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Karolinska Institutet, Stockholm, Sweden

# **Clinical Ethics in Childhood Cancer Care**

## The Value of Inter-professionally Shared Reflection

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**Karolinska  
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# **Clinical Ethics in Childhood Cancer Care**

## **The Value of Inter-professionally Shared Reflection**

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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“Everyone were together, it created a united pathway. Respected. . . .The ethics case reflection session made it unanimous. Amazing! Everything came up.”

(Quote from a nurse participant, study IV)

To my beloved family: My husband Johan and our children Elin, Karl and Erik – the dearest team on earth.





## ABSTRACT

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Today's increased survival rate, which is related to more effective treatment, contributes to new research areas. Each child's particular situation often causes ethical issues and divergences about treatment and life and death when important values are at stake. The intense and demanding treatment often leads to new difficult situations. The overall aim of the research in this thesis was to gain empirical knowledge and a deeper understanding of ethical issues in childhood cancer care and how healthcare professionals deal with these issues.

In study I a modified model for ethical analysis of ethical problems is presented using theoretical reasoning and the study includes a discussion on pros and cons with the presented procedure. The important aspects of the presented modified model are that it explicitly focuses on values and moral principles with a case-based approach through interprofessional reflection. In study II healthcare professionals who care for children with cancer answered a study-specific questionnaire. The content analysis revealed that ethical concerns were based on health care professional's experiences of infringing on autonomy, deciding on treatment levels and conflicting perspectives. It also revealed healthcare professionals' desire to deal with ethical concerns through interprofessional consideration, and they expressed the need for time, personal space and ethics education. Study III is based on the responses to the Hospital Ethical Climate Scale (HECS). The paediatric hospital ethical climate is described, concluding that the ethical climate is perceived differently between professions and that the perception of being able to practice ethically good care diverged. Some items in the HECS were rated less positively than others. In study IV a Grounded Theory methodology was used. The emerging theory explains how healthcare professionals were able to consolidate care by clarifying perspectives in the context of Ethics Case Reflection (ECR) sessions which overall had positive consequences for the team.

The comparative analysis of the four studies resulted in discovering the value of interprofessionally shared reflection. An ethically justifiable care for the child can be reached by the unique knowledge, dealing with ethical conflicts, a trusting atmosphere and a consolidated care. Even if difficult ethical concerns were found and there were factors in the ethical climate that were not optimal, there seems to be a shared wish for solving ethical concerns within the team, with focus on the best interest of the child. Quality of care would possibly be improved by solving ethical concerns. However, further research is needed to explore effects on the quality of care and possible patient outcomes.

**Keywords:** childhood cancer care; ethical issues; ethical analysis; interprofessional; reflection

## LIST OF SCIENTIFIC PAPERS

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The thesis is based on the four following studies, referred to in the text by their Roman numerals:

- I. **Bartholdson, C.**, Pergert, P., Helgesson, G. (2014). Procedures for clinical ethics case reflections: an example from childhood cancer care. *Clinical Ethics*, 9(2–3), 87–95
- II. **Bartholdson, C.**, Lützén, K., Blomgren, K., Pergert, P. (2014). Experiences of ethical issues when caring for children with cancer. *Cancer Nursing*, 38(2), 125-132
- III. **Bartholdson, C.**, af Sandeberg, M., Lützén, K., Blomgren, K., Pergert, P. (2015). The paediatric hospital ethical climate - perceptions in childhood cancer care. *Nursing Ethics*, accepted for publication April 25<sup>th</sup>, 2015
- IV. **Bartholdson, C.**, Lützén, K., Blomgren, K., Pergert, P. (2015). Clarifying perspectives: ethics case reflection sessions in childhood cancer care. *Nursing Ethics*, E-published ahead of print March 3<sup>rd</sup>, 2015

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## LIST OF ABBREVIATIONS

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ECR	Ethics Case Reflections
GT	Grounded Theory
MCD	Moral Case Deliberations
NOBOS	Nordic Society of Paediatric Oncology Nurses
NOPHO	Nordic Society for Paediatric Haematology and Oncology
SIBO	The Swedish Organisation for Nurses in Paediatric Oncology
SIOP	International Society of Paediatric Oncology



# INTRODUCTION

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My experience as a specialist nurse in paediatric care has given me the opportunity and privilege to care for many children and their families. This experience has been important for my professional development as well as my insight into the complexity of caring for children. In my work at the advanced hospital-based home care unit I have had the opportunity to care for children with cancer and their families in their home environment. Children with cancer make up approximately one third of the advanced hospital-based homecare patients.

During the years in paediatric care difficult situations have led me to reflect on ethical issues. Questions such as ‘What is the right thing to do?’ have often crossed my mind, resulting in an interest in ethics. These questions have also led to a curiosity to know more. When the opportunity to become a PhD candidate in the research-project ‘Difficult Ethical Situations in Childhood Cancer Care’ appeared, I saw the chance to combine my interest for ethics with my interest in research. My previous experience in paediatric nursing could be seen as a disadvantage in regards to potential assumptions, preconceptions and difficulties to obtaining relevant data due to cross departmental, functional or hierarchical boundaries.<sup>1</sup> On the other hand a pre-understanding of the organisational dynamics, the knowledge of everyday hospital life, the jargon and the possibility to participate freely were great advantages. A further advantage was that by understanding the internal jargon, follow-up replies to questions when interviewing was possible, resulting in richer data.<sup>1</sup>

This compilation thesis covers clinical ethics in childhood cancer care, and the overall aim was to gain empirical knowledge and a deeper understanding of ethical issues and how healthcare professionals deal with these in the context of childhood cancer care. The four studies include: (I) a model for ethical analysis, (II) healthcare professionals’ experiences of ethical concerns and how they handle ethical concerns, (III) perceptions of the ethical climate and (IV) social interactions during ethics case reflection sessions in the team. I sincerely hope that this will be read by healthcare professionals who, like me, face ethical questions in clinical practice and researchers interested in ethical concerns from the perspective of healthcare professionals.



## BACKGROUND

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This chapter includes the presentation of the context of *childhood cancer care*, including a *case* and, *ethical issues in childhood cancer care*. Further, important concepts as *the ethical climate* and, *the process of reflection in healthcare* are described. Finally the subject area of *clinical ethics* and *ethical analysis* are presented.

### CHILDHOOD CANCER CARE

Each year approximately 300 children are diagnosed with cancer in Sweden.<sup>2</sup> The majority are small children between the ages of 2-6 years old. Children diagnosed with leukaemia constitute 30% of diagnoses, CNS tumours 28% and solid tumours 42%. Teenagers are often affected by bone tumours.<sup>2</sup> The current survivor rate of childhood cancer in Sweden is 80 % which is among the highest in the world.<sup>3</sup> Key success factors necessary to reach such a high survival rate while providing among the best childhood cancer care and treatment in the world are engaging in international as well as national collaborations.

International collaboration started in 1969 when the International Society of Paediatric Oncology (SIOP) was formed.<sup>4</sup> SIOP members collaborated in medical treatment studies. The importance of collaboration was understood at an early stage and in addition to SIOP the Nordic Society for Paediatric Haematology and Oncology (NOPHO) was established in the 1980s. In addition to medical cooperation, nursing collaboration has been developed as well. The Swedish Organisation for Nurses in Paediatric Oncology (SIBO) was founded in 2000 and prior to that SIOP nurses and the Nordic collaboration named the Nordic Society of Paediatric Oncology Nurses (NOBOS) were established.

Childhood cancer care has nationally been developed in Sweden since early 1961 when Karolinska Hospital established a team of physicians for treating children with solid tumours. In order to create nationally uniform diagnostics and treatment of children with leukaemia a group named the Swedish Paediatric Leukaemia Group was formed in 1967. This highly specialised care was later coordinated in specialised paediatric cancer units in Sweden at the end of the 1970s and the beginning of the 1980s.<sup>2</sup> Today childhood cancer care is provided at six childhood cancer regional centres in Sweden<sup>2</sup> where cancer is diagnosed and specific cancer treatment is given. General Paediatric wards collaborate with the centres and treat, for example, side effects such as neutropenic fevers. In Stockholm the advanced hospital-based home care unit works closely with the childhood cancer unit. Various professions work at each childhood cancer regional centre. They include paediatric oncologists, paediatric nurses, general nurses, nurse-aides and other healthcare professionals such as social workers, psychologists, physiotherapists and play therapists. The different professions hold a variety of roles and responsibilities. The most common main responsibility is to provide highly specialised care for children with a potentially life-threatening disease.

The treatment is intense and exigent between six months and two and a half years depending on the type of childhood cancer,<sup>4</sup> and challenges such as severe side effects and physical and emotional suffering are common. The treatment is also a major concern for parents who are initially expected to become important members of the team.<sup>5</sup> The basic diagnose-related information and treatment must be communicated to them.<sup>5</sup>

The development of childhood cancer care is thus based on medical research and caring science research. A systematic literature review, conducted by Enskär and colleagues<sup>6</sup> found that 137 published articles on childhood cancer were relevant in the field of healthcare science in Sweden. Almost half of the studies were focused on parents and almost one third from the children's perspective. Only 5% concerned staff and 7% the care.<sup>6</sup>

The increased survival rates are related to more intense and demanding treatment. The treatment is often related to severe side effects causing suffering and ethical questions are raised when important values concerning life and death are at stake. Each child's particular position often causes ethical issues and divergences about treatment and care.<sup>7-9</sup> In the following section a case will be presented which aims to offer insight into the complexity of caring for children with cancer. This case also aims to relate to descriptions of ethical issues in order to illustrate it further.

## **CASE**

The following case is fictitious and presents a possible scenario from childhood cancer care.

*Sophia is 13 years old and was diagnosed with bone cancer in her leg several years ago. She was growing tired, had periods of obscure fever and suffered from weight loss. She often complained about pain in her leg during night-time. If you looked closely you could see that Sophia had a slight limp. The tumour turned out to be large and aggressive. Sophia and her family were prepared to do everything to try to cure her and they had strong hopes that she could get well. In the initial phase Sophia was treated with chemotherapy. She was also treated with radiotherapy due to the tumour being inoperable. She suffered from severe side effects such as nausea and poor blood values. In order to save her life the decision to amputate her leg was taken. The operation was associated with severe pain and Sophia got sepsis. She also suffered heavily from psychological problems: she felt lonely and isolated and thought a lot about whether her life could return to normal again? She kept her concerns to herself to avoid hurting her parents. After two years without chemotherapy she had a relapse, this time in her lungs. Despite the great efforts made to once again treat Sophia with chemotherapy the cancer spread further and resulted in extensive breathing problems.*

*Currently the breathing problems come in episodes and are increasingly difficult. Sophia's parents want to continue with a curative treatment intention at any price. Sophia is breathless, tired and pale and does not voice her opinion, but only expresses that she wants to be left alone. At times, Sophia strongly opposes blood sampling and having the subcutaneous venous port needle put in.*

*She tells one of the nurses that she is tired of the pain and she complains about specific pain in her upper arm. The treating physicians suspect an additional relapse in her arm. Her nutritional status is dependent on total parenteral nutrition. The prognosis for survival is extremely poor.*

*Opinions in the healthcare team about the curative treatment intention diverge. For some, mostly the nurses, the extremely poor prognosis and the related suffering argue in favour of palliative treatment.*

## **ETHICAL ISSUES IN CHILDHOOD CANCER CARE**

Childhood cancer care includes many ethical issues but here two areas will be briefly explored. *Respect for autonomy* and *end-of-life care*. Ethical issues are often concerned with what we should do in relation to what we can do and for whose sake.<sup>10</sup> Moreover ethical issues are often grounded in value conflicts which involve what is ethically right to do in a difficult ethical situation.<sup>11</sup> Factors like culture<sup>12</sup> and professional affiliation<sup>13</sup> have an impact on our experience of an ethical issue.

