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MORAL DISTRESS AND ETHICAL CLIMATE IN PEDIATRIC ONCOLOGY CARE

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Moral distress and ethical climate in pediatric oncology care

Thesis for Doctoral Degree (Ph.D.)

By

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*To my patients, past and present, the children with cancer whom I held
in my heart as I composed each line of this thesis.*

Popular science summary of the thesis

Caring for children with life-threatening diseases involves numerous ethical issues, and far from always, healthcare professionals can follow their moral compass. Not being able to take the right action can lead to lingering feelings of frustration and anguish, also called moral distress. Moral distress negatively affects the well-being of healthcare professionals and ultimately, reduces the quality of care.

This thesis explored experiences of moral distress and perceptions of ethical climate among pediatric nurses, nursing assistants and medical doctors who care for children with cancer in the Nordic countries. The results show that only one third of the healthcare professionals could most often practice care the way they thought they should. This, however, varied widely depending on which hospital they worked at. Healthcare professionals, and nurses in particular, experienced moral distress when hurdles - busyness, poor staffing levels, lack of continuity, and disagreements on children's best interests - hindered them from meeting the comprehensive needs of sick children and their families. Overall, moral distress was less common at the workplaces with ethical work climate, that is, at those childhood cancer units where staff members supported and respected one another, and discussed ethical issues.

Our findings suggest ensuring appropriate staffing levels and continuity among staff who provide care for children with cancer, and improving communication about children's best interests.

Abstract

Background: Despite the high survival rates, childhood cancer still is a life-threatening disease. Many ethical dilemmas and constraints challenge healthcare professionals who provide care for these children, causing moral distress and reducing the quality of care.

Aims: To explore experiences of moral distress and ethical climate in Nordic pediatric oncology care.

Methods: A cross-sectional survey study was carried out among healthcare professionals at twenty Nordic pediatric oncology centers: In addition, an interview study with a grounded theory approach was conducted among pediatric nurses working at a university hospital in Sweden.

Results: The 543 healthcare professionals who completed the survey, assessed situations that involved unsafe staffing, lack of time, and poor continuity of care as the most frequent root causes of moral distress. On average only 31% of healthcare professionals could almost always practice care the way they thought it should be practiced. Perceptions varied significantly between individuals and centers, but not between countries. Moral distress was less frequent at the centers with an ethical climate. Those who considered leaving their jobs because of moral distress, reported higher levels of moral distress and perceived the ethical climate as less positive, compared to the ones who had no intention to leave. The interviews with 25 nurses confirmed that organizational constraints often challenged nurses' endeavors to provide timely, safe care to sick children. While healthcare professionals in general were attentive to patients' and parents' wishes, nurses perceived that children's voices too often were overpowered, leading to unnecessary procedures and limited truth-telling. Collegial support and collaboration, as well as savoring good moments and joys of pediatric nursing, motivated nurses to stay.

Conclusions: Organizational constraints were the leading cause of morally distressing situations in the Nordic pediatric oncology care. To proceed from here, it is essential to ensure appropriate staffing and continuity of care. All staff members need to listen to children's voices, and there should be more opportunities to interdisciplinary discussions about children's best interests.

List of scientific papers

- I. Ventovaara P, af Sandeberg MA, Räsänen J, Pergert P. Ethical climate and moral distress in paediatric oncology nursing. *Nurs Ethics*. 2021;28(6):1061-72.
- II. Ventovaara P, af Sandeberg M, Petersen G, Blomgren K, Pergert P. A cross-sectional survey of moral distress and ethical climate - Situations in paediatric oncology care that involve children's voices. *Nurs Open*. 2022;9(4):2108-16.
- III. Ventovaara P, af Sandeberg M, Blomgren K, Pergert P. Juggling competing responsibilities: A grounded theory study of pediatric nurses' experiences. Submitted
- IV. Ventovaara P, af Sandeberg M, Blomgren K, Pergert P. Moral distress and ethical climate in pediatric oncology care impact healthcare professionals' intentions to leave. *Psychooncology*. 2023;32(7):1067-75.

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List of abbreviations

BIS	Best Interest Standard
ECQ	Ethical Climate Questionnaire
HECS-S	Hospital Ethical Climate Survey – shortened
MDD-HP	Measure of Moral Distress for Healthcare Professionals
MDS-R	Moral Distress Scale - revised
MDT	Moral Distress Theory
NOBOS	Nordic Society of Pediatric Oncology Nurses
NOPHO	The Nordic Society of Paediatric Haematology and Oncology

Introduction

Have you ever felt distressed about not being able to do your work as good as you would like to? Or maybe you have felt pressured to act against your own ethical values? In that case, you might have experienced an anguish feeling that is also called moral distress. Moral distress is triggered by a mismatch between one's ideals and actions. While it can occur at any workplace where ethical reasoning takes place, this thesis focuses on the experiences of healthcare professionals who care for children with cancer. The thesis will provide insight into morally distressing experiences through interviews with pediatric nurses, and by analyzing data from a Nordic survey study on healthcare professionals' perceptions of ethical climate and moral distress.

1 Literature review

Caring for children and adolescents with cancer is rewarding, but there are many challenges along the bumpy road. Time and again, healthcare professionals witness suffering, distress, and grief. While striving to provide best care to sick children and their families, healthcare professionals must resolve a wide range of ethical dilemmas that emerge. What to prioritize when all patients have urgent needs? Is concealing news about a poor prognosis against children's right to know? How much suffering is justified in a seemingly hopeless situation?

This literature review gives an overview of pediatric oncology care in the Nordic countries and some of its ethical challenges. Thereafter, it touches the surface of biomedical ethics, clarifies the concepts of moral distress and ethical climate by reviewing prior research, and lastly, explains the aims and objectives of this research project.

1.1 Pediatric oncology care in the Nordic countries

In the Nordic countries of Denmark, Finland, Iceland, Norway, and Sweden, each year approximately one thousand families hear the devastating news of a pediatric cancer diagnosis (1). Sometimes the disease manifests unexpectedly, for example as a random finding at x-rays after a bone injury, or as an abnormal blood count of a child with flu symptoms. Other times, the family has sought medical advice over a long time period before the indistinct symptoms are revealed to be caused by a life-threatening disease. These children suffer from leukemias, brain tumors, or other solid tumors originating from body organs such as bone tissues, retina, or kidneys (1). When a malignancy is suspected, the child is usually referred to a pediatric oncology center. Cancer treatments are given either at these specialized centers, or at clinics close to home that collaborate with the centers. Most treatment protocols include chemotherapy, that can be combined with radiation and/or surgery, depending on the diagnosis (2). Many cancer treatments cause side-effects such as nausea, pain, and neutropenic infections (2). Some severe complications can, at the uttermost, cause lifelong morbidity and even death (3). All in all, frequent clinic visits and periods of hospitalization are an inevitable part of children's cancer journeys.

Cancer during childhood is rare, and international exchange of knowledge and experience has been essential. An extensive cross-border collaboration has contributed to huge advances in treatment strategies and significantly improved supportive care. Currently, statistics testify of over 80% long-term survival in the Nordic countries (1).

1.2 Ethics in pediatric oncology care

1.2.1 Ethically challenging situations

In pediatric oncology care, complex medical decisions must be balanced with families' wishes and values, development of a growing child, chances of survival, comfort, and quality of life. Numerous obstacles challenge healthcare professionals' ethical behaviors when they strive to meet the intense needs of sick children. One common challenge is busyness, that leaves little time for emotional support (4). Some ethical problems emerge from children's lack of autonomy, which can manifest during medical procedures when physical restraint is used (5), or due to the surrogate decision-making, allowing parents to limit the truth-telling about a diagnosis or a poor prognosis (4, 6). Parents' desire to protect their child from an unpleasant truth often derives from cultural beliefs, that alongside with religious convictions sometimes cause struggles in communication and impact

children's care (6). With many actors involved, it is not uncommon with different views on children's best interests, and discrepancies on withdrawal of treatment can arise when cure is no longer granted (7, 8). According to Winter et al (9), an obligation to provide a non-beneficial treatment is the most common issue driving ethics consultations.

The clinical exposure to end-of-life care has become quite infrequent in acute hospital setting, as the care of dying children most often is provided at home or at a hospice. Inexperience increases the uncertainty about the right actions and contributes to distress among healthcare professionals, especially if they perceive that their lack of knowledge and skills reduces the quality of care (7). In addition to the uncertainty about right actions and moral conflicts about children's best interests, caring for terminally ill children involves personal grief, feelings of powerlessness (10), and witnessing suffering (11). Especially nurses are exposed to these challenges due to their forefront position during end-of-life care (10).

The medical and technological advances have brought along ethical challenges. Next-generation sequencing (12), participation in early phase trials (13), integrating research and care (14), and fertility preservation concerns (15) can all trigger novel ethical dilemmas.

1.2.2 Ethical principles and pediatric oncology care

How do the basic ethical principles apply in pediatric oncology care? The United Nations Convention on the Rights of the Child warrants children the right to be heard and to participate in matters that affect them (16), but the principle of *respect for autonomy* (17) hardly applies as such in pediatrics. Children's capacity for making own decisions develops as they grow and mature, and many decisions in pediatric oncology care are made by parents and healthcare professionals. The surrogate decision making on matters that concern non-autonomous children involves weighting benefits against risks and burdens, guided by the principles of *beneficence* (doing what's best for the child) and *non-maleficence* (not to harm). The Convention on the Rights of the Child (16) states that "*in all actions concerning children...the best interests of the child shall be a primary consideration*". The best interest standard (BIS) is an ethical principle that guides healthcare professionals in finding the most reasonable choices to protect and promote children's interests. This involves balancing different interests, rights and needs of multiple people: children's best interests are often intertwined with their parents' interests, and furthermore, children's needs must be also considered from a future perspective (18, 19).

