Façading in Transcultural Caring Relationships
Healthcare Staff and Foreign-born Parents in Childhood Cancer Care

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“In fact it is quite superficial things that separate immigrant families … from Swedish families, it is the frames of our thinking and behaviour that may be different, but the core of being a human being is yet quite independent of whether you come from Turkey or Sweden or wherever you come from. … if you consciously think about it, these superficial things that you see at first sight are actually only the frame for something where the core actually consists of a human being who is very much like me in needs, feelings and pain, so then it [Transcultural care] is not that awfully hard I think.”

(Quote from a nurse participant, study III)

To my family: the “project” closest to my heart; Mats, my pillar in life; our children Emilia and Jonah, who came to the world during this research project, and their big brother Anton.
ABSTRACT

The overall aim of this thesis was to explore the caring situation of families with a foreign background within the context of pediatric oncology in Sweden. Pediatric cancer entails a long period of continuous and cumulative stress for the entire family. Furthermore, Sweden has become an increasingly multicultural society, resulting in a need for studies and training in transcultural care.

The present thesis is based on 4 exploratory studies; I to III are from the perspective of healthcare staff and study IV from the perspective of foreign-born parents. The studies were used to generate a grounded theory unifying them. Grounded theory (GT) methodology was chosen for this thesis as it aims to discover how participants resolve their main concern; explaining patterns of behaviour that are problematic and relevant. Studies I and II included 5 focus group interviews with healthcare staff and 5 individual interviews with registered nurses. In study III, individual interviews were conducted with 12 nurses from different areas of pediatric care. In study IV, 11 foreign-born parents were interviewed; 4 of them with an interpreter. Data were analyzed according to the constant comparative method of GT.

Study I presents obstacles to transcultural caring relationships, including linguistic, cultural and religious, social, and organizational obstacles. Bridging, presented in study II, is the way healthcare staff resolve this, using communicational, transcultural and organizational tools. In study III overwhelming emotional expressions were found to override nurses’ professional preparedness; they continuously resolve this by protecting professional composure, using various strategies. In study IV, foreign-born parents’ need to struggle on accounts for much of their behaviour, which includes ways of resourcing and protecting self-interest in health care. Façading is the latent pattern of behaviour used by healthcare staff and foreign-born parents to resolve the main concern of protecting self-interest and is central in transcultural caring relationships.

These studies provide insights into social interactions in transcultural childhood cancer care that could be used to explain, interpret and predict. Formal theories of core categories would be of value and presented strategies could be used in achieving a more congruent and equal childhood cancer care for families with a foreign background.

Keywords: pediatric oncology; coping; foreign-born; transcultural; caring relationships; communication; grounded theory; interviews.
LIST OF PUBLICATIONS

The present thesis is based on four exploratory studies, referred to by their Roman numerals I – IV. Studies I to III are from the perspective of healthcare staff, study IV from the perspective of foreign-born parents.


The retained right to reprint articles II & III in this thesis was granted in publishing and copyright agreements; for article I, written permission was obtained from SAGE Publications.

Paper III has also been published in a short, early version (Pergert, Ekblad, Enskar, & Bjork, 2007).
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This study originated from a clinically-grounded area of interest, as Swedish-born parents and healthcare staff often vented their perception that there were a large number of families with a foreign background in childhood cancer care. Until now, no one has studied whether this observation is related to a growing foreign-born population, differences in morbidity resulting in longer hospitalization, or merely reflects a complicated caring situation related to the diversity between families with a foreign background and healthcare staff from the majority population. As a nurse, the latter interested me as I could see that conflicts in transcultural care encounters were creating much frustration. Furthermore, my personal motivation to carry through this research was based on my previous education and working experience from international health and relief and on a genuine interest in people with a foreign background and in attaining a better understanding of transcultural encounters. I believe that it has been a great advantage to use and trust a well-tried methodology, especially when doubting my own capacity, and I have used the rigour of this methodology to the best of my ability. In writing this thesis it has been my hope that it would be read by clinically active healthcare staff in general, and especially nurses within childhood cancer care, but also researchers and sociologists in other areas.

The outline of this thesis is as follows. The background will give an introduction to pediatric cancer care, families with a foreign background in Sweden and transcultural care. Then the aims of the studies will be presented, followed by a section on methods and a discussion of methods. A summary of the results will be given with a short presentation of the major categories, followed by a discussion of the results. Thereafter, a grounded theory of façading will be presented and a discussion of façading, followed by a section on implications. After the summary in Swedish and the acknowledgements, references will follow and, last of all, the four papers.
BACKGROUND

Pediatric Cancer Care

The incidence of pediatric cancer varies across the world and there are even larger differences in the possibility to treat and cure pediatric cancer. “More than 85% of pediatric cancer cases occur in developing countries that use less than 5% of world resources” (Lie, 2007, p.92). Pediatric oncology includes many different diagnoses with different treatments and prognosis; the most common diagnostic groups in Sweden are leukemia and CNS tumours, constituting about 60% of pediatric cancer cases in 1984-2005 (Gustafsson, Heyman, & Vernby, 2007). During the same period, the mean annual incidence for all cancer diagnoses was 16.3 cases/100,000 children <15 years of age (Gustafsson et al., 2007), which is about 300 children a year. Medical developments in pediatric oncology have been outstanding over the last 5 decades and survival has improved considerably (Berglund, Garwicz, Kreuger, & Åhström, 2007); today, survival for all malignant diseases is close to 80 % in Sweden (Gustafsson et al., 2007). However, the medical treatment is very intensive and demanding, lasting between six months and two and a half years (Gustafsson et al., 2007), depending on the type of cancer. Furthermore, the treatment has serious side-effects, often resulting in long hospitalizations; thus, nursing, psychosocial and supportive care are important aspects of pediatric oncology. Furthermore, a consequence of the high survival rate is a rapidly increasing group of children who have survived pediatric cancer, as well as families with this experience. It is therefore important to investigate this group.

One factor behind the success story of survival in pediatric oncology has been the strong focus on collaboration: on an international level within the framework of the International Society of Pediatric Oncology (SIOP), established in 1969, including joint treatment studies; the same year the first national medical treatment group was formed to create national treatment programs; 1981 saw the first Nordic treatment program, which was the beginning of the Nordic Society for Pediatric Hematology and Oncology (NOPHO).

Also in nursing there is international and national collaboration through SIOP nurses, the Nordic Society of Pediatric Oncology Nurses (NOBOS) as well as the Swedish organization for nurses in pediatric oncology (SIBO). The first national nursing programs for different diagnostic groups, as well as general programs for different areas such as nausea and psychosocial issues, came in 2005.