### **Respect for Autonomy**

Not only does cancer affect children differently than adults in regards to number, type and manifestations,<sup>4</sup> but the age-range of children can cause different ethical issues concerning respect for autonomy. Children's capacity for decision-making is developed throughout childhood and the child's wishes should be taken into account according to their developmental level and growing autonomy in pace with their increasing age.<sup>14</sup> Decision-making competence include 'understanding information and ability to communicate that understanding; reasoning and deliberation; and possession and application of a set of values or conception of the good'.<sup>15</sup> (p. 100) The involvement in the decision-making process is related to the respect for autonomy which partly includes the patient's right to refuse or choose their treatment. Furthermore, the child's parent/guardian needs to participate in caring procedures and has the right and obligation to decide on matters concerning the child<sup>14</sup>, which could both assist and complicate the decision and respect for autonomy further. Thus, the child's family plays an important role in the care of children. 'Family-centered care is based on the assertion that the family is the child's best adviser and source of support'.<sup>5(p.113)</sup> Furthermore, it has been argued in the literature that children, depending on their age, usually prefer that parents make the decisions in care-related matters. Such a child-centred view defends the family-integrity by considering the wish of the child while employing surrogate decision-making.<sup>15</sup> However, family-centred care may not sufficiently include the children in discussions and decision-making. Attention should be directed to child-centred care which involves the child's right to participate in all parts of care in combination with family-centred care.<sup>16</sup> Considering this, complex questions regarding decision-making and what actions should be performed when children are unwilling to cooperate are examples of ethical issues in relation to the respect for autonomy.

*In Sophia's case, this involves difficult ethical questions like: can Sophia oppose the subcutaneous venous port needle being put in, which in the long run would cause her death? Should Sophia's parents be able to make the decision concerning the possible futility of her treatment?*

## **End-of-Life Care**

Advances in treatment and in supportive care have improved the survival rate dramatically over the last several decades<sup>4</sup> which has resulted in fewer patients confronting end-of life issues. When end-of-life care of children is a fact it is often connected to complex decisions about life and death.<sup>12</sup> These difficult decisions usually involve continued treatment with the aim to cure or limiting a possibly meaningless and thus unethical treatment and consequent suffering.<sup>7, 8, 12</sup> According to Svantesson, the main ethical problem for both nurses and physicians in relation to end-of-life care is the overtreatment of dying patients.<sup>17</sup> Previous research has stated that physicians find it more difficult than parents to decide the exact time at which the transition from curative to palliative treatment intentions occur.<sup>15</sup> Nevertheless, research has shown that, at the time of death, most children dying from cancer were treated with a non-curative intent.<sup>18</sup> The breaking point, meaning when the treatment shifts from curative to palliative, can vary with the different kinds of cancer diagnoses. Children with haematological malignancies had curative treatment intentions closer to death.<sup>18</sup> Considering the best interest of the child, after all the medical possibilities for cure have been explored, Liben stated that children should be entitled to the right to be free from the compulsive lengthening of their dying.<sup>19</sup>

*When caring for Sophia, the ethical question raised from an end-of-life-care point of view would be: should we continue to treat Sophia with a curative intention?*

The possibility to handle ethical issues in care is influenced by the ethical climate of the workplace.<sup>20</sup>

## **THE ETHICAL CLIMATE**

The ethical climate is a central concept in this thesis due to the impact it has on ethical issues and the possibilities to handle them. The ethical climate influences the emergence of ethical issues and how well they are identified and dealt with.<sup>20</sup>

The ethical climate is a part of the organisation's climate and has been described by Olson as the individual perception of the organisation that influences attitudes and behaviour and serves as a reference for employee behaviour.<sup>21</sup> Organisations are built and dependent on individuals. Peens and Louw<sup>22</sup> wrote about Kohlberg's theory suggesting that when an individual's morality is developed the individual uses different ethical criteria and shows various types of ethical reasoning.

The authors further described that Kohlberg proposed that the moral development naturally occurs in several stages and sequences that have been developed through a reasoning rooted in fear of punishment, care of others and care for universal rights and humanity as a whole.<sup>22</sup>

The organisational climate is often seen as the organisation's personality. When professionals share the same view emerging from interaction their attitudes and behaviour are affected.<sup>23</sup> The researchers Victor and Cullen began to measure the ethical climate by developing a questionnaire<sup>24, 25</sup> based on Kohlberg's ethical reasoning which was later used in commerce and industry, within education<sup>26</sup> and in several service organisations.<sup>27</sup> Researchers then used modified versions of the instrument to measure the ethical climate in healthcare settings and in 1998 Olson developed the Hospital Ethical Climate Survey (HECS).<sup>21</sup>

The development of the HECS was based on a literature review on business ethics and nursing ethics as well as concept analysis of organisational concepts<sup>23</sup> and analysis of conditions for ethical reflection.<sup>21</sup> Previous international research on hospitals' ethical climate has been described in relation to effects on positional and professional turnover intentions among nurses;<sup>28</sup> nurse-physician perspectives within intensive care;<sup>29</sup> moral stress; demographic characteristics and job satisfaction;<sup>30-32</sup> moral sensitivity;<sup>33</sup> experience of medical errors and intent-to-leave;<sup>34</sup> and organisational commitment.<sup>35</sup> It has been stated that moral stress arises when there is moral sensitivity towards the patients' suffering and vulnerability. Moral stress also occurs when the right action is prevented by external factors and when there is a feeling of powerlessness.<sup>20</sup>

With regards to paediatrics, a study was conducted with the objective to explore perceptions of moral stress, moral residue, and ethical climate among registered nurses working in paediatric/neonatal units. This study was the second part of a larger study in which the first part had the same objectives but was based on adult care, after which differences between the two groups were discussed. The perception of the hospital ethical climate was that the work climate was perceived as moderately ethical and did not differ between the groups. However, nurses in paediatric/neonatal care scored the moral stress level lower than their colleagues in adult care.<sup>36</sup> When investigating the levels of moral stress in paediatric oncology, Lazzarin and colleagues<sup>37</sup> found similar distressing items as the study performed in neonatal care. In the oncology setting the means were higher for all items and the authors arrived at the conclusion which stated that close interactions with children in end-of-life situations and pain control issues on a daily basis may lead to higher levels of moral distress.<sup>37</sup>

In Sweden, further studies have been performed among psychiatric professionals where the ethical climate was examined in relation to moral stress and moral sensitivity. The ethical climate and two aspects of moral sensitivity (moral burden and moral support) influenced levels of moral stress.<sup>38</sup> Another Swedish study from general care explored the relationship between moral distress and the ethical climate among nurses and found that the perception of a more positive ethical climate were related to fewer reports on morally distressing situations.<sup>39</sup> Moreover a study in acute care explored and described actions that nurses perceived to promote a positive ethical climate. These actions were; meeting the needs of patients and next of kin in a considerate way and receiving and giving support and

information within the work group.<sup>40</sup> Furthermore, in a recent study, the hospital ethical climate has been used to evaluate ethics rounds.<sup>41</sup> To our knowledge there are no studies which concern the ethical climate in paediatrics in Sweden.

In the complex care of patients, like ‘*Sophia*’, reflection is important. Healthcare professionals often reflect on issues related to their patients, alone or through sharing with others, in their daily practice.

## **THE PROCESS OF REFLECTION IN HEALTHCARE**

Reflection is considered to be a key element of professional practice<sup>42</sup> because reflection involves a conscious process of thinking about a clinical situation, which leads to awareness and modifications in practice.<sup>42</sup> Reflection has been widely described in the literature and a large number of definitions can be found. To guide this thesis the idea of Dewey’s definition of reflection described by Mann, Gordon, and Macleod<sup>43</sup> is applicable. Dewey defined reflection in 1933 as an ‘active, persistent and careful consideration of any belief or supposed form of knowledge in the light of the grounds that support it and the further conclusion to which it tends’.<sup>43(p.597)</sup> According to Branch reflection can enable re-evaluation as described in the following statement: ‘Reflection promotes re-evaluation and integrations of facts and reframing of experiences into one’s pre-existing knowledge, beliefs, values and attitudes’.<sup>44</sup> (p.164)

A previous study into nursing identified reflection as a process which involved four phases. These were framing of the situation, pausing, engaging in reflection, and emerging intentions.<sup>42</sup> Another study described registered nurses’ experiences of reflection, which includes thinking back, considering and reflecting before and after.<sup>45</sup> In the perspective of healthcare learning, reflection is a type of thinking associated with deep thought, aimed at achieving better understanding. Research has shown that a learning culture committed to reflection is a valuable way to help nurses make sense of their practice. In a previous study students and teachers described reflection as a way of ‘being’ rather than simply ‘thinking’ or ‘doing’, because reflection interlinked propositional, affective and active elements. The process of reflective ‘being’ is connected with a humanistic approach to nursing, which stresses the importance of actively using and expressing oneself in order to care for people.<sup>46</sup> Reflection is the process of critically analysing practice to detect underlying impacts, motivations and facts.<sup>47</sup>

A literature review conducted by Mann, Gordon, and Macleod<sup>43</sup> found that reflection was a part of practice in all the eight studies highlighted; six were in medicine and two were in nursing. Furthermore the study revealed that shared reflection was even more effective due to the fact that it provides information from several sources and several perspectives.<sup>43</sup> When reflecting over ethical questions deriving from the clinical context, the area of ethics is conceptualised as clinical ethics.

## CLINICAL ETHICS

This section aims to provide insight into the area of ethics that this thesis builds on and also to point out different perspectives on clinical ethics. Clinical ethics is a practical discipline that provides a structured approach to support healthcare professionals to identify, analyse and deal with ethical issues in clinical practice. Clinical ethics are similar to relational ethics since it concerns the relationship between healthcare stakeholders such as patients, relatives and caregivers, while relational ethics focus on the quality of the commitment between them.<sup>48</sup> Perspectives on ethics are most likely connected to professional codes of ethics and responsibilities. In the literature these different perspectives are often referred to as medical ethics and nursing ethics. Different professional ethical guidelines and codes partly define what optimal care and treatment includes and provides ethical guidance. However, the guidelines do not define what should be done in a clinical situation. These guidelines are described in different writings. For example, the Swedish Health and Medical Services Act,<sup>49</sup> states that the goal of healthcare is that it should be practiced on equal terms for the entire population. Care shall be provided with respect for human equality and dignity. Moreover, physicians are governed by the Declaration of Tokyo and Geneva, UN resolutions and the Hippocratic Oath.<sup>50</sup> The International Council of Nurses (ICN) adopted the first Code of Ethics for Nurses in 1953 and the latest version was established in 2005.<sup>51</sup>

Medical ethics involve the values and guidelines governing decisions in medical practice.<sup>10</sup> In the clinical setting an example of a medical ethical question could be: ‘should we turn off the respirator?’ The four principles that are a common framework and the core of ethical reasoning in healthcare are: respect for autonomy, non-maleficence, beneficence, and justice.<sup>52</sup>

Nursing ethics shares the same principles as medical ethics, and nurses’ four fundamental responsibilities have been described in the ICN Code of Ethics for Nurses as: promoting health, preventing illness, restoring health and alleviating suffering.<sup>51</sup> Furthermore nursing is based on the respect for human rights, including the right to life, to dignity and to be treated with respect.<sup>51</sup> Milton stated that nurses are guided by a value framework.<sup>53</sup> The value framework may be derived from ‘within the discipline with nursing theoretical perspectives or outside of the discipline as evidenced by nurse professionals who incorporate biomedical philosophical ethical principles, such as deontology and utilitarian underpinnings, in professional practice’.<sup>53(p.212)</sup>

Clinical ethics promotes a reflective practice in making choices in ethical issues. An ethical analysis can be used to explore and seek answers to ethical issues.

## **ETHICAL ANALYSIS**

Reflective practice, such as ethical analysis, is usually based on facts, empirical data and probabilities as well as on values, ethical principles and theories.<sup>10</sup> In clinical practice when different individuals who work together confront difficult ethical issues regarding patients, ethics case reflection (ECR) sessions are one way to deal with ethical issues. In the ECR sessions an ethical analysis can be performed.