Ethical principles are prima facie obligations that should be fulfilled unless they are overridden by conflicting norms. However, managing conflicting obligations can leave a moral trace. Overriding a prima facie obligation does not entail that it ceases to exist, nor does it guarantee that ethically best actions can be taken without a sting of conscience (17). The mismatch between ethical ideals and feasible actions can negatively impact healthcare professionals' well-being when it impairs the quality of care and trespasses one's ethical values. One of the negative consequences, moral distress, will be explained in the following chapter.

1.3 Moral distress

1.3.1 What is moral distress?

The term "moral distress" was first presented in 1984 by a philosopher Andrew Jameton. He described moral distress as a challenge that occurs when a nurse has a different opinion about a care matter than

those in charge (20), and, as cited by Corley (21), an anxiety that arises when the ethical conduct of a nurse is hindered by institutional constraints. However, Jameton (20) has pointed out that literature on moral distress can be traced back more than some one hundred years. At those times, the term “moral distress” had not been coined yet, and the moral problems faced by nurses were described in other words (20). According to Skretkowicz, as cited in Jameton (20), even Florence Nightingale had observed job-related distress and disagreements between nurses and physicians about patient care.

In 2002, dr. Mary Corley (21) proposed a Moral Distress Theory (MDT), based on an assumption that moral distress arises when (institutional) constraints interfere with nurses’ endeavors to advocate for and to meet the needs of their patients. The MDS explains how different moral concepts interrelate, and how they can culminate either in moral distress or in moral comfort, which Corley regards as the opposite of moral distress. The MDT suggests that moral commitment, moral sensitivity, moral autonomy, moral sense making, moral judgement, moral conflict, moral competency, and moral certainty all influence actions and psychological responses of a nurse. According to Corley, a committed, morally sensitive nurse who lacks moral courage or moral autonomy is more likely to experience moral distress. In addition to nurses’ psychological responses, the theory acknowledges the impact of work environment on moral distress (21).

As proposed in the MDT (21), morally distressing situations are judged subjectively. While the withdrawal of life supportive treatment can cause moral distress to one nurse, continuing the very same treatment might cause moral distress to another who perceives it as futile (22). The judgment does not have to be correct or to prove an existing ethical problem. Experiences of moral distress can signal of empathy, compassion (23), moral responsibility (24), and moral sensitivity (25, 26). Morally distressing experiences can even be beneficial, and stimulate discussions, decision-making, reflexivity, advocacy (23), and increase awareness of moral issues (27).

Various definitions of moral distress have emerged during the past decades, and some researchers have argued for a broader concept (28), an umbrella term, that would cover a range of experiences (29). The Moral distress model by Morley, Bradbury-Jones and Ivespowell (30), provides a broad definition that explains moral distress as a combination of a moral event (e.g. moral uncertainty, conflict, or dilemma), psychological distress (negative feelings such as powerlessness, anger or frustration), and the causal relationship between these two experiences. Despite the controversies about the explicit meaning emerging from the conceptual fuzziness, moral distress is often described as a distress arising from moral events when one is either unable to take the ethically correct action or feels pressured to act unethically (29).

1.3.2 Prior studies on moral distress

During the past two decades, the number of studies on moral distress has multiplied. Dimensions and root causes of moral distress have been explored by using focus groups, interviews, and surveys. The qualitative research, allowing in-depth exploration of lived experiences, has widened the understanding of the phenomenon, while quantitative methods have satisfied ambitions to explore moral distress in large groups of respondents (31). Much of the research has been carried out among nurses in adult healthcare settings (32). Although a variety of studies have confirmed the existence of moral distress, only publications with a primary focus on moral distress have been included in this literature review.

The most frequently used survey instrument so far has been the Moral Distress Scale (MDS) (33), that was originally created by Corley to assess moral distress among nurses (34). The MDS, the revised version of it (35), and other versions that have been directly derived from or inspired by the MDS, such as the MMD-HP (36), enable researchers to study moral distress and its' relationship with multiple variables in large samples. This is achieved by assessing frequencies and magnitudes of disturbances of clinical situations that healthcare professionals can experience as troublesome, for example unsafe staffing, ineffective communication, and disagreements on end-of-life care. In addition, there are some other instruments that have been used to assess moral distress among healthcare professionals, for example the Moral Distress Thermometer (37).

Although many have attempted to rewrite the definition of moral distress, the consensus on its causes and consequences has been much higher. A number of studies have linked moral distress with challenging situations anchored in end-of-life care and in futile care not in the best interest of a patient (38-41). Others have found that moral distress often is prompted by compromised care due to excessive documentation demands (42), lack of resources (43), unsafe staffing levels (44), and low nurse-to-patient ratios (45). Although moral distress usually arises when one is hindered from taking the right action, it can also occur when the right action is taken, but it conflicts with other obligations, such as legal issues (46). Healthcare professionals in adult care have usually reported higher levels of moral distress than their counterparts in pediatrics (40, 47).

The majority of studies in pediatric healthcare settings have focused on nurses working in pediatric and neonatal intensive care units. Healthcare professionals in high-tech, fast-pace intensive care units, experience ethical conflicts and moral distress when giving life-support to severely ill children and participating in resuscitation of newborns with uncertain outcomes (48, 49). Even in pediatrics, moral distress has been linked with end-of-life care and with initiation or continuation of care that is not in the best interest of a child (50-56). Compromises on patient safety or on the quality of care has been identified as common causes of moral distress in pediatrics, often caused by lack of time (57), poor communication (52, 56, 58, 59), unsafe staffing levels (53, 54, 58), lack of competence (54, 60), and uncertainty (49).

Many multi-ward studies have investigated experiences of moral distress in different pediatric care settings (40, 47, 56, 61-64), but the findings have been mostly presented without distinction between the wards, and the specific results from pediatric oncology care are difficult to extract. However, there are several studies that have investigated moral distress experiences exclusively in pediatric oncology care settings. One of them, an Italian survey study (65), found situations in end-of-life care as top causes of moral distress, while an interview study conducted in Canada (66) suggested that the discrepancy between nurses' moral identities and institutional constraints (e.g. inadequate staffing) generates moral distress. The Swedish study (67, 68), that set off the current doctoral project, assessed unsafe staffing levels, lack of time, and lack of continuity as top causes. One of the most distressing situations among Swedish pediatric oncology nurses involved poor communication within the team, a finding that is in line with Newman et al. (69) who proposed an association between reduced moral distress, prognosis-related communication and collaboration. The impact of decision-making and group dynamics on moral distress has been previously reported (70).

1.3.3 Consequences of moral distress

Regardless of the root causes, moral distress has a profound impact on caregivers. Unattended, it can lead to burnout (52, 71), intention to leave a clinical employment (38-40, 47, 72-76), decreased work

engagement (77) and even to diminished quality of patient care (73). Psychiatric nurses tackling with complex moral dilemmas have described feelings of guilt, inadequacy, and frustration (78). Jansen et al., (78) has implied that moral distress can cause emotional numbness, high blood pressure, and sleeping problems.

Prior findings have proposed an association between moral distress and the ethical climate at work (54, 79-82). The concept of ethical climate will be described in the following chapter.

1.4 Ethical climate

1.4.1 What is ethical climate?

Ethical climate is a moral atmosphere that affects employees' ethical behaviors. The interest in it was sparked by Victor and Cullen, who described ethical climate as: "*the shared perception of what is correct behavior and how ethical issues should be handled*" (83, pp. 51-2). While the significance of individual characteristics cannot be ignored, research has confirmed that organizational infrastructures and interpersonal influences from peers and leaders strongly impact our (un)ethical behavior, (84). For example, at a workplace with a negative ethical climate, where shortcuts and excuses are viewed as acceptable, the pressure from others can make it more difficult to carry out ethically right actions (85). A quick glance to the scenes behind Victor and Cullen's groundbreaking research may further clarify this connection.

Victor and Cullen were inspired by prior organizational climate research, and by Kohlberg's theory of Moral Development. According to Kohlberg, as Victor and Cullen wrote (83), an individual's sense of morality develops through different stages, progressing from 1) the egocentric thinking of a child who obeys for a fear of punishment and aims to satisfy his own needs, to 2) ensuring good relations with others and following the rules to maintain the social order, and lastly, to 3) an abstract ethical reasoning based on universal ethical principles such as equality and justice. The theory also suggests that most adults function at the second level, often seeking for external guidance when making ethical decisions. Taking this into consideration, Kohlberg's theory explains the impact of external influencers, such as colleagues, leaders, rules and codes, on employees' ethical behavior and decision-making (84).

Believing that ethical climates are, alike individuals, influenced by the predominant types of ethical reasoning, Victor and Cullen applied Kohlberg's theory into organizations. The different dimensions and types of ethical climates that they distinguished constructed the ethical climate typology, which became the theoretical base for the Ethical Climate Questionnaire (ECQ) (83), a survey instrument that has been widely used to study ethical climates in organizations.