When a child is diagnosed with cancer, a large circle of people will be affected, such as relatives, neighbours, friends at schools and parents’ work. Pediatric cancer is very stressful for the entire family (Bjork, Wiebe, & Hallstrom, 2005; Marky, 1982; Woodgate & Degner, 2003), a complex situation with a long period of continuous and cumulative stress (Boman, Lindahl, & Bjork, 2003; Norberg, Lindblad, & Boman, 2005). Several descriptive studies of
pediatric cancer care have explored the experiences of families (Bjork et al., 2005; Enskar, Carlsson, Golsater, Hamrin, & Kreuger, 1997a; Robinson, Gerhardt, Vannatta, & Noll, 2007; Woodgate & Degner, 2003) and parents (Enskar, Carlsson, Golsater, Hamrin, & Kreuger, 1997b). The family’s experience has been described as “getting through all the rough spots” (Woodgate & Degner, 2003) and “a broken life world” (Bjork et al., 2005). In Sweden, at least one family member or relative is usually active in the care of the child and stays at the hospital. In a study by von Essen et al. (von Essen, Enskar, & Skolin, 2001), parents of children with cancer considered that the most important aspects of care were social competence, information, adequate care of their child, emotional support and time. Given the duration of treatment, long-term caring relationships are involved that are important to develop and optimize. The caring relationship has been described as the foundation of the “caring process” (Eriksson, 2000) and is a professional relationship that aims to support the health process of patients. The caring relationship within pediatric oncology care has been addressed by the SIOP working committee on psychosocial issues in pediatric health (Masera et al., 1998). The committee has issued guidelines for the therapeutic alliance between families and staff, but these guidelines do not address transcultural relationships. How families understand and manage pediatric cancer will be influenced by their culture; health beliefs, family structure, religious practice, and communication beliefs (Thibodeaux & Deatrick, 2007).

Families with a Foreign Background in Sweden

Sweden has a population of a little more than nine million, of whom a good 17% have a foreign background (SCB, 2008). Foreign background is the term used by Statistics Sweden (SCB) and includes foreign-born as well as Swedish-born with two foreign-born parents (SCB, 2002). The term immigrant background, as used in papers I and II, refers to the same people but there is a stronger focus on immigration.

Sweden became an immigrant instead of an emigrant country in connection with the Second World War (Swedish Migration Board, n.d.-a); the countries of origin and the reasons for immigration have changed over time. Immigration for labour market reasons, primarily from European countries, dominated in the post-war period (Swedish Migration Board, n.d.-a). During the mid-1980s-90s asylum-seekers dominated; the countries of origin reflected the conflicts in the world. In the new millennium, the largest groups of asylum seekers have come from Iraq, Somalia, and former Yugoslavia (Swedish Migration Board, 2008a). During 2007, 48% of immigrants came from European countries, 36% came from Asia, including immigrants from Iraq as the largest group, 10% came from Africa, and 2% from other regions (Swedish Migration Board, 2008b). Further, 34% of residence permits were granted on the grounds of family ties (Swedish Migration Board, n.d.-b), with the largest groups from Iraq and Somalia (Swedish Migration Board, 2008c).
Sweden has become an increasingly multicultural society; in 2007 Sweden had foreign-born persons from almost 200 countries (SCB, n.d.). Arabic is a language that is commonly interpreted in Sweden (Botkyrka Interpreting Agency, n.d.). However, families with a foreign background are a heterogeneous group and differ from each other in many ways, such as language, ethnic background, reasons for immigration, culture, social situation and status, religion, socioeconomic level and level of integration (Baarnhielm, Ekblad, Ekberg, & Ginsburg, 2005). Thus, cultural and linguistic variety is evident in our society, including health care, resulting in a need for studies and training in transcultural care.

The importance of equity in health has been highlighted by the World Health Organization (1991), which has proposed that discrepancies in health status between groups, in and between countries, need to be reduced by raising the level of health of disadvantaged groups. The National Public Health Commission (2000) in Sweden has developed a national health policy with a strong focus on reducing health inequalities; Sweden also has regional and national policies for equal access to care regardless of background (Blomgren & Stockholm County Council, 2002). However, this does not include adult undocumented migrants and asylum seekers, who only have the right to emergency care; on that issue, Sweden is one of the most restrictive countries in the European community; according to Hunt (2007), “such differential treatment constitutes discrimination under international human rights law” (p. 19). Furthermore, despite the policies and requirements in Sweden, a national review (Lindencrona, Ekblad, Johansson Blight, & Swedish Migration Board, 2006) has indicated inequalities in health and health care between patients with a foreign background and the majority population. This inequality also exists in research because families with a foreign background are a heterogeneous group and that, combined with language barriers, tends to result in their exclusion from research.

### Transcultural Care

The notion of transcultural nursing, launched by Leininger (2002) in the mid-1950s, includes caring across cultures, and has been defined as “a formal area of study and practice focused on comparative human-care (caring) differences and similarities of the beliefs, values, and patterned lifeways of cultures to provide culturally congruent, meaningful, and beneficial health care to people” (Leininger, 2002, p. 5-6). Leininger further defined culture as “the learned and shared beliefs, values, and lifeways of a designated or particular group that are generally transmitted intergenerationally and influence one’s thinking and action modes” (Leininger, 2002, p. 9-10). Many have followed in these footsteps; for instance, Campinha-Bacote (1994; 2002) suggested a conceptual model of cultural competence which includes cultural awareness, cultural knowledge, cultural skill, cultural encounters, and cultural desire. Culturally congruent and competent care includes good cross-cultural communicational skills, as people

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1 The term multicultural simply denotes many cultures, whereas transcultural means across cultures (Andrews, 2003).
with limited language proficiency have been found to be more vulnerable to misunderstandings (Munet-Vilaro, 2004) and to discrimination.

Healthcare staff in general, as well as in pediatric oncology, “must be prepared adequately to meet the needs of the whole population” (Chevannes, 2002, p. 291) and have an obligation to provide culturally congruent and competent care (Covington, 2001; Lavizzo-Mourey & MacKenzie, 1995; Leininger, 2002; Price & Cortis, 2000; Richardson, 1999). There is a need for culturally competent nursing (Chenowethm, Jeon, Goff, & Burke, 2006; Leininger, 2002), particularly in pediatric care (Berlin, Johansson, & Tornkvist, 2006; Munet-Vilaro, 2004), because this entails participation with parents who are not the direct caretakers, and culture has been shown to exert a strong influence on parents’ and staff’s perceptions and expectations of this participation (Shields & King, 2001; Shields & King, 2001). Culturally competent nursing is also essential in end-of-life care (Fürst & Ekblad, 2006; Kemp, 2005; Lundqvist, Nilstun, & Dykes, 2003) and bereavement care, as “all domains of end-of-life care are shaped by culture” (Koenig & Davies, 2003, p. 510), but also because it is so emotionally intensive (Sandgren, Thulesius, Fridlund, & Petersson, 2006). There are cultural differences and similarities in how people express and communicate emotions; some patterns of expressive behaviour are universal, whereas other behavioural modes are culture-specific in that culture helps define the appropriate expression of emotions (Koenig & Davies, 2003) outside and within the family.