### **Ethics Case Reflection Sessions**

ECR sessions are organised meetings where reflection and dialogue is performed regarding ethical issues, and often involves the inter-professional team and an external facilitator.<sup>11, 54, 55</sup> Not only does the model for analysis differ, there are also differences in the procedures. Procedure-related differences, as described in the literature, for example concerns the legal status of the decision made, patient and relative participation and relatives and whether healthcare professionals or external consultants are key participants.<sup>56-60</sup> Several models on ethical analysis have been described in the international literature. In case-based models (inductive), values and moral principles that are found to be relevant in the case are central.<sup>61</sup> In principle-based models (deductive) moral principles and values which apply in the case are specified beforehand.<sup>61</sup>

Several descriptive studies have been conducted regarding moral case deliberations (MCD),<sup>55, 62, 63</sup> and similarities have been shown in studies of ethics rounds conducted in Sweden. However, Swedish studies have not been able to show differences on job satisfaction, sense of coherence, burnout<sup>64</sup> or moral distress.<sup>65</sup> When looking at whether ethics rounds stimulated ethical reflection, the researchers were not able to show significant differences either.<sup>66</sup> Nevertheless, results from a qualitative study indicates that participants found ethics rounds useful and necessary.<sup>67</sup> Participants felt that ethics rounds contributed to wider reflection and helped them see the case from different perspectives. Ethics rounds also assisted the healthcare team in dealing with the ethical issue.<sup>67</sup> To our knowledge there are no studies concerning healthcare professionals' main concerns and how they deal with these concerns during ECR sessions.

The following Table (1) shows three examples of models of ethical analysis including the various steps.

Table1. Models of different ethical analysis (three examples)

	<b>Actors model for ethics analysis</b> <sup>68</sup>	<b>The procedure for case discussion recommended by the CEC manual, Norway</b> <sup>69</sup>	<b>Dilemma method</b> <sup>11, 70, 71</sup>
1.			Case presenter presents his/her case briefly
2.	Identify the ethical problem	Define the ethical problem(s)	[Formulation of a general moral question] Formulation of the moral dilemma according to the case presenter - Should I do A or B?
3.	Collect medical facts	Describe all facts (including medical and psychosocial facts)	Clarification round with possibilities for clarification & questions
4.	Identify the actors	Who are the involved parties	
5.	Identify the interests of the actors	Identify the values and relevant laws at stake	Table with perspectives, values and norms - Connect values/norms to original dilemma (A or B) - Position dilemma in scheme
6.		Identify and discuss possible solutions of the case	List all possible alternatives (without discussing feasibility)
7.	Judge the consequences of the actions	Conclusion, follow-up and evaluation	Orientation of possible answers to the dilemma Make individual round (write down first) - I think the right thing to do is ... - Because - Therefore I'm not able to do ... - How can I cope with or decrease moral loss related to the other side of the dilemma? - Which virtues and actions are necessary to do the right thing?
8.			Reflect upon possible group consensus or decision ('weigh' values & norms)
9.			Make practical appointments and plan date to evaluate those appointments

## **AIMS OF THE STUDIES**

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The overall aim of this thesis was to gain empirical knowledge and a deeper understanding of ethical issues and how healthcare professionals deal with these in the context of childhood cancer care.

The following specific aims were included in the four studies:

- I. To describe the procedures, including a model, for clinical ethics case reflections and to discuss pros and cons of the presented procedures.
- II. To describe healthcare professionals' experiences of ethical issues and ways to deal with these when caring for children with cancer.
- III. To describe perceptions of the paediatric hospital ethical climate among healthcare professionals' caring for children with cancer.
- IV. To explore healthcare staff's experiences of participating in ethics case reflection sessions in childhood cancer care.

## METHODS

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In the following chapter *design, flow of the studies in the project, sampling and participants, data collection, data analysis and ethical consideration* will be presented.

### DESIGN

The present research project has an inductive approach comprising the action of unconditionally observing reality and searching for patterns in experiences.<sup>72</sup> The project is based on four studies and combines different methods for analysing qualitative data. Qualitative research methods helps us to see the perceived phenomenon, portray the social world, and to generate models and theories.<sup>73</sup> Furthermore, qualitative research has been described to explore the personal meaning of the individual's experiences and actions in their social context<sup>74</sup> as well as focusing on recurring incidents and patterns of experiences.<sup>75-77</sup> The inductive approach was followed by; including participants which had experience from ethical issues and ways of handling them, collect data with open questions in observations, interviews and individual encounters and, analysing data by for example using the participants own words when naming codes.

Data collected from multiple-choice questions are also qualitative<sup>78</sup> because they cannot be measured and given a value, for instance in the way that you can determine body weight. Thus, the different methods used were based on the overall aim, the specific objectives and the research questions in each study which enabled a view on clinical ethics from different complementary perspectives. In summary, study I is a theoretical reasoning study based on previous research and experience. Study II is a descriptive qualitative study based on written answers collected by questionnaires. Study III is a descriptive quantitative study based on categorical data,<sup>78</sup> and study IV is an exploratory study following grounded theory methodology.<sup>76, 79, 80</sup>

### FLOW OF THE STUDIES IN THE PROJECT

As a project starting point, a model for ethical analysis was modified in order to use it in the upcoming research project. The model, which is named the KS Model for Ethical Analysis, had never been published nor tested in research. After the modification of the model in study I, study II and III were conducted to investigate healthcare professional's experiences of ethical issues and how to handle them as well as their perceptions of the ethical climate in the paediatric setting. Study II revealed that healthcare professionals wanted to have ethics case reflection (ECR) sessions, and study III found that healthcare professionals lacked the time for reflection and discussion. It was therefore relevant that ECR sessions were initiated and conducted. Study IV explored what happened during ECR sessions with the aim to discover healthcare professional's main concerns and how they resolved these concerns.<sup>76, 79, 80</sup> Figure 1 shows a flowchart of the research project.

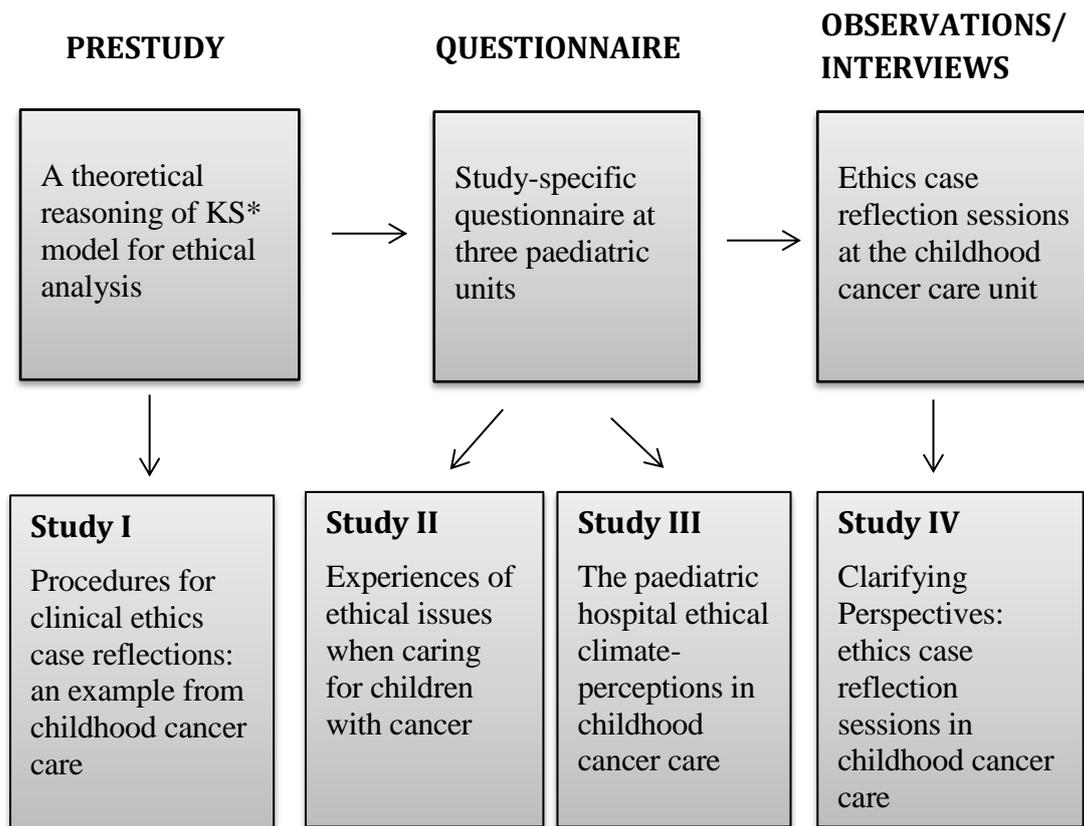


Figure 1. Flowchart on the different studies in the research project

## SAMPLING AND PARTICIPANTS

The four studies included in this thesis were performed between 2010 and 2015.

**Study I.** At the Karolinska University Hospital a model for ethical analysis has previously been developed by Chenik while used in the clinic.<sup>81</sup> This model, named the Karolinska University Hospital Model, originated from The Actor’s Model formulated by Hermerén.<sup>82</sup> The Karolinska University Hospital Model has not been published in scientific journals, but was available on the hospital website. An important quality feature is that the model can accommodate any ethical aspect that participants would find relevant to reflect on. Despite the quality features of the model there was still a potential for further improvements. Overall, this model has been used in the clinic and appreciated among healthcare professionals and ethicists and was thus chosen as a basis for a critical analysis.

**Study II-III.** Physicians, nurses and nurse-aides working at three units at a major Children’s Hospital in Sweden, caring for children with cancer, were invited to participate in the study by answering the study specific questionnaire ‘Ethical Tools in Paediatric Care’. The inpatient units were the cancer care unit, the one unit for children with chronic diseases within paediatric medicine and the neurology unit. Study II is based on 87 completed questionnaires with responses to open-ended questions and Study III is based on 89

completed questionnaires with responses to multiple-choice questions. Thus, a few participants chose to respond to different parts of the questionnaire. Response details are presented in Table 2.

Table 2. The response-details in the two descriptive studies (II-III)

<b>Questionnaire: Ethical Tools in Paediatric Care</b>		<b>Physicians</b>	<b>Nurses</b>	<b>Nurse-aides</b>	<b>Total</b>
<b>Study II</b> Open-ended Questions	Cancer Care unit	8/13	11/25	9/14	87
	Chronic diseases/ Neurology	7/*	23/39	29/43	
<b>Study III</b> Multiple- choice Questions	Cancer Care unit	8/13	11/25	8/14	89
	Chronic diseases/ Neurology	7/*	25/39	30/43	

\* Questionnaires were placed beside the physicians' letterboxes, at their joint administrative area, due to the uncertainty of where they received their letters when having multiple affiliations. For example some physicians were working both in the clinic and at a research unit. It is therefore impossible to calculate the response rate for physicians at the two indicated units.

**Study IV.** In accordance with Grounded Theory (GT) initially purposive and convenience sampling were conducted as the aim was to include persons with knowledge of the area under study as well as easily accessible.<sup>79</sup> Six ECR sessions were carried out with 5–7 healthcare professionals involved in the care of the child (physicians, nurses, nurse-aides, psychologists, and play therapists) from the childhood cancer care unit and the advanced homecare unit. This was followed by theoretical sampling. According to Glaser the process of theoretical sampling contains collection, coding and analysis of the data in order to decide what data to collect next and where to find them. Theoretical sampling provides more data for the emerging categories, with focus on the core category, and is controlled by the emerging theory.<sup>76, 79, 83</sup> Thus, individual interviews and individual informal encounters were performed with persons who had participated in the ECR sessions. For example, participants were interviewed with the aim to further refine and elaborate on the category of *deliberating ethics*.

In summary, 35 healthcare professionals who were part of the interprofessional team from the childhood cancer unit and the advanced homecare unit participated in the six ECR sessions. Additionally 10 healthcare professionals were individually interviewed, formally and/or informally, following the sessions. Participant details are presented in Table 3.