Another instrument, the Hospital Ethical Climate Survey (HECS), was developed by dr. Linda Olson (86) to measure nurses' perceptions of ethical climate. Olson combined 1) her own expertise from healthcare, 2) prior ethical climate research from business and healthcare, 3) Brown's conditions for ethical reflection, and 4) Schneider's concept of types of organizational climates. Olson considered that nurses experience ethical climate through their "*perception of organizational conditions and practices having to do with the way difficult patientcare problems which have ethical implications are discussed and decided in their work setting*" (86, p. 348). Accordingly, the HECS items describe conditions that affect individuals' engagement in ethical reflections, practices on how ethical issues are solved, and nurses' relationships to peers, physicians, patients, management, and hospital.

Paralleling Brown's conditions for ethical reflection, that Olson cites (86), some items capture nurses' perceptions of feeling free to express their own opinions (power), to disagree with others (trust), to be included in the decision-making process as a stakeholder (inclusion), and to be encouraged to ask questions (inquiry).

1.4.2 Short summary of prior studies

Although ethical climate research was launched in business organizations, a number of other fields, including healthcare, joined in later on. Some researchers have applied qualitative approaches, while most nursing studies have been based on surveys, using either Victor and Cullen's Ethical Climate Questionnaire (ECQ) or Olson's Hospital Ethical Climate Survey (HECS), or one of the modified versions derived from them (87, 88).

Prior studies on antecedents and consequences of ethical climate have linked positive ethical climate with job satisfaction (89, 90), organizational commitment (91), moral courage (92), satisfaction with quality of care (93), teamwork (94), fewer medical errors (95), and a lower degree of turnover intentions (96). As described in the previous chapter, several studies have identified an inverse association between positive ethical climate and moral distress.

Several ethical climate studies have been conducted in Nordic healthcare (25, 97, 98). Some studies have described a validation of a translated version of the HECS (44, 99, 100), or a development of a novel instrument (101). An interview study by Silén et al (102) has proposed that collegial support, information, and teamwork can enhance ethical climate.

A few studies have explored ethical climate in pediatric healthcare (47, 54, 58, 81), and the research conducted in pediatric oncology care seems to be even more scarce. Bartholdson et al (103), who explored ethical climate perceptions at a pediatric hospital, found that only one-third of healthcare professionals perceived that they were always able to practice ethically good care. Another Swedish study (104), that also sparked the present doctoral project, found that physicians had more positive perceptions of ethical climate than nurses and nursing assistants did.

1.5 Rationale

Many challenges pressure nurses, nursing assistants, and physicians to transgress their own ethical values. When healthcare professionals are not able to follow their own moral compass, moral distress can occur. The existing research recognizes the negative impact of moral distress and the concept has been widely studied in critical care. However, less is known about its existence at pediatric oncology wards. Therefore, it should be evaluated how prior findings fit in the context of Nordic pediatric oncology care.

The studies in this thesis contribute to the growing area of research by identifying common morally distressing situations in Nordic pediatric oncology care, as well as through a deeper understanding of how nurses experience and handle obstacles that prevent them from providing the best possible patient care. Healthcare professionals' perceptions of ethical climate will be studied to assess its association with moral distress, and with intention to leave a clinical employment. It is hoped that this thesis generates new ideas on dealing with moral distress and on fostering an ethical climate. The findings could be used to build strategies to manage moral distress and to plan targeted interventions that support healthcare professionals' ethical conduct. The improvements can enhance the well-being of

healthcare professionals and reduce the staff turnover, that in turn could lead to improved continuity, help to maintain collective competency, and ultimately, improve the quality of care and patient safety.

2 Research aims

The overall aim was to explore ethical climate and moral distress in Nordic pediatric oncology care.

2.1 Specific aims

The specific aims of the four sub-studies are:

I. To translate the Swedish MDS-R and the Swedish HECS-S into Finnish, and to study pediatric oncology nurses' perceptions of ethical climate and experiences of moral distress, and to assess the relationship between them.

II. To study pediatric oncology nurses' perceptions of ethical climate and moral distress with a focus on situations that involve children's voices.

III. To study pediatric nurses' experiences of not being able to provide the best possible care, and to explore how they deal with these situations.

IV. To compare perceptions of ethical climate and moral distress between healthcare professionals, centers and countries, and to analyze whether these perceptions are associated with an intention to leave.

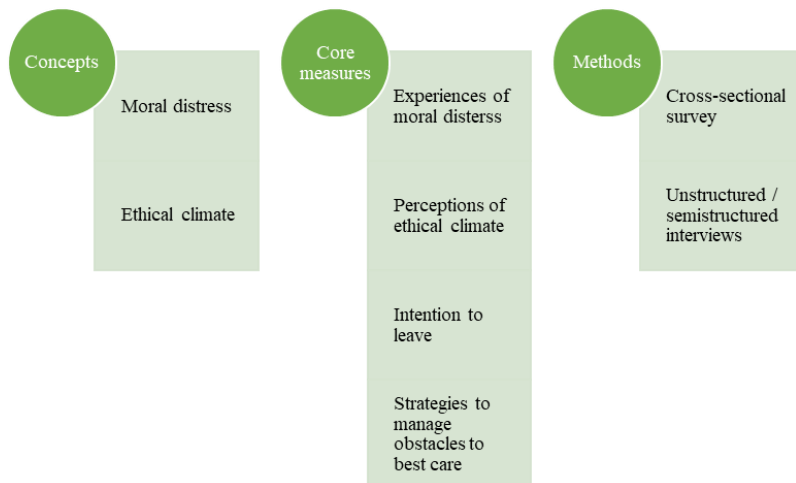


Figure 1. Overview of concepts, core measures and methods of the four studies

3 Materials and methods

3.1 Overview of research design and methods

Studies I, II and IV were quantitative, cross-sectional questionnaire studies, conducted at all pediatric oncology centers in Denmark, Finland, Iceland, Norway and Sweden. These studies were built on a single set of data collection at each center. The studies also involved translations and validations of the survey instruments.

Study III was a qualitative interview study using a classic grounded theory approach, with Swedish nurses who provide care for hospitalized, sick children.

The overall methods used in these four studies are summarized in Table 1.

Table 1. Methods of the four studies

	<i>Timeline</i>	<i>Participants and setting</i>	<i>Design</i>	<i>Outcome measure</i>	<i>Data analysis</i>
I	May 2019- Jan 2020	Pediatric oncology nurses (n=93) in Finland	Cross-sectional survey	Intensities and frequencies of morally distressing situations, ethical climate perceptions	Mann Whitney U, Spearman's correlation
II	Dec 2019- Mar 2020	Pediatric oncology nurses (n=66) in Denmark	Cross-sectional survey	Perceptions of ethical climate, experiences of moral distress, adherence to children's voices	Dichotomization
III	Sep 2021- April 2023	Pediatric nurses (n=25) in Sweden	Interview study	Strategies nurses use when unable to provide the best possible care	Grounded Theory
IV	Feb 2016- Sept 2022	Healthcare professionals (n=543) at Nordic pediatric oncology centers	Cross-sectional survey	Moral distress levels, ethical climate perceptions, intention-to-leave, differences between groups	Mann Whitney U, Kruskal-Wallis H, Spearman's correlation

3.2 Research setting and population

3.2.1 Cross-sectional studies (I, II and IV)

Studies I, II and IV were conducted in pediatric oncology care setting. Altogether, there are twenty specialized oncology centers in the Nordic countries of Denmark, Finland, Iceland, Norway and Sweden. Sweden, that has the largest population, has six centers, while Iceland, the most sparsely populated country, has one center. Study I was conducted at pediatric oncology centers in Finland and Study II in Denmark. Study IV was a multicenter study that includes all twenty Nordic pediatric oncology centers. All registered nurses, nursing assistants and physicians, who worked in direct patient care, were invited to participate.

3.2.2 Interview study (III)

Study III was conducted at a large University hospital in Sweden. Initially, pediatric oncology nurses were identified as suitable informants to provide information relevant to the study. By using a theoretical sampling, additional nurses were recruited from two other pediatric units.

3.3 Data collection

3.3.1 Cross-sectional studies (I, II and IV)

Data collection in Sweden had been performed in 2016-2017, when I had not yet come into the project. The other data collections were performed after the onset of the doctoral project, starting in Finland and Denmark in 2019, and followed by Iceland in 2021. Three Norwegian centers wished not to carry out data collections during the ongoing covid-19 pandemic, and thus, the last data collections in Norway were completed in September 2022, as illustrated in Figure 2. All data collections were performed by local study coordinators, such as research nurses, or nurses who were members of NOPHO/NOBOS Working Group in Ethics. Data were collected once at each study site, during a period of a few weeks to several months, and the study coordinators sent reminders during that time to improve response rates. Study I and Study II are built on the same data collections as Study IV.