Research on and around cultural competence and transcultural care may have made great strides internationally and in other areas of care. However, much remains to be done; within pediatric oncology care this area remains a challenge in which discoveries are waiting to be made (Hicks & Lavender, 2001; Munet-Vilaro, 2004). Most studies in pediatric oncology have concerned people from Asian cultures; empirical knowledge of the influence of culture on families’ understanding and management of pediatric cancer is lacking (Thibodeaux & Deatrick, 2007) and there is a need for studies to facilitate communication across language barriers (Abbe, Simon, Angiolillo, Ruccione, & Kodish, 2006; Sobo, 2004). Further, there is to our knowledge no previously published research in Swedish transcultural pediatric oncology care.
AIMS OF THE STUDIES

The overall aim of this thesis was to explore the caring situation of families with a foreign background within the context of pediatric oncology in Sweden. The aims of each of the studies were formulated as below.

I. To gain knowledge about healthcare staff’s experiences and their main concern in caring for families with a foreign background within the context of pediatric oncology care.

II. To gain knowledge about how healthcare staff continuously resolve “obstacles to transcultural caring relationships” as they care for families with a foreign background within the context of pediatric oncology care.

III. To gain knowledge about nurses’ experiences of pediatric care in the context of overwhelming emotional expressions of families with a foreign background.

IV. To gain knowledge about the experiences and main concern of foreign-born parents in the context of pediatric oncology care.

Studies II and III have narrower aims since they are further explorations of what emerged in study I. A further aim was to use the four studies to generate a grounded theory explaining the latent pattern of behaviour and unifying the studies.
METHODS

This section will detail methods used in this research project and for each study, followed by a discussion of methods, including a section on validity and generalizability, and ethical issues.

Design

This thesis consists of four exploratory studies using qualitative data. The four studies provided a basis for generating a grounded theory of façading.

The area explored in the studies is fairly new; qualitative data are therefore needed for an attempt to arrive at a holistic understanding of the situation (Polit & Hungler, 1999) of families with a foreign background in the context of childhood cancer care. Qualitative studies can provide an understanding in creating models and theories explaining the social world (Morse & Field, 1995). Grounded theory (GT), which is a general method useful and suitable for qualitative data, was formulated by Glaser & Strauss (1967) and elaborated by Glaser (1978; 1998) and others. GT is highly appropriate for nursing research (Nathaniel & Andrews, 2007; Schreiber & Stern, 2001) and was chosen for this thesis as it aims to discover how participants resolve their main concern (Glaser, 1978, pp 107-113), explaining patterns of behaviour that are problematic and relevant (Glaser, 1978).

The results are not proved facts because “Grounded theory is not findings, but rather an integrated set of conceptual hypotheses. It is just probability statements about the relationship between concepts [and categories]” (Glaser, 1998, p. 3) based on empirical interview data generated from the substantive area (Glaser, 1998; Glaser & Strauss, 1967) of transcultural pediatric oncology.

Sampling and Participants

At the start of this research project it was decided to include healthcare staff and parents as participants; the initial decisions for sampling in each of these groups were based on the general subject area as presented in the section on purpose, which is consistent with grounded theory methodology (Glaser & Strauss, 1967, p. 45). Thus, purposive and convenience sampling were utilized in the sense, recommended by Glaser (1978), that it aimed to include people who were knowledgeable about the phenomena being studied and easily accessible. This was followed by theoretical sampling of comparative groups and literature. “Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges. This process of data collection [and sampling] is controlled by the emerging theory” (Glaser & Strauss, 1967, p. 45), that is, data were collected to further refine and elaborate on induced categories and with focus on core categories.
The representativeness of a sample is not an issue in grounded theory, neither is there an ideal sample size, this is rather based on saturation (Glaser, 1998; Glaser & Strauss, 1967). Sample size in the present studies was based on a judgement, in coding and analysing, of theoretical saturation of categories, which implies that “no new properties emerge and the same properties continually emerge” (Glaser, 1978, p. 53) and that gaps in major categories were more or less filled (Glaser & Strauss, 1967). Furthermore, theoretical sampling was delimited by a judgment of the scope of this dissertation project. If new relevant data were to be brought in from new fields and further theoretical sampling, this would undoubtedly lead back to theoretical non-saturation (Glaser, 1978); but then again, a grounded theory is always modifiable.

**Studies I and II**

Initially purposive and convenience sampling was utilized, followed by theoretical sampling of healthcare staff for focus group interviews and individual interviews.

Sampling for the initial data collection through focus group interviews was based on the general subject area (Glaser, 1978, 1998; Glaser & Strauss, 1967), using purposive and convenience sampling. Three focus group interviews were conducted with nursing staff, including: registered nurses, child minders and nurse aides (including one pilot group) within the pediatric oncology care setting. Two other groups were sampled for the comparative analysis: a group of physicians and a group of consultant nurses within the pediatric oncology setting. The physicians have experience working with interpreters and consultant nurses with information. The consultant nurses are registered nurses with long experience in the field of pediatric oncology care; they are attached to pediatric oncology care centres in Sweden and work with coordination and information at the centre but primarily with the schools and day care centres of the children with cancer. Participants predominantly had a Swedish background, very occasionally a European background. The groups consisted of 4 to 10 participants, a total of 24 women and 11 men. Their individual experience with pediatric oncology care ranged from 1 to 27 years; physicians and consultant nurses had longer experience, with an estimated average of 15 years, whereas nursing staff had a median in each of the groups of 2.25 years. Taking only profession and position into consideration produced a balance between the homogeneity and diversity of the participants in the groups, with a view to attaining good group dynamics (Dilorio, Hockenberry-Eaton, Maibach, & Rivero, 1994; Ekblad & Baarnhielm, 2002).

Registered nurses for individual interviews were theoretically sampled; the sampling process was guided by the emerging theory (Glaser, 1978). Five nurses, all women, were sampled with experience of end-of-life care of families with a foreign background within the pediatric oncology care setting. These interviews were sampled to further explore and to verify the category of “differences in emotional expressions” but were also coded and used in the comparative analysis for other categories and properties that had emerged...
through the focus group interviews. The nurses’ experience from pediatric oncology care ranged from 2 to 27 years, median 4 years.

