensson Hallström, I. (2017). Age-appropriate preparations for children with cancer undergoing radiotherapy – a feasibility study. *Journal of Child Health Care*. doi: 10.1177/1367493517727070. Epub 2017 August 22.
- IV Gårdling, J., Törnqvist, E., Edwinston Månsson, M. & Kristensson Hallström, I. Impact of age-appropriate preparations for children with cancer undergoing radiotherapy on parents' and family functioning, parents' anxiety and hospital costs. *Submitted*.

Abbreviations

CCC	Child-centred care
CCT	Controlled Clinical Trial
CEMS	Children's Emotional Manifestation Scale
CG	Control Group
CT	Computer Tomography
FCC	Family Centred Care
FPS-R	Facial Pain Scale-Revised
GA	General Anaesthesia
HR	Heart Rate
HRQOL	Health-Related Quality of Life
IG	Intervention Group
MRC	Medical Research Council
MRI	Magnetic Resonance Imaging
PedsQL	Pediatric Quality of Life Inventory
RT	Radiotherapy
RTN	Radiotherapy Nurse
SEK	Swedish Kronor
SOC	Sense of Coherence
UNCRC	United Nations Convention on the Rights of the Child
VAS	Visual Analog Scale

Introduction

When a child is diagnosed with cancer radiotherapy (RT) may be a part of the treatment with the intention to cure or relieve symptoms. RT is a repetitive treatment divided into daily fractions, scheduled five days a week from one up to several weeks depending upon the child's diagnosis. Although RT is a non-invasive treatment it can be stressful and cause anxiety for the child (Filin, Treisman, & Peles Bortz, 2009; Slifer, 1996; Tyc, Klosky, Kronenberg, de Armendi, & Merchant, 2002) since the child is exposed to an unfamiliar environment, separated from the parents during treatment and having to keep completely still. Depending on the child's age or inability to comply, sedation or general anaesthesia (GA) may be required, meaning that some children receive GA over 30 times during RT. The procedure of GA involves risks, sleep disruption and sub-optimal nutrition, which may create additional discomfort for children (Buchsbaum et al., 2013; Fortney, Halperin, Hertz, & Schulman, 1999; Seiler et al., 2001) and for the parents (Ångström-Brännström et al., 2015; Houtrow, Yock, Delahaye, & Kuhlthau, 2012). RT also puts high demands not only on the child and the parents but also on the radiotherapy nurse (RTN) who is responsible for the care process (Diggins & Chesson, 2014; Probst, Griffiths, Adams, & Hill, 2012). Research about RTNs' perceptions of caring for children undergoing RT is lacking but caring for adult patients during RT has shown to entail both positive and negative aspects, e.g. developing a relationship with the patient (Diggins & Chesson, 2014; Lawrence, Poggenpoel, & Myburgh, 2011) and seeing the patients suffering (Diggins & Chesson, 2014; Sehlen et al., 2009).

Qualitative studies about parents' experiences of having a child undergoing RT are scarce. However, quantitative studies including both children and parents receiving interactive-educational intervention in connection with RT have shown that anxiety decreases before and during RT (Klosky, Garces-Webb, et al., 2007; Klosky et al., 2004), children experience more support and their ability to comply increases (Barry, O'Callaghan, Wheeler, & Grocke, 2010; Pimm, Fitzgerald, & Taylor, 1997). Different interventions for children undergoing RT containing increased information, professional-child interaction and/or technical facilities have also shown to decrease the use of GA (Filin et al., 2009; Haeberli et al., 2008; Scott, Langton, & O'Donoghue, 2002; Scott et al., 2016; Slifer, 1996; Tsai et al., 2013; Willis & Barry, 2010).

Earlier research has focused on interventions with one component, included small children, few participants and/or were technically advanced. Combining different interventions could lead to greater importance for the child and family (Edwinson Månsson, 1992; Törnqvist, Månsson, & Hallström, 2015). Thus, it is important to continue to explore methods that integrate different components, which are not costly, to decrease children's and parents' anxiety during RT and the use of GA in children. Extended information and a better understanding of what it implies to be treated with RT might as a result improve care when children undergo RT and facilitate children to undergo RT without GA, with less anxiety and restrictions for the child and parents and reduced hospital costs.

Background

Children undergoing radiotherapy

Every year globally more than 250 000 children below the age of 20 year are diagnosed with cancer and nearly 35% of these children do not survive (Childhood Cancer International, 2017). In Sweden, about 390 children aged 0-19 years are diagnosed yearly (Socialstyrelsen, 2015) and of these children nearly 75% survive (Socialstyrelsen & Cancerfonden, 2013). The diagnosis of cancer include various diagnoses, of which about 70% are leukemia, lymphoma and brain tumours (Swedish Childhood Cancer Registry, 2013). The treatment for cancer may involve surgery, chemotherapy and RT, and many children receive a combination of treatments. Approximately 120 children in Sweden per year receive RT (Björk-Eriksson & Glimelius, 2005) and the aim of RT is either to cure (curative treatment) or to relieve symptoms (palliative treatment). Cancer diagnoses treated with RT are for example tumours in the central nervous system, solid tumours and total body irradiation prior to stem cell transplantation.

During RT, the child is alone in the treatment room due to radiation and needs to keep completely still. However, some children experience stress and anxiety during RT (Tyc et al., 2002) and may require GA. GA may also be given to children due to the child's age, inability to comply or according to hospital routines.

GA during RT means daily GA five times a week for one up to several weeks. The process of GA also include 6 hours of fasting before each GA and care at the postoperative department after each RT, and when stable the child is discharged to the day-care department at the pediatric hospital before going home. GA also involves risks (airways and circulation), sleep disruption and malnutrition (Buchsbaum et al., 2013; Fortney et al., 1999; Seiler et al., 2001).

Before the start of RT, immobilization devices are constructed to help the child to lie still during RT, for example a facial mask and/or a mattress (Image of facial mask see Paper II). Computer tomography (CT) and sometimes magnetic resonance imaging (MRI) with the immobilization device on is then performed to localize the target area for the RT and to calculate the radiation dose (Kristensen, 2017). If it is decided that the child requires GA the construction of the immobilization device, the CT and/or MRI is done with GA.

Radiotherapy

The aim of RT is the death of tumour cells and to avoid as little damage as possible to healthy cells. Tumour cells do not have the same ability as healthy cells to repair the damage that occurs in the cell's DNA when exposed to radiation. They also grow faster than healthy cells and thus they are more radiation-sensitive (Degerfält, Moegelin, & Sharp, 2008).

The total radiation dose given to the patient is divided into daily treatments, fractions. A reason to give daily fractions is to target the tumour cells when they are in the right phase of the replication cycle but also to give healthy cells a possibility to repair damage that occurs when exposed to radiation and thus lower the risks of side effects. Even though healthy cells are to be spared from radiation those in the near area of the target are affected, which gives the patient side effects. The side effects vary depending on radiation dose and treatment area, and occur early (acute) and/or late (Statens beredning för medicinsk utvärdering [SBU], 2003:162). The early side effects heal and give no long-term problems and can be for example effects on the skin, mucous, fertility organs and blood-producing organs. The late side effects occur months or years after RT and have a chronic course and can be cognitive, endocrine, reproductive, cardiac and pulmonary effects. RT also increases the risk of secondary malignancies in long-term survivors (Armstrong, Stovall, & Robison, 2010; Oeffinger et al., 2006; Strålsäkerhetsmyndigheten (SSM), 2011:25). During RT, it is important to lie still and in reproducible position in order to optimize the treatment. Otherwise irradiation to normal tissue may occur which may give additional early and late side effects (Armstrong et al., 2010).

The procedure of RT involves advanced technology and healthcare professionals with specialized competence. Today there are six pediatric cancer centres in Sweden (Göteborg, Linköping, Lund, Stockholm, Uppsala and Umeå). When a child undergoes RT in Sweden, a RTN is responsible for the care process. The competence required to work as a RTN is one year of work experience as a registered nurse or radiographer and advanced courses in oncology care and RT. Internationally a RTN is a radiographer specialized in RT and the professional title is radiographer or radiotherapist. Apparatus used to treat children consists of linear accelerators and in Lund tomotherapy is available, meaning a linear accelerator moving around the patient while the patient table is moving as well (Kristensen, 2017). Proton-radiation therapy has been available in Uppsala since 2015 and is expected in the near future to treat a large number of children all over Sweden. The method is preferred when the target area of RT includes radiation-sensitive organs or when the patient is a child, since the method reduces the radiation exposure to healthy tissue (Doyen et al., 2016) and in that way reduces late side-effects (Björk-Eriksson & Glimelius, 2005; Kristensen, 2017).

Information and preparation procedures for children

Undergoing RT may entail anxiety in children due to separation from parents, the environment and the need to keep still. Studies on children's experiences and needs during RT are few, thus studies about children with cancer and children's experiences of hospital care have been a starting point.

When children are diagnosed with cancer they will be exposed to various tests and treatments that can be difficult to understand, which creates stress, anxiety and suffering (Björk, Wiebe, & Hallström, 2009). It has also been shown that children with cancer experience physical problems and psychosocial dysfunction, for example fatigue and not being able to attend school (Enskär & von Essen, 2008), and that they struggle to feel normal, try to be brave and need to accept unpleasant things that are happening to them (Björk, Nordström, & Hallström, 2006; Enskär & von Essen, 2000).

When children are hospitalized, it has been shown that they experience fear of separation from parents and family, the unfamiliar environment, testing and treatment and the loss of self-determination (Coyne, 2006). During hospitalization, children need to have their parents close, play and feel joy, participate in care and have good relation with the healthcare professionals (Björk et al., 2006; Runeson, Hallström, Elander, & Hermeren, 2002a). During various treatments children need to know what to expect (Coyne, 2006) as this enables them to handle the situation better with increased coping and compliance and with decreased pain and anxiety (Flowers & Birnie, 2015).

Concerning children's experiences and needs during RT, a study by Kuhlthau et al. (2012) showed that children reported lower health-related quality of life (HRQOL) for instance concerning procedural anxiety, communication (difficulty to ask questions, explaining to others, telling how they feel) and worry (related to treatment, adverse effects and tumour recurrence). A study by Tyc et al. (2002) showed that children, aged 2-7 years, experienced distress, measured by observed behavioural distress and heartrate, before the first fraction. A study by Engvall et al. (2016) showed that information and preparation prior to RT and need for distraction during RT and strategies to deal with emotions such as fear, worry and sadness were important for children when receiving RT.

In different contexts, age-appropriate preparations have shown an impact on the child's anxiety and ability to comply during different procedures (Edwinsson Månsson, 1992; Flowers & Birnie, 2015; Törnqvist et al., 2015). Interventions designed for children have been tested in the context of RT with the aim of decreasing children's anxiety and the need for GA. Klosky et al. (2004) tested a cognitive-behavioural intervention before and during RT on children, aged 2-7 years, which decreased their anxiety measured by the heart rate. Music therapy creation (Barry et al., 2010) and the use of a pediatric radiographer (Pimm et al., 1997) have also been shown to give children support, a positive experience and increased cooperation. Various interventions including play

preparation (Scott et al., 2002; Scott et al., 2016; Tsai et al., 2013), behavioural training (Slifer, 1996), psychoeducational preparation (Haeberli et al., 2008), multidisciplinary team (Filin et al., 2009) and audiovisual interventions (Willis & Barry, 2010) with aim of decreasing the need for GA have shown positive results. However, most of those interventions were designed for small children (Filin et al., 2009; Klosky et al., 2004; Scott et al., 2002; Slifer, 1996; Tsai et al., 2013; Willis & Barry, 2010), contained one component (Barry et al., 2010; Willis & Barry, 2010), had few participants (Barry et al., 2010; Pimm et al., 1997; Slifer, 1996; Tsai et al., 2013) or were technically advanced (Klosky et al., 2004). Interventions addressing both small and older children, which are easy for the healthcare professionals to deliver and for the families to use and non-costly, need to be developed, tested and further evaluated from the perspectives of both children and parents.

For the child and the parents, RT means daily treatment for a long period, which gives restrictions in the family life, less income due to daily absence from work and increased expenses due to travelling to the hospital. If GA is required, it involves an increased number of healthcare professionals and longer hospitalization, which in turn increases the hospital costs. Interventions in the context of RT aiming to decrease the number of children requiring GA have not included an economic evaluation (Filin et al., 2009; Scott et al., 2002; Slifer, 1996; Tsai et al., 2013; Willis & Barry, 2010). However, a study by Haeberli et al. (2008) indicated that when children received a psychoeducational intervention the use of GA decreased which might reduce the costs of anesthesia. Also a study by Scott et al. (2016) indicated that cost savings might be achieved with a child life specialist due to decreased use of GA. A study by Törnqvist et al. (2015) in the context of children undergoing MRI showed that the hospital costs were reduced when the number of children requiring GA decreased due to age-appropriate information and preparation procedures. Despite the majority of interventions with positive outcomes for the child and parents, few have been implemented in clinical practice. An economic evaluation is important in order to assess the costs and consequences of the different alternatives from different viewpoints to ensure that they are justified before implementation (Drummond, Sculpher, Claxton, Stoddart, & Torrance, 2015; Medical Research Council (MRC), 2008).