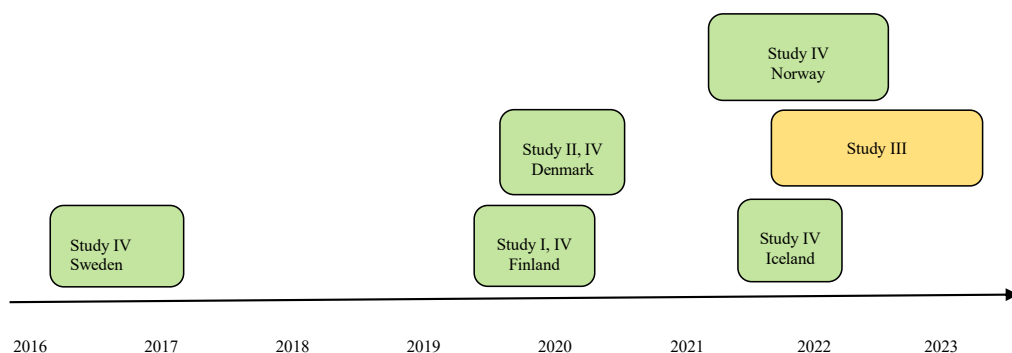


Figure 2. Timeline of data collections. Data collections in Norway were carried out in 2021 (at one study site) and 2022 (at three study sites).

In Sweden, Finland, and Iceland data were collected by using paper questionnaires while in Norway and Denmark, web-based surveys were used, in line with the preferences of the NOPHO/NOBOS Working Group in Ethics. The questionnaire included three instruments: The Swedish Hospital Ethical Climate Survey- shortened (HECS-S), The Swedish Moral Distress Scale –revised (MDS-R), and The Communication Over Language Barriers - questionnaire. The last instrument was not included in the doctoral project, and thus, only the Swedish HECS-S and the Swedish MDS-R will be described below.

3.3.1.1 Survey instruments

As already mentioned in the background section, both survey instruments had been originally developed at a turn of the millennium to assess nurses' perceptions of the ethical climate and experiences of moral distress. In the years to follow, both instruments have gained an excessive

popularity among researchers. Prior to the Swedish survey in 2016-2017, a shortened version of the HECS (HECS-S) and a revised version of the MDS (MDS-R) were translated and culturally adapted to the Swedish pediatric oncology context (67, 99, 105). The Swedish HECS-S consists of 21 items, and the Swedish MDS-R of 26 items (please see the appendix). During the doctoral project, the Swedish versions were translated into Finnish (Study I), Danish (Study II), Icelandic (Study IV) and Norwegian (Study IV). However, the Danish and Norwegian translations were based on non-validated, English back-translations of the Swedish instruments. The translation procedure will be explained in detail further down in this chapter.

The Swedish HECS-S items are rated according to how often respondents perceive them to be true (almost never = 1; almost always = 5). The higher scores indicate more positive perceptions of the ethical climate. At the time of the data collections, there were no nursing assistants at half of the centers, and therefore, the three items (4b, 9b, 15b) describing relations between nurses and nursing assistants were excluded from the analyses. By adding up the remaining 18 item scores, a so called HECS-S score, with a possible range of 18 to 90, is achieved.

The 26 items in the Swedish MDS-R are rated twice: firstly, how disturbing the respondent perceives the situation (not at all = 0; very disturbing = 4), and secondly, how often she/he has experienced the situation (never = 0; very often = 4). Higher scores indicate greater disturbance/frequency of moral distress. It should be mentioned that “disturbance” is quite commonly called “intensity”. When evaluating total moral distress caused by a certain situation, both disturbance and frequency are taken into account. The total moral distress is calculated by multiplying the scores (disturbance x frequency) and thus, it can range from 0 to 16. Thereafter, these products can be added up, resulting in a MDS-R score (with a possible range of 0 to 416). Respondents are also asked to describe in words other morally distressing situations they might have experienced. Two additional items linked to the MDS-R scale inquire respondents’ previous resignations, as well as their current intentions to leave their clinical position because of moral distress (35).

3.3.1.2 Translation process and validation of the instruments

Prior to the data collections, the Swedish HECS-S and the Swedish MDS-R were translated into the majority language of each country. While this paragraph describes the translation process from Swedish to Finnish, the procedures were roughly the same in all translations. The process followed a method described by Daniel, Miller and Wilbur (106), to ensure of the conceptual and content equivalence of the translations. According to the method, the survey instruments were first translated into Finnish: one translation was conducted by a professional translator, and another by me, who am a native Finnish speaker, fluent in Swedish, and familiar with the context of pediatric oncology. These two versions were then converged during a focus group discussion with three healthcare professionals, all native Finnish speakers. They were asked to discuss the two translations item-by-item, and to select which one they preferred. Thereafter, six individual, cognitive interviews, based on Think aloud technique (107), were conducted to test the validity. All interviewees were Finnish-speaking healthcare professionals: three nursing assistants, one registered nurse and two physicians. Three of them lived in Finland and the other three in Sweden. The healthcare professionals were asked to narrate their thoughts while they were reading through the survey instruments, in order to capture their interpretations of the items. The wording was revised several times during the course of time. Many tricky issues were solved during continuous discussions between me and my supervisors, who had previously coordinated the translation and adaptation of the instruments into Swedish. An existing

Finnish version of the original HECS (100) was also used as an inspiration, with a permission from its developer (email R Suhonen 19 Dec 2018).

3.3.2 Interview study (III)

Purposive sampling was used to recruit nurses who provide care for children with potentially life-threatening diseases. In September 2021, nurses at a large pediatric oncology center in Sweden were informed about the study at a nursing meeting. After the meeting, all nurses received written information by email, and they were asked to reply if they were willing to participate. Shortly afterwards, study invitations were also mailed to pediatric oncology nurses working at another pediatric oncology center, but none of them volunteered. The recruitment continued at the first center until the concurrent data analysis indicated a need to expand the study setting, and additional nurses were recruited from two other pediatric units.

3.3.2.1 In-depth interviews and focus group discussions

Data were collected by using two different methods: in-depth interviews and focus group discussions. To start with, interviews were unstructured as suggested by Glaser and Strauss (108). This allows participants to freely explore the subject from their perspectives. Participants were asked to describe situations when they had not been able to provide care that they believed should have been provided. An interview guide had been developed in case interviewees needed encouragement and guidance in describing their experiences, and probing questions were used to investigate topics that had emerged in preceding interviews. Interviews lasted between 15 and 90 minutes. All interviews were recorded, except for one individual interview, when only written notes were taken because the batteries to the digital voice recorder had been discharged. Data collection was completed in April 2023, as seen in Figure 2.

3.4 Data analysis

3.4.1 Cross-sectional studies (I, II and IV)

All statistical tests were run in IBM SPSS Statistics, and the data analysis included descriptive statistics and nonparametric tests. To start with, a missing value analysis was performed to identify responses with more than 10% unanswered items, in order to delete them from further analyses. Frequency distributions for categorical data were displayed as counts and percentages. Although both survey instruments produce ordinal level, Likert scale data, the commonly used praxis in the field has been to report means with standard deviations, and in order to allow comparisons with prior research, means with standard deviations were computed for the variables in Study I. To compare perceptions between study participants, a statistician at our department recommended to calculate participant mean values for all items and scales.

Initially, medians were reported in Study II, but these were replaced by mean values according to the peer-reviewers' recommendations based on the praxis in the field. Study II also involved dichotomization to simplify the presentation of the results (109). By dichotomizing, the five-point scales were divided into three groups: the middlemost value, and the values below and above it. Whilst the middle option was considered to be neutral, the scores above were interpreted as positive perceptions of ethical climate (i.e. the described situations were perceived to occur "often"), or as disturbing/frequent experiences of moral distress.

Thus, it was only in Study IV that distributions were described as medians and interquartile ranges.

In all studies, Spearman's rank-order correlation was used to evaluate associations between variables. Differences between groups were studied by testing null hypotheses with non-parametric tests by using Mann Whitney U test, or, in case of more than two variables, Kruskal-Wallis H test. P-values less than 0.05 were considered as statistically significant.

3.4.2 Interview study (III)

In accordance with classic grounded theory methodology, data analysis started right after the first interview and continued throughout the data collection period (108, 110, 111). All interviews were transcribed the same day they had been conducted. The transcribed interviews were then printed, so that the initial, line-by-line coding could be performed by hand in the margin next to the raw data (110). Then the initial codes were summarized, and labeled in gerund forms to emphasize action. Categories developed during constant comparison of codes, incidents, and written memos (informal analytic notes produced by me). Once the main concern of the participants had been identified, coding continued selectively by focusing on the recurring issues related to the core category (111). Inclusion of study participants ceased when coding no longer produced new insights, but the interpretation of data continued toward theory development by synthesizing and conceptualizing the categories.

3.5 Ethical considerations

3.5.1 Cross-sectional studies (I, II and IV)

3.5.1.1 Ethical review

Ethical review was not required in Denmark, according to the Act on Research Ethics Review of Health Research Projects (ML Nielsen, The Danish Council on Ethics and National Committee on Health Research Ethics, email conversation, February 1, 2018), in Sweden [advisory statement from the Swedish Ethical Review Authority 2015/1782-31/5], or in Norway. Neither was ethical review needed for a questionnaire study in Finland, according to the Finnish National Board of Research Integrity (email P Louhiala 28 Feb 2018), since it did not involve vulnerable populations or explore sensitive topics. However, after an initial contact with the head nurses at each Finnish pediatric oncology center, research permissions were applied. The applications were reviewed and the study was approved by all five hospitals (50H116, 62/2019, 110/2019, HUS/284/2019, T08/014/19). In Iceland, the study was approved by the Ethical Committee of Administrative Research at the National University Hospital of Iceland [11/2021].