**Study III**

For individual interviews, registered nurses were sampled theoretically. The sampling process was guided by the emerging theory (Glaser, 1978) and yielded 12 nurses from different areas of pediatric care. Five of the nurses, all women, had experience of end-of-life care of families with a foreign background within pediatric oncology. Their experience of pediatric oncological care ranged from 2 to 27 years, median 4 years. These interviews were used to further explore nurses’ experiences of overwhelming emotional expressions of grief and to verify the category of “differences in emotional expressions” that had emerged from focus group interviews in a previous study (I). Another four nurses—three women and one man—had experience of caring for families in triage within the pediatric emergency setting. Their experience of pediatric emergency care ranged from 4 to 7 years, median 6 years. These interviews were used to further explore overwhelming emotional expressions of anger. These nine participants predominantly had a Swedish background, very occasionally a European background. Finally, three nurses experienced in pediatric care had a foreign background; they had come from Iran between 6 and 27 years ago. Their median experience of nursing was 9 years, and their median and mean experience of pediatric care was 1 year. One had experience of working as a nurse in Iran as well as in Sweden. These interviews were used to further explore differences and similarities concerning consequences of overwhelming emotional expressions.

**Study IV**

Sampling was based on the general subject area (Glaser, 1978, 1998; Glaser & Strauss, 1967) as presented in the section on purpose, aiming for easily accessible parents who were knowledgeable about the phenomena being studied. Inclusion criteria included: the parent had a foreign background, the parent had been present at the hospital during the child’s admissions, at least 3 months had passed since the diagnosis and the child was still undergoing treatment at the childhood cancer care unit. This yielded 11 foreign-born parents – 10 mothers and 1 father. The diagnoses for the informants’ children were leukemia (5), brain tumour (1) and solid tumour (4); both parents of one of the latter children participated. The parents’ ages ranged from 26 to 47 years, median 40 years. Parents came from the Middle East (5), Europe (4), Africa (1) and South America (1). The time interval since immigration ranged from 2 to 18 years, median 6 years. The self-reported reasons for immigration varied but most parents (8) stated family ties.

**Data Collection**

The major source of data collection was interviews, both focus groups and individual.
An interview guide was used by the moderator in focus group interviews (I, II) to stimulate the discussion and focus it on the research topic. Also in individual interviews (I-IV) an interview guide was used with a list of potential questions based on the major areas of interest, as stated in the section on aims. The technique of “open-ended conversations” (Glaser & Strauss, 1967, p. 75) was employed as much as possible in individual interviews, using the first broad question of the interview guide. In individual interviews with registered nurses the aim was to use laddered questions (Price, 2002) about actions, knowledge, and philosophy, the latter including feelings, values, and beliefs; in practice, the participants often covered these three steps spontaneously. Data were analyzed between interviews, and this influenced the questions in subsequent interviews, enabling the author to further refine, elaborate, and saturate the emerging categories, all according to grounded theory method (Glaser, 1978, 1998; Glaser & Strauss, 1967). In later interviews, theoretical sampling should, according to GT, delimit data collection using focused questions based on emergent categories (Glaser, 2002; Glaser & Strauss, 1967). This technique has not been followed completely, as all individual interviews have included the open-ended conversation part, while focused questions have been added at the end of interviews. This was done to make the fullest possible use of each participant, instead of sampling more participants.

Field notes were written about the authors’ experience, thoughts and preconceived notions and used as data in the comparative analysis, which is consistent with GT (Glaser, 2002). Field notes were also written immediately after each interview and recorders were used in all but one of the interviews; the exception was a focus group interview (I, II) where notes were taken by the observer since some participants objected to tape recording. Interviews were recorded, even though this is not recommended by Glaser (1998), in order to have transcriptions for the comparative analysis, quotations as illustrations of various points and to enhance the transparency in the supervision of the scientific work. Another reason was that recording is more acceptable to the scientific community since field notes are often viewed as selective and biased (Glaser, 1998).

While these delimiting tools were not used in data collection, delimiting tools were used in the analysis.

Relevant literature was searched, primarily through Pub Med and the Cumulative Index of Nursing and Allied Health Literature, during the sorting phase and used as additional data in the comparative analysis (Glaser, 1978, 1998) and is specified in the papers (I-IV) and in footnotes (Theory).

Studies I and II

Five focus group interviews (N 35) were conducted; standard focus group methodological techniques were applied and the settings for the interviews were arranged in accordance with methodological recommendations (Dilorio et al., 1994; Ekblad & Baarnhielm, 2002; Jamieson & Williams, 2003). Focus group interviews were used for data collection because this makes it possible to explore new fields and grasp the “real” problem, besides helping to discover
ways in which healthcare staff feel that services could be improved (Ekblad & Baarnhielm, 2002). The interviews were conducted in a conference room that provided good conditions for relaxed interviews. For practical reasons, the optimal number of participants could not be obtained in every group. The main supervisor acted as moderator; guiding the conversation, encouraging participants to provide a diversity of opinions, reflections, and to give examples drawn from personal experience. The author acted as observer; taking field notes on group interaction and nonverbal behaviour, and summarizing the discussion, thereby enabling participants to evaluate and comment upon issues, make corrections, and provide additional information. The author was able to start to code at this stage; emerging codes were verified through the summary and the ensuing discussion in each focus group interview. The pilot group interview was done with the author as moderator and contributed to the findings in similar ways as subsequent focus groups. The interviews lasted for 60–90 min. and were conducted during 2003 except for the pilot interview, which was done in 2002.

Four individual interviews were carried out by the author during 2004 (with two pilot interviews in 2003) and lasted about one hour each. The interviews were conducted in a room at the hospital that provided good conditions for relaxed interviews.

Study III

Twelve individual interviews were carried out by the author during 2004 and 2006–2007 (with two pilot interviews in 2003), and lasted approximately 30 to 60 minutes each. The four first interviews were the same as in studies I and II and the pilot interviews were also used for an examination in a course taken by the author.

Study IV

Eleven individual interviews were carried out by the author during 2004 to 2006 (with a pilot interview in 2003) and lasted 30 to 150 minutes each, median 70 minutes. A questionnaire including questions on socio demographic characteristics was used and this and the original interview guide were translated into Arabic and back translated by independent authorized translators. The pilot interview was conducted to test the questionnaire before translation, and it contributed to the results in the same ways as the subsequent interviews.

The author is a nurse in the field of pediatric oncology on leave from clinical duty; to prevent role confusion as described by Asselin (2003), the interviewer (author) wore everyday clothing and the interview room for individual interviews with parents (IV) was located at the research department.

All participants in study IV were offered an interpreter and decided whether or not they wanted to use one. Four interviews were conducted with one and the same female Arabic-speaking authorized healthcare interpreter. Some of these interviews would not have been possible at all without an interpreter. The interpreter came from a municipal interpreter agency, had been used in the clinical context of pediatric oncology and participants had met her in that
context. The interpreter was informed of the aim of the study; triangular seating (Phelan & Parkman, 1995) and consecutive translation were used during the interviews. Based on the literature (Abbe et al., 2006; Wallin & Ahlstrom, 2006), it was considered more important to use one and the same interpreter rather than match gender, culture and religion. Rapport was established in all interviews between the author and the participant.