Table 3. The participant details in the ECR sessions in study IV

<b>ECR Session</b>	<b>Duration (h)</b>	<b>Participants; Male=(m), Female=(f)</b>	<b>Follow-up Interviews</b>
1	1.30	1 nurse-aide (f); 2 nurses (f); 2 physicians (m)	1 (f) nurse (informal)
2	1.25	1 nurse-aide (f); 2 nurses (f); 3 physicians (m); 1 play therapist (f)	2 (f) nurses
3	1.05	3 nurses (f); 1 physician (m); 1 psychologist (f)	1 (f) nurse (informal)
4	1.02	3 nurses (f); 3 physicians (m)	1 (f) nurse,
5	1.20	2 nurses (f); 3 physicians (m)	1 (f) nurse, 2(m) physicians (informal)
6	1.21	1 nurse-aide (f); 3 nurses (f); 1 physician(m); 2 physicians (f)	1 (f) nurse, 1 (f) nurse-aide

## **DATA COLLECTION**

In study I attention was given to the literature containing different models for ethics analysis, participation of patients and relatives, the role of the facilitator and interprofessional interactions. In study II-IV data were collected using *a study specific questionnaire, observations, interviews and informal encounters.*

### **Questionnaire**

The study specific questionnaire which provided data for study II and III was named ‘Ethical Tools in Paediatric Care’ and consisted of different sections covering socio-demographic data, open-ended questions and multiple-choice questions. The socio-demographic questions were about profession, age, gender, unit and working experience in paediatrics. The different sections included in this research involved ethical problems and ways to handle them (open-ended) and the ethical climate (multiple-choice). In order to test the questionnaire in a pilot study several participants, with expertise in ethics and questionnaire methodology, tested the questionnaire during different occasions. After that a group of four participants with experience in clinical ethics support completed the questionnaire, all in the same room, and gave responses. As a result of that some multiple-choice questions were changed into open-ended questions.

Study II focused on the seven open-ended questions. Four questions concerned ethical concerns and three questions concerned how healthcare professionals were dealing with ethical concerns. Please see Appendix 1 for the full description of the questions.

Study III focused on the responses to multiple-choice questions covering a modified version of the Hospital Ethical Climate Survey (HECS).

In previous research, conducted by Olson,<sup>21, 84</sup> the HECS was developed and validated. Lützén et al.<sup>38</sup> translated the HECS into Swedish and tested it in a pilot study. Evaluation of psychometric properties showed good validity and reliability.<sup>38</sup> In its original form the HECS is a 26-item instrument for assessing nurses' perceptions of the hospital ethical climate at their workplace. A 5-point Likert-scale is used to respond to statements about the situation at the workplace. The statements concerns accessible support in clinical ethics, organisational ethics, and organisational culture as well as relationships with the management, co-workers, and patients.<sup>21</sup> HECS was originally designed for nurses in adult care and therefore minor revisions were made to make it more relevant for multiple professions, including nurse-aides, and also to include a question regarding parents. Three questions were added regarding nurse-aides and these questions used the same wording as questions directed to nurses. Furthermore, the question: "At my unit the patient's wishes are respected" was supplemented with the same question concerning parents. In the present study the participants' responses were one of the following choices: 'Never', 'Hardly ever', 'Sometimes', 'Almost always' and 'Always'. Questions about management were excluded, due to research ethical considerations leaving the final version with 17 items related to the paediatric hospital ethical climate. The statements used in the modified version on the HECS are presented in Appendix 2. Reliability of the 17 items turned out to be as good as the Swedish version.<sup>38</sup>

Study II and III revealed that the participants wanted ECR sessions and felt they were a necessity, it was therefore relevant to study what happens during ECR sessions when the healthcare team shares their reflections, and so observations were subsequently made.

## **Observations**

GT was originally explained by Glaser and Strauss<sup>80</sup> and further developed by Glaser,<sup>76, 79</sup> and it is suitable for qualitative observation data. Guided by the objective and the area of interest, observations using GT methodology were suitable as one of the data collection methods. Moreover, GT was chosen for this study because the study-specific question aimed to discover how participants resolve their main concern.<sup>79</sup> The author of this thesis attended the ECR sessions as a participating observer to quietly observe, and made note of the participants' nonverbal communicational and social interactions.<sup>72</sup> Field notes were taken about the authors' experiences and reflections during the ECR sessions and memos were written immediately afterwards.<sup>76</sup> Memos are anything that capture the point of a conceptualised pattern.<sup>83</sup> Five out of six ECR sessions were audio recorded. In one of the ECR sessions the participants did not agree with the audio recording which resulted in more detailed and extensive field notes.

When an ECR session was conducted as part of the research project the procedure was as follows: Healthcare professionals, who were working at the childhood cancer care unit, experienced an ethical issue when caring for a child suffering from cancer and would then initiate the ECR sessions by contacting the consultant nurse who had information about the research project. Healthcare professionals that were closely involved in the care of that child were invited to participate, and a facilitator with expertise in ethics was asked to facilitate the

ECR session. The facilitators had different professional affiliations such as an ethicist, specialist nurse, and priest. ECR sessions lasted 60–90 minutes and were guided by the model for ethical analysis developed in study I.

## **Interviews**

Following Grounded Theory, healthcare professionals who were believed to be able to enrich the data by sharing their experience of participating in the ECR session were invited to participate in an individual interview after each ECR session. The interviews lasted approximately 30 minutes and most were held in a private room at the hospital, although one of the interviews was performed over the telephone. All interviews started with an opening phrase, such as: ‘Please tell me about your experience of participating in the ECR session’. Glaser and Strauss terms this as the technique of open-ended conversations.<sup>80</sup> Moreover laddered questions were used<sup>85</sup> about what happened and how the participants dealt with their concerns as well as their feelings and thoughts about the situation. According to GT, data were analysed between the ECR sessions and the interviews which influenced the questions in the upcoming interviews. Field notes were taken during the interviews and memos were written immediately afterwards.

## **Informal Encounters**

After each ECR session the author performed additional theoretical sampling by asking informal questions to healthcare professionals who had participated in the ECR sessions. Further questions were asked in the hallway or in the staff room, rather than in the meeting room where the ECR session was held and data about the emerging categories were collected. Thus, informal encounters enabled the discovery of the emerging theory by further complementing the data collection.

## **DATA ANALYSIS**

In study I a critical analysis of the ethics literature was done in order to modify a model for ethical analysis.

## **Qualitative Analysis**

### *Study II*

In study II written text from the answers to the seven open-ended questions in the questionnaires were analysed with inductive qualitative content analysis.<sup>75, 77</sup> Qualitative content analysis is often used in nursing studies and aims ‘to attain a condensed and broad description of the phenomenon, and the outcome of the analysis is concepts or categories describing the phenomenon’.<sup>75(p.108)</sup> The analysis was performed according to the following steps which are based on the content analysis literature. First the data were divided into 2 domains as a precursor to roughly dividing the text into different subject areas.<sup>86</sup> In this study these areas reflected the different open-ended questions from the study-specific questionnaire.

The written text, which is described in the literature as units of analysis<sup>72</sup>, were then read through several times in order to make sense of the data and find meaning from it. Later coding was done line by line and notes were taken simultaneously and meaning units were condensed into codes. The meaning units consisted of one or several sentences.<sup>75</sup> The codes were set as labels of the meaning units and had to be understood in relation to the context.<sup>75,77</sup> The codes were then compared and grouped in order to finally create subcategories. The categories are a description of a phenomenon with a higher level of abstraction.<sup>87</sup> Finally, the abstraction process generated categories in the two domains.<sup>75</sup> This analysis was repeatedly done during the interpretation process in order to explore alternative interpretations. The authors had an open and a critical dialogue until consensus was reached.<sup>88</sup>

#### *Study IV*

In study IV data analysis was performed following GT.<sup>76, 79, 80</sup> The main difference from descriptive qualitative content analysis is that GT aims to generate theory by the constant comparison of integrated concepts and categories conceptualised from the substantive area. 'The theory explains how a core category and its subcategories continually resolved a main concern.'<sup>83(p.27)</sup> As a participant in two of the Grounded Theory Institute trouble shooting seminars, the author of this thesis had the privilege to hear Dr. Barney Glaser state: 'GT is conceptual, get off the descriptive level...Stop story talk, conceptualise! Make a conception out of it!'<sup>89,90</sup>

The analysis started when attending the ECR sessions, by reflecting on and observing non-verbal communication during social interactions among healthcare professionals in the team. This was written down in field notes. After the ECR session the author transcribed the audio recorded data in Swedish and used the software program NVivo 9.0<sup>91</sup> as an assisting tool for coding the data. At this time the main supervisor (Pergert) read all transcripts and field notes from ECR-sessions. Once all the data were transcribed into digital documents open-coding was performed and recurring interchangeable indicators in the data created substantive codes. Memos were written about each code to catch the conceptualised pattern.<sup>79</sup> Codes were then grouped into categories through constant comparison.<sup>79</sup> The main supervisor and one of the co-supervisors (Lütznén) and members of the Grounded Theory Institute's trouble shooting seminar assisted with the conceptualisation of the participants' main concern and how participants were dealing with their main concern. The categories were renamed during the conceptualisation process in order to best explain the pattern from the empirical data. As a result of the constant comparison, and in line with Grounded Theory, the core category emerged. After the core category was discovered selective coding was applied to delimit analysis to those categories that related to the core.<sup>79</sup> Following Glaser's recommendations the next step was to saturate the categories using theoretical sampling, for example by interviewing nurses to explore the category of *deliberating ethics*.<sup>83</sup> Furthermore memos were written for the categories and the comparison between them, and during that process new ideas came to light.<sup>83</sup> When having the core category and the related categories identified, the next phase involved sorting the memos that finally resulted in the integration of categories through emergent theoretical coding. In this study theoretical coding resulted in approaches

and consequences for resolving the participants main concern. The analysis was done in Swedish, but the names of the codes, the core-category and the related categories were written in English.

## **Quantitative Analysis**

### *Study III*

In study III categorical data<sup>78</sup> were analysed with descriptive statistics assisted by the Statistical Package for Social Science (SPSS), version 22. The distribution of responses was calculated in percentage. To determine differences in proportions between groups a chi-square test was performed and the significance level was set to  $p \geq 0.05$ . To facilitate the interpretation and the analysis responses were dichotomized, which often is done in medical research.<sup>78</sup> In this study this dichotomization enlarged the groups making the result presentation more sharp and distinct.<sup>92</sup> The responses 'Never', 'Hardly ever' and 'Sometimes' were referred to as 'negative/ neutral' responses and were interpreted as a poor ethical climate in the result section, while 'Almost always' and 'Always' were referred to as 'positive' responses and were interpreted as an ethical climate. When analysing work experience two different year classifications were set. In the first group the limit was based on the median, which was 9 years of experience, and in the second group the limit was set according to Benner's criteria in the model of the development from a novice nurse to an expert nurse.<sup>93</sup> The classifications were thus divided according to the following: group 1 (1-9 years) towards (10-40 years) and group 2 (1-5 years) towards (6-40 years).

## **ETHICAL CONSIDERATIONS**

This research project was approved by the regional ethical review board in Stockholm (2009/1666-31/5). Oral information regarding the upcoming research project was provided to the participating units before the distribution of the questionnaire. An informative letter was attached to the questionnaire when it was put into the healthcare professionals' letter boxes which included information about the purpose of the study and information regarding confidentiality and anonymity. On one of the units nursing professionals were invited to answer the questionnaire during an educational session. At that time oral information was given and the participants were given the option to return the questionnaire blank.

When participants were invited to attend the ECR sessions they were told beforehand that the author would attend as an observer. When observations were made the author introduced the session by explaining the aim of the research project and that participation was voluntary, therefore they could withdraw their participation at any time and without having a reason. The names of children and their parents were neither used during the ECR sessions nor during the follow-up interviews in order to protect their anonymity. Oral informed consent was collected from parents in the prospective cases where quotes are used.

General information about the project was also posted on a notice board placed on the unit during the project. Additionally, oral and written information was provided before the interviews and the same procedure for the ECR sessions was applied with regards to the voluntary nature of participation. A list of the participants' names and workplaces is stored separately from the data and locked away.

## KEY FINDINGS

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In the following chapter a summarised presentation of key findings will be given from the different studies (I-IV) and following this, a synthesis based on conclusions from the same. For a complete presentation, all four studies are found at the end of the thesis.

### PROCEDURES FOR CLINICAL ETHICS CASE REFLECTIONS (I)

Study I consists of theoretical reasoning in relation to the procedures, including an eight-step model for structuring Ethics Case Reflection (ECR) sessions with examples from childhood cancer care. A summarised presentation about the most important arguments and key differences are given below and details of the models are presented in a figure.

The main argument for improvements were that the Karolinska University Hospital Model focused strongly on individual interests and was deductive regarding how values and moral principles were reflected on in the ECR session. Figure 2 shows the original model<sup>81</sup> and the modified version described in study I.