3.5.1.2 Ethical conduct

Common ethical principles for research guided this project and ensured a good ethical practice. The healthcare professionals were informed about the study, and about the voluntary nature of the participation. A consent statement was included in online surveys, and at the centers where paper questionnaires were used, returning it was considered as a consent to participate. The following personnel data were collected: gender, profession, continued education, length of work experience in pediatrics, and workplace. Participants were assured of the confidentiality: that the questionnaires would be stored in a locked safe with no access for unauthorized persons, and the results would be reported in a way that does not allow identification of individual participants or pediatric oncology centers.

3.5.1.3 *Survey instruments*

Permission to use the survey instruments had been granted by the developers (email AB Hamric 6 Oct 2014; email L Olson 15 Nov 2014; email L Olson 29 May 2015).

3.5.2 **Interview study (III)**

3.5.2.1 *Ethical review*

Ethical approval was applied from the Swedish Ethical Review Authority, but the review was not required. However, the agency provided an advisory opinion (2021-02255). According to the advisory opinion, an external contact person was recruited, in case some of the participants would need professional support afterwards. The agency also advised against interviewing one's own colleagues. Since the enrolment was voluntary, we (unfortunately) disregarded this recommendation.

3.5.2.2 *Ethical conduct*

To avoid coercion during recruitment, I never approached my colleagues in person about the study, but only used emails to send invitations and reminders. Participants signed a written consent after receiving study information, and they were informed about their right to withdraw at any moment without any explanation. The signed consents are stored in a locked safe with no access for unauthorized persons. All interviews were anonymized during the transcription process, including the names of the patients and the coworkers. Other potentially identifiable characteristics, such as patients' diagnoses, have been concealed when reporting the results.

4 Results

This chapter summarizes the key findings. For a more detailed presentation, please see the full-text articles at the end of this thesis.

4.1 Study I

4.1.1 The questionnaire

The validity of the Finnish translation was tested by conducting six Think Aloud interviews as earlier described. To test the reliability of the instruments, a Cronbach's alpha value was calculated for each scale. All alpha values exceeded 0.8, suggesting a good internal consistency.

4.1.2 Participants

Altogether, 96 nurses out of 169 (57%) returned the questionnaire. Three respondents did not meet the inclusion criteria, as these nurses did not work in direct patient care. During the data analysis, a few respondents were excluded due to more than 10% unanswered items: one from the ethical climate study, and six respondents from the moral distress study.

4.1.3 Key findings

The mean value for overall ethical climate perceptions among nurses was 4 (SD 0.4) on a scale of 1 to 5. Nurses assesses their coworkers as highly competent (mean 4.8; SD 0.4). Nurses found the morally distressing situations described in the Swedish MDS-R as very disturbing with a mean value of 3.1 (SD 0.5) on a scale of 0 to 4, but many situations happened only occasionally (mean frequency 1.1; SD 0.4). The most frequent situation was *“perform painful/unpleasant procedures on school-aged children who resist such treatment”* (mean 2.5; SD 1.0), followed by situations that involved compromised care due to lack of time (mean 2.0; SD 1.1), cost reductions (mean 1.9; SD 1.1), and unsafe staffing (mean 1.8; SD 1.1). Although most frequent, performing procedures was the second least disturbing situation (2.6; SD 1), after *“giving an increased dose of sedatives/opiates to a child, despite that you believe it could hasten the child's death”* (2.4; SD 1.1). A negative correlation between ethical climate and moral distress ($r = -.435$, $n = 86$, $p < .001$) suggested less frequent experiences of morally distressing situations at the centers with more positive ethical climate.

4.2 Study II

4.2.1 Participants

Altogether, 66 nurses (66/137; 48%) completed the survey. One participant was excluded from the moral distress study due to more than 10% unanswered items.

4.2.2 Key findings

According to the nurses' perceptions, healthcare professionals were slightly more attentive to parents' than to children's wishes. Most nurses (83%) assessed the item *“perform painful/unpleasant procedures on school-aged children who resist such treatment”* as disturbing, and every fifth (14/65; 22%) nurse was often involved in such a situation. Almost every nurse (62/65; 95%) found *“follow family's request not to talk about death with a dying child who asks about dying”* as disturbing and six nurses (9%) reported that they often experienced it. The frequencies of these two situations correlated

(albeit weakly) with “*having no time to conduct conversations with patients and families in a way you think they should be carried out*”. Almost half of the nurses (28/65; 43%) often struggled with too little time for conversations. One nurse out of four (15/65; 23%) often worked with other nurses whom they perceived not qualified enough for a patient’s care. An inverse correlation was found between ethical climate and the frequencies of morally distressing situations ($r = -0.523$, $n = 65$, $p < .001$).

4.3 Study III

4.3.1 Participants

Thirteen pediatric oncology nurses were interviewed onsite at the pediatric oncology center, and twelve nurses from two other pediatric medical units participated in one of the three focus group discussions. Participants had practiced nursing for 14 years in average (median 13; range 1-34).

4.3.2 Key findings

Nurses’ main concern was to fulfill their responsibilities as a nurse in order to provide best possible care that would meet the comprehensive needs of sick children and their families. Nurses often struggled with lack of time and high workloads, but even different views on children’s best interests caused concern. The theory that emerged was *juggling competing responsibilities*. It explains how nurses handle situations when simultaneous obligations challenge their endeavors to provide best possible care. Oftentimes, the strategies that nurses used when juggling competing responsibilities involved *prioritizing, adapting to the situation, collegial backing, and/or savoring*. (Figure 3).

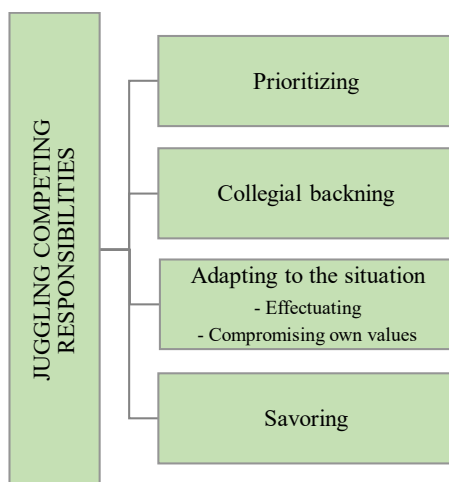


Figure 3. A model illustrating the theory of Juggling competing responsibilities.

Nurses described several kinds of situations when they had not been able to meet the needs of sick children and their families. Usually these situations were caused by time constraints, different views on children’s best interests, or by poor communication/collaboration within the care team or with the families. Several nurses expressed concerns about patient safety. They worried about keeping unstable children at a ward with inadequate resources, and about missing important details during busy work shifts.

Lack of time often hindered nurses from providing the comprehensive care they perceived they should provide. *Prioritizing* was not easy in situations when several nursing tasks needed to be taken care of at the same time point. Even when nurses managed to meet the physical needs of their young patients, they felt frustration over not having time for emotional support, such as comforting an upset parent or having time for a proper conversation. Priorities were reevaluated when caring for dying children: nurses felt compassion for the families who were about to lose their child, and tried to prioritize end-of-life care. Sometimes it resulted in compromised care quality or jeopardized patient safety for their other patients, which caused feelings of inadequacy and guilt.

Nurses regarded other nurses as their best support, and used *collegial backing* when juggling competing responsibilities. They assisted one another with clinical tasks, exchanged advice, or talked through distressing events. Nurses also needed backing from physicians to resolve challenging situations with parents, such as disagreements about which care action was in a child's best interest. During busy work shifts nurses *adapted to the situation* by *effectuating*, which often meant working faster. Overall, nurses were more concerned about compromised care and failing to uphold children's best interests than about the busyness per se.

Nurses *compromised their own values* when they had to implement decisions that they disagreed with, especially if the intervention caused unnecessary suffering to a child. Nurses questioned the limited truth-telling, because in their opinion, it conflicted with children's rights to know. While all nurses reluctantly accepted it, the ones with longer work experience were more likely to question other decisions that they perceived might harm the child, for example unnecessary procedures.

Savoring was one of the strategies nurses used when juggling with competing responsibilities. Despite the struggles and the stress, nurses found their work as meaningful and rewarding. Seeing children return to health boosted nurses with energy and motivated them to continue with pediatric nursing.

4.4 Study IV

4.4.1 Participants

Out of 970 administered questionnaires, 567 (58 %) were returned, and 543 participants (56 %) fulfilled the inclusion criteria. The details can be seen in Table 2.

Table 2. Total number of invited and included participants from each country.

Country	Centers	Invited HCPs	Returned questionnaires	Included
Sweden	6	312	281	267
Finland	5	210	110	105
Denmark	4	165	77	77
Norway	4	230	72	70
Iceland	1	53*	27	24
Total	20	970*	567	543

*estimated number of invited healthcare professionals (HCPs)

The majority of healthcare professionals were nurses (Figure 4). Almost all nursing assistants (62/68; 91%) worked in Sweden. There were some nursing assistants in Iceland, but none at the Danish or Norwegian centers at the time of the survey. In Finland, there were only few nursing assistants at three of the centers.