Data Analysis

The author transcribed the data in Swedish and analyzed them according to the constant comparative method of grounded theory (Glaser, 1978, 1998; Glaser & Strauss, 1967). The software program NVivo 2.0 (QSR International, 2002) was used as a tool. The main supervisor listened to the recordings of individual interviews independently, read all transcripts and field notes, and discussed emerging categories with the author. Open coding was used until the core and related categories had emerged, whereupon selective coding was conducted. Coding is about “fracturing the data, then conceptually grouping it into codes that then become the theory which explains what is happening in the data” (Glaser, 1978, p. 55). Open coding includes analysing the data line by line and using a set of questions such as: “What category does this incident indicate?” and “What is the main concern of participants?” (Glaser, 1978, p. 57; 1998, p.140). Selective coding implies delimiting coding around the core (Glaser, 1978). The Swedish language was used in most of the analyses, but categories were named in both Swedish and English. Assistance with analyses were received; with coding in the main supervisor’s research group, and with conceptualization of core categories at grounded theory troubleshooting seminars (Grounded Theory Institute, 2005a, 2005b, 2006, 2007). The constant comparative method (Glaser & Strauss, 1967) was used to compare concepts and incidents; throughout the analysis memos were written about the data, categories and their properties and the connections between categories (Glaser, 1978). The integration of categories was facilitated by sorting printed memos (Glaser, 1998) and theoretical coding. Literature was used as additional data in the comparative analysis (Glaser, 1978, 1998) in all studies (I-IV), including the one on façading.

The four studies were used to generate a GT unifying these studies. Façading emerged as the core, based on the cumulative data, of all four studies. Memos on categories from the four studies were printed and re-sorted and the constant comparative method (Glaser & Strauss, 1967) was used to compare concepts and incidents; memos were written throughout the analysis. Saturation of the core and the related categories was achieved when different incidents kept indicating the same categories (Glaser, 1998).

Ethical Issues

This project was approved by the Ethical Research Committee at the Karolinska Institutet, Case no. (D nr) 02-446. Interviews with healthcare staff were conducted during or in connection with their working hours and were voluntary.
Potential participants for study IV were invited to participate by a nurse who was not involved either in the patients’ direct care or in the research project. The nurse was informed of the aim of the study and the importance of participant consent; which she explained to potential participants, reinforced by an information sheet in Swedish or Arabic. Before the interviews (I-IV), the author again provided the information sheet, while emphasizing confidentiality, the voluntary nature of participation and the right to withdraw at any time. In focus group interviews (I, II) confidentiality was assured by the author and the main supervisor, and stressed as regards participants. All participants in study III and all participants in focus group interviews in studies I and II were sent a copy of the results section of the manuscript and were invited to give their comments and opinions. Furthermore, all quotes from individual interviews (I & II) have been accepted and approved by the participants in question.
DISCUSSION OF METHODS

Discussion of Design
This research was anchored in clinical practice by defining the clinically relevant “area of interest” (Glaser, 1998, p. 118), which is the wide purpose presented in the section on aims. GT was then used to let the participants’ main concern emerge, instead of focusing on what Glaser (1998) calls “professional concern” (p. 99) or a “professionally preconceived problem” (p. 118). At the time of the first focus group interviews, however, the preconceived notion was that the study would be concerned with medical information; this was also healthcare staff’s spontaneous answer to what was the biggest challenge in transcultural care. As data were analysed, using grounded theory, bridging obstacles to transcultural caring relationships emerged instead as the core. Bridging is what Glaser (1998, p. 5) calls the ‘latent pattern’ of behaviour, of which participants are not necessarily aware. The preconceived notion of giving medical information was something that healthcare staff were aware of, while obstacles to transcultural caring relationships were actually a major concern. This major concern would probably not have been identified with a method that focuses more on predefined problems, testing hypothesis, and using preset and narrower questions. For example Strauss and Corbin (1998) proposed that professional experience and suggestions could be used to identify the research problem.

Discussion of Sampling and Participants
Is full saturation possible? Even though there are methodological guidelines, saturation is always a subjective judgement and the decision to stop theoretical sampling also weighs in a judgement of the research project’s scope, such as time and resources. In the present research, further theoretical sampling could have been carried out, for instance to saturate the category of trust-building in study I. In study IV, theoretical sampling could have been carried out among Swedish-born parents but it was decided to use literature for comparative analysis, which is consistent with grounded theory methodology (Glaser, 1998). Other comparative groups could always be sampled and in all of the studies further theoretical sampling, bringing in new relevant data from new fields, would undoubtedly lead back to theoretical non-saturation (Glaser, 1978) and modification. Furthermore, only one father was included in the individual interviews with foreign-born parents. This did not emerge as relevant but could be seen as a limitation, as support-seeking, for example, is used more frequently among women (Norberg, Lindblad, & Boman, 2006).

Discussion of Data Collection
In qualitative research, the interviewer and analyst is often referred to as an instrument (Kvale, 1996; Lincoln & Guba, 1985), while in GT the autonomy of
the “researcher” is central (Glaser, 2004). Furthermore, the constructivist orientation—producing data through interactive, mutual interpretations—is frequent in qualitative research, and in new versions of GT (Charmaz, 2006). Glaser (2002) argues that constructivism tends to force the data and is held to a minimum through careful application of all the GT procedures; the impact on data of the researcher, whenever it emerges as relevant, is just one more variable to consider. “For example, when nurses study a problem on a type ward they have worked on for years, they will compare notes of themselves, not impose their experience on the interview or data” (Glaser, 2002, paragraph 34).

The author could be defined as an “insider researcher” since she is a nurse in the field of pediatric oncology on leave from clinical duty. Glaser (1998) holds that research is easier to do where you know nothing; on the other hand, doing research in a familiar area leads to motivation and more variables to deal with. Insider research is common in the qualitative field in the context of nursing (Asselin, 2003; Cudmore & Sondermeyer, 2007) and could be seen as an advantage as the double role may enhance the trust in the interviewer (Glaser & Strauss, 1967) and positively influence the relationship (Asselin, 2003) and consequently also the data, which was also the experience of the author in the present case. One of the interviews contained lots of properline data (what the informant thought was proper to tell) but otherwise the data was considered to be the best description the informants were able to give. In focus groups (I & II), the authors’ experience in pediatric oncology could have influenced the data as participants may have been reluctant to give examples of incidents they believed to be “obvious” to someone acquainted with the field; the main supervisor therefore acted as moderator.

Focus group interviews may not be the preferred method for data collection in classic grounded theory, but “the process of generating theory is independent of the kind of data used” (Glaser & Strauss, 1967, p. 18). Focus group interviews were found highly relevant for collecting data in the beginning of a grounded theory, while the method would probably not be as good later in the process since theoretical focusing and delimiting can be hard. One problem could be the large amount of data from a few focus groups, which could delay the start of theoretical sampling and lead to premature closure of data collection, leading to a lack of conceptual depth.