Parental needs and experiences

A child's diagnosis of cancer affects the entire family and causes distress to the parents. During the child's treatment, the parents wield the burden of finding ways for the child and for the entire family to cope (Björk et al., 2009; Enskär, Hamrin, Carlsson, & von Essen, 2011). Research has been performed on parents' general experience of having a child with cancer (Björk, Wiebe, & Hallström, 2005; Björk et al., 2009; Dockerty,

Williams, McGee, & Skegg, 2000; Enskär et al., 2011; Gibbins, Steinhardt, & Beinart, 2012; Ångström-Brännström, Norberg, Strandberg, Söderberg, & Dahlqvist, 2010). These studies showed that during a child's cancer period parents experience a great deal of anxiety and uncertainty (Enskär et al., 2011; Gibbins et al., 2012), poor mental health and lack of social support (Dockerty et al., 2000). The parents feel drained, locked up, isolated and that they have an everyday struggle focusing on their child's suffering from cancer (Björk et al., 2009; Enskär et al., 2011; Gibbins et al., 2012). To cope with the situation they express a need for support to be able to keeping the family together and take care of the ill child (Hallström & Elander, 2007). However, the parents try to be positive, hopeful and live in the moment (Björk et al., 2005; Gibbins et al., 2012) and find it important to try to maintain normality in daily life despite the cancer diagnosis (Björk et al., 2009).

Parents' needs for comfort are prominent during hospitalization when their child is chronically ill. Their comfort rises when they experience competent caregivers and can be close to their child (Enskär & von Essen, 2000; Hallström, Runesson, & Elander, 2002). A literature review showed that participation in the care, a feeling of being in control and cooperation with the healthcare professionals are further important needs for the parents (Hallström & Elander, 2007).

Studies have shown that parental behaviour affects the child anxiety (Forsner, 2006; Kain, Mayes, O'Connor, & Cicchetti, 1996; Peterson et al., 2014). Parental involvement in educational interventions together with their child is important and studies have shown that this decreases parents' anxiety prior to surgery (Felder-Puig et al., 2003; Kain et al., 2007; Li, Lopez, & Lee, 2007), and in the context of MRI parents experienced better communication with healthcare professionals (Törnqvist et al., 2015).

It may add further to the anxiety to have a child undergoing RT due to radiation, side effects, and daily treatment for several weeks. A study in the context of RT showed that parents' anxiety decreased compared to a control group when their child received an interactive-educational intervention before and during RT (Klosky, Garces-Webb, et al., 2007). However, there is a knowledge gap in research exploring parents' experience of having a child undergoing RT. Two studies, one from Sweden (Ångström-Brännström et al., 2015) and one from the USA (Houtrow et al., 2012) showed that parents are in need of support, both emotional and practical, during their child's RT since it is a strenuous period. Parents were aware that RT could cure or relieve their child's symptoms, but also that RT causes negative side effects, which was worrying (Houtrow et al., 2012). Nevertheless, they learned to cope with the process over time (Ångström-Brännström et al., 2015).

Radiotherapy nurses caring for children

The RTN is responsible for the care process and interacts with both adults and children, but most RTNs are not specialized in pediatric nursing. Research on RTNs experiences of caring for children undergoing RT is lacking. However, RTNs caring for adult patients report that their work entails balancing patient care and technical skills, fostering patient-focused relationships, being present, assuming the role of communicator, and being the patient's advocate (Bolderston, Lewis, & Chai, 2010). Developing relationships with patients and knowing that they are helping the patient is experienced as central in RTNs' care and gives them a sense of meaning in their profession (Diggins & Chesson, 2014; Lawrence et al., 2011).

However, studies have shown that RTNs experience within their profession emotional exhaustion (Probst et al., 2012; Singh et al., 2017) and occupational stress (French, 2004). Identified stressful factors that the RTNs experience are keeping the patient alive by any means, witnessing patients' disease progression, carrying a high physical workload, and seeing the patients suffer discomfort as a result of the therapy (Diggins & Chesson, 2014; Sehlen et al., 2009). Another identified stressful factor is the possibility to cause errors, which can have damaging effects on the patient (French, 2000).

Theoretical framework

Child- and family-centred care

In most parts of the world, especially in the West, family-centred care (FCC) is a common way of caring for children, which means that the healthcare professionals plan the care around the whole family, not just the individual child (Shields, Zhou, Pratt, et al., 2012). FCC was developed in the 1950s due to the work of John Bowlby and James Robertson who demonstrated emotional, psychological and developmental consequences in children when separated from mothers (Jolley & Shields, 2009). However, there have been some difficulties in implementing FCC (Foster, Whitehead, & Maybee, 2010) and no firm conclusions about the effectiveness can be drawn (Shields, Zhou, Taylor, et al., 2012). Due to the often uneven power balance in the relationship between the parent, child and the healthcare professionals, which may take away the focus from the child (Hallström et al., 2002) a discussion about child-centred care (CCC) has emerged (Coyne, Hallström, & Söderbäck, 2016).

A CCC approach takes place in the context of the family but entails involvement of the child's right to participate in the healthcare and in decisions where the child's views and needs are taken into consideration. CCC is a philosophy and the rights of the child as mentioned in the United Nation Convention on the Rights of the Child (UNCRC) (1989) are key-elements in CCC (Coyne et al., 2016). Article 12 of the UNCRC (1989) states that children have the right to express their opinion and to be heard in all matters concerning them according to the child's age and maturity. However, research has shown that children experience hindrances to participation in the decision-making process (Coyne, 2008; Coyne, Amory, Kiernan, & Gibson, 2014; Hallström & Elander, 2005) and are not involved in consultations or decision-making about their healthcare (Coyne, 2008). In Sweden, a new Patient Act (SFS, 2014:821) was enacted in 2015 with the aim of strengthening the patient's autonomy, integrity and participation. In this law the children are specifically mentioned and it is stated that when healthcare is given the child's best interests should be considered (SFS, 2014:821, article 3, chapter 3). It further states that adequate information should be given to the child's caregivers whereby they may help the child to decide on the best alternative treatment. The Patient Act (SFS, 2014:821, article 3, chapter 5) also states the importance of understanding and clarifying the child's reaction to the current treatment, while taking into consideration the child's age and maturity. However, a recent evaluation of Swedish healthcare (Vårdanalys, 2017) showed that the Patient Act (SFS, 2014:821) has not improved patients' position. The implementation of the law and the knowledge of its content was unfamiliar to most healthcare professionals. The evaluation reported a decrease in terms of accessibility, information and participation for adults and for caregivers (parents). Caregivers to children reported a deterioration of information, that their child is never or rarely part of the decisions made and that the child's age and maturity are not taken into consideration (Vårdanalys, 2017). There was no evaluation from the children's viewpoints of how their best interests were upheld and expressed in hospitals.

Including the child's perspective in decision-making in healthcare, contributes to a better understanding of the child's needs and experiences (Söderbäck, Coyne, & Harder, 2011). Research shows that children prefer to be included in their care, receive information about what to expect, and be listened to (Hallström et al., 2002; Runeson, Hallström, Elander, & Hermeren, 2002b). Children also want to be involved in decisions about their care (Coyne et al., 2014; Coyne & Gallagher, 2011) and when receiving information and being involved they feel more prepared and less anxious, for example before MRI (Törnqvist et al., 2015). Healthcare professionals need to ensure children's rights and they have a responsibility to involve the child in their care. However, this can be difficult when a child diagnosed with cancer is seriously ill and when parents are anxious about their child's health.

Comfort theory

In this thesis, the comfort theory is used to enable an understanding of the complex interplay between an intervention and its outcomes. The comfort theory was developed by Katharine Kolcaba and is a midrange theory for nursing practice and research (Kolcaba, 2003). The theory has been tested and supported in various populations and settings such as palliative care, women with breast cancer undergoing RT, critical care, peri- and intra-operative care etc. (Kolcaba & DiMarco, 2005). Comfort is defined as: “the immediate state of being strengthened through having the human needs for relief, ease, and transcendence addressed in four contexts of experience (physical, psychospiritual, sociocultural and environmental)” (Kolcaba, 2003, p. 251).

An essential part of the nursing profession, according to Kolcaba (1994), is to help patients to have their basic comfort needs met since they heal more quickly and do better if they are comfortable. In order to deliver comfort the nurse needs to deliver the appropriate intervention that complements the medical treatment or examination. The basic assumption of the comfort theory is that humans have holistic response to complex stimuli, i.e. interventions that are intended to enhance one or more aspects of comfort indirectly enhance other aspects (Kolcaba, 1994).

According to Kolcaba (2003), interventions to provide comfort are: 1) standard interventions to maintain homeostasis and control pain, 2) coaching interventions such as providing information and instilling hope and 3) “comfort for the soul” interventions, meaning those extra things that strengthen the patient such as massage or guided imaging.

The dimension of comfort consists of three states; relief, ease and transcendence. *Relief* is the state of having a specific need met. *Ease* is the state of calm or contentment meaning the absence of specific discomforts, which is necessary for effective performance (Kolcaba, 1994). *Transcendence* is the ability to rise above discomforts when they cannot be eliminated or avoided (Kolcaba & DiMarco, 2005). When nurses provide holistic comfort, needs for relief, ease and transcendence are identified through experience and they move back and forth of these three states of comfort. For example if complete relief is not possible, interventions that enhance transcendence are appropriate (Kolcaba & DiMarco, 2005).

The three states of comfort occur in four contexts; physical, psychospiritual, sociocultural and environmental (Kolcaba, 2003). The physical context includes bodily sensations, which can be treated, such as pain, nausea and vomiting. The psychospiritual context includes the internal awareness of self, including esteem, sexuality, meaning in one’s life, and relationship to a higher order or being. The sociocultural context includes relation, family and societal relationships (finances, teaching, healthcare professionals etc.), family tradition, rituals and religious practice. The environmental context includes the patient’s experience of light, noise, atmosphere,

colour, odor, temperature, furniture etc. (Kolcaba, 1994, 2003; Kolcaba & DiMarco, 2005). The context in which comfort is needed is addressed, which leads to total enhancement of comfort in the remaining contexts (Kolcaba & DiMarco, 2005). Enhanced comfort strengthens the patients and family to engage in activities to achieve health and remain healthy, which benefits the hospital in terms of increased patient satisfaction and reduced costs due to shorter hospitalization (Kolcaba, 1994).

In pediatric care children and families live through stressful healthcare situations and thus interventions to give comfort to both the child and the family during stressful intervention are important (Kolcaba & DiMarco, 2005). In the context of children undergoing RT such comfort could be information (sociocultural comfort), inviting the parent to be present and to be in contact with each other during treatment (sociocultural and psychospiritual comfort), preparations to have the ability to handle anxiety (physical comfort) and to paying a visit to the department before RT (environmental comfort). However, instruments to measure comfort have been developed but not tested for appropriate use with children of different developmental levels and cognitive abilities (Kolcaba & DiMarco, 2005), and therefore other instruments to measure children's comfort are needed.

Rationale of this thesis

According to the UNCRC (1989) and the Swedish Patient Act (SFS, 2014:821) the best interests of the child must be considered. For healthcare professionals to be able to provide the best care and give comfort to children and their parents, more research is needed in the area of children undergoing RT. There is a knowledge gap within the field of RTNs' perceptions of caring for children undergoing RT. There is also a knowledge gap concerning parents' experience of having a child undergoing RT. By exploring their perceptions and experience, important aspects of care that need to be developed can be identified, thus enabling healthcare professionals to give better support.

Various interventions for children undergoing RT with the aim of decreasing children's anxiety and the need for GA have shown positive results. However, some of the studies focused on small children, had just one component, had few participants and/or were technically advanced. Children learn and understand situations differently depending on age and cognitive development, thus it is important to test a combination of different parts in an intervention. A non-costly intervention might also be easier to implement in healthcare. Thus, an intervention with age-appropriate information and preparation procedures might result in better understanding of the child and parents of what it implies to be treated with RT and help children to avoid GA, which reduces risks, anxiety and discomfort for the child and the family.

Aims

The overall aim of this thesis was to explore care from the perspective of radiotherapy nurses and parents, and then based on the findings, previous research and theoretical framework, to develop and test information and preparation procedures for children with cancer undergoing radiotherapy from the perspectives of children, parents and hospital costs. The thesis is based on four papers, each with its own specific aim.