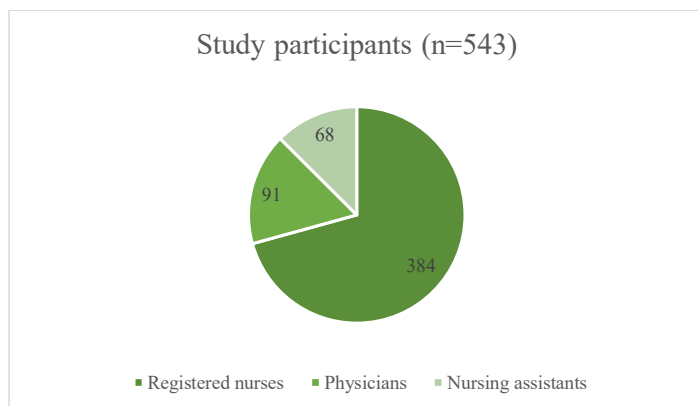


Figure 4. Participants in the Nordic survey per profession.

Most participants had worked in pediatric healthcare for 5 years or longer (374/543; 69%). This was especially true among physicians: 95% (86/91) of them had at least five years of experience in pediatrics. Almost all physicians (83/91; 91%) had continued education while the prevalence in general was 54% (292/543). Most participants were females (474/543; 87%). However, the proportion of females among physicians alone was much lower (48/91; 53%).

4.4.2 Key findings

According to the healthcare professionals' perceptions, and physicians' in particular, ethical climates at the Nordic pediatric oncology centers were positive. The median HECS-S score was 72 (IQR 65-78) on a scale of 18 to 90. Median scores varied between centers from 65 to 79. The differences between centers were statistically significant ($H(18) = 83,593, p < .001$).

Items describing relations to co-workers and patients attained highest scores. Only every third healthcare professional (157/510; 31%) perceived that they could "almost always" practice care the way they believed it should be practiced. However, this perception varied widely between centers: at one of the centers, none of the respondents felt able to do that.

The MDS-R scores were low, with an overall median of 85 (IQR 62-115), on a scale of 0 to 416. Median MDS-R scores varied between centers from 57 to 120 ($H(19) = 45,252, p < .001$). Figure 5 illustrates variations between groups. As seen in the figure, nursing assistants reported lowest levels of moral distress in this study. Differences between females and males resulted from higher disturbance levels among women.

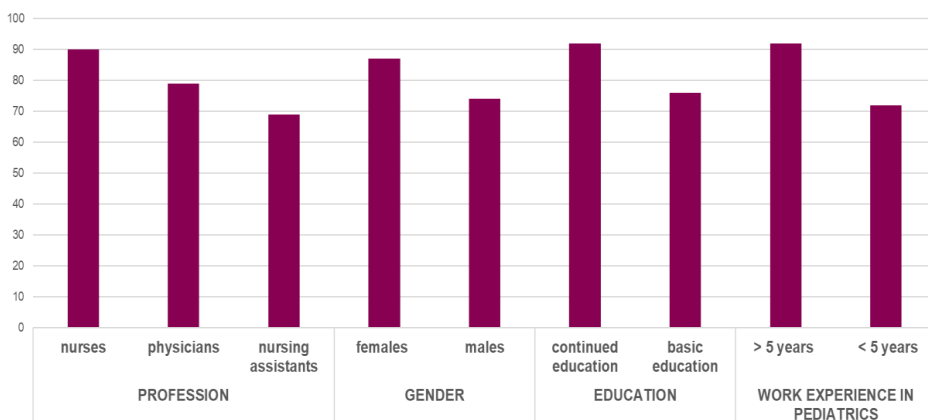


Figure 5. The median MDS-R scores (n=520) for each group. The possible range for the MDS-R score is 0 to 416.

Out of the 26 situations that were described in the Swedish MDS, those involving lack of continuity and lack of time were top-ranked among nurses and physicians (Table 3). Unsafe staffing levels and performing painful procedures caused moral distress especially among nurses.

Table 3. The three top situations causing moral distress (range 0-16).

Item	All	RN	MD	NA
	Median (Q1-Q3)	Median (Q1-Q3)	Median (Q1-Q3)	Median (Q1-Q3)
See ... care suffers because of lack of continuity...different healthcare providers	6 (3-8)	6 (3-8)	6 (4-8)	4 (2-8)
Work in a staffing situation... that you experience as unsafe	6 (4-9)	7 (4-12)	4 (3-8)	4 (3-8)
Not having time to conduct conversations with patients...in a way you think they should be carried out	6 (3-9)	6 (3-9)	6 (3-8)	4 (3-8)

RN=registered nurse (n=369), MD = physician (n=89), NA = nursing assistant (n=62). Q1 = the first quartile, Q3 = the third quartile

A negative correlation was found between the HECS-S scores and the MDS-R scores ($r_s(488) = -.409, p < .001$). Lower HECS-S scores and higher MDS-R scores were associated with an intention to leave. As seen in Figure 6, the median for the item *“I am able to practice care on my unit as I believe it should be practiced”* was 4 in both groups, but the ones who reported intentions to leave perceived in a lower degree that they were able do that.

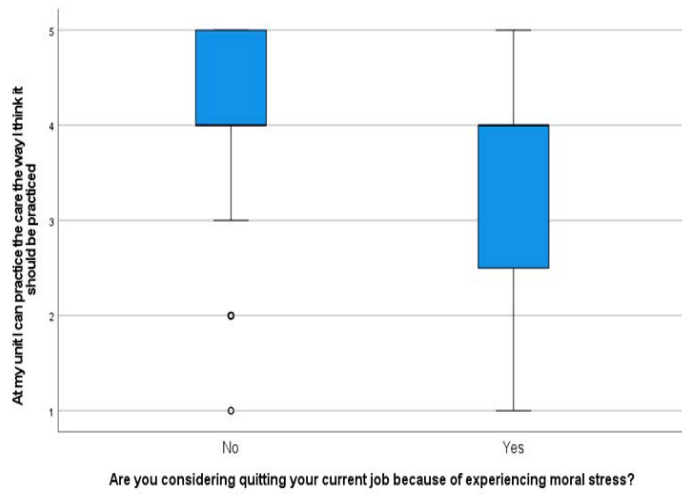


Figure 6. Overall patterns of intent-to-leave (yes/no) and its association with perceptions of how often one is able to practice care as it should be (possible range 1-5; a score 5 equals “almost always true”). N=508.

5 Discussion

5.1 Main findings

This thesis aimed to explore moral distress and ethical climate in Nordic pediatric oncology care. A cross-sectional survey study was conducted at twenty pediatric oncology centers to study the topics, and thereafter, twenty-five pediatric nurses were interviewed about their experiences of not being able to provide best possible care.

While perceptions of ethical climate were positive in general, only one third of healthcare professionals felt that they almost always could practice care the way they thought it should be practiced. The findings show that moral distress most often stemmed from organizational shortcomings such as unsafe staffing, lack of time and poor continuity of care that diminished the care quality. Other than that, morally distressing situations occurred quite rarely.

5.1.1 Mismatch between the ideals of high-quality care and the actual actions

The findings showed that the most common root causes to morally distressing situations were unsafe staffing, lack of time, and poor continuity of care (Study II, IV). In line with the Moral Distress Theory (21), that holds organizational policies and procedures responsible for hindering nurses from meeting the needs of patients and patients' families, unsafe staffing levels have been linked with moral distress in previous studies (44). Caring for more patients than one can safely care for is morally distressing (112), and intensive care nurses caring for fewer patients have indeed reported less moral distress (45). The findings support the idea that combating moral distress requires system-level actions (113).

The findings demonstrate that safe staffing levels are not only about the number of staff members, but also about matching patient needs and staff competencies. In contrast to the ethical climate survey that implied competent coworkers, the moral distress survey (Study II) revealed that almost one nurse out of four often worked with colleagues that lacked necessary skills. The interview study (Study III) confirmed that both others' and one's own lack of skills added stress, for example when sick children at crowded hospitals were placed at wards where nurses were not trained to meet their specific needs. Article 3 in United Nation Convention on the Rights of the Child (16) stresses children's rights to be taken care for by qualified healthcare providers, but unfortunately, its realization seems to fall short at times.

Witnessing the quality of care to suffer because of lack of continuity with many different healthcare professionals was among top causes of moral distress at many centers (Study IV). Similar findings have been previously reported (112). Although poor continuity of care was common at many centers, there were several centers that probably had achieved continuity of care. Achieving continuity of care is not only about preventing moral distress, but the ultimate goal of continuity should be the welfare of sick children. The European Association for Children in Hospital (EACH) endorses continuity of care and advocates for "*a limited and defined number of persons working together as a group...*" (114, p. 23). Similarly, Duffy, Baldwin and Mastorovich (115) argue for limiting the number of healthcare professionals that a patient encounters, and for establishing a core group who gets to know patient's individual needs and preferences. This resonates with parents' thoughts on continuity ("knowing my child") as a prerequisite for individualized care (116). Continuity of care is a cornerstone of trustful relationships between patients and healthcare professionals. According to Darcy et al (117) continuity

allows children with cancer and healthcare professionals to get to know each other, and makes children feel more safe and secure. Even parents trust more and feel more comfortable with healthcare professionals whom they meet often (118).

Situations related to end-of-life care were perceived as highly disturbing, but contrary to many prior studies they were not among the most frequent causes of moral distress (Study I, II). This conclusion holds true at least when moral distress is assessed by using the Swedish MDS-R. The instrument describes several situations that many healthcare professionals had never, or only rarely, experienced (Study IV). A possible explanation to the rarity of the situations could be the limited exposure to end-of-life care in general, resulting from high survival rates in high-income countries (119), and from an increased availability of home and hospice care for dying children.