Data collected with interviews can be incorrect but the “comparative analysis and different slices of data correct the inaccuracies of data” (Glaser & Strauss, 1967, p. 223). Thus, “in generating theory it [evidence from data] is not the fact upon which we stand, but the conceptual category (or a conceptual property of the category) that was generated from it” (Glaser & Strauss, 1967, p. 23). In the present studies the major source of data collection was interviews and the lack of observational data could be seen as a limitation since GT was discovered in sociological field studies (Glaser & Strauss, 1965, 1967). For example, in study I, further research is needed to find out what patients and families are actually told in health care that favours truth-telling.
Although field notes and transcribed recordings were used in the analysis, when analyzing data from interviews with an interpreter (IV), the author heard the voice of the interpreter rather than the participant. This is a limitation of the study; a translator could have been used to also translate and transcribe data in Arabic into Swedish. Furthermore, it could be argued that, rather than aiming for one and the same interpreter, it is more important to consider participants’ preferences regarding individual interpreters or attributes for matching, for example, gender, country of origin, religion and ethnical background; this could be seen as an act of respect for the participants and possibly enhance rapport between interpreter and participant.

Discussion of Data Analysis

Conceptualization is central in GT. The name of the core category should have grab and often takes the form of a gerund (-ing) to bring out its nature of explaining a pattern of behaviour to resolve the main concern (Glaser, 1978, 1998). In the present studies the author named categories in both English and Swedish, the latter being her native tongue. However, while the use of gerund verbs is characteristic of GT, the Swedish language lacks the gerund verb form, so the core is often interpreted as an infinitive, for instance “to bridge” instead of “bridging”. Furthermore, naming a category with grab is more difficult in a language that is not one’s mother tongue, as nuances and subtle meanings are easily missed. The author had the opportunity to participate in international grounded theory seminars (Grounded Theory Institute, 2005a, 2005b, 2006, 2007), providing great assistance in naming core categories; she has also had discussions with English text editors in the search for the best possible names of categories.

The ambition was to use full GT procedures in every study but different conceptual levels were reached in the analysis. The constant comparative analysis of GT was applied in all studies even though in studies I and II it resulted in grounded conceptual descriptions, which also has scientific and clinical value. This could be related to the GT learning process of the author but also to the utilisation of NVivo (QSR International, 2002), which in the first two studies was used initially in the analysis for organizing code trees and creating models (Bazeley & Richards, 2000). Even though the main concern emerged, the use of code trees and models may have preconceived an outline rather than letting the integration emerge in later sorting of memos (Glaser, 1998).

Discussion of Validity and Generalizability

Qualitative researchers should, according to Strauss and Corbin (1998), adapt the standards or canons of quantitative research, namely validity, reliability, efficiency and sensitivity (Polit and Hungler 1999). In judging the credibility of a grounded theory, however, one should use the four criteria of fit, work, relevance and modifiability (Glaser, 1978, 1998). Fit implies “validity”, as the theory must directly relate to the data; adequately expressing what is happening in the empirical situation. Workability means that the theory should have
explanatory power of how the main concern is resolved. When the research deals with a real concern of participants as this emerges from the data, it is important and relevant. And finally, when compared with new data, the theory must be adaptable and modifiable.

This thesis is based on exploratory studies and should not be used to draw definitive empirical generalisations—where findings may be generalised to a larger population in a probabilistic sense (Guba & Lincoln, 1994). On the other hand, theoretical generalisation may suffice, since the findings from the current studies give theoretical insights and are sufficiently generalizable to allow projection to other contexts or situations. Grounded theories can have different conceptual levels and generality, for example the level of concepts in the present studies, vary; the concept concern-focusing on the ill child is less general than just concern-focusing. “The higher the level of conceptualization of the unit data, makes for a higher level of generalization” (Glaser, 1998, p. 137).

Discussion of Ethical Issues

The principles of research ethics in the humanities and social sciences (Swedish Research Council, 2002) include four major requirements: information, consent, confidentiality and utilization of research data.

In the present research the information requirement was met since the letter of information, which all participants received before the start of the interview, included information on the aim of the study, how to contact the author and supervisors, what participation would involve and the voluntary nature of their participation, which was emphasized.

As to the requirement of consent, this was obtained orally when potential participants were invited to participate. The right to withdraw at any time was emphasized just before the interviews started and parents were assured that their participation or otherwise would not influence the care of their child in any way.

The requirement of confidentiality was met on the part of the author and the main supervisor with access to data; information about participants is locked away. In focus groups, confidentiality was stressed to the participants but could not be guaranteed. In publications, quotes are anonymous and healthcare staff had the opportunity to disapprove of quotes before publication, though this never happened.

Finally, the requirement of utilization of data is met in the present research since it will be used only for research.

The “results” have been made available through publications but the author also intends to present them in a way that is more accessible for participants, for instance in Swedish. Furthermore, the author has presented the results at several conferences for staff in pediatric oncology, including meetings arranged by; The Swedish national organization for nurses in pediatric oncology (SIBO) 2003; the Association of Pediatric Oncology Nursing (APON) 2005; the International Society of Pediatric Oncology (SIOP) 2005 and 2007, as well as the Nordic Society of Pediatric Oncology Nurses (NOBOS) 2008.
SUMMARY OF RESULTS

A summary of the results will be given below with a short presentation of the major categories, followed by a discussion of the results. Thereafter a grounded theory of façading will be presented and a discussion of façading, followed by a section on implications and concluding remarks.

This thesis is based on four studies conducted in Stockholm, Sweden to explore the situation of families with a foreign background in childhood cancer care. Studies I to III are from the perspective of healthcare staff, study IV from the perspective of foreign-born parents.

Obstacles to Transcultural Caring Relationships (I)

In study I, obstacles to communication and consequently to development of transcultural caring relationships have emerged as a main concern of healthcare staff in the context of transcultural care. Obstacles are conditions that hinder and aggravate the social interaction between staff and families. Bridging, presented in study II, is the way healthcare staff resolve this. Being able to communicate is fundamental in all human interaction; miscommunication is the primary obstacle in the process of developing transcultural caring relationships. Obstacles may obstruct mutual understanding; lead to misunderstanding and perhaps damage the transcultural caring relationship or even prevent it from developing in a positive manner. These obstacles result in inequity in care because a foreign background often leads to families experiencing more obstacles in the caring relationship and thus receiving less qualitative care. Obstacles are divided into four main categories: linguistic, cultural and religious, social, and organizational. They are often interrelated; for example, culture will influence the culture-dependent process of communication and the social identity of the family and staff.

Linguistic Obstacles

This is about healthcare staff and family not having a shared language and the consequences thereof, including lack of nursing communication, lack of caring conversation and chatting, and interpreter dependency. Consequences of the latter have been categorized as triadic relationships, loss of information control, and information compacting.