<b>The Karolinska University Hospital Model</b>	<b>The modified version of the Karolinska University Hospital Model</b>
<ol style="list-style-type: none"><li>1. Identify the ethical problem</li><li>2. Bring in the relevant facts</li><li>3. Identify the parties involved</li><li>4. Identify the interests of the different parties involved</li><li>5. Identify available action alternatives</li><li>6. Evaluate the consequences of each alternative action for each party in short and long terms</li><li>7. Carry out the ethical argumentation in relation to moral principles; try to reach agreement on a recommendation and motivate it briefly</li></ol>	<ol style="list-style-type: none"><li>1. Briefly present the background/case</li><li>2. Identify the ethical problem</li><li>3. Bring in the relevant facts</li><li>4. Identify the parties involved</li><li>5. Identify what is at stake (interests, values, and moral principles)</li><li>6. Identify available action alternatives</li><li>7. Evaluate each alternative action</li><li>8. Carry out the ethical argumentation; try to reach agreement on a recommendation</li></ol>

Figure 2. Presentation of the different steps for each model

In additions to modifications in the model, Study I also includes a presentation of characteristics in the procedure that are noteworthy and these are inter-professional interaction and that patients or relatives are not directly involved.

Group composition is important and members of the interprofessional healthcare team take an active role in the ECR session. The active role includes presenting the case, reflection over values and argumentation, aided by a facilitator. The arguments and the underlying rationale for this are: If healthcare professionals attend the ECR sessions then they are not only presented with a recommended solution and a summary of the reasons behind it, they also get a chance to follow the reasoning process. The deep and relational knowledge of the case, provided by the healthcare team, are of great importance. Furthermore, the knowledge and skills of the facilitator are important. They include the ethics training, responsiveness, in-depth communication and structure. The role of the facilitator involves trying to make sure that everyone is, and feels, included in the interprofessional reflections. The facilitator becomes particularly important when there are power structures and conflicting views in the group.

With regards to patient and family participation, there are four main arguments as to why they are not included: 1) Patient and family-participation in ECR sessions could possibly expose them to stress. 2) There is a risk that too much consideration would be given to the patient and family's views and wishes if they were present during the ECR sessions. 3) Healthcare team members might feel uneasy and insecure. 4) There is a risk that not all of the facts would be presented in the case, or that they will be presented in an overly considerate and sensitive way.

## EXPERIENCES OF ETHICAL ISSUES WHEN CARING FOR CHILDREN WITH CANCER (II)

The data in Study II were divided into two domains based on the open-ended questions. The first domain is about healthcare professionals' experiences of *Ethical Concerns* and the second is about *Dealing with Ethical Concerns*. A summarised text about the categories will be presented below. Table 4 shows an overview of the analysis in study II.

Table 4. Overview of the domains, categories, and subcategories in study II

Domain	Categories	Subcategories
Ethical concerns	Infringing on autonomy	Inflicting suffering
		Limiting truth-telling
	Deciding on treatment levels	Timing the breaking point
		Balancing pain relief
	Conflicting perspectives	Interprofessional differences
		Parents' perspectives
Cultural differences		
Dealing with ethical concerns	Interprofessional consideration	Teamwork
		Reflection on ethical concerns
	Resources for ethics	Time and personal space
		Ethical competence

### Ethical Concerns

#### *Infringing on Autonomy*

Disregarding a child's need to be included in hospital care decisions can be perceived as infringement on their increasing autonomy. Participants in this study, mainly nursing staff, believed that children's increasing autonomy can be disrupted and this will cause difficult feelings about care. Analysis of the data revealed two subcategories of *infringing on autonomy* that was conceptualised as *inflicting suffering* and *limiting truth-telling*; Inflicting Suffering mostly included forced procedures that were carried out routinely when the child had a very small chance of survival. One example would be when blood sampling had to be done despite the fact that the results did not change treatment decisions. Limiting truth-telling refers to healthcare professionals' experiences of being prevented from telling the truth about the child's diagnosis, treatment and prognosis by parents, medical circumstances and/or colleagues.

### *Deciding on Treatment Levels*

Problems related to decisions on treatment levels occurred when there were uncertainties in the healthcare team about the benefits for the child. This included *timing the breaking point* and *balancing pain relief*. Timing the breaking point was based on the difficulty in deciding when the treatment should transition from curative to end-of-life care interventions. Healthcare professionals had different opinions about when to proceed to the breaking point, and this major concern often led to conflicts in the team. Balancing pain relief included parents and healthcare professionals' different views regarding both the over- and under treatment of pain. Overtreatment was connected to fears on chemical addiction or because the parents wanted the child alert rather than dizzy and asleep on high doses of analgetics. Under treatment was related to anxiety in children and the level of pain acceptance.

### *Conflicting Perspectives*

Different views regarding care resulted in conflicting perspectives. The different conflicting perspectives originated from *interprofessional differences, parents' perspectives and culture differences*. Interprofessional differences were based on professional cultures, experiences and education. Personal moral preferences were also determining factors which were included in interprofessional differences. Parents' perspectives involved that the parents had different values about treatment and care. The parents also had an important role as a link between the child and the healthcare professionals, which complicated the relationship in those cases where values diverged. Cultural differences referred to healthcare professionals experiences of conflicts with patients/parents due to cultural beliefs or religious convictions. Different preferences on whether the child should be informed about the severity of the illness and treatment related issues were examples of conflicting perspectives related to cultural differences.

## **Dealing with Ethical Concerns**

### *Interprofessional Consideration*

There was some variation in how participants experienced teamwork. Some were satisfied with their current teamworking situation, but the majority wanted more interprofessional consideration. This included more *teamwork* and *reflection on ethical concerns*, as a way to better deal with difficult ethical situations. A desire for teamwork derived from on a lack of interprofessional interaction. Participants strongly wanted interprofessional communication to be improved. Furthermore, interprofessional consideration included reflection on ethical concerns which involved a desire and a need to come together and reflect on difficult ethical situations early on in the care process.

### *Resources for Ethics*

Participants reported that having a lack of resources endangered the possibility to perform ethically correct actions in the clinical context. The two resources that were identified were *time and personal space*, and *ethical competence*. A lack of time and personal space caused ethical concerns in situations such as when a lack of time meant that children could not be prepared for procedures and this led to the risk of using unnecessary force. A lack of time even affected teamwork as it had a negative influence on the possibility to communicate with each other. A lack of personal space was an obstacle to private conversations and space for reflections. Moreover ethical competence was described as a desired feature for being able to handle ethical concerns. Low levels of ethical competence contributed to uncertainty about ethical reasoning and core values which led to challenges in difficult ethical decision-making situations.

## THE PAEDIATRIC HOSPITAL ETHICAL CLIMATE (III)

A summary of the descriptive statistical data derived in study III are presented below.

### Perceptions from the Entire Group

The responses from each of the 17 items in the study are presented separately. Different perceptions of the ethical climate were rated as positive or neutral/negative. First, the entire group was examined. The analysis showed that in 6 of the 17 items, less than 25% selected a positive alternative, which indicated that they perceived a poor ethical climate. In 5 of the 17 items, more than 75% selected a positive alternative. For the remaining 6 items the percentage of participants who selected a positive alternative ranged from 34.8% - 71.9%. Table 5 presents the results from the entire group of participants i.e. all professionals.

Table 5. Presentation of items rated positively, in percentage (%)

Items rated positively	
My co-workers listen to my concerns about patient care (77.5)	Physicians ask nurse-aides about their opinions regarding decisions concerning treatment (5.6)
On my unit the patients' wishes are respected (80.9)	Physicians ask nurses about their opinions regarding decisions concerning treatment (14.6)
On my unit the guardians' wishes are respected (83.1)	There is time for reflection and discussions when there are ethical problems in treatment/care (15.7)
Nurses and nurse-aides on my unit trust one another (84.3)	The feelings and values of all parties involved are taken into account when a decision needs to be made about an ethical issue/problem (16.9)
I work with competent co-workers (95.5)	Healthcare professionals on my unit have access to the necessary tools to solve ethical problems (18.0)
	Nurses and physicians on my unit respect each other's opinions, even when they disagree about what is best for patients (24.7)

## **Perceptions of the Different Professions**

Data revealed that nurses rated all 17 items less positively than the physicians. The items that differed most were: those concerning trust; questions about whether nurses are asked their opinion regarding decisions concerning treatment; access to necessary tools to solve ethical problems; respecting each other's opinions, even when there were disagreement about what was best for patients; and respecting patient's wishes. Nurse-aides responses were the most similar to the physicians' responses. The two items that nurse-aides rated less positive than nurses were about whether co-workers listened to concerns about patient care and if co-workers helped in ethically difficult situations.

## **Perceptions on Being Able to Practice Ethically Good Care**

One third of the participants stated that they were able to practice ethically good care, and this group more often stated that nurses and physicians trusted one another and that guardians' wishes were respected. However, the two-thirds that stated they were unable to practice ethically good care also stated that they had less access to the necessary tools to be able to solve ethical issues/problems; that conflicts concerning ethical issues/problems were openly dealt with and not avoided; and that there was an atmosphere that encouraged them to question, learn, and seek creative responses to ethical problems/issues in treatment/care.

## CONSOLIDATING CARE BY CLARIFYING PERSPECTIVES (IV)

The theory of consolidating care by clarifying perspectives will be briefly explained in its entirety below.

When healthcare professionals participate in ECR sessions with the care team, their main concern is to *consolidate care*. Consolidating care is about striving for a common understanding and a shared view of the care of the child. The core category, *clarifying perspectives*, and two related categories explain how care is consolidated. Participants clarify their perspectives by having a dialogue and reflecting on their professional views on the ethical issue. The different professional viewpoints provide different aspects of the child's situation and contribute to a variety of dimensions and breadth of reflection. The two related categories were named: *Deliberating ethics* (approaches) and *unifying interactions* (consequences). Different approaches for deliberating ethics are used during the sessions including *raising values* and *making sense*, leading to *increased understanding*, *group strengthening* and *decision grounding*. Figure 3 shows a model over the integrated categories.

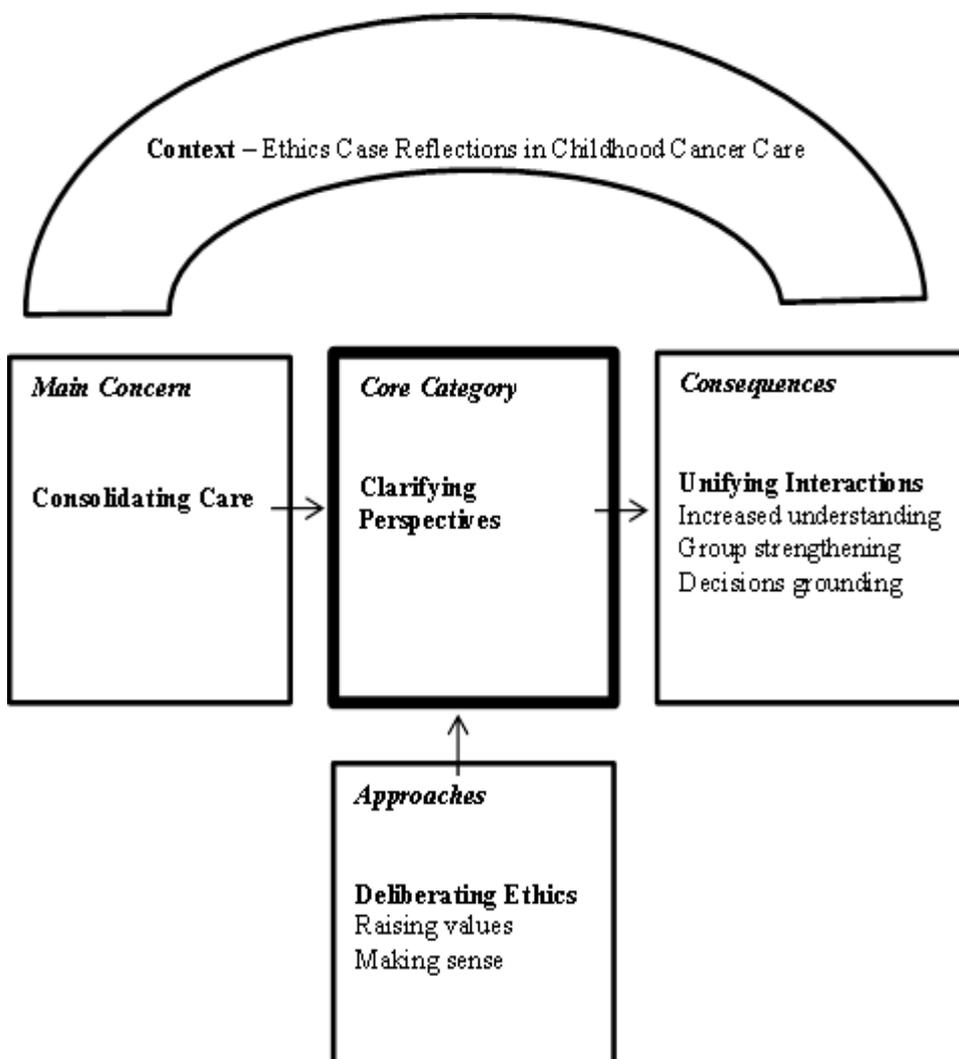


Figure 3. A model explaining the theory: Consolidating Care by Clarifying Perspectives

# SYNTHESIS

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## THE VALUE OF INTER-PROFESSIONALLY SHARED REFLECTION

*The value of inter-professionally shared reflection* emerged through the analysis of the common latent content of the four studies in this thesis. In childhood cancer care a chain of relationships and interactions among healthcare professionals possibly form the caring outcome. The interprofessional team plays an important role in order to conduct a holistic view and provide individualised care of the child. An ethically justifiable childhood cancer care can be facilitated by inter-professionally shared reflection including: *the unique knowledge, dealing with ethical conflicts, a trusting atmosphere and a consolidated care.*

### The Unique Knowledge

The unique relational knowledge about the child's situation is about the knowledge that the members of the interprofessional team provide when they reflect together, concerning what is at stake and which values are most important in each specific case. This can be compared to a puzzle, where all the different parts make a new whole and create a new picture of the situation. Thus, the relational *interprofessional interaction* contributes to a fuller picture of the child's situation.