The interview study, however, revealed experiences of moral distress anchored in end-of-life care: protraction of breaking bad news, unnecessary interventions, not being able to alleviate the suffering, and parents who conceal the truth about the imminent death. These findings suggest that although rare, morally distressing situations in end-of-life care can have a long-lasting impact on healthcare professionals. Nurses strove to “get it right” when providing end-of-life care, also described by Pearson (7) and Taylor and Aldridge (120), and some nurses devotedly prioritized the care of dying children over their other patients (Study III). Dying children and their families should get whatever support and care they need (114), but as long as nurses struggle with organizational constraints they fulfill this standard at the cost of care quality and safety of other patients. As reported by Suhonen et al (121), prioritizing can also cause moral distress.

5.1.1.1 Females and nurses reported the highest levels of moral distress

In general, nurses reported higher levels of moral distress than other professions (Study IV). Prior research (52) has proposed nurses’ place in a hierarchy as one reason, and interestingly, studies among physicians (59) and residents (60) have identified a similar pattern. Another common explanation has been that nurses spent much time at bed-side, building long-term relationships with the families (122). However, if these two explanations were the only truth, it should have been the nursing assistants who reported the highest levels of moral distress, since they also work in direct care, and get orders from both physicians and nurses. Surprisingly, they reported the lowest levels of all (Study IV).

The complexity of moral distress allows several possible explanations to this difference, and a third plausible explanation is that each profession has different care responsibilities. Consequently, it affects how often they experience the situations described in the MDS-R. The original MDS (34) was developed to measure nurses’ experiences, which naturally influenced the construction of the items. It is no surprise that nurses reported most frequent experiences of performing painful and unpleasant procedures against school-aged children’s wishes - one of the situations described in the Swedish MDS-R (67) - because most of the procedures, such as inserting nasogastric tubes, peripheral vein catheters, and central vein accesses, are usually carried out by nurses.

To get around the problem, prior research (123) has suggested that moral distress should be studied separately among physicians, because their experiences extend beyond the ideas of moral distress in nursing studies. Rodriguez-Ruiz et al (112) found higher moral distress levels among physicians by using the Measure of Moral Distress for Healthcare Professionals (MDD-HP), and argues that it better captures moral distress related to system-level factors that often cause moral distress among physicians, rather than the patient-level factors that nurses witness at bed-side. Although present

findings show that system-level factors cause moral distress among nurses as well, it still holds true that the question you ask determines the answer you get. It is possible that The Swedish MDS-R mainly captured situations experienced by nurses, which is a possible weakness of this study.

Study IV also revealed higher levels of moral distress among women. Interestingly, this was due to the perceived disturbances of the situations: men experienced morally distressing situations just as often (or seldom) as women did, but they tended to find them less disturbing. According to the Moral distress theory (21), several moral components affect how moral distress is experienced. One of the components is moral sensitivity, that is, a person's ability to recognize moral dilemmas and the vulnerability of the patients. A meta-analysis by You, Maeda and Bebeau (124) indicates that women show higher levels of moral sensitivity. Compared to men, women tend to suffer more often of bad conscience and not having time to do enough for the patients, according to Lütznén et al (25). However, the role of moral sensitivity in gender differences and its association with moral distress should be studied in more detail before drawing any conclusions.

5.1.1.2 Not being able to provide best possible care

All in all, moral distress emerged as a consequence when healthcare professionals were hindered from realizing ethically ideal actions. This happened, for example, when nurses compromised their own values by (reluctantly) accepting limited truth-telling, or when parents did not allow nurses to give pain medication to a child in pain. Oftentimes there was no distinct ethical dilemma that preceded moral distress, but the ideal action was about providing high-quality care for the patients. This accords with Corley (21), who considered nursing as a moral endeavor, and implied that nurses suffer moral distress when they cannot provide what is best for the patient. Quality of care was indeed a recurring theme in all four studies. The moral distress survey suggested that moral distress could occur when quality of care was reduced by constraints, such as poor continuity or poor communication. The ethical climate survey showed that only one healthcare professional out of three could most often practice care in the right way, and lastly, many nurses in the interview study were concerned about compromised care quality.

Up to date, there is no consensus about the definition of quality of care (125). Stravopoulou et al (126) describes it with attributes such as holistic care, best patient outcomes, and meeting patients' needs, which accords quite well with the nurses' intentions in Study III, whose main concern was "to fulfill their responsibilities as a nurse in order to provide best possible care that would meet the needs of sick children and their families". The present findings allude that ethical climate, moral distress, and quality of care all interrelate with the others. Even previous studies have linked ethical climate and moral distress with quality of care (73, 127).

5.1.1.3 Distress or moral distress?

It should be questioned whether the mismatch between ideals and actions always mirror moral distress. Moral distress is a theoretical term and seldom used in clinical care (128), and thus, it can easily be confused with related phenomena such as distress arising from tragedy or medical uncertainty (23). For example, restraining a patient can be distressing, but it becomes morally distressing only when it is considered to be wrong (24). Many nurses assessed performing painful procedures against school-aged children's wishes as both disturbing and frequent (Study II), but the interviews, on the contrary, suggested that nurses found procedures as morally distressing only when they considered them as unnecessary (Study III). Similarly, the difference between work-related stress

and moral distress is that work-related stress can occur due to long work hours, but moral distress occurs only when working long hours is feared to have a negative impact on patient care (129). Taken this into account, it is uncertain whether the high scores for unsafe staffing levels result from moral distress alone, or if the assessments have been influenced by work-related stress without a moral component. However, the interviews suggest that inadequate staffing and busyness led to consequences that nurses perceived as morally distressing, such as not having time to sit down and comfort a sad parent (Study III).

5.1.2 The relationship between ethical climate and moral distress

The majority of healthcare professionals perceived ethical climate as positive (Study IV). The findings also confirmed a negative correlation between moral distress and ethical climate: moral distress levels were lower at the centers with the most positive ethical climates, and vice versa (Study I, II and IV). While descriptive research cannot explain the causality, it can help to gain a deeper understanding of the correlation. Healthcare professionals do not work in isolation, but they need others to discuss with, to get support, and to manage simultaneous tasks. Relationships at work were also recognized by Olson (86), who formulated and categorized the HECS items according to nurses' relations to peers, physicians, patients, managers, and hospital. In the following, some of these relationships will be discussed to clarify their connection with moral distress.

5.1.2.1 Relations to coworkers

Healthcare professionals at the Nordic pediatric oncology centers highly valued their coworkers, and according to the ethical climate study, their professional relationships were characterized by trust, respect, support and competence (Study I, II and IV). The interviews revealed that nurses often found their best support in other nurses, but they also wanted to discuss patient care matters with physicians, not only to voice their views, but also to increase their understanding about reasons behind medical decisions, which sometimes could even alleviate moral distress (Study III). These findings reflect prior research that have shown that healthcare professionals assess collegial support (63) and open communication (60) as helpful in reducing moral distress. The present findings also revealed that the opposite, poor communication and working with unsupportive or unqualified coworkers, added moral distress (Study II, III), all the while these situations - luckily - only occurred rarely (Study I). Taken together, communication, competence, and collaboration are crucial in pediatric care, and furthermore, they also influence quality of care (130).

5.1.2.2 Relations to patients

Sometimes nurses had trouble cultivating relationships with the families; for example, when pulled in different directions they simply did not have time to chat at bed-side (Study III). The results confirm prior findings that have identified busyness as one of the major challenges in pediatric nursing, not allowing enough time to support the families (4). Despite of having insufficient with time for conversations with the families (Study I - IV), healthcare professionals most often considered children's, and especially parents', viewpoints (Study I - IV). Balancing children's voices with parents' opinions was a delicate art and, according to the Swedish nurses (Study III), it too often favored the parents. To some extent this finding reflects "parent-oriented nursing care", described by Mattson et al (131), that focuses on parents' needs, and treats children as a part of their parents rather than their own persons. While it may not be a conscious choice to place the child on the periphery, sick children should be given opportunities to express their interests, by actively seeking and

acknowledging their views on care (132). A child-centered care approach strengthens child's perspective and focuses on children's needs in all situations (133). Parents are the most important people in the lives of their children, and according to the best interest standard, the bond between children and parents must be weighted in when identifying children's various interests, but even so, our commitment should first and foremost be to the child (19). Should children's best interests be at risk, ethical discussions ought to be carried out even on a short notice.

5.1.2.3 Relations to managers

No clear patterns concerning the items that describe relations to managers were identified in the ethical climate survey, and consequently, none of the papers further discusses it. During the interviews, only few nurses mentioned their immediate managers, which can partly result from head nurses' focus on administration over clinical work. The impact of leadership is an important issue for future studies. After all, prior research has identified an association between ethical leadership and positive ethical climate (134, 135), and several other studies have argued for the importance of managers in enhancing the ethical climate (88). This corroborates with Olson's (136) approach, that emphasizes the key role of leaders in creating ethical nursing standards.

5.2 Methodological considerations

Hamric (31) has recommended mixed-methods, multi-center studies utilizing validated instruments for future research on moral distress. The present thesis follows this recommendation, but some caution must be applied. While the survey study was conducted at twenty centers, all participants were recruited from pediatric oncology care (except for a handful of nurses in Study III). Because the discussion section combines findings from all four studies, it is important to bear in mind that the interviews represent experiences of Swedish nurses alone, who all worked at the same hospital. Therefore, my interpretations and conclusions cannot be extrapolated to other healthcare settings without caution.