- To explore radiotherapy nurses' perceptions of the care they give to children undergoing radiotherapy treatment for cancer (Paper I).
- To explore parents' lived experience during their child's radiotherapy (Paper II).
- To test age-appropriate information and preparation procedures for children with cancer undergoing radiotherapy for feasibility and effectiveness in terms of the need for general anaesthesia and anxiety (Paper III).
- To evaluate the impact of age-appropriate information and preparation procedures for children with cancer undergoing radiotherapy on 1) parents' and family functioning, parents' anxiety and 2) hospital costs compared to traditional care (Paper IV).

Method

This thesis includes three studies. An overview of the methods used is presented in Table 1.

Table 1. Overview of the methods

Study	Design	Sample	Data collection	Analysis	Paper
A	Inductive descriptive	12 radiotherapy nurses	Semi-structured interviews	Phenonemo-graphy	I
B	Inductive descriptive	10 parents to children undergoing radiotherapy	Diaries	Hermeneutic phenomenology	II
C	Quasi experimental controlled clinical trial	Children aged 3-18 years Control group: 16 children Intervention group: 17 children	Anxiety Heartrate Emotional behaviour	Descriptive and comparative statistics	III
C	Quasi experimental controlled clinical trial	Parents Control group: 31 parents Intervention group: 32 parents	Anxiety Questionnaires Hospital costs	Descriptive and comparative statistics	IV

Design

The design used was an exploratory sequential mixed methods design. In mixed methods different types of data are collected and analysed, which may provide a stronger understanding of the problem studied (Creswell, 2014). This thesis had a two-phase approach. In the first phase, qualitative data was collected and analysed (Paper I and Paper II). Based on the findings, previous research and theoretical framework, an

intervention was developed and tested in the second phase (Paper III and Paper IV). The three studies were based on the Medical Research Council (MRC) framework for developing and evaluating complex interventions (MRC, 2008).

In Study A, an inductive descriptive design using interviews was used (Paper I). Phenomenographic methodology was chosen where the aim is to describe and understand different ways in which individuals perceive a phenomenon in their world (Dahlgren & Fallsberg, 1991; Marton, 1981).

In study B, an inductive descriptive design using diaries with a hermeneutic phenomenology approach inspired by van Manen (1997) was chosen to capture the lived experience of parents having a child undergoing RT (Paper II). The methodology aims to explore lived experience, the nature of a certain experience, in order to achieve an understanding of the deeper meaning of the phenomenon (van Manen, 1997).

In study C, a quasi-experimental controlled trial (CCT) was chosen consisting of a control group (CG) and an intervention group (IG). The feasibility and effectiveness of an intervention of age-appropriate information and preparation procedures for children with cancer undergoing RT was developed and then tested and evaluated (Papers III and IV).

Methodological framework

The research was based on the MRC framework for developing and evaluating complex interventions (MRC, 2008). The framework was developed in 2000 and revised in 2008, and intends to give guidance to researchers to develop, evaluate and implement complex interventions to improve health. The framework consists of four main stages: development, feasibility/piloting, evaluation and implementation (see Figure 1). The main stages are not to be followed linearly or cyclically, but are to interact with each other aiming to strengthen the intervention and the design.

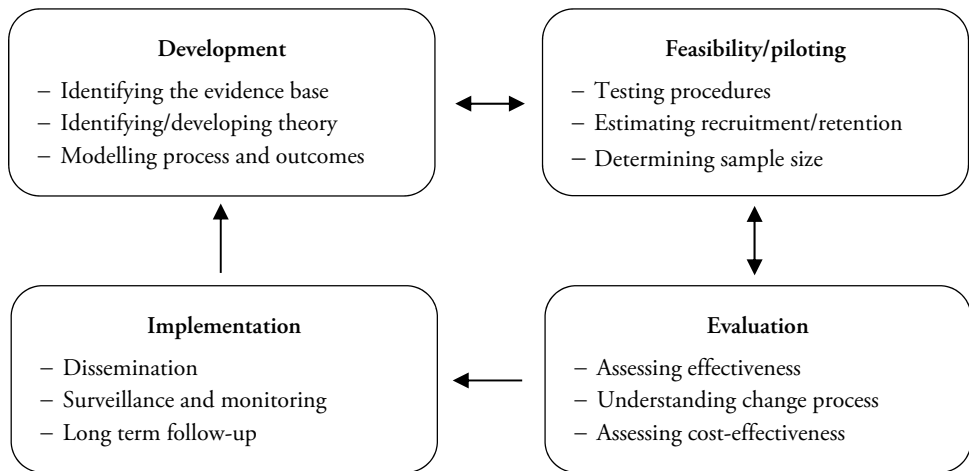


Figure 1. The development and evaluation process of complex interventions (accessed from MRC, 2008).

Development of the intervention was the first stage. A literature review was performed to identify relevant best existing evidence (MRC, 2008), which showed a gap of knowledge concerning children undergoing RT. Thus, to gain knowledge about how to care for children undergoing RT study A was performed to identify RTNs' perceptions when caring for children undergoing RT (Paper I). Furthermore, in study B parents of children undergoing RT were asked to keep a diary during the treatment sessions with the aim of exploring their lived experience (Paper II). Then the intervention was modelled, which consisted of age-appropriate information and preparation procedures for children undergoing RT, and the findings of Paper I, Paper II and the literature review were taken into consideration. The comfort theory of Kolcaba (2003) was identified and used as a theoretical understanding, and with the CCC-approach in mind suitable parts of the intervention (safety-sting, information material and routines, doll-size model of the apparatus to play with, possibility to watch a DVD) and outcome measurements to assess the intervention were chosen (self-rating and observation). The literature review also gave knowledge about hindrances, and what changes to expect due to the intervention and how these changes were achieved (MRC, 2008).

Assessing feasibility and piloting methods was the next stage, which is an essential step before a large-scale evaluation. Likely rates of recruitment and retention of subjects were estimated and an appropriate sample size was calculated. The intervention developed was then tested, as recommended, for feasibility and effectiveness, in terms of acceptability, compliance, delivery of the interventions and measurements of effectiveness (MRC, 2008), in study C as a quasi-experimental CCT. The CCT was

conducted as a scale model of the planned mainstage evaluation with focus on the uncertainty of the intervention identified in the development stage.

The third stage is evaluation, meaning assessment of the effectiveness of the intervention, evaluation of the change process and assessment of cost-effectiveness of the intervention. The last stage is implementation, including dissemination of the findings and the intervention. Before implementation the decision-makers needs to be convinced and when implementing long-term follow-up and further evaluation needs to be done (MRC, 2008). The remaining main stages, evaluation in a full-scale randomised controlled trial and implementation, are not included in this thesis, but the findings and dissemination of the findings can provide a basis for future evaluation and implementation.

Context of the study

The studies were conducted at a university hospital in the south of Sweden, which is one of six child-cancer centres in Sweden and cares for children from the neighbouring counties. At the specific RT department approximately 20 children under the age of 18 are treated with RT each year. The data collection for study A was conducted from January to May 2013 and data collection for study B was conducted from May 2012 to April 2014. From May 2012 to April 2016 data collection for study C was conducted. During the time of the data collection two kinds of apparatus were used when the children were treated, linear accelerators and tomotherapy, with tomotherapy signifying longer duration per fraction.

Children were referred to RT with a variation of fractions depending on the child's diagnosis. The attending physician at the pediatric department decided, after discussion with the child and parents, whether the child should receive GA or be awake during RT. If it was decided that a child should receive GA, creation of the immobilization device, CT and/or MRI to localize the target area and all fractions were done with GA. When a child received GA an anaesthetic team was involved consisting of a nurse and a physician. The child had to fast six hours prior to the RT and after each RT the child was cared for at the post-operative recovery unit at the pediatric department. If not hospitalised the child went after recovery briefly to the pediatric day-care before the family went home. All children, if possible, received their RT as outpatients.

Study population and recruitment

In study A (Paper I) all RTNs working in the RT department, approximately 60 RTNs, were contacted and invited to participate in the study through email and at a department meeting. In order to be included in the study and interviewed by the author of this thesis, the RTNs had to work in the RT department and have experience of caring for children undergoing RT. Information about which RTNs that had experience of caring for children was not available, thus invitations were sent to all RTNs at the specific department. A strategic sample was planned but not possible due to few participants. Those who wished to participate were asked to send an e-mail with their contact information. Altogether 12 RTNs chose to take part in the study. They were contacted by e-mail or phone and time and place for an interview were decided. The participants could decide place for the interview, and all chose to be interviewed in a room in another department at the hospital. The participating RTNs were all females and their mean age was 49 years. They had worked as nurses or radiographers outside the RT department with a range of 1-19 years (mean: 8 years) and as RTNs with a range of 1-28 years (mean: 13 years).

In study B (Paper II), parents included in the CG and two parents in one family in the IG in study C were asked to keep a diary during their child's RT. When the parents visited the RT department for the first time they were given the diary, a hand-bound notebook, and information about what they could write about by one of the researchers. At their child's last RT session the diary was handed back or sent in a prepaid envelope. Nineteen families including 33 parents were asked to participate and 10 parents in 10 families in the CG chose to keep a diary. Of the participating parents, eight were mothers and two were fathers. Their age ranged from 25 to 45 years.

In study C, consecutive series of children aged 3-18 years, diagnosed with cancer and referred for RT and who understood and spoke Swedish, were asked to participate in a CCT including a CG and an IG. Children with intellectual and other impairment, as assessed by the referring physician, were excluded. When it was decided that a child was to be treated with RT the parents were contacted by a nurse from the pediatric department and asked if they were interested in participating in the study. If they were interested their names were forwarded and they were contacted, by the author of this thesis, by phone or at the pediatric department during a visit, and given both oral and written information about the study. In total 33 children (Paper III) and 63 parents from 33 families (Paper IV) were included in the CCT. In the CG 19 children with family fulfilled the inclusion criteria. Two families declined due to the child's young age, 3-4 years, and one adolescent declined. Altogether 16 children with 31 parents agreed to participate. In the IG a total of 25 children with family fulfilled the inclusion criteria. For three children RT was cancelled, three families declined due to the child's young age or because they could not cope with participation in a research study and

two adolescents declined. Figure 2 shows an overview of the recruitment for Study B and C, and Table 2 shows the sample characteristics of the participating children and parents in Study C.

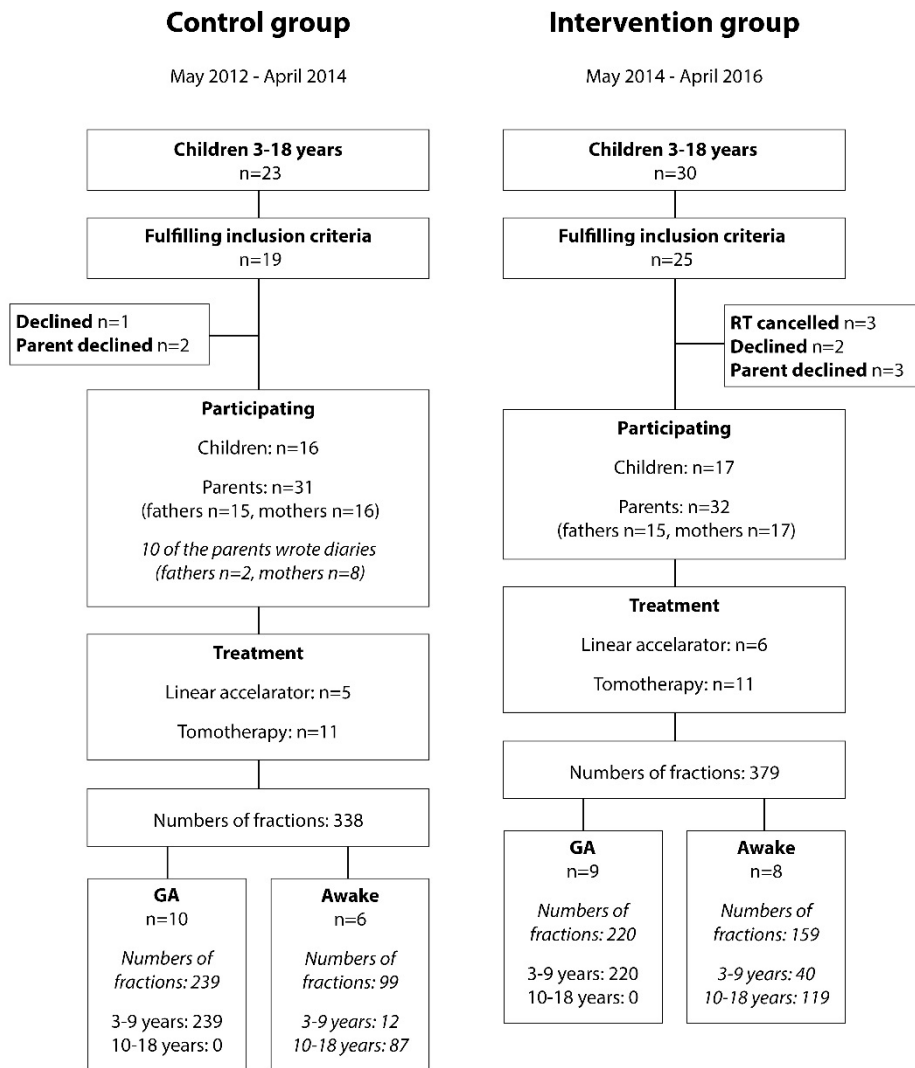


Figure 2. Overview of the recruitment for Study B and C

Table 2. Sample characteristics of participating children and parents in Study B

	Children N=33		Parents N=63	
	Control group n=16	Intervention group n=17	Control group n=31	Intervention group n=32
Age median (range)	7 (3-16)	6 (3-17)	39.5 (25-48)	40.5 (24-29)
3-9 years (median)	11 (5)	11 (4)		
10-18 years (median)	5 (13)	6 (13.5)		
Gender				
Male	6	10	15	15
Female	10	7	16	17
Diagnosis				
Brain tumour	9	6		
Solid tumour	6	10		
Leukemia	1	1		
Married or cohabiting/non cohabiting/missing data			26/3/2	27/5/0
Born in/outside Scandinavia/ missing data			29/1/1	25/7/0
Education				
Nine-year compulsory school			1	2
High school			12	13
University			14	16
Missing data			4	1
Employed/unemployed/ missing data			23/4/4	25/6/1