Cultural and Religious Obstacles

This includes views and practices regarding social codes, social roles and social space needs. Cultural and religious obstacles have several potential consequences; those most relevant in this study have been categorized in terms of differences in emotional expressions and truth-telling.
**Social Obstacles**
This concerns differences in social situation, identities and status and a consequence is *racism and prejudice*.

**Organizational Obstacles**
This is about when an organization or unit is not providing the necessary resources and conditions to deliver transcultural care and thereby obstructing the development of transcultural caring relationships. It is about unadjusted policies and routines and a consequence is *lack of time*.

**Bridging Obstacles to Transcultural Caring Relationships (II)**
In study II, *bridging* emerged as the way in which healthcare staff deal with obstacles to transcultural caring relationships. The concept of “bridging” implies action; various tools are used and combined. Using only one tool or using tools inappropriately can lead to failure in bridging. If several tools are combined and bridging is successful, the transcultural caring relationship will continue, with varying degrees of quality, depth, and intensity. Tools for bridging include communicational, transcultural and organizational tools.

**Communicational Tools**
Communication is important in the care situation and in developing caring relationships and is about sharing information, caring conversation and “chatting”. Communicational tools include non-verbal communicating and interpreter reliance. *Non-verbal communicating* is used for sharing information and/or for feelings and is categorized as *signs and “charades”, caring touch*, and *providing printed information*. *Interpreter reliance* concerns using interpreters when they are required to bridge linguistic obstacles. In cases with a higher level of linguistic diversity, this tool should be used not only for conveying medical information but also for nursing communication and for caring conversations and “chatting”.

**Transcultural Tools**
These tools, which include transcultural learning, reflecting and linking, are used by healthcare staff in an endeavour to attain transcultural understanding, which involves willingness and a desire to understand. *Transcultural learning* is a continuous process that includes theoretical knowledge about cultures and religions and an awareness of one’s own culture. This general cultural knowledge should be combined with specific knowledge about the individual patient. *Transcultural reflecting* is used to understand other people, cultures, one’s own culture and the underlying reasons for differences, but also similarities. *Transcultural linking* is the process whereby a person with transcultural experience and/or knowledge can function as a transcultural link or mediator.
**Organizational Tools**

These are about adjusting policies and routines to provide necessary resources and conditions for bridging obstacles; they include *time-allocating* and *transcultural training*. The latter is about providing opportunities for transcultural learning, reflecting and further education in the field of transcultural care.

**Protecting Professional Composure (III)**

Differences in emotional expressions in transcultural care, including *overwhelming emotional expressions* of *wailing* and *anger*, have been found to *override* nurses' *professional preparedness* on account of a disjuncture between the expression and the norm. When their professional preparedness is overridden, nurses resolve the situation by *protecting professional composure*, which involves protecting oneself and others by means of various strategies, including rationalizing, controlled expression, power display, escape/avoidance, distancing, sharing, and management of space.

**Strategies for Protecting Professional Composure**

The strategy of *rationalizing* is about constructing a logical justification for the emotional expression, as well as for one’s own actions and reactions. It includes interpreting, evaluating and explaining to make it understandable and meaningful. In order to maintain a proper professional façade despite the nurses' own strong emotional reactions and to calm things down, the strategy *controlled expression* is used. When this has failed, *power display* is commonly employed, consisting of threats, raised voices, and/or sending for hospital guards as a strategy for ending the emotional expression. The strategy of *escape/avoidance* includes various ways of getting away from the overwhelming emotional expressions. One common avoidance strategy is to busy oneself with other patients, other members of the family, or practical and/or technical issues. Furthermore, the strategy of *distancing* is used as nurses have to strike a balance between closeness and distance in their professional relationships with patients and/or families, as well as in the level of emotional involvement. This strategy can be overridden by overwhelming emotional expressions because it can be difficult to cope with emotions that are strongly expressed. *Sharing* strategies are used, both in the acute situation and over time, to deal with the experience and include talking, hugging and comforting to help each other maintain professional composure and to seek support in the difficult task of facing overwhelming emotional expressions. This occurs most commonly among nursing staff and a consequence is protection by bonding. Finally, *management of space* is a common strategy in end-of-life care and includes managing spaces of nurses, patients, relatives, and especially the person with overwhelming emotional expressions.
Struggling On (IV)

In study IV, the main concern of foreign-born parents in the context of childhood cancer care is how to achieve the best possible care for their child and protect their family’s interests by struggling on. Much of foreign-born parents’ behaviour is accounted for by their need to struggle on, which involves resourcing and protecting self-interest in health care.

Resourcing

This is done by staying strong, support-seeking and concern-focusing on the ill child. Staying strong is an approach to maintain, regain, or appear to be in control and involves reassuring thinking and façading strength. Support-seeking is an approach to seek practical assistance and/or psychological support by holding on to one’s family and friends, and seeking supportive relationships with staff and other parents on the ward. Concern-focusing on the ill child is about parents concentrating almost exclusively on the child with cancer. This causes them to suppress their own needs; competing activities are disregarded and put on hold; all that matters is the sick child.

Protecting Self-interest in Health Care

This entails using various approaches in interaction with healthcare staff. Parents present different levels of powerlessness and the interactive approach will vary with the parent’s personality, the situation and conditions related to the interaction. The different approaches include: trustful cooperation, fighting and despondent surrendering. Trustful cooperation is about trying to stay on good terms with the staff and creating good relationships. When negotiating with staff about the care of the child, the goal is to cooperate. Fighting is often linked to a strong feeling of powerlessness; lack of mutual trust has a negative influence on fighting. One approach to fighting is persuasive communicating, which involves providing convincing information in a persistent way, sometimes with emotional display and threats. Despondent surrendering is about giving up, often with a feeling of being mistreated. This is a result of feeling despondent and psychologically beaten and the perceived experience of a failure to protect self-interest in health care.
DISCUSSION OF RESULTS

The aim of this thesis was to explore the caring situation of families with a foreign background within the context of pediatric oncology care in Sweden. In other words, the general problem area (Glaser, 1978; Glaser & Strauss, 1967) directing the research was: what happens in transcultural pediatric oncology, and what is the main concerns of participants.

In study I, obstacles to transcultural caring relationships emerged as the main concern of healthcare staff; the well recognized conceptual model of cultural competence (Campinha-Bacote, 1994, 2002) did not fit the data. In another study in Sweden, the main concern of staff was to understand the culturally diverse rather than to have cultural competence (Shahnavaz & Ekblad, 2007). At the same time, cultural competence might help healthcare staff and give them the ability to deal with obstacles and gain an understanding of the culturally diverse, even though it is not their primary concern.