5.2.1 Cross-sectional studies (I, II and IV)

5.2.1.1 Study design and data collection

All three studies were cross-sectional surveys studies where a questionnaire was used to gather information. Cross-sectional, correlational studies cannot explain causality, but the descriptive research rather observes and describes the areas of interests (137). The consensus of opinion among our research group was to abstain from parametric tests when analyzing ordinal level data, a controversy decision that indeed finds support in literature (138).

The long data collection period of seven years must be considered when discussing potential weaknesses. The last three centers completed the survey in 2022, after the Covid-19 pandemic. Covid-19 strained healthcare systems worldwide, especially during 2020-2021, causing exhaustion among healthcare professionals. This could have influenced the experiences and perceptions of our respondents, but the results do not suggest that. Apparently, the Swedish MDS-R did not capture the novel ethical issues in pediatric oncology care during the pandemic, such as repeated Covid-19 nasopharyngeal swabs and visitation restrictions (139).

5.2.1.2 *Instruments and validation*

Both instruments were well-established tools that have been tested and validated in numerous international studies. As described in the methods section, the face validity of the translated survey instruments was tested during the translation process, and the reliability was confirmed by Cronbach's alpha values greater than 0,7 for each scale.

Despite the widespread popularity of the MDS, the instrument has not escaped criticism. Some critics have argued that the MDS overestimates moral distress by measuring even distress that is not of moral character (140). On the other hand, rare situations that are highly disturbing, risk getting insufficient attention because they cannot, arithmetically, produce high scores when assessed by the MDS-R. Even if a healthcare professional has only once experienced a situation that has generated such high levels of moral distress that it had led to burnout, sick leave or even resigning, this single incident passes quite unnoticed in a quantitative study. It could be said that despite the extensiveness of survey studies, they tend to be superficial as they do not dig deep into feelings and experiences (137). To fill this gap, a qualitative interview study was conducted.

5.2.1.3 *Generalizability*

The greatest advantage of conducting a survey study is that one can approach large populations. All cross-sectional studies were multicenter studies, and one of the studies (Study IV) is based on data from five different countries, which additionally increases the generalizability of the results. Unfortunately, many healthcare professionals chose not to participate, and the low response rates at some of the centers are potential sources of bias, because there can be differences between those who participated and those who did not. A nonresponse analysis was not carried out because we lacked personal information about the respondents. A review by Suhonen et al (141) found an average response rate of 54% based on 23 ethical climate studies. This percentage equals quite well with the present survey. Nonresponse has probably been due to characteristics of research design and to characteristics of non-respondents. Some respondents had actually commented in the end of the questionnaire, that it had been too time-consuming to complete (as described in the methods section, the questionnaire included three instruments) and that the questions were too many and/or too complicated. Other possible reasons for nonresponse could be lack of time, negative perceptions of ethical climate, over-researched staff (141), and possibly, lack of interest.

5.2.2 **Interview study (III)**

5.2.2.1 *The pursuit of quality*

A diversity of criteria for evaluating quality in grounded theory research has emerged along with different versions of the method (142) and the evolution of terminology (143). Initially, Glaser and Strauss (108) focused on credibility, and they also believed that a theory that was grounded on data would fit, be general enough and understandable, and proposed four requisite properties: fitness, understanding, generality, and control. However, qualitative research in general can be evaluated by its trustworthiness (137), which usually is described in terms of credibility, transferability, dependability, and confirmability (137, 144). Prolonged engagement (both my own and my supervisors long experience in pediatric oncology care), persistent observations (rereading the data and constant comparisons during the analysis) and triangulation (methodological triangulation, analyst triangulation and triangulation of sources) were used to assure of credibility. Methodological triangulation involved different data collection methods: in-depth interviews and focus group

discussions. Analyst triangulation was applied throughout the process: two of my supervisors were involved in the data interpretation, and they also attended the focus group interviews. Unfortunately, none of the nurses from the other pediatric oncology unit chose to participate, and triangulation of sources was first applied when the theoretical sampling took place and additional interviewees were recruited from two other units. The research process and the participants has been thoroughly described in attempt to achieve transferability. The aspects of dependability and confirmability were enhanced by involving others to assure objectivity: that the findings would mirror participants' words rather than mine. In addition to my supervisors' involvement, some data extracts were discussed at a journal club meeting. All steps of the research process have been documented in an electronic platform for research documentation at Karolinska Institutet.

Korstjens and Moser (144) regard reflexivity as an essential part in assuring the quality of qualitative research. Although the expression "grounded theory" refers to a theory that is grounded on data, several factors inevitably risk influencing a qualitative data synthesis. Since half of the interviewees were my colleagues, I recognized many patients, staff members and situations that nurses described, which challenged my objectivity. I did my best to repress any subjective interpretations and assumed understandings during the data analysis, but the interaction between me and the informants was inevitable. Presumably, interviews have been influenced by over-disclosure, power disparities in relationships, or other adversities linked with studies using insider interviewers (145). Kathy Charmaz, who has developed the constructivist grounded theory method, suggests that grounded theory always is co-constructed (146). My own experience suggests giving careful consideration before interviewing one's own colleagues on topics that are of sensitive nature or that could be perceived as such.

Study III explored exclusively experiences of pediatric nurses, all from the same hospital in Sweden. By interviewing nursing assistants and physicians, we could have enriched our understanding of the differences between professions, that we later identified in Study IV. It is important to bear in mind that the results should be interpreted with caution, as they may not be generalizable to all healthcare professionals, Nordic countries, or even to other Swedish hospitals.

6 Conclusions

Moral distress in Nordic pediatric oncology care typically arises from reduced care quality, that results from constraints such as inadequate staffing levels, lack of time, and poor continuity of care. The interviews suggest that it is not the busyness per se that is perceived as most worrisome, but rather its consequences: compromised care and failing to uphold children's best interests.

A dialogue on ethical issues and supportive coworkers are integral components of ethical climate. In general, morally distressing situations seem to occur less frequently at the centers with a positive ethical climate. The results also imply that healthcare professionals working in a positive ethical climate are more likely to feel able to provide good care, and that fewer of them consider leaving because of morally distressing experiences.

Although morally distressing situations related to end-of-life care occur only rarely, such experiences should not be dismissed as unimportant. The results show that compromises on care quality and on moral values are highly disturbing when caring for dying children; there may not be another chance to ameliorate the suffering.

The contribution of this thesis has been to confirm root causes of moral distress, and to deepen our understanding of the importance of being able to provide quality care for children with potentially life-threatening diseases. The results suggest ensuring adequate staffing levels and continuity of care. Interdisciplinary communication and opportunities to discuss different views on children's best interests also are important means in alleviating moral distress and ensuring best care actions.

7 Points of perspective

7.1 Suggestions for further research

This was a descriptive study that aimed to explore experiences of moral distress and perceptions of ethical climate. A natural progression of this work is to conduct experimental studies, that align with the clinical implications below. It is important to examine the effects of all interventions in order to assess whether they truly benefit healthcare professionals and patients.

This study has raised some questions in need of further investigation. Now that we have, once again, confirmed that unsafe staffing and lack of time are common root causes of moral distress, we need to explore ways to work around such constraints.

If the research on moral distress is to be moved forward, a better understanding of individual differences is essential to shed more light on the matter. Several questions still remain unanswered. Further research might, for example, explore factors that contribute to differences between sexes and professions. An in-depth interview study on physicians' and nursing assistants' experiences could identify ethical challenges that they are facing, and that the MDS-R possibly failed to capture.

The link between moral distress and ethical climate should also be studied more closely, to deepen our understanding of how and why these elements impact each other. Also, the role of a manager in creating an ethical climate could be explored in detail.

7.2 Clinical implications

These results suggest several courses of action, that might improve working conditions and well-being of healthcare professionals. Most importantly, continued efforts are needed to ensure safe staffing levels. As this study suggest, adequate nurse-patient ratios are crucial when caring for patients with comprehensive care needs, for example terminally ill children. Ensuring safe staffing levels and manageable workloads would better allow healthcare professionals to practice ethically good care, and ultimately, enhance the quality of care for children with cancer. Support during distressing work shifts could be practical (such as a pair of extra hands), emotional (for example informal discussions), or moral (for example when prioritizing care actions).

Safe staffing levels are also about competency. Sick children should not be placed at units where staff members are not trained to provide their special care needs. This aligns with another suggestion to tackle staffing issues, namely, ensuring continuity of care. Prior literature indicates that safe and stable relationships would even benefit sick children and their parents. A child-centered care approach could help sick children get their voices heard, and their needs to be taken into consideration at all times.

With current staff shortages, it is important to build resilience in healthcare professionals: they need to be equipped to withstand adversities in order to overcome occupational stressors. Without doubt, there are several approaches to build resilience. Since this thesis did not further explore resilience, only few suggestions can be drawn from the findings: nurturing a positive mindset ("savoring") and encouraging collegiality.

It is important to bear in mind, that severe moral distress that results from a single, rare event, can contribute to build-up of moral distress over time (31), and therefore, it should not be left unaddressed. Morally distressing patient issues can be discussed at interprofessional rounds or during formal ethical

reflections (147), but opportunities for informal reflections and social talks during workhours should also be created (120). Overall, nursing staff, who spend most time bedsides, and physicians, who possess the medical expertise, should share their perspectives on difficult patient care matters.

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