Traditional care and intervention design

Traditional care

The parents and children in the CG received traditional care consisting of non-standardized information, which varied between professionals and was not performed in a systematic way. A booklet, addressed to children, with images and text about a child going through RT and a doll with an immobilization device for the head was

available and used only occasionally at the pediatric department. At the RT department the child together with the parents were informed by the oncologist about the RT and its side effects at a meeting in advance or on the same day as the immobilization devices, CT and/or MRI were made. Children not receiving GA could listen to music or a story during RT.

Intervention design

Based on earlier research (Björk et al., 2006; Filin et al., 2009; Runeson et al., 2002a; Scott et al., 2002; Slifer, 1996; Törnqvist et al., 2015; Willis & Barry, 2010), the theoretical framework (Coyne et al., 2016; Kolcaba & DiMarco, 2005) and the findings of Papers I and II, an intervention including age-appropriate information and preparation procedures before and during RT was developed.

The healthcare professionals involved in the child's care carried out the intervention, which consisted of seven different parts: (1) A booklet and (2) a storybook were given the family before the RT (Törnqvist et al., 2015). Two booklets explained the procedure with photographs and easily understandable text and were adapted to the age groups 3–10 years and 11–18 years. The storybook was about two children going through RT consisting of text and painted pictures in 22 pages. (3) In advance, at the meeting together with the oncologist, the family met a RTN responsible for the child's RT, care and treatment (Paper I, Paper II). (4) At the meeting with the oncologist and RTN two “doll-size” models, representing the two kinds of apparatus the children were treated with, were available to play with or to watch depending on the child's age (Törnqvist et al., 2015). (5) The family were invited to pay a visit in advance to the RT department and the treatment room to be acquainted with the environment and the healthcare professionals (Filin et al., 2009; Scott et al., 2002; Slifer, 1996, Paper I, Paper II). (6) During RT the child could listen to music/story or for those children not having RT to their head they could watch a movie through audiovisual (AV) goggles (Törnqvist et al., 2015; Willis & Barry, 2010). (7) During RT the child could also hold onto a “safety string”, a string of yarn with a ball of yarn at each end, connecting the child with the parent in the waiting room during the RT (Björk et al., 2006; Runeson et al., 2002a). The child, together with the parents, received the preparation parts 1–4 and could choose from parts 5–7.

Data collection

In Study A, individual semi-structured interview with open-ended questions were used (Dahlgren & Fallsberg, 1991). A total of 12 interviews with RTNs were performed. All interviews started with a presentation of the aim of the study, and the participants had the opportunity to ask questions about the research. This approach enabled a relaxed relationship between the interviewer and the interviewee (Kvale & Brinkmann, 2014). Each interview started with the question “Can you describe how you care for children during RT?” Other parts of the interviews addressed differences in caring for children, adults, and family members, as well as differences in caring for children who are awake and children who receive GA during RT. Follow-up questions included “Can you explain more?” “Can you give an example?” and “Can you describe in what way?” A topic guide was used to ensure that all the topics were discussed. A pilot interview was performed in order to evaluate the topic guide, which was found to work well; therefore, the pilot interview was included in the analysis. The interviews lasted between 23 and 54 minutes (mean: 32 minutes). All interviews were recorded, and transcribed verbatim (Paper I).

In study B ten parents included in the CG in study C wrote a diary during their child’s RT (Paper II). The parents were asked to write freely in the diary about their experience of their child’s RT. The child was also invited to write or draw in the diary. Daily notes, both short and long, were encouraged. Some parents wrote daily in the diary while others wrote a summary at the end of the child’s treatment. None of the children wrote or drew in the diaries. The diaries were digitally reprinted and all names of children, family members or places in the diaries were replaced with fictitious names. The reprinted diaries contained a range from 1 to 31 pages (mean: 5 pages). The number of entries in the diaries varied from 1 to 31 (mean: 8 entries) and the length of the entries ranged from 1 to 56 lines (mean: 14 lines).

In study C (Papers III-IV), children and parents who agreed to participate in the CCT were included in a CG, which started in May 2012 and lasted to April 2014, and to an IG, which started in May 2014 and ended in May 2016. In connection with inclusion the parents received an envelope with questionnaires assessing parents’ and family functioning, parents’ sense of coherence (SOC) and describing background variables of the participating children and parents. During the child’s RT data was collected at the child’s first three fractions, then every fifth fraction and at the last fraction. All data collection in the CCT was performed by the author of this thesis and occasionally (42 times of 237) by a radiographer in diagnostic imaging in the research team. Data collections consisted of the child’s and parents self-rated anxiety, measurement of the child’s heartrate and observation of the child’s emotional behaviour. At the last fraction the questionnaire assessing parents’ and family functioning was answered once more. The number of occasions for data collection

varied because the children had different numbers of fractions. Sometimes both parents were not always able to follow their child throughout the RT since the treatment went on for a long period. Those parents who followed their child self-rated their anxiety.

Instruments

Reliable and valid instruments were used to assess children and parents included in the CCT. Instruments used for the children were tested in a pilot study at a diagnostic imaging department with seven children, aged 5–16 years, and were considered easy to understand and to complete. Figure 3 shows a flowchart of the data collection and the number of measurements conducted with the instruments in Study C.

Sense of coherence

The Swedish version of the Sense of Coherence (SOC) questionnaire was used (Antonovsky, 1987), which measure the parents' ability to cope with stressful life events. The questionnaire consists of 29 items, which are divided into three components comprehensibility (11 items), manageability (ten items) and meaningfulness (eight items). Each item is rated on a seven-point Likert scale, from "never" to "very high". Thirteen of the questions are negatively stated and are reversed before analysis. The total score is 29 to 203, where high score means strong SOC. The parents completed the questionnaire at their child's first fraction. The instrument has demonstrated acceptable internal consistency and a high level of validity (Antonovsky, 1993; Eriksson & Lindström, 2005).

PedsQL™ Family Impact Module

The Swedish version of the questionnaire PedsQL™ Family Impact Module (Tiberg & Hallström, 2009) was used which measure the impact of pediatric chronic health conditions on parents and family. The questionnaire consists of 36 items comprising eight dimensions (physical-, emotional-, social- and cognitive functioning, communication, worry, daily activities and family relationships). Each item consists of a five-point Likert response scale, 0 = never a problem and 4 = always a problem. The items are reverse scored and linearly transformed to a 0-100 scale (0=100, 1=75, 2=50, 3=25, 4=0). Total score of the PedsQL™ Family Impact Module is the sum of the 36 items divided by the number of items answered. Parents' health-related quality of life (HRQOL) is the sum of 20 items comprising four dimensions (physical, emotional, social and cognitive functioning) and parents' self-reported family functioning is the sum of eight items comprising two dimensions (daily activities and family relationships). High scores indicate better functioning, less negative impact. The questionnaire has demonstrated acceptable internal consistency and construct validity

(Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004). The parents completed the questionnaire at the child's first fraction and once again after the last fraction.

Facial Pain Scale Revised

To assess the child's self-rated anxiety the Facial Pain Scale Revised (FPS-R) (Hicks, von Baeyer, Spafford, van Korlaar, & Goodenough, 2001) was used for children aged 3–11 years before and after each fraction. The origin of the scale is the Facial Pain Scale (Bieri, Reeve, Champion, Addicoat, & Ziegler, 1990) which has been further developed. Besides pain, anxiety has also been measured with the FPS-R (Dufresne et al., 2010; Johnson et al., 2009). FPS-R consists of six faces and the rating scale is metric, 0–2–4–6–8–10, where 0 indicates no anxiety and 10 indicates high anxiety. The scale is validated for children aged 4–12 years (Hicks et al., 2001), but has been used in research including children aged 3 years that showed proper understanding and use of the scale (Spagrud et al., 2008). The FPS-R has shown strong correlation to VAS (Hicks et al., 2001).

Visual Analog Scale

The Visual Analog Scale (VAS) was used for children aged 12–18 years and parents to measure their self-rated anxiety before and after the child's fraction at the first three fractions, then at every fifth fraction and at the last fraction. The scale consists of a 10 cm horizontal rating scale from 0 to 10, where low ratings indicate low anxiety and high ratings indicate high anxiety. The scale is suitable for describing emotions (Aitken, 1969) and is a validated instrument (Jakobsson, 2004).

Heart rate

The child's heart rate (HR) was measured to assess their anxiety (Klosky, Tyc, et al., 2007; Li, 2007; Tyc et al., 2002). The measurements were done with a digital automatic wrist blood pressure monitor, Omron R6 Intellisense, which was calibrated after two years. Data were collected before and after each fraction at the first three fractions, then every fifth fraction and at the last fraction.

Children's Emotional Manifestation Scale

The Children's Emotional Manifestation Scale (CEMS) (Li & Lopez, 2005), was used to observe children's emotional behaviour during RT. CEMS was used three times at each fraction; at the beginning (preparation and placement of the immobilization device), during and at the end. Children who had GA were assessed only at the beginning of the fraction. The CEMS consists of five categories: facial expressions, vocalization, activity, interaction and level of cooperation. Each category consists of five different observable behaviours rated by level and intensity, and each level is explained in detail with an operational definition. Each category is scored 1–5, the total score is 5 to 25, where higher scores indicate more negative emotional behaviour. The

instrument CEMS was translated with permission from the developer of the instrument for the study into Swedish and then back translated into English according to World Health Organization guidelines (WHO) (2016). The CEMS is validated for children 7-12 years but has been used in research including children aged 3-21 years (Staab, Klayman, & Lin, 2014). The instrument has shown good internal consistency and content validity (Li & Lopez, 2005).

Control group		Intervention group	
May 2012 - April 2014		May 2014 - April 2016	
Children 16 - Parents 31		Children 17 - Parents 32	
Data collection at 1st fraction	Number of measurements	Data collection at 1st fraction	Number of measurements
SOC	24	SOC	27
PedsQL	21	PedQL	25
Data collection at 1st, 2nd, 3rd, every 5th and last fraction		Data collection at 1st, 2nd, 3rd, every 5th and last fraction	
Before fraction		Before fraction	
FPS-R/VAS	107	FPS-R/VAS	124
HR	100	HR	120
CEMS	113	CEMS	124
Parents VAS	153	Parents VAS	151
During fraction		During fraction	
CEMS*	39	CEMS*	54
After fraction		After fraction	
FPS-R/VAS	106	FPS-R/VAS	123
HR	92	HR	97
CEMS*	39	CEMS*	54
Parents VAS	148	Parents VAS	148
Data collection at last fraction		Data collection at last fraction	
PedsQL	25	PedsQL	21

* Measurements only on children awake; 6 children in the CG; 8 children in the IG.

Figure 3. Flowchart of the data collection and number of measurements performed on children and parents in study C

Study protocol

To assess hospital costs for the intervention a specific protocol was made for the study. In the study protocol notes were made at the child's first three fractions, every fifth and at the last fraction about: the apparatus that was used, duration of RT, RT with or without GA, duration of postoperative care and care at the day-care department. To estimate costs the Southern health care region (2015) pricelist was used. Costs for development and preparation material used in the intervention was noted, i.e. the two leaflets, the storybook, the two doll-models, the AV-goggles, the DVD-player and the meeting with a RT nurse.