Obtaining this unique relational knowledge is guided by the model for ethical analysis, described in study I. The case-based model facilitates that values, discovered by healthcare professionals closest to the child, are reflected on. Thus, having interprofessional interactions may assist deliberating on the unique knowledge. Furthermore, decisions that are based on the unique knowledge provide conditions for improving the quality of care.

### Dealing with Ethical Conflicts

This category indicates a willingness to meet *interprofessional differences* and respond to the underlying appeal to be listened to. Interprofessional differences were an ethical concern of *conflicting perspectives* that included a lack of dialogue. The value of inter-professionally shared reflection is based on that dialogue is performed during the reflection which will meet the expressed need for dialogue and create possibilities to deal with ethical conflicts related to the child. When ethical conflicts are solved decisions about what actions should be taken are more likely grounded in a shared interprofessional view. This will also contribute to the care of the child including both nursing and medical aspects. In study II the analysis showed that the interprofessional team both valued and wanted to engage in shared reflections. This was expressed through a desire for *interprofessional consideration* that includes *teamwork and reflection on ethical concerns* which could contribute to the possibility to handle ethical concerns.

## **A Trusting Atmosphere**

With regards to the ethical climate in study III, healthcare professionals' perceptions were different, especially those among nurses' and physicians'. Even though two thirds of the participants stated that they were unable to practice ethically good care, the majority stated that they trusted each other and that they worked with competent peers. Interprofessional teamwork need to be based on trust and competence. Interprofessional trust and the perception of working with competent peers influence the reflection by creating opportunities for an open dialogue. Moreover, an open dialogue could be a foundation for achieving a better quality of care for the child and the family and for consolidating care.

## **A Consolidated Care**

As explored in the emerging theory of *consolidating care by clarifying perspectives* (IV) the main concern strongly indicates that healthcare professionals want to reflect together in order to enable a multi-perspective view of the care of the child and common care goals. A multi-perspective view is more likely to be holistic and thus will reduce the risk of missing important values for the child. A major component for the value of inter-professionally shared reflection is also when healthcare professionals are *clarifying perspectives*. By clarifying perspectives within the interprofessional team, the team has the ability to reflect over the most reasonable and ethically justifiable care for the child. *Increased understanding* is also an important component because it increases awareness and knowledge about the child's specific situation.

## DISCUSSION

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### DISCUSSION OF KEY FINDINGS

Ethics Case Reflection (ECR) sessions, in this project, consist of interprofessional dialogue about difficult ethical issues in childhood cancer care. A model developed for ethical analysis is used during the reflection. This model can be used by healthcare professionals, but it is advantageous if the reflection is led by a person who is trained in facilitating reflections on ethical issues. If we are to argue for that this model should be used in clinics, facilitators need to be educated and made available. In a study written by Stolper and colleagues<sup>94</sup> a training programme is presented on how to train healthcare professionals to become facilitators. The central principles were learning by doing, reflection instead of readymade knowledge and dialogue on dialogue, which is in line with the approach behind the ECR session in our study. Teaching how to facilitate is not about teaching the ideal way of facilitating, but rather to stimulate learning by doing.<sup>94</sup> This would be an interesting approach for the context of childhood cancer care. Healthcare professionals interested in ethics could be trained as facilitators and then help colleagues to handle ethical issues. This, in the long run, would impact care.<sup>95</sup>

A study done by Källemark and colleagues supports the above statement. The authors concluded that healthcare organisations could reduce moral distress by offering better support, resources and structures.<sup>96</sup> The same study also concluded that there is a need for further education in ethics as well as a forum for dialogue over difficult ethical situations experienced in the clinic.<sup>96</sup> Thus, offering ECR sessions to healthcare professionals. However, another study could not show that ethics rounds, equal to ECR sessions, including how ethical issues were dealt with, improve the ethical climate.<sup>41</sup> The study, which aimed to investigate whether ethics rounds could improve the ethical climate in a psychiatry outpatient setting, used a quasi-experimental method. No difference was found in the intervention group despite the fact that ethics rounds were viewed as a positive experience.<sup>41, 65</sup> But, when the same authors continued with an qualitative approach to gain a deeper understanding through using individual interviews, they found that ethics rounds were experienced positively and that ethics rounds enabled the healthcare team to see issues from a multi-perspective angle.<sup>97</sup> The authors conclusion was that participating in interprofessional dialogue regarding an ethical issue improved awareness of ethical issues.<sup>97</sup> In study I we arrived at the same conclusion; our proposed procedure for ethical analysis can help healthcare professionals learn how to structure their thinking about ethical issues in the clinic.

The results of study III also support ECR sessions. One- third of the participants in study III perceived that they were able to practice ethically good care. The two thirds that perceived that they were not being able to practice ethically good care also perceived a lack of necessary tools available to solve ethical problems. A suitable tool could be ECR sessions because these sessions provide the opportunity to deal with ethical problems.

In study II, the categories *infringing on autonomy*, *deciding on treatment levels*, and *conflicting perspectives* were presented as ethical concerns in childhood cancer care. All of these ethical concerns can be deduced to questions about children's participation in decision-making. Should children be able to make decisions on matters concerning procedures that they don't want to be involved in? Should children be involved in treatment-related issues? Different reasoning among healthcare professionals concerning issues such as forced procedures may occur. Some feel that it is extremely hard to go against the child's wishes, but others might feel that some procedures have to be done without negotiation. Here questions are raised about whether it really is an ethical issue to hold a small child down? Some actions are probably believed to be in the best interest of the child. An important ethical question that can be derived from this is: What is best for the child? This question is impossible to answer. However, child-centred care today is commonly discussed in the literature. A study performed by Söderbäck and colleagues<sup>16</sup> discusses the importance of including both a child perspective and the child's perspective in healthcare. Both perspectives are needed to be able to see children as equals in child-centred contexts.

In study II *limiting truth-telling* was perceived as an ethical concern and healthcare professionals felt that they were infringing on the child's autonomy when they did not share the truth with the child. Limiting truth-telling was usually based on parents wanting to protect their child from the sometimes painful truth. The child's opportunities for being included in decisions and making their viewpoint known was limited when truth-telling was limited. Coyne and Harder argued for that protection should be balanced with shared decision-making.<sup>98</sup> Children should be seen as individuals and not as a homogenous group, and every situation is affected by specific circumstances. A situational perspective enables the ability to act in the best interest of the child.<sup>98</sup> Another study was based on interviews with children about their participation in communication and decision-making<sup>99</sup> and found that children's preferences can vary. Children wanted to be included in communication and they wanted to be involved in decisions about their care in the context of every day issues. At the same time they had a minor role in discussions that were held between parents and healthcare professionals and were limited by actions made by adults.<sup>99</sup> This study highlights that, in some cases, limiting truth-telling is not in the best interest of the child. Research on children's wishes and feelings about hospital life showed that children want more information, and they want to be included in the dialogue with physicians and nurses.<sup>100</sup> Children also want healthcare professionals to listen to them and respect their views.<sup>100</sup>

There seems to be limited studies on the ethical climate in paediatric settings. Several studies have been conducted within adult care.<sup>21, 28-35, 38-40</sup> However, one study performed in neonatal care aimed to explore perceptions of moral distress, moral residue and the ethical climate among registered nurses.<sup>36</sup> Comparing the results of this study with the results from study III, similarities among nurses' responses were very clear. The items rated the highest by nurses in study III were similar to the ones rated highest in the study performed in neonatal care in the USA.<sup>36</sup> For example, nurses stated positively in both of the studies that 'my co-workers listens to my concerns about patient care', that 'I work with competent co-workers' and 'On my unit the patient's wishes are respected'. The items rated less positively were also very similar in the two studies. Examples of these negative statements are 'Physicians ask nurses

for their opinion regarding decisions concerning treatment’ and ‘Conflicts concerning ethical issues/problems are openly dealt with and not avoided’. Study III included all professions while the study conducted in neonatal care did not, leaving it impossible to compare physicians’ perceptions or perceptions on a group level. Even if the contexts were different, the nurses’ perceptions seem to be similar. This allows for the possibility to draw a conclusion that nurses in paediatric care struggle with the perception of not being heard regarding decisions concerning treatment.

In study IV the theory of *consolidating care by clarifying perspectives* emerged. When healthcare professionals can resolve their main concern there are positive consequences, these were identified as *increased understanding*, *group strengthening* and *decision grounding*. Paediatric healthcare would benefit from further research into interventions with positive outcome consequences that might lead to an improved quality of care for children. The findings in study IV are supported by a study performed by Söderhamn and colleagues.<sup>101</sup> In that study a mixed method was used to evaluate ethical reflections. The authors found that ethical reflections improved understanding between healthcare professionals and argued that it could impact on care by influencing the attitudes towards patients.<sup>101</sup> The same authors also found similar results with *group strengthening* as they described that ethical reflection could create more solidarity in the team.<sup>101</sup>

Another study done by Janssens and colleagues also supports the findings in study IV.<sup>102</sup> ECR sessions, which in their study were named moral case deliberations (MCD), were evaluated positively by the participants. Similarities included that respondents indicated that the relationship of healthcare professionals improved after participating in the MCD session.<sup>102</sup> This is similar to our *group strengthening* category. More openness and understanding for different perspectives were highlighted<sup>102</sup> which is similar to *increased understanding*. Having such positive outcomes further encourages the continuation of research which using ECR sessions. The published literature reveals that no studies have been done in Sweden with regards to how often ECR sessions are performed in the country overall and in which contexts. However, research has been done to provide an overview of the prevalence of MCD<sup>103</sup> in Dutch healthcare institutions. The prevalence of MCD was relatively high (44%), especially in mental healthcare (62%).<sup>103</sup> Mental healthcare and paediatric care share a lot of ethical issues and have similar ethical concerns regarding the respect for autonomy which suggests that ECR/MCD would be useful in paediatric care.

## DISCUSSION OF THE VALUE OF INTER-PROFESSIONALLY SHARED REFLECTION

One could argue for that there is an increased value for healthcare professionals who work with children in childhood cancer care to reflect together because the *inter-professionally shared reflection* will have the possibility to impact care, which might result in improved quality and ethically justifiable care for the child. Interaction between participants is necessary. The literature argues that relationships are formed through interactions, therefore suggesting that interaction is a useful tool for professional practice.<sup>104</sup> Still, there seems to be a lack of evidence for the value of interprofessional teamwork related to patient outcomes.<sup>105</sup> However one study, performed in different healthcare settings, found that greater interdependence and closer cooperation within teams resulted in higher efficiency and a better climate<sup>105</sup> which supports the idea that inter-professionally shared reflection creates the possibilities for improved quality of care.