Data analyses

Phenomenography

Phenomenography as a methodology is a descriptive, empirical, and content-oriented approach used in human research and was developed in Gothenburg, Sweden, during the 1970s within the domain of human learning (Dahlgren & Fallsberg, 1991). The central perceptions in phenomenography are what and how, i.e. what something is and how something is perceived. The first-order perspective is to define what the participants talk about and aims to describe various aspects of the world. The second-order perspective presents how the participants talk about what, including different perceptions (Marton, 1981). The outcome is not to find singular essence as in phenomenology, but to identify a variation of perceptions of a perceived phenomenon among the population. Findings in phenomenographical research may help healthcare professionals to understand and care for individuals with different needs (Sjöström & Dahlgren, 2002).

In study A, Paper I, the interviews with the RTNs were analysed according to the steps proposed by Dahlgren and Fallsberg (1991). Throughout the analysis there was a constant interplay between the various steps. First, the transcripts were read through carefully several times to become familiar with the text. The significant statements in the text were selected to provide a condensed but representative version of the entire dialogue concerning RTNs' perceptions of caring for children. What the participants talked about and how these things were described were of interest. The selected significant dialogues were then compared and discussed by the researchers to find variation or agreement. Those perceptions that were in accordance were grouped, for example individualized information, individualized preparation, teamwork, and maintaining balance. Differences and similarities were compared and discussed and then preliminary categories were articulated, for example security. Each group of

categories was compared, and borders between them were defined. Both grouping and articulating were repeated several times until a consensus was reached. A suitable label to cover the meaning of the description categories was constructed, for example creating a sense of security. In the final step, contrasting, the description categories were compared to find similarities and differences (Dahlgren & Fallsberg, 1991). The outcome of the analysis, called description categories, comprises clear ideas that are brought together to describe the perceived world of the RTNs and they are logically related, often hierarchical (Marton & Booth, 1997). The sum of all description categories is referred to as “outcome space” and it is a way of looking at collective human experiences of a phenomenon holistically (Åkerlind, 2005).

Hermeneutic phenomenology

In hermeneutic phenomenology the lifeworld, the world of lived experience, is the starting point, and the aim is to capture the meaning and variation in patients’ lived experience (van Manen, 1997). Lived experience is a reflection on experience that is already passed or lived through. Phenomenology is the descriptive part of the methodology and aims to describe the phenomenon pre-reflectively, the lifeworld as we immediately experience it. Hermeneutic is the interpretive part and consists of a writing activity involving rewriting, rethinking, reflecting and recognizing. The methodology aims to give the material depth, i.e. the internal meaning structures of the experience as lived through are brought back, as it were, and in such way that the reader recognizes the description as a possible interpretation of the experience. van Manen (1997) identified four existential themes, existentials, which are to be found in all human beings’ lifeworld, regardless of the historical, cultural or social situation. These are lived space (spatiality), lived body (corporeality), lived human relations (relationality or communality) and lived time (temporality). These existentials may guide hermeneutical phenomenological reflection in the research process.

In study B, Paper II, the analytical process of the diaries was guided by hermeneutical phenomenological reflection (van Manen, 1997) and started with a holistic approach where all authors read the diaries multiple times and tried to capture the main significance of the text as a whole, which was also done for each diary. Following that, each diary was read in order to find statements or phrases that captured the experience of having a child with cancer undergoing RT, known as the selective or highlighting approach. Then the text was analysed in detail, looking at every sentence and sentence cluster in order to find what it reveals about the experience being described. Preliminary themes were identified and as recommended by van Manen (1997), the writing process started as a part of the analysis. During the analysis, all four authors discussed the relation between the parts and the whole, integrating the line-by-line approach and holistic approach, in an attempt to generate deeper insights and understandings.

Consensus about the themes was reached following discussions between all four researchers and repeated rewriting. In accordance with van Manen (1997), the preliminary results were discussed with junior and senior researchers from different fields in order to gain a broader perspective on the analyses.

Pre-understanding

None of the authors of Study A and B had any work experience in RT that shaped their pre-understanding. The authors' background and knowledge of the phenomena studied comes from experience in pediatric nursing, diagnostic imaging and research with children and their families. The author of this thesis had worked several years as a radiographer in diagnostic imaging and as a university lecturer in radiography. To gain increased knowledge about RT and the context while the child underwent RT, children and their parents were accompanied during four days. In phenomenographical studies, the pre-understanding is important because the researcher needs to be aware of the interviewees' world and the ways they may experience the phenomenon (Dahlgren & Fallsberg, 1991). In hermeneutic phenomenological studies, according to van Manen (1997), the pre-understanding makes us more likely to interpret the phenomenon before we come to an understanding of what it means. However, the pre-understanding is not to forget but to keep in mind and to set in contrast to the results. In order to decrease the effects of pre-understanding on the analysis, the authors' discussed their pre-understanding and reflected on it before and during the analytical process in order to make it explicit.

Statistical analyses

The questionnaire used, SOC and PedsQL™ Family Impact Module, had a few cases of missing items. Concerning missing items within the SOC questionnaire, they were replaced by a mean value within the components' of SOC (comprehensibility, manageability, meaningfulness). In the questionnaire PedsQL™ Family Impact Module, missing items were processed according to the recommendations (Varni et al., 2004). The instruments FPS-R and VAS both had a rating scale from 0 to 10 and thereby merged into the variable FPS-R/VAS.

Descriptive statistics was used for children (Paper III), parents' background variables (Paper IV) and to describe feasibility in Paper III. For comparison between groups, CG versus IG and children awake versus children receiving GA regardless of group, Mann-Whitney U-test was used due to the small samples and not normally distributed data. Since the children had different numbers of fractions and both parents were not always able to follow their child throughout the RT, this resulted in different number of measurements. To be able to compare both groups of children the median of

FPS-R/VAS, CEMS and HR and the mean for parents' VAS was calculated. To see whether there were differences between the groups over time, comparing all measurements to the first fraction, the regression analysis mixed models was used which took into account the repetitive visits for each child (Björk, 2011).

To calculate hospital costs (Paper IV) data collection from the children's first, second, third, every fifth and last fraction were used. To explore the clinical relevance the mean time and the mean costs of the procedure and postoperative care were calculated for the IG and CG and for children awake and receiving GA regardless of group. Mann Whitney U-test was used for comparison between groups. Costs in Swedish kronor (SEK) according to the Southern health care region (2015) pricelist for the development and preparation material used in the intervention were also calculated.

In study C statistical software, SPSSTM version 23 (Paper III) and SAS Enterprise Guide version 6.1 (Paper IV), was used for statistical evaluation carried out by an independent statistician. Statistical significances were defined as p -value <0.05.

Ethical considerations

For Study A, no ethical permission was required when interviewing healthcare professionals according to Swedish law since no ethically sensitive questions were asked (SFS, 2003:460). For studies B and C, the Regional Ethical Review Board in Lund, Sweden (2011/453) gave ethical approval. Permission to conduct the studies was obtained by the managers of the RT department (Studies A, B and C) and the pediatric oncology department (Studies B and C). All studies were carried out according to the Declaration of Helsinki (World Medical Association (WMA), 2013) and the four principles of ethics – autonomy, non-maleficence, beneficence, justice – were considered (Beauchamp & Childress, 2013).

Autonomy

In research, respect for autonomy is essential, meaning that individuals act freely in accordance with a self-chosen plan (Beauchamp & Childress, 2013). Before they gave informed consent, all participants included in this thesis were informed in writing and verbally about the research, that participation was voluntary and that they could withdraw at any time without any effect. Informed consent is an individual's autonomous permission of participation in research (Beauchamp & Childress, 2013).

In study A (Paper I) the RTNs were informed about the study through an electronic information letter and at a department meeting. Before the interview started,

participating RTNs were additionally informed about the study and the aim, then written consent was signed.

In Study B (Paper II) and C (Papers III-IV), when a child was referred for RT the nurse at the pediatric department contacted the family and informed about the research. If they were interested in participating, their names were forwarded to the author of this thesis and they were contacted and given both verbal and written information. The family were encouraged to contact the researchers if they had further questions. Before the child's RT began the parents gave written consent. However, parents were living under extremely difficult circumstances during their child's RT, which may affected the inclusion of parents writing diaries.

In study C, children were involved, thus special considerations were taken regarding inclusion. Informed consent should not only be required from the parents but also, if possible, from the child. To be able to give consent to participate in research, an ability to understand the information given is required so that the child understands what it means for him or her (SFS, 2003:460). Children from the age of 12 received age-specific written information about the research and thereafter they gave consent. Children under the age of 12 received age-appropriate information about the research verbally (SFS, 2014:821), and thereafter they gave their assent.

Non-maleficence and beneficence

The principle of non-maleficence means that one should “*not inflict evil or harm on others*” (Beauchamp & Childress, 2013, p. 113). All participants were guaranteed confidentiality, meaning protection against unauthorized access to the data (WMA, 2013). All names and places in the transcribed interviews and diaries were replaced with fictitious names and all questionnaires were coded. The code list together with all the material (Papers I-IV) were kept in separate locked safes accessible only by the researchers.

Writing a diary can cause difficult feelings and emotions. Due to the child's cancer diagnosis, all parents were offered professional support from a counsellor or psychologist through the pediatric oncology department at the children's hospital. Thus, if the parents needed more support during the research project they all knew where and whom to turn to.

The principal of beneficences refers to an action to benefit others (Beauchamp & Childress, 2013). In study C, the children in the IG were invited to undergo their RT if possible without GA. Repeated GA involves risks to the child and increased anxiety for the parents and the tested intervention offered the child and parents an alternative to GA. The intervention might also reduce hospital costs, which gives more resources to inform and prepare children. However, if the child is not able to lie still during RT

when awake this could be a risk since healthy tissue might be irradiated. Thus, it was important that parents and child were informed about potential risks of both procedures so that they could decide, together with the oncologist, on how the treatment was to be carried out, awake or with GA.

Justice

The principal of justice refers to a fair and appropriate recruitment of participants in the studies (Beauchamp & Childress, 2013). In study A, all RTNs at the RT department were asked to participate regardless of gender, age and ethnic background. In studies B and C, participants required some knowledge of Swedish since they were asked to keep a diary, the questionnaires were in Swedish and some parts of the intervention were written in Swedish (leaflet and storybook), which meant that families who did not speak Swedish were excluded. In studies B and C, a consecutive selection was made, meaning all families who fulfilled the inclusion criteria were asked about participation.

Both the UNCRC (1989) and the Swedish Patient Act (SFS, 2014:821) state the importance of including children in matters concerning them, which enables them to give their opinions. The intervention developed in study C was aimed at children and involved them actively. Thus, when assessing the intervention it was important to include the child's perspective.

Findings

Radiotherapy nurses' perceptions

Caring for children undergoing RT was perceived by the RTNs as a complex work situation. The RTNs perceived that they provided holistic care, which involved focus on the child, family, procedure and development of the profession. When they provided holistic care, they could give a sense of security to the child and parents, which included individualization of information and preparation, working as a team and maintaining the balance among those involved. When the RTNs provided holistic care, and gave a sense of security to the child and parents, they perceived that they became committed with both positive and negative outcomes.

Providing holistic care

To provide holistic care the RTNs found it important to take responsibility for the care they provided to the child and family (parents and siblings), as well as for the technical aspects of the procedure. They also indicated that holistic care required taking responsibility for the development of their profession. It was desirable to meet the child early before RT began, when they could observe, listen and put questions to the child, and thus personalize the care. Parents needed to be involved in the child's treatment, as the RTNs perceived that the parents' anxiety was reduced when they knew what would happen. The RTNs perceived that they took responsibility for the technical aspects of the treatment and procedure. To avoid the possibility of making errors, they felt a need to be effective and to create a strategy for each child and family. In order to give holistic care the RTNs perceived that they needed to know their limitations, take greater responsibility and develop their skills concerning the children's care.

Giving a sense of security

In order to give a sense of security the RTNs perceived that they made an effort in terms of the information and preparation they gave the child and in their teamwork with those involved (i.e. the child, family members, colleagues and anaesthesiologists).

RT was perceived as strenuous for the children since they had to lie still, be alone in the treatment room and sometimes wear a facial mask. Involving the child and parents in decisions regarding the care was important. The RTNs tried to adapt their care to each child, to the specific situation and the child's level of development. The treatment was easier to carry out when they worked as a team with child, parents and the anaesthetic team and when they all had the same objective. Continuity in routines and healthcare professionals was also important. Maintaining balance amongst all those involved and fulfilling their own tasks was perceived as a challenge since the treatment was different every time depending on the children's and parents' emotions and behaviour, but the RTNs perceived that their efforts created a sense of security for the child and family.

Being committed

The RTNs perceived that they were committed, in terms of giving more of their strength and were closer, when they cared for children undergoing RT. It was important that everyone in the family was cared for and received the support they needed. A professional manner was important when trying to help the family to cope with the situation and they could not focus in their own negative emotions. However, such commitment could cause emotional strain for them, such as sadness and grief but also joy and gratitude.

Parents' lived experiences

Parents' lived experience was described as a balancing act between coercing and protecting their child, despair and hope and being powerless and gaining control.

Coercing and protecting

Parents coerced their child to undergo RT in order for the child to survive or to live longer. They had to expose their child to radiation, its side effects and feelings of loneliness during RT, which contributed to anger, stress and anxiety in the child, and this was experienced to be extremely hard. The parents protected their child from negative experiences such as poor communication with healthcare professionals, appointment changes, difficulty in getting food and different anaesthetic teams. By doing this, the parents had a sense that they eased their child's treatment and that their child handled the situation better. The parents tried to hide their feelings from the child so that the child would not worry. This was described as being difficult since the parents

felt that they hid information from their child and were afraid that the child would lose respect for them. On the other hand, they found it difficult to tell the child everything, as they did not want their child to know about all the potential side effects.

Despair and hope

At the same time as they coerced and protected their child, they experienced a balancing act between despair and hope, not only in the present, but also when thinking about the future. The cancer diagnosis and all the possible side effects worried them and gave a feeling of despair. Sometimes they wondered if their child would cope since they experienced their child's deep suffering. They hoped that their child would make a full recovery and not have too many negative experiences while going through their treatment for cancer. To remain hopeful the parents tried to regain normality in their daily life and to involve their child in activities like swimming, meeting friends or going to school. Their child was happy in these moments, which made the parents feel better. The parents' greatest wish was that the treatment would help. The existence of a technology that could make the child healthy felt overwhelming and the treatment itself felt magical. To remain hopeful they searched for positive feedback from their child and healthcare professionals, which helped them to cope with everyday life. Their child's fighting spirit also gave them hope that there would be a positive outcome.

Being powerless and gaining control

The parents experienced themselves as powerless, trying to gain control. The cancer diagnosis itself gave a sense of powerlessness since it felt as if the power was in someone else's hand. Their impression was that they had no choice and that their child was paying a high price. The parents asked for more coordination in their child's care due to the feeling of powerlessness since they received different answers, experienced poor communication and felt that they had to phone, organize and ask questions in order to make things happen.

Being in control was essential for the parents, helped them to cope with the situation, and allowed them to focus on their child. In order to gain control, it was important to find routines and strategies in the family's daily life. Following routines helped the parents and their child to accept the situation, improved their mood and allowed them to be more relaxed. However, despite these routines and strategies for gaining control, the parents were aware that their control could disappear at any time, which made them feel powerless.

Age-appropriate information and preparation procedures for children undergoing radiotherapy

Feasibility

Altogether 17 children with 32 parents agreed to participate in the IG. Of the 17 children and 32 parents included in the IG there were no dropouts. The intervention was delivered as intended without additional healthcare professionals at the pediatric and RT department and was found acceptable by the healthcare professionals. The RTN who attended to the child's first appointment with the oncologist arranged the visit to the treatment room and provided the child with chosen parts of the intervention. Altogether 13 children out of 17 made a visit prior to RT. Two out of six children used the AV-goggles. Music/story and the safety string were available for eight children; five listened to music/story and three used the safety string.

Measurements were performed on a total of 237 occasions. The instruments used to measure effectiveness, FPS-R, VAS and CEMS, were found easy to understand and to complete. When measuring HR an internal dropout occurred due to the child's refusal, side effects of the GA such as anger and sleepiness, or technical difficulties. Concerning the parents, both parents were not always able to follow their child throughout the RT since the treatment went on for a long period. This resulted in a small dropout of parents' self-rated anxiety (VAS) and completion of the questionnaires SOC and PedsQL™ Family Impact Module.

Effectiveness

Need for general anaesthesia

There were no significant differences between the CG and IG in the numbers of children requiring GA. However, in the IG three children first planned to have RT with GA went through the treatment awake and altogether they had 73 fractions without GA. Regardless of CG and IG younger children, 3-9 years, had GA, which also was significant ($p<0.001$) whilst all the older children, 10-18 years, were awake ($p<0.001$).

Anxiety and emotional behaviour

The analysis showed that children receiving GA regardless of CG and IG had more negative observed emotional behaviour (CEMS) before the start of the RT compared to those children who were awake, which also was significant ($p<0.001$). Parents of

children receiving GA also had significantly higher self-rated anxiety compared to parents of children who stayed awake ($p=0.040$).

There were no significant differences between the CG and IG concerning children's observed emotional behaviour (CEMS) before RT, children's self-rated anxiety (FPS-R/VAS) and parents' self-rated anxiety (VAS). The children's HR before RT was significantly higher in the IG ($p=0.040$), also over time meaning all fractions compared to the first fraction ($p=0.003$), but no difference after RT was shown between the CG and IG.

SOC and PedsQL™ Family Impact Module.

In the SOC questionnaire, there were no significant differences between the parents in the CG and IG total score and the three dimensions of comprehensibility, manageability and meaningfulness.

Concerning parents and family functioning (PedsQL™ Family Impact Module), the parents' in the IG experienced statistically significantly better communication than the parents in the CG, both at the child's first ($p=0.010$) and last fraction ($p=0.008$). In the questionnaire communication was described in terms of: others understanding of the family situation, and easier communication with others and healthcare professionals about their child's state of health and their own health.

At the child's first fraction, parents in the IG self-reported higher median score in the dimensions physical, emotional, social and cognitive functioning, worry and daily activities. Also total score, HRQOL and Family function had higher median scores. This indicates better functioning although differences were not significant.

At the child's last fraction, parents' social functioning scored higher in the IG than in the CG ($p=0.022$), which indicates that the parents felt less isolated, had fewer problems receiving support from others and had increased time and energy for social activities. The parents in the IG also reported at their child's last fraction higher median scores in physical function, emotional function and worry, total score and HRQOL, although this was not significant.

Hospital costs

Concerning estimated hospital costs, the mean costs for children receiving GA regardless of CG and IG were SEK 7113 higher per visit than for children who were awake, which also was significant ($p=0.002$). Within the IG, the mean cost for the procedure when children received GA was higher per visit, due to longer time and more personnel involved, than for children awake, meaning that if a child within the IG was awake the hospital reduced its costs by SEK 5274 per visit ($p=0.055$). The calculated costs for the development of the intervention was SEK 38700.

Discussion

Methodological considerations

The research followed the framework of the MRC (2008), thus an exploratory sequential mixed method design was used. In the first phase, qualitative research was done, interviews with the RTNs and diaries written by parents. The findings together with previous research and the theoretical framework were used to develop an intervention including age-appropriate information and preparation procedures for children undergoing RT, to test the effectiveness in terms of the need for GA, anxiety, parents- and family functioning and hospital costs. In the second phase, a feasibility study was chosen because fewer than 20 children each year are treated at the specific hospital. Another reason was to detect problems of acceptability, compliance, delivery of the intervention, recruitment and retention before a full-scale evaluation.

Children, their parents and RTNs all participated with the aim of deepening the understanding of the phenomenon studied. Traditionally, research to explore children's perspectives has been conducted with parents/adults as proxy, although their experiences may differ from the child's (Söderbäck et al., 2011). Thus, when research involves children, it is important to explore the children's experiences, perceptions and understanding of the context. Both the UNCRC (1989) and the Swedish Patient Act (SFS, 2014:821) indicate that it is important that the children's best interest is considered in all matters concerning them, thus were children included in this thesis and their experiences were assessed through self-rating, observation and by measurement of vital parameters.

When conducting research the chosen methods and instruments may contribute to strengths as well as limitations in the findings, which is essential to discuss in order to assess the quality. In qualitative research, the quality is often assessed in terms of trustworthiness (Lincoln & Guba, 1985) and in quantitative studies in terms of validity and reliability (Creswell, 2014).

Trustworthiness

In this thesis two different qualitative methodologies were used, phenomenography in Paper I (Dahlgren & Fallsberg, 1991) and hermeneutic phenomenology in Paper II (van Manen, 1997). Criteria for determining various aspects of trustworthiness in qualitative research, according to Lincoln and Guba (1985), are the concepts of credibility, transferability, confirmability and dependability. These criteria help the researcher to check the validity of the findings and whether the researcher's approach is reliable (Creswell, 2014).

Credibility in research refers to the attempt to demonstrate that a true picture of the phenomenon explored is being presented (Lincoln & Guba, 1985) including the selection of appropriate participants, methods and data collection approach (Creswell, 2013).

In Paper I, strategic selection is recommended in phenomenographical studies, although this was not possible despite several written reminders and orally communicated information. Nevertheless, RTNs of different ages and working experiences with children were interviewed. The phenomenographical approach stresses two concerns when conducting interviews. First, the reason for participating and secondly the researcher's pre-understanding of the phenomenon studied (Sjöström & Dahlgren, 2002). There is a possibility that only the most-interested RTNs participated, but the findings reflect a variety of perceptions. Semi-structured interviews was conducted in order to describe the RTNs perception of caring for children undergoing RT. The pre-understanding is important, as the interviewer needs to be aware of the participants' world and the way the phenomenon might be perceived (Dahlgren & Fallsberg, 1991). As the researcher did not work with RT prolonged engagement in the field was necessary, which was one way to assure credibility (Creswell, 2013) as it developed an understanding of the phenomenon. Spending time in the field and on data collection meant that trust was established with the participants, which in turn gave rich data.

In Paper II, all parents included in the CG and two parents in one family in the IG in the CCT, altogether 33 parents, were informed about the study, but altogether ten parents in the CG, eight mothers and two fathers, with children of different ages agreed to participate. Writing a diary requires certain skills, which might have excluded parents not accustomed to writing about their experiences. Another reason for not participating might be the severe situation their child and they were in. Diaries as a method could cause problems as the parents wrote their lived experience rather than retrospectively recalling during an interview. Explanations and interpretations might have been written instead of the parents' experience as they lived through it, which was taken into consideration during the analysis process. The author of this thesis met the families during the child's RT at the three first fractions, every fifth fraction and the last one,

and at these encounters the parents had the opportunity to ask questions about the expected content in the diaries. In order to minimize bias in the analysis, the pre-understanding was made clear and reflected on (van Manen, 1997).

In both Paper I and Paper II all researchers contributed to the analysis to prevent bias. Furthermore, the manuscripts of the two articles were peer reviewed to obtain an external check of the research process (Creswell, 2013) in a research group consisting of doctoral students, junior and senior researchers in various areas concerning children and families.

Transferability refers to whether the findings can be transferred to other contexts (Lincoln & Guba, 1985). A detailed description of the participants is needed and allows the reader to make decisions about transferability (Creswell, 2013). This was done by presenting the setting and background variables of participating RTNs and parents. In Paper I, the findings represent common variations of perceptions among RTNs (Dahlgren & Fallsberg, 1991) which may provide prerequisites for developing professional guidelines. In hermeneutic phenomenological research (Paper II) the findings can never be generalized according to van Manen (1997). However, the results can contribute to healthcare professionals' understanding of the parents' experience and deepen their knowledge of how to care for parents and their child during repeated and strenuous treatment or examinations. In this thesis, according to the MRC (2008) framework for developing and evaluating complex interventions the findings in Papers I and II contributed to the development of the intervention tested in Papers III and IV.

Confirmability refers to whether the findings are grounded in the data collected (Lincoln & Guba, 1985). The background and knowledge of the phenomenon studied in the involved researchers came from experiences in pediatric nursing, diagnostic imaging and research with children and families. To obtain a true picture of the phenomenon studied, all four authors were involved in the analysis process. Quotations from the text were used which reveal interpretations of the text and allow the reader to judge the trustworthiness (Creswell, 2013).

Dependability refers to the stability of the finding over time and conditions (Lincoln & Guba, 1985). To increase dependability, the research process was described thoroughly in order to make it easy to follow. An interview guide was used in Paper I, and in Paper II the parents received written instructions on how to use the diaries, which increases possible duplication.

Validity and reliability

In quantitative research, validity and reliability are two concepts used to evaluate a study's strength and weakness (Creswell, 2014). In terms of validity, there are four

dimensions: internal validity, external validity, construct validity and statistical conclusion validity (Shadish, Cook, & Campbell, 2002).

Internal validity refers to the conclusions drawn from the study (Shadish et al., 2002). Through triangulation, i.e. multiple data sources, children and parents, and multiple methods sources, observation, vital parameters, self-rating and questionnaires, the internal validity was strengthened (Creswell, 2014).

In Papers III and IV children, aged 3-18 years, with cancer undergoing RT and their parents were included in a CCT consisting of a CG and an IG. Instead of randomization, which is preferred to minimize selection bias (MRC, 2008), consecutive sampling was used due to the low number of children treated each year. With two groups not running parallel diffusion of the intervention could be avoided, which facilitated for the healthcare professionals involved. Data collection lasted for four years, which is a threat to the internal validity. A long timeframe implies that the organizational conditions will not be the same for all included families, which could bias the findings (Persson & Sahlin, 2013; Shadish et al., 2002). During the four years the study lasted, there was no external effect in terms of new apparatus, treatment routines and personnel. To minimize history bias a study protocol was used to assure that the child and family received the different parts of the intervention and there was also a recurrent control, i.e. presence at the child's RT, that the routines were the same and that the intervention was carried out according to the planned design.