*The unique knowledge* was found to be an important part of the value of inter-professionally shared reflection. The knowledge about the child, which emerges through interaction, is not the only valuable knowledge. Shared interprofessional reflection might also contribute to interprofessional learning, meaning that healthcare professionals are learning from each other. Interprofessional learning has been discussed in relation to shared learning that contributes to professional development.<sup>106</sup> Moreover, recent research describes active learning strategies and found that case studies, small group discussion, problem-based learning, and reflective exercises were to prefer<sup>107</sup> which mirrors the way ECR sessions are conducted. Interprofessional learning could contribute to better care, because it generates improved competence of the healthcare professionals caring for the patient.

ECR sessions can be seen as a tool for reflecting together. Previous research examined the need for a tool for securing ‘successful inter-professional learning and developing personal, professional and inter-professional competence to improve the quality of care’.<sup>108(p.85)</sup> The authors argued that if the team has common tools it will contribute to communication and understanding within the team. The author’s conclusion that ‘the overall winner of inter-professional practice has to be the patient’, says it all.<sup>108(p.90)</sup>

The four components (*the unique knowledge, dealing with ethical conflicts, a trusting atmosphere* and *a consolidated care*) included in the synthesis can be linked to the results in a previous study where interprofessional team members were interviewed in order to find the reasons for developing good, cooperative working relationships. Three themes behind positive team working were discovered: personal qualities and commitment, communication and the possibility to produce creative methods for working.<sup>109</sup> Furthermore, a study from adult oncology concluded that respectful team relationships, as one of the components in a moral community ‘could foster comfortable dialogue about moral differences and prevent or mitigate ethical conflicts and the moral distress that frequently follows’.<sup>110 (p.130)</sup>

## **METHODOLOGICAL CONSIDERATIONS**

In this section arguments and motives for the methods used as well as a discussion of the most important methodological issues will be presented. This will also include discussing issues that arose about interference with the findings, ethical considerations and validity and generalizability.

This research project used four different methods, which can be challenging to learn and use during four years of research education. This challenge was met by taking methodological doctoral courses, attending seminars and being properly supervised. It is important that methods are chosen depending on the overall aims with the studies and the specific research questions.<sup>111</sup> Content analysis is a descriptive method<sup>75,77</sup> which aims to describe the phenomenon in a conceptual form.<sup>75</sup> Grounded Theory aims to generate theory/ integrate concepts. Grounded Theory methodology is a method where categories and concepts are conceptualised and later compared to explore how participants resolve their main concern.<sup>76,79,80</sup> Grounded Theory can thus be seen as a continuation of inductive content analysis and therefor methodological knowledge generated in study II was initially very useful in study IV.

### **What Interfered with the Findings?**

In study II a study specific questionnaire was used. A pilot of the questionnaire was performed prior to the final distribution. Several healthcare professional with training in ethics tested the questionnaire, focusing on content and the time it took to complete it. The open-ended questions were added as a result of the pilot study. During data collection frustration arose among participants. They stated that the questionnaire was too extensive, too long and that it required too much time to complete. Despite that, the collected responses were very extensive and juicy, resulting in rich qualitative data. With hindsight into the frustration and with respect for the participants, focus group interviews could have been chosen for the open-ended questions. There is a chance that it would have been easier for some participants to express themselves in words. Focus groups would possibly have also generated rich data because of the interaction between the research participants<sup>112</sup> and it would have given the opportunity to ask follow-up questions to gain deeper understandings. However, 87 answers with written text are satisfactory and could be considered as a large sample in qualitative research. Other difficulties with regards to the open-ended questions were related to healthcare professionals having concerns about distinguishing between issues such as the most frequent and the most difficult ethical issue. Several participants wrote the same answer on both of the questions. This could partly be related to the construction of questions but perhaps also partly on how we look at ethical issues: Do the daily problems count as much as the difficult questions?

The same issue concerned study III because study II and III shared data collection. When the participants' frustration was obvious they were kindly asked to prioritise the open-ended questions and the last section in the questionnaire including the Hospital Ethical Climate Survey (HECS). Eventually, 89 questionnaires with responses to the HECS were collected.

Even if a larger sample would have been more optimal, the sample was sufficient to analyse with descriptive statistics. Considering sample size, the distinct responses led to the possibility to draw conclusions.

In study IV, the initial goal was to perform 6-10 ECR sessions. Because of the clinical situation at the childhood cancer unit during the time for data collection, where healthcare professionals were exposed to time constraints, six ECR sessions were finally conducted. Despite the lower limit of the goal the main concern and how participants dealt with it emerged early on. After each ECR session theoretical sampling was done by individual interviews and encounters. Further theoretical sampling could have been done to ensure a higher level of saturation, but considering the clinical conditions and with respect for the participants the decision to stop theoretical sampling was taken. This was especially true for physicians, who were exposed to extreme time constraints and were not formally interviewed afterwards. Individual encounters were performed with physicians in order to offset this and enrich the data collection. Glaser argues for that there are at least four types of data.<sup>76</sup> The first type of data is named baseline data and is the best description a participant can provide.<sup>76(p.9)</sup> Informal encounters could contribute with baseline data because the participants answers spontaneously, are not prepared and have not been given the chance to think through the situation beforehand.

Another explanation for the lower number of performed ECR sessions could be found in previous research<sup>113</sup> that examined an Ethics Screening and Early Intervention Tool designed to detect at-risk clinical situations and prompts early actions to mitigate conflict and moral distress. The tool was reported to be beneficial but nurses reported some risk to themselves when initiating follow-up actions (in our study that would be similar to initiating an ECR session). Discussing ethical concerns with physicians, calling for ethics consultation, and initiating patient conversations were considered to be the riskiest actions. Nurses explained this risk through the following themes: 'being the troublemaker' and 'questioning myself'. The authors concluded that all members of the healthcare team needed to feel safe in raising ethics-related questions in order to improve patient care and encourage teamwork.<sup>113</sup> If this is applicable for nurses in childhood cancer care, i.e. they felt unsafe and at risk for themselves for being the troublemaker, the lower limit of ECR sessions is not surprising.

According to Glaser<sup>76</sup> there are a number of reasons for not audio recording interviews and observations, but for the possibility of obtaining quotes to illustrate categories, the decision to respectfully disagree with that recommendation was taken. Additionally, the recordings of the ECR and the individual interviews created the opportunity to be listened to by co-authors, enabling validation of the concepts. It even created the opportunity to re-experience the unwritten data, such as voice inflection patterns. However, field notes were taken in order to not delay the start of the comparative analysis of the data and thus limiting preconceptions.<sup>114</sup>

## **Dealing with Ethical Considerations**

Research ethics in humanities and social science is built on four main requirements. These are information, consent, confidentiality and utilization of research data.<sup>115</sup> In the following section a description and discussion of how the requirements were met will be held in relation to the research project.

### *Requirement of Information*

Oral information was given about the overall aim and structure of the research project to the participating units in connection to staff-meetings and meeting with managers prior to the start. When the questionnaire was distributed an information letter was attached that described the purpose of the research project and how the research was to be conducted as well as the PhD student and main supervisor's contact information. The voluntary nature for participation was highlighted. All healthcare professionals that participated in observations and interviews received information about the research project before the start, both in writing and orally. In addition to the above described information, the oral information included possible follow-up interviews and encounters, which were informed to be a part of the data-collection.

### *Requirement of consent*

With regards to the questionnaires, this was not considered to be an issue. If the participants chose to respond, they gave their consent to participate in the study. At one time participants answered the questionnaire during an educational session, they were then given the opportunity to turn in the questionnaire blank in order to protect them from having to explain why they did not want to respond. They were told that by participating in one part of the project, such as answering the questionnaire, this did not mean they automatically had to participate in another part, such as in the ECR sessions. Before the start of ECR sessions and individual interviews information was given about the right to withdraw at any time without needing to give a reason.

The project was approved by the regional ethical review board in Stockholm and the children's and their parents' names were not mentioned during the ECR sessions or in follow-up interviews in order to protect their anonymity. Despite that, concerns were raised about how parents and children were not being informed about that the ECR session were carried out within the research project and that they did not have an opportunity to consent. Reflections over ethical issues are done every day in clinical practice, but in these cases a facilitator and the author attended. Questions were directed to the regional ethical review board in Stockholm with the answer that informed consent from children and parents are not necessary. Regardless, in the end oral consent was collected from parents in the prospective cases, although the regional ethical review board and the application to the board did not require that parents should be informed. However, the oral consent from parents enabled the use of anonymised quotes from the ECR sessions and interviews.

Parents were additionally given the opportunity to read the quotes, before they were used in the presentation of data, but no one chose to.

#### *Requirement of confidentiality*

Data has only been available to the author and the main supervisor and information regarding names of participants has been (and still is) stored in a locked locker.

#### *Requirement of utilization*

Data arrived from the studies has only been and will continually be used for research. This includes that data has been and will be presented in international and national publications, and finally at conferences.

### **Validity and Generalizability**

Even if Grounded Theory methodology was not used in study I, it is relevant to discuss this model in relation to the four criteria for judging credibility used in Grounded Theory. Credibility can be seen as the quality of being believable. The four criteria are fit, work, relevance and modifiability.<sup>76, 79</sup> All of these seems to match the model because the model directly relates to empirical data (fit), it has the power to work in the clinical context (work), the model is relevant for its purpose, that is analysing difficult ethical situations and reflect on possible actions (relevance) and finally, it can be further modified after being evaluated in future research (modifiability).

The theory in study IV is based on exploratory data, therefore even if definitive generalizations could not be drawn the findings can still be generalized into other contexts. The author discovered the core category and the main supervisor (Pergert) and one of the co-supervisors (Lützén) validated the findings by stating that consensus was reached. When applying the four criteria (fit, workability, relevance and modifiability) for judging credibility according to Glaser<sup>76, 79</sup> in relation to study IV, it can be seen as follows: The theory of consolidating care by clarifying perspectives has a *fit* as it originates from empirical data and expresses what happens when healthcare professionals reflect over ethical concerns together. *Workability* means that the theory should explain how the main concern is resolved. The core category, clarifying perspectives, explains how care is consolidated together with the strategy of deliberating ethics. Furthermore, the theory is *relevant* in the context of childhood cancer care and if it were to be explored in other contexts, with new data it would be possible to *modify* it.

The quality of the research is often judged by the validity and generalizability. Qualitative researchers use different terminology when evaluating the quality of the research.<sup>72, 111</sup> The studies are often assessed by their trustworthiness which involves dependability, conformability, credibility and triangulation.<sup>72, 111</sup> One could argue that study II reached

trustworthiness because consistent empirical data was derived from the healthcare professionals' writing and by the fact that the method applied was suitable for the data. Finally triangulation between the team of researchers, in the analysis, ensured the trustworthiness.

In quantitative studies parameters such as reliability and validity are often examined. In study III, analysis of responses to the Hospital Ethical Climate Scale (HECS) was done and previous evaluation of psychometric properties of the HECS showed good validity and reliability.<sup>38</sup> When testing reliability for the 17 items, used in our study, the result turned out to be as good as the Swedish version.

## CLINICAL IMPLICATIONS

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The model for ethical analysis, modified in study I, can provide a structure for dealing with ethical issues in clinical settings. The model can be used with or without a facilitator. Study I describes the model used in the research project in childhood cancer care, but it can be used in all healthcare settings where reflection on important ethical values are performed. Furthermore, the model can assist healthcare professionals by structuring their thinking about ethical issues, which can be seen as a learning opportunity and thereby contribute to improved ethical competence that creates opportunities for a better quality of care. Because Ethics Case Reflection (ECR) sessions, guided by the model, can be conducted with the interprofessional team, one can argue for that the model stimulates interprofessional reflection. As explored in the synthesis, it is there is a specific value for children in childhood cancer care that healthcare professionals reflect together because the *inter-professionally shared reflection* will impact care, resulting in improved quality and ethically justifiable care for the child.