Regarding recruitment and retention in the feasibility study, in total three children, all adolescents, and five parents declined to participate in the study. There may be various reasons for not participating. A reason for adolescents not participating may be that they are in a period of finding their own identity and becoming independent (Piaget, 1953). Another reason could be that the child and the entire family were affected during the child's cancer treatment and life was experienced as an everyday struggle (Björk et al., 2009; Enskär et al., 2011; Gibbins et al., 2012), and that parents experienced the RT as a difficult time (Paper II). After inclusion in the study there were no dropouts.

The great variation of children with various preconditions might have decreased the possibility to show significant differences in our studies. There were few children to include, thus children included were of different ages and cognitive development, had both curative and palliative RT and different diagnoses, which included different immobilization devices, positioning of target area, duration of each fraction, number of fractions and choice of machine. In future studies a more homogeneous patient group might be preferable, for example, children aged three to nine, but this would imply a longer time-frame, which might include difficulties and other challenges due to possible reorganization, apparatus etc. To include more hospitals in a multi-centre study could also be preferable, but then quality assurance of recruitment and compliance with the study protocol would be needed. In a research project proceeding over-long term the participants experience many natural changes such as maturity, side

effects of the RT etc. that would occur even if not included in a project (Shadish et al., 2002), which might influence the findings. These events, so-called maturation threats, were considered equal in both CG and IG since the children's background variables were comparable. Background variables of the parents in the CG and IG in terms of SOC, age, gender, marital status, education and employee were also comparable. However, in the IG more parents of non-Scandinavian origin were included, which might have affected the results as religion, culture and lifestyle affect how emotions are expressed (Gibbins et al., 2012).

Statistical validity refers to whether the conducted statistical test is adequate and sustainable (Shadish et al., 2002). A power calculation for sample size was done, which showed that two equally sized samples of 57 children needed to be included to be able to show a power of 80% and detect a 25% decrease in the use of GA with 5% significance (p -value < 0.05). Inclusion of altogether 114 children was not possible because fewer than 20 children are treated each year at the specific department, thus the findings should be interpreted with caution. Despite the small sample some statistical significances were found, which indicates that some conclusions can be drawn.

Construct validity refers to whether the instrument used measures what it is supposed to measure and whether the constructs of interest in the intervention is measured (Creswell, 2014). FPS-R (Hicks et al., 2001) and VAS measured children's and parent self-rated anxiety. Both instruments are validated (Hicks et al., 2001; Jakobsson, 2004) and have been used in previous studies. FPS-R has also shown strong correlations to VAS (Hicks et al., 2001). FPS-R is validated for children aged 4-12 years but was used on children aged 3 since a study by Spagrud et al. (2008) has shown that 3-year-olds understand and are able to use the instrument.

CEMS were used to observe children's emotional behaviour. The instrument has shown high content validity and strong correlation with an instrument measuring children's anxiety, and heart rate (Li & Lopez, 2005). The instrument has been used in previous studies on children undergoing stressful medical procedures (Li, 2007; Li et al., 2007). CEMS has only been validated for children aged 7-12 years. However, in a study by Staab et al. (2014) CEMS was used to assess distress in children aged 3-21 years during healthcare-encounter and the instrument was found positively significant with an instrument assessing children's psychosocial risks and with healthcare professionals' and parents' rating. The instrument was translated into Swedish according to WHO guidelines (WHO, 2016) in the research team and then tested in a pilot study for face validity by the author of the thesis, and was found to be understandable and useful.

Heart rate was measured to assess the child's anxiety response to the situation, which has been used in previous studies to assess anxiety (Klosky, Tyc, et al., 2007; Tyc et al., 2002). A digital automatic wrist blood pressure monitor was used, but there were some difficulties such as child's refusal, side effects of the GA such as anger and sleepiness or technical issues. A HR monitor, for example a handheld pulse oximeter, may be

preferred since it is easier to use, although some loss due to technical errors and refusal was seen in studies by Tyc et al. (2002) and Klosky, Tyc, et al. (2007).

Two questionnaires were used in Paper IV, SOC and PedsQL™ Family Impact Module, which are two well-known instruments and both have shown high construct validity (Antonovsky, 1993; Eriksson & Lindström, 2005; Varni et al., 2004). The SOC questionnaire was used as background parameter, as according Antonovsky (1987) people's life orientation will have an impact on health. The PedsQL™ Family Impact Module was given when the child and family were included and once again when the RT was completed.

External validity refers to generalizability of the result, if inferences about the extent to which a causal relationship holds over variations in persons, settings, treatments and outcomes (Shadish et al., 2002). The findings in Paper III and Paper VI were based on a small sample, which is a hindrance for generalization. All children and families fulfilling the inclusion criteria were invited, which reduced the risk of selection bias (Creswell, 2014). The sample represented different ages, cancer diagnosis, family constellations, education levels of the parents and origin. The setting and conditions for RT are almost the same in Sweden, except that at the specific RT department some children were treated with tomotherapy, not available elsewhere in Sweden, which implies longer duration. Study C was designed and planned as a feasibility study according to the framework for developing and evaluating complex interventions (MRC, 2008) and the future step is a full-scale evaluation.

Reliability refers to the consistency of the measure (Creswell, 2014). All instruments used have reported good internal consistency (Antonovsky, 1993; Jakobsson, 2004; Li & Lopez, 2005; Varni et al., 2004), which increases the reliability. Concerning FPS-R (Hicks et al., 2001) the FPS (Bieri et al., 1990) which the FPS-R is based on has shown good internal consistency. Observations of the children with the CEMS were made by two of the researchers, and to minimize bias the observations was carried out together at the beginning of the study and the results were compared and discussed.

General discussion of the findings

RTNs' perceptions and parents' lived experience

When children underwent RT the RTNs wished to meet the child and parents before the start of RT in order to establish a connection and to personalize the care. However, this was perceived as difficult due to organizational matters at the department. Previous research has shown that good relationships with healthcare professionals are essential for the children (Björk et al., 2006; Runeson et al., 2002a) and parents (Hallström & Elander, 2007; Hallström et al., 2002) as it helps them to comply with treatments and examinations (Flowers & Birnie, 2015). Both the UNCRC (1989) and the Swedish Patient Act (SFS, 2014:821) state the importance of involving the child in matters concerning them, which can contribute to a better understanding of the child's needs, previous experiences and expectations (Söderbäck et al., 2011). Meeting the child and family before RT might make it easier to individualize information and preparation for each child and family, which increases the child's ability to comply and comfort within the environmental, psychospiritual and physical aspects of RT such as lying still, being alone during treatment, and wearing immobilization devices. Meeting before RT might also enhance sociocultural comfort as the RTN is able to inform and prepare the child and parents, and psychospiritual comfort as a relationship is established.

Routines and strategies were important for both the RTNs and parents. The RTNs perceived that routines and continuity in healthcare professionals gave comfort and helped the child to comply with the RT. The parents felt more in control and appreciated when routines were planned, recurrent and performed in the same way. By using routines and strategies, i.e. information and preparation procedures, when children undergo RT has been shown to decrease the child's anxiety (Klosky et al., 2004), parents' anxiety (Klosky, Garces-Webb, et al., 2007) and increase the child's ability to comply (Barry et al., 2010; Pimm et al., 1997). Furthermore, RTNs wished for guidelines to better care for the children since caring for the child and at the same time focusing on the technical parts of the RT was sometimes perceived as a challenge, which also was shown when caring for adult patients in a study by Bolderston et al. (2010). When guidelines are developed, involvement of healthcare professionals, child and family is needed, and previous research in the field needs to be reviewed to find the best existing evidence (MRC, 2008). Instead of working ad hoc, implementation of guidelines and tools to care for children and their family might help the RTNs to balance care and technical aspects, and help the child and family to better comply with RT with increased comfort in the four contexts mentioned by Kolcaba (2003).

The RTNs sought to give holistic care as this was perceived to give comfort, and their goal was to give CCC. However, the parents had a need to protect their child from

unpleasant information and wished to sort the information their child would receive. These findings might cause an ethical conflict between the parents and the RTNs. The RTNs are obliged to involve the child in the care (SFS, 2014:821; UNCRC, 1989). However, the parents have the legal right to decide but they should take into account the child's views and wishes in line with the child's rising age and development (SFS, 1949:381). If the child do not receive information about their treatment, it might decrease their participation and complicate their decision-making. It might also add anxiety to the procedure, which might decrease the child's physical, psychospiritual and sociocultural comfort (Kolcaba & DiMarco, 2005).

When a child underwent RT the parents experienced increased anxiety and problems maintaining a normality in daily life. The parents also called for more coordination to decrease the feeling of powerlessness and to gain control over the situation. Several studies have shown that during a child's cancer period parents experience anxiety, uncertainty (Enskär et al., 2011; Gibbins et al., 2012), poor mental health and lack of support (Dockerty et al., 2000), and to regain normality was an important part for the parents well-being (Björk et al., 2009; Gibbins et al., 2012). To help parents to gain control and thus decrease their anxiety they need to receive information before the RT and be involved as much as possible in the child's care during the RT, which also was shown by Klosky, Garces-Webb, et al. (2007). To facilitate communication with the healthcare professionals at the hospital regarding the child's care a coordinator could plan encounters, tests, special care visits and between-visit follow-up, which might also give the parents some kind of control and a possibility to regain some normality in daily life. A coordinator within asthma-, type I diabetes- and obesity care for children was shown in a systematic review (Raphael, Rueda, Lion, & Giordano, 2013) to e.g. improve the health status of the child and parental quality of life. The parents had fewer missed workdays and the child fewer missed schooldays.

Age-appropriate information and preparation procedures

Both the RTNs and parents (Papers I and II) found continuity in personnel, routines and strategies important, which might facilitate the procedure of RT for all involved parties. The parents needed to be close to their child and to be involved in care to handle the situation. Furthermore, the RTNs stressed the importance of meeting the child and family before RT. These findings together with previous research and theoretical framework were included in an age-appropriate information and preparation procedures intervention, which was tested for feasibility and effectiveness according to the framework for developing and evaluating complex intervention (MRC, 2008). The intervention tested aimed to gain knowledge about the procedure of RT and to give the child a choice of distractions to use during RT to be able to undergo RT without GA. Thus, the intervention gave an increased possibility to the

child and parents' to participate in the planning of the care. Participation can increase comfort for both the child and parents, increasing the child's ability to comply with RT and to be included in the decision-making.

The findings showed that the intervention was delivered as intended and that both healthcare professional and children found the different parts acceptable (Paper III). As children learn and understand situations differently depending on their age and cognitive development (Piaget, 1953) a combination of different parts in the intervention was considered as an advantage since it has shown a decreased use of GA in earlier studies (Edwinsson Månsson, 1992; Filin et al., 2009; Scott et al., 2002; Slifer, 1996; Törnqvist et al., 2015; Willis & Barry, 2010). The different parts in the intervention were chosen to actively involve the child and parents (Coyne et al., 2016) and to give the child sociocultural-, psychospiritual-, physical- and environmental comfort (Kolcaba & DiMarco, 2005). However, the study did not investigate which part was the most effective or whether there were other parts the children and parents' wished for. The difference between the CG and IG were that the children in the CG received non-standardized information that varied and was not performed in a systematic way. In the IG, all children were introduced to the different parts and they could chose the parts they wanted or needed to be able to comply with RT. In the IG, eight out of 17 children were awake. Unfortunately, four of the children awake who had RT to the head with tomotherapy for technical reasons could not use the AV goggles.

The costs for the intervention developed was calculated at SEK 38500. The intervention was delivered with ordinary healthcare professionals, which entailed no extra costs for the hospital. In other studies (Filin et al., 2009; Haeberli et al., 2008; Scott et al., 2002; Scott et al., 2016; Slifer, 1996) which all showed less use of GA for children undergoing RT, additional personnel specially trained to care for children performed the intervention. A child life specialist in pediatric diagnostic imaging has also been shown to increase parents' satisfaction and decrease children's anxiety (Tyson, Bohl, & Blickman, 2014) and the use of GA, especially children aged 5-10 years (Durand, Young, Nagy, Tekes, & Huisman, 2015). The intervention in study C was not done with personnel specially trained to care for children at the RT department, which might affect the effectiveness of the intervention. However, additional personnel increases the costs for the hospital.