Study II provides important insights into healthcare professionals' experiences of ethical issues when caring for children with cancer. The emerged knowledge can serve as a basis in educational sessions for all healthcare professions and as a basis for discussion in the clinic. This will help prevent ethical issues and focus actions. For example, the ethical concern on infringing on autonomy is a problem that nurses in paediatric care face daily and therefore it should be more thoroughly considered. When ethical problems concerning coercion within psychiatry care occurred in the Netherlands several MCD were performed focusing on coercion as a theme.<sup>55, 116</sup> Guidelines were then formulated on the basis of the MCDs. The same could be done with coercion in paediatric care. The sessions may change peoples' attitudes, but the guidelines could also service as being supportive for healthcare. Awareness of conflicting perspectives and an expressed need for interprofessional consideration, such as teamwork and reflections on ethical concerns, would be important for the leaders of the healthcare organisation when planning for the distribution of resources in the clinic.

The results of the analysis on the specific items in the Hospital Ethical Climate Scale (HECS) in study III additionally provides important information for both healthcare professionals working with childhood cancer care and other paediatric settings as well as the management. Knowing what factors contribute (trust) as well as hinder an ethical climate (lack of resources) is clinically relevant because this information can be used to plan interventions. For example, the perception of not being able to practice ethically good care was related to the perception of lack of ethical tools, which again stresses the importance for healthcare professionals to participate in structured inter-professionally shared reflections on ethical issues. Furthermore the results in study III revealed that physicians and nurses had different perceptions for all items, which indicates a need for dialogue.

ECR sessions were experienced as necessary and they providing positive consequences. The procedures and the model described in study I can be used to implement these within the clinic. This research could hopefully encourages leaders and management in healthcare organisation to promote interprofessional teamwork because shared interprofessional reflections, based on the unique knowledge of important values and a competent and trustful atmosphere, could contribute to reasonable and ethically justifiable care for the child. As data in all the studies speak in favour of conducting interprofessional ECR sessions, there should not be doubt about their value.

## CONCLUDING REMARKS AND FUTURE RESEARCH

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Results from the four studies included in this thesis provide empirical knowledge and a deeper understanding about how healthcare professionals deal with difficult ethical situations in childhood cancer care. Further, the synthesis explores the common latent content of the four studies that unifies them.

Even if difficult ethical concerns were found and there were factors in the ethical climate that were difficult to face, there seems to be a shared wish to solve these ethical concerns within the team, and a focus on the perceived best interest of the child. Healthcare professionals gave suggestions on how to solve their ethical concerns, and when they participated in ECR sessions, different approaches of deliberating ethics were explored. If resources for ethics, in terms of education, time and forums for inter-professionally shared reflections would be prioritised there is an optimistic future when it comes to dealing with ethical concerns. When ethical concerns are dealt with then better possibilities exist which can improve the ethical climate and provide ethically justifiable care for children in vulnerable situations. However, one should be aware of that there is a risk that ECR sessions could be misused. For example, participants may claim that because of the ECR session was held and a consensus was reached, this consensus should be prevailed. One should also be aware of hidden agendas, like using the ECR session to convince participants.<sup>117</sup> This study thus raises a challenging question: How can we obtain these optimal circumstances that in a larger proportion could contribute to a holistic perspective on ethics in childhood cancer care?

It would be of great interest to implement and evaluate ECR sessions nationwide in future research. An instrument, called the Euro-MCD, which measures a wide range of possible outcomes of ECR sessions has now been developed<sup>118</sup> and it could possibly be used. It would also be of great interest to study patient outcomes related to inter-professionally shared reflections.

The Childhood Cancer Healthcare Research group has received funding from the Swedish Childhood Cancer Foundation to continue studying the ethical climate nationally, and this study will focus on moral stress and its relationship to the ethical climate in paediatric cancer care.

## SUMMARY IN SWEDISH

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Det övergripande syftet med avhandlingen var att få empirisk kunskap och djupare förståelse av etiska problem och hur hälso- och sjukvårdspersonal hanterar dessa i samband med svåra etiska situationer i barncancervården. I all sjukvård kan komplexa etiska problem och motsättningar om behandling och vård uppstå, speciellt i samband med vård i livets slut. Vid etiska problem finns värdekonflikter gällande vad som är rätt i den kliniska kontexten. Vård av cancersjuka barn innebär komplexa beslut om liv och ställningstagande till fortsatt behandling med syfte att bota eller begränsning av meningslös och därigenom oetisk behandling samt åtföljande lidande. Det är viktigt att påpeka att behandlingen mot barncancer varierar med diagnos men den är ofta både fysiskt, psykiskt och socialt mycket påfrestande för både barnet och familjen samt vårdpersonalen som ständigt är vid barnet och föräldrarnas närhet.

Avhandlingen består av fyra studier. Den första studien beskriver en modell för etisk analys (I), den andra undersöker vilka etiska problem personalen har erfarenhet av och hur de hanterar dem (II), den tredje beskriver uppfattningar av det etiska klimatet som undersöktes på tre avdelningar som vårdar barn med cancer (III) och slutligen förklarar den fjärde studien vad som händer när personalen deltar i etik-fall reflektioner (IV). De fyra studierna användes sedan för att djupare beskriva det gemensamma innehållet i en syntes. En jämförande analys av resultat och slutsatser genomfördes som resulterade i en syntes som förklarar värdet av delad inter-professionell reflektion.

Syftet med studie I var att beskriva tillvägagångssätt för etik-fall reflektioner, inklusive den modifierade modell som används i forskningsprojektet, samt beskriva fördelar och nackdelar med det presenterade tillvägagångssättet i relation till litteraturen. Studien som bygger på teoretiskt resonemang omfattas utav en litteraturgenomgång där reflektionsmodellen, KS modell för etisk analys, diskuteras i relation till tidigare forskning och tidigare erfarenhet. En jämförelse med nuvarande modell och modifieringar som har gjorts presenteras även i artikeln. Den modifierade modellen består av åtta steg för strukturerade så kallade etik-fallreflektioner som används i samband med svåra etiska situationer i barncancervården. Vi föreslår att den modifierade versionen av KS modell för etisk analys kan användas i det inter-professionella teamet och där kan bidra med en möjlighet för personalen att förbättra sin etiska medvetenhet och sina etiska färdigheter för etisk analys på ett praktiskt plan.

Syftet med studie II var att beskriva hälso- och sjukvårdspersonalens erfarenheter av etiska problem och hur de hanterar dessa i samband med vård av cancersjuka barn. Läkare, sjuksköterskor och undersköterskor från tre pediatrika avdelningar (n=87) besvarade öppna frågor i ett studiespecifikt frågeformulär som analyserades med kvalitativ innehållsanalys. De skriftliga svaren från enkäterna skrevs ner i löpande text och data delades även in i två domäner som baserades på frågorna. Materialet bearbetades genom att meningsbärande enheter kondenserades, kodades och delades in i underkategorier och kategorier. En djupare analys med frågan om det latent innehåll bidrog till att kategorinamnen konceptualiserades och beskrevs utifrån en högre abstraktionsnivå.

Ett flertal etiska problem/angelägenheter identifierades. "Att inskränka autonomi" (Att vålla lidande, Att begränsa sanningssägande); "Att besluta om behandlingsbegränsningar" (Att tidsbestämma brytpunkten, Att balansera smärtlindring); "Att ha motstridiga perspektiv" (Inter-professionella skillnader, Föräldraperspektivet, Kulturella skillnader). Även kategorier för hur hälso- och sjukvårdspersonalen önskar hantera dessa utkristalliserades; "Inter-professionella överväganden/hänsyn" (Teamarbete, Reflektion över etiska angelägenheter); "Resurser för etik" (Tid och personliga utrymmen, Etisk kompetens).

Syftet med studie III var att beskriva hälso- och sjukvårdspersonalens erfarenheter av det etiska klimatet. Personal från tre avdelningar (n=89) besvarade ett studiespecifikt frågeformulär, där det etiska klimatet undersöktes i en separat del. Frågorna som täcker det etiska klimatet modifierades minimalt från sitt ursprung (Hospital Ethical Climate Survey) för att passa barnsjukvård och för att riktas mot både omvårdnadspersonal samt läkare. Totalt bestod denna del av 17 delfrågor som visade sig ha god reliabilitet. Data analyserades med beskrivande statistik. Chi-två-test genomfördes för att analysera proportioner. Olika uppfattningar av det etiska klimatet presenteras som positiva eller neutrala/negativa. Samtliga frågor presenteras var för sig och analysen visar att sjuksköterskor skattar det etiska klimatet mer neutralt/negativt än läkare på samtliga frågor. Ingen skillnad återfanns på gruppnivå mellan avdelningarna men när antal år av arbetslivserfarenhet sattes i relation till samtliga frågor föll en skillnad ut. Informanter med mindre erfarenhet fyllde mer sällan i att sjuksköterskor och läkare litar på varandra. En tredjedel av informanterna skattade att de kunde praktisera den etiskt goda vård som de ansåg att de borde kunna praktisera. Den positiva tredjedelen svarade i högre utsträckning att läkare och sjuksköterskor litade på varandra och att föräldrar var lyssnade till. De två tredjedelar som inte ansåg sig kunna praktisera den etiskt goda vård som de borde uttryckte till en lägre utsträckning att de hade tillgång till etiska verktyg, att konflikter hanterades med öppenhet och att det fanns en atmosfär som uppmanade dem att fråga, lära sig och att söka efter kreativa lösningar i samband med etiska problem i vården.

Syftet med studie IV var att utforska Hälso- och sjukvårdspersonalens erfarenheter av att delta i etik-fall reflektioner i team i barncancervården. Data samlades in genom observationer och individuella intervjuer och analyserades induktivt med grundad teori. Den framkommande teorin namngavs "Att sammanföra vården genom att klargöra perspektiv". Att sammanföra vården innebär att sträva efter gemensamma mål med vården och konsensus samt att skapa en gemensam syn på vården i det specifika fallet. Det inter-professionella perspektivet på etiska aspekter i vården klargörs genom att deltagarna framför sin professionella syn på fallet. Olika tillvägagångssätt för att överväga etiska aspekter används under etik-fall reflektionerna vilka framträdde som att lyfta värderingar och att resonera om vad som ter sig rimligt i fallet som slutligen leder till förenande interaktioner/samspel. Även om svåra etiska problem identifierades och det fanns faktorer i det etiska klimatet som inte var så tillfredsställande, verkar det finnas en gemensam önskan hos hälso-och sjukvårdspersonalen om att lösa etiska frågor, med fokus på den bästa vården för barnet.

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## APPENDIX 1

1. Please mention examples of external circumstances that have prevented you from doing what you believe is right / best in relation to ethical issues in clinical care / treatment of patients.
2. Please, briefly describe the ethical issues you feel are the most frequent in your work.
3. Please, briefly describe the ethical issues you feel are most difficult when it comes to knowing what is right / wrong, in your work.
4. Please, briefly describe the ethical issues which, in your experience, lead to the most frequent conflicts with your co-workers.
5. Please, mention different ways of dealing with ethical issues that you commonly use at your unit.
6. Do you have any other ideas about what you could do to deal with ethical issues?
7. Please, briefly describe your experiences of teamwork in dealing with ethical issues in health care / treatment of patients at your unit.

## APPENDIX 2

1. My co-workers listen to my concerns about patient care.
2. Nurses and physicians at my unit trust one another.
3. Nurses and nurse-aides at my unit trust one another.
4. Physicians ask nurses about their opinion regarding decisions concerning treatment.
5. Physicians ask nurse-aides about their opinion regarding decisions concerning treatment.
6. My co-workers help me in ethically difficult caring situations.
7. Healthcare professionals at my unit have access to necessary tools to solve ethical problems.
8. The feelings and values of all parties involved are taken into account when a decision about an ethical issue/problem is to be taken.
9. Conflicts concerning ethical issues/problems are openly dealt with and not avoided.
10. Nurses and physicians at my unit respect each other's opinions, even when they disagree about what is best for patients.
11. Nurses and nurse-aides at my unit respect each other's opinions, even when they disagree about what is best for patients.
12. I work with competent co-workers.
13. At my unit the patient's wishes are respected.
14. At my unit the guardian's wishes are respected.
15. There is an atmosphere that encourages us in questioning, learning, and seeking creative responses to ethical problems/issues in treatment/care.
16. There is time for reflection and discussion when there are ethical problems in treatment/care.
17. At my unit I am able to practice the ethically good care as I believe it should be practiced.