Parents in the IG experienced better communication compared to the parents in the CG and at the last fraction they had higher scores in social functioning. Similar results concerning communication were found in a study by Törnqvist et al. (2015) for children receiving age-appropriate preparation undergoing MRI. Communication has been shown in previous studies to be an important need for parents when having an ill child (Hallström & Elander, 2007; Hallström et al., 2002). In the IG the RTNs who were responsible for the child's care met the child prior to RT. Continuity in healthcare

professionals, which might increase sociocultural and psychospiritual comfort, might help the parents to gain control and make them able to relax, since the professionals know them and their child (Björk, 2008). Furthermore, if parents gain knowledge, oral, visual and written, prior to the child's RT it enables them to communicate with healthcare professionals and others about their child's state of health and their own health. Knowledge may also facilitate parents' social functioning in terms of gaining control and normalcy in their life, which was shown to be important by Björk et al. (2005).

The findings showed no significant differences in the need for GA between CG and IG. However, those children who received GA, regardless of IG and CG, were in the age group 3-9 years, had more negative observed emotional behaviour and their parents also showed higher self-rated anxiety. The findings also showed that children in the IG had significantly higher heart rate. The child's ability to comply with RT due to age and developmental stage might explain some of the findings. The increased heart rate in the IG could be that gained knowledge might increase anxiety but could also increase compliance despite anxiety. Another reason that might explain the findings could be that the decision about GA was made in advance to information and preparation procedures by the attending physician, together with the child and parents, at the pediatric department due to the existing routines. In the IG the child and parents received the leaflet and storybook, which enabled them to be a part of the decision-making process, but this might not have been enough. Unfortunately, they were not able to meet the professionals at the RT department or pay a visit to see the apparatus before the decision about GA. Involvement of the child in the decision-making process means that he/she needs information about the process of RT and what it implies before a decision can be made (SFS, 2014:821), and involvement of the child has shown to improve cooperation, recovery, patient satisfaction and trust in relationships (Coyne et al., 2014).

There are several advantages for the child and family if the child is able to undergo RT without GA. The child can avoid the risks that GA might imply (Buchsbaum et al., 2013; Fortney et al., 1999; Seiler et al., 2001), does not need to fast, the hospital stay will be shorter and the family have a greater possibility to live a normal family life. However, there is also a risk of increased side effects and non-optimal treatment if the child is not able to lie still during RT. To prevent this the RTN supervises the child during treatment and if the child moves, the radiation is discontinued. Before a decision is made about GA it is important that the parents and the child are informed about the advantages and disadvantages of both procedures.

A finding with clinical relevance was that three children in the IG first planned for GA went through the RT without GA, including 73 fractions. The findings showed that the mean costs in the IG was reduced with SEK 5274 per visit compared to those children who were awake. Altogether the costs for these three children were lowered

by SEK 385002. These three children chose the safety string and used it during all fractions. During examinations and treatment previous studies have shown that children have a need to have their parents close (Björk et al., 2006; Runeson et al., 2002a) and as a parent to be close (Enskär & von Essen, 2000; Hallström & Elander, 2007; Hallström et al., 2002). In the context of RT parents felt that they abandoned their child during RT when leaving them all alone (Ångström-Brännström et al., 2015). The safety string in the intervention enabled a sense of closeness as it connected the child with the parent in the waiting area, which might have helped the child to endure the RT and parents to give comfort to their child. Furthermore, if children undergo RT without GA the availability of anaesthetic personnel increases, which enables the hospital to prioritize other areas of care.

Conclusion and clinical implications

When developing professional guidelines, as well as information and preparation material for children undergoing RT, continuity in healthcare professionals, routines and strategies, letting the parents be close to their child and involved in the care, and a possibility for the RTN, child and family to meet before RT are important aspects to include in order to facilitate the process for all involved parties.

Age-appropriate information and preparation procedures including different parts must be considered as an advantage since children in different ages and developmental stages have different needs. Furthermore, if parents are involved in the child's care and receive information and preparation together with the child it is shown to have an effect of improved communication and social functioning for the parents and family, which might enable them to gain better control over the situation and regain normalcy in life.

The thesis showed that children, aged 3-9 years, who received GA and their parents had more anxiety than children without GA and their parents. This implies that it is important to offer an alternative to GA to help the child comply with the RT, if it is possible due to the child's age and development stage. Becoming familiar with the procedure of RT and involved in the decision-making process about GA might facilitate more children to undergo RT without GA.

Thus, age-appropriate information and preparation procedures before and during RT, consisting of basic and non-costly utilities and a structured approach, are important as this might increase the children's ability to participate in the care, comply with the RT and thus experience comfort, which might increase the number of children undergoing RT without receiving GA. Furthermore, if a child is able to undergo RT without GA it means, for the individual child, fewer risks and restrictions, and for the child and parents decreased anxiety. For the healthcare it means lower costs, which enables other

areas of pediatric anaesthetic care to be prioritized. However, the intervention needs to be further evaluated in a larger study, for example a multi-centre study, with a more homogeneous group of children.

Further research

The intervention tested here was developed from the findings in the qualitative studies, i.e. RTN perceptions and parents' lived experience. However, when developing interventions that target children, the child's perspective also needs to be included together with parents and healthcare professionals. Further research in the area is important to understand the experiences of all involved parties when children undergo RT.

A finding in the diaries written by the parents was that the parents called for increased coordination in the care of the child to help them to manage and focus on their child. The intervention tested did not affect the coordination between the pediatric oncology department and the RT department. A coordinator responsible for planning the child's cancer care might ease the parents' burden and help them to enhance their feeling of gaining control. Thus, a coordinator planning the child's cancer care would be interesting to explore.

The intervention tested showed good compliance and acceptability. However, further evaluation of the intervention is needed. In the feasibility study the child and parents in the IG were not asked about their experience about the impact and content of the intervention and the care that they received. This would be interesting to find out and then implement the findings in the design of the intervention. Since each cancer centre in Sweden treats approximately 20 children with RT each year, a full-scale evaluation in a multi-centre setting with a more homogeneous patient group might be preferable to assess the effectiveness of the intervention. A multi-centre study facilitates faster recruitment and increased generalization due to the participation of a larger population.

In the near future, more children might be treated at the Skandion clinic with proton-radiation therapy. Implementation of common information and preparation procedures nationally is essential as the child's preparation is planned to be carried out at their home hospital. If all children are prepared for RT as similarly as possible this might increase the child and family comfort and facilitate the healthcare professionals to give the best care possible to the child and the family.

Summary in Swedish

När ett barn får en cancersjukdom påverkas hela familjen och det upplevs som en påfrestande tid för både barn och föräldrar. En del av barnets behandling kan vara strålbehandling, vilket innebär behandling fem dagar i veckan, under en period från en upp till 7 veckor. Trots att strålbehandling är smärtfri och icke invasiv upplever många barn oro då de är ensamma i samband med behandlingen, måste ligga still och befinner sig i en främmande miljö. Oro, barnets ålder eller dess oförmåga till samarbete leder till att många barn sövs vilket kan för en del barn innebära över 30 gånger. Att söva ett barn vid strålbehandling innebär risker samt ökat obehag för barnen och föräldrarna. Dessutom blir behandlingen mer tidskrävande och ger ökade kostnader för sjukvården eftersom mer personal och utrustning krävs. Åldersanpassade förberedelser har visat positiv inverkan på barns oro och samarbetsförmåga. När barnet strålbehandlas är det strålbehandlingssjuksköterskan som möter och ansvarar för omvårdnaden. I det dagliga arbete möter hon både barn och vuxna patienter samt kombinerar omvårdnad med högteknologiska uppgifter vilket kan vara en utmaning.

Avhandlingens övergripande syfte var att undersöka vården utifrån strålbehandlingssjuksköterskors och föräldrars perspektiv och baserat på resultaten, tidigare forskning och det teoretiska ramverket utveckla och testa information och förberedelserrutiner för barn som strålbehandlas utifrån barns och föräldrars perspektiv och sjukhuskostnader. Studie A undersökte strålbehandlingssjuksköterskors uppfattningar av att vårda barn med cancer i samband med strålbehandling. Tolv strålbehandlingssjuksköterskor intervjuades och intervjuerna analyserades med en fenomenografisk ansats. Resultatet visade att strålbehandlingssjuksköterskor uppfattade att de gav holistisk vård där de försökte skapa en trygghet för familjerna i samband med strålbehandlingen. Sjuksköterskorna blev engagerade och de önskade att möta familjen och barnet i ett tidigt skede. Kontinuitet i rutiner och personal var en prioritet. Att finna balans mellan omvårdnaden, tekniken och kommunikation var viktiga delar liksom behovet av att bredda sin kompetens gällande vård av barn (Artikel I).

I studie B undersöktes föräldrars upplevelser av att ha ett barn med cancer som strålbehandlas. Sammanlagt tio föräldrar, 8 mödrar och 2 fäder, skrev dagbok under sitt barns strålbehandlingstid. Dagböckerna analyserades med hermeneutisk

fenomenologisk ansats. Resultatet visade att föräldrarna upplevde sitt barns strålbehandling som en balansgång mellan att skydda och tvinga sitt barn. De balanserade mellan hopp och förtvivlan samtidigt som de kände sig maktlösa och försökte få kontroll över situationen de befann sig i. Det var viktigt för föräldrarna att vara nära sitt barn, möta samma personal och att finna rutiner och strategier under behandlingstiden. Hela familjen var i behov av stöd och önskade hjälp med att samordna vården. Att kunna behålla normalitet i vardagen var viktigt för att få kontroll (Artikel II).

I studie C utvecklades åldersanpassade pedagogiska förberedelser och rutiner vilka jämfördes i två grupper för att se om antalet barn som sövdes i samband med strålbehandling blev färre och om barns och föräldrars oro samt kostnader för sjukhuset minskade. Under en fyra års period inkluderades 16 barn och 31 föräldrar till en kontrollgrupp och 17 barn och 32 föräldrar till en interventionsgrupp. Barnen var mellan 3 och 18 år. De barn som ingick i kontrollgruppen genomförde sin strålbehandling enligt befintliga rutiner vid strålbehandlingsavdelningen. Barnen i interventionsgruppen fick förberedelser bestående av: 1) en broschyr, 2) en sagobok, 3) möta en strålbehandlingssjuksköterska i förberedelsefasen, 4) leka med en dockmodell av behandlingsapparaturen och 5) besöka strålbehandlingsavdelningen. Under behandling 6) titta på film med audiovisuella glasögon eller lyssna på musik och 7) hålla i ett säkerhetssnöre som sammanlänkade barnet och föräldrarna i väntrummet. Alla barn fick tillgång till de första fyra delarna och kunde välja bland de övriga. Barnets och föräldrars oro mättes samt barnets känslomässiga beteende observerades vid de tre första behandlingarna, därefter vid var femte och sista behandlingstillfället. Föräldrarna besvarade dessutom enkäter om deras känsla av sammanhang (KASAM) och om deras och familjens funktion under strålbehandlingsperioden.

Resultatet visade att de åldersanpassade förberedelserna gick väl att genomföra inom ramen för befintlig personal. Inga signifikanta skillnader visades mellan grupperna av antalet barn som sövdes samt deras och föräldrarnas oro. Dock var tre barn i interventionsgruppen, först planerade att sövas, vakna med hjälp av interventionen vilket innebar 73 tillfällen där barnen inte sövdes. De sövda barnen oavsett grupp visade mer negativt känslomässigt beteende jämfört med de vakna barnen. Även föräldrarna vars barn sövdes visade en signifikant ökad oro. Föräldrar till barn i interventionsgruppen upplevde en bättre kommunikation vid första och sista behandlingen och upplevde en bättre social funktion vid barnets sista behandling (Artikel III och IV).

Gällande undersökningstid och kostnader per besök så fanns det inga signifikanta skillnader mellan grupperna. Medelkostnaden per besök för de barn som var sövda i interventionsgruppen var 5 274 kronor lägre än för barn som sövdes i kontrollgruppen.

Kostnaden för de tre barn som inte sövdes i interventionsgruppen beräknades att vara 385 002 kronor lägre jämfört med om de hade sövts. Kostnaderna för utveckling och skapande av interventionen beräknades till 38 700 kronor (Artikel IV).

Sammanfattningsvis visar resultaten att åldersanpassade förberedelser och information för barn med cancer i samband med strålbehandling är betydelsefullt för barnen, föräldrarna och sjukvården. Med relativt enkla och billiga hjälpmedel och ett strukturerat arbetssätt finns det möjligheter för ett ökat antal barn att genomgå strålbehandling utan att sövas. Om ett barn kan genomgå strålbehandling utan att sövas innebär det för det enskilda barnet färre risker och restriktioner samt lägre oro för både barnet och föräldrarna. Kostnaderna för sjukvården blir lägre vilket möjliggör att andra områden där anestesipersonal behövs kan prioriteras. För att påvisa effektiviteten bör en större studie med en mer homogen grupp av barn genomföras.

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