Communication is fundamental in all interactions. Linguistic obstacles and their consequences, including lack of nursing communication, lack of caring conversation and chatting, and interpreter dependency, are of major concern in transcultural care (I). This is in line with the literature, as research from different areas of care keeps finding language as an important barrier to care (Levin, 2006; Schlemmer & Mash, 2006; Scuglik, Alarcon, Lapeyre, Williams, & Logan, 2007; Shahnavaz & Ekblad, 2007; Wong et al., 2006) that now needs to be addressed in education and clinical practice. Understanding obstacles, not only to the broad concept of care, but to transcultural caring relationships from the perspective of healthcare staff, is an important first step and as these obstacles are recognized, they can be used to guide practice. Furthermore, healthcare staff need to be sensitized to cultural variations and obstacles in transcultural caring relationships, since a failure in this respect might result in inequity in the care of families with a foreign background (I). Inequity in care as a consequence of “exactly the same care” for people with different prerequisites has also been found in previous studies (Blackford & Street, 2002; Vydelingum, 2006); in a study from Swedish primary care, addressing cultural differences was avoided even though they were significant for interaction (Wachtler, Brorsson, & Troein, 2006). Healthcare staff also need to be aware of and avoid stereotyping. Stereotyping is to assign people to a group without taking individual and group differences into consideration (Leininger, 2002). The comparative focus on differences and similarities is central in transcultural nursing (Leininger, 2002) and could be used to discover not only similarities but also the enriching blessings of differences.

In study II, bridging emerged as the way in which healthcare staff deal with obstacles to communication and the development of transcultural caring relationships. Various tools may be used and combined in bridging, including: communicational, transcultural and organizational tools. In this section the discussion will concentrate on communicational tools and especially interpreter reliance. This tool is very important even though it may not be optimal or easy
to use as *interpreter dependency* has been identified as an obstacle to transcultural caring relationships (I), which is consistent with studies describing complexities and difficulties with using interpreters (Abbe et al., 2006; Fatahi, Hellstrom, Skott, & Mattsson, 2008; Schlemmer & Mash, 2006). In study I, the blame for problems with communication through interpreters were mostly ascribed to interpreters, but if healthcare staff obtain experience of and training in the use of this tool, it could be profoundly sharpened. Quite small means of planning and action are sufficient to improve communication through interpreters (Abbe et al., 2006; Fatahi et al., 2008); training of healthcare staff will both improve the quality of the interpreting communication and increase nurses’ use of interpreters (Gerrish, Chau, Sobowale, & Birks, 2004). Despite challenges, the use of professional interpreters to bridge linguistic obstacles is associated with improved quality of care and reduced inequity in care (Karliner, Jacobs, Chen, & Mutha, 2007) and should be used, when needed, not only to share information but to develop caring relationships (II). This may be more easily said than done but if interpreters are used more often for nursing communication, then caring conversation and chatting can be part of that communication if nurses are aware of this and also have planned enough time with the interpreter. Considering the insufficiency of this tool, it should be combined with other measures to enhance communication and reduce miscommunication, such as *transcultural linking* (Abbe et al., 2006; Dohan & Levintova, 2007; Nadeau & Measham, 2006) and *providing printed information* (Abbe et al., 2006) (I).

In study III, nurses use different strategies to *protect professional composure* when they meet overwhelming emotional expressions in transcultural care. One strategy that is presented is *distancing*, which nurses use to strike a balance between closeness and distance in the caring relationship (III); this strategy has previously been found to be used by nurses to avoid stress (McGrath, Reid, & Boore, 2003). This is in line with the literature and there are plenty of studies on this issue. For example, restrained sensing is a strategy to keep a professional distance when healthcare staff are balancing sensing of patients wishes and needs (Thulesius, Hakansson, & Petersson, 2003). Further, different strategies of striving for emotional survival, including emotional shielding, are outlined in an explorative study from the context of palliative nursing (Sandgren et al., 2006). Sandgren et al. (2006) also present the subcategory of professional shielding, including balancing intimacy and shifting between professional and private life. Machintosh (2007) stresses professionalism in the caring relationship and suggests that nurses develop a working persona that facilitates switch off. According to Holsclaw (1965), unconscious withdrawal only contains the anxiety, while an awareness of the stress and the use of conscious withdrawal enable the nurse to look at the anxiety and meet it. Hence, it is important for nurses to be aware of strategies for protecting professional composure, including distancing, and use them in a conscious and positive manner. Strategies for managing nurses’ composure related to awareness of dying in end-of-life care are considered by Glaser and Strauss (1965) and shielding has been identified as a strategy to keep cool and maintain professional composure in a study on
nurses’ responses to anger (Smith & Hart, 1994). Thus, a formal theory about protecting professional composure would be of value, as this is a major element in the nursing profession (III) and probably also in other professions, for example flight attendants and policemen. A formal grounded theory “is a theory of a SGT [substantive grounded theory] core category’s general implications generated from, as wide as possible, other data and studies in the same substantive area and in other substantive areas” (Glaser, 2007, p. 4).

In study IV, the main concern of foreign-born parents in the context of childhood cancer care is how to achieve the best possible care for their child and protect their family’s interests by struggling on. Struggling on is similar to “getting through all the rough spots” (Woodgate & Degner, 2003) and “striving to survive” (Bjork et al., 2005), two concepts from childhood cancer care, and it is arguable that the conceptual framework of “struggling on” is applicable in other situations where parents are coping with childhood cancer, aside from transcultural care. However, struggling on has general implications beyond this substantive area and could probably be useful in any area where people meet challenges in a situation of perceived powerlessness, so a formal theory would be very useful.

Childhood cancer is known to alter the entire family’s life situation and the long and very intensive treatment requires involvement, responsibility and self-effacement from parents, besides entailing long period of continuous and cumulative stress (Boman et al., 2003; Norberg et al., 2005). On top of this, study IV provides important insights into the extra strains on foreign-born parents in childhood cancer care. First of all; there are several examples of foreign-born parents’ experiences of being excluded from supportive relationships because of their foreign background and as a consequence of their emigration, which may lead to higher levels of anxiety as support perceived to be good has been substantially associated with less anxiety in parents (Norberg & Boman, 2007). Secondly; it is possible that the perceived powerlessness in relation to healthcare staff is greater among parents with a foreign background, especially if there is suspicion of racism (I). Thirdly, obstacles to transcultural caring relationships, including linguistic obstacles (I), will influence parents’ possibility to succeed with persuasive communication (IV) and in fighting for their rights. A combination of these extra strains could result in an increased risk of foreign-born parents experiencing that they are failing to protect self-interest in health care, and thereby, ending up in despondent surrendering.
The four studies (I-IV) were used to generate a grounded theory of façading, the category that represents the latent pattern of behaviour which was found to unify these studies. Below follows a presentation of façading and façading to protect, including the subcategories emotional façading and façading sensitive issues. Then, façade-interpreting will be introduced, followed by a section on bridging obstacles in transcultural façading and façade-interpreting.

**Façading**

Façading and façade-interpreting (presented below) is used in all social interactions between people. Façading is the latent pattern of behaviour used in order to present, impress and cope, and to protect oneself and others. Façading is the core in this study, used to resolve the main concern of protecting self-interest in care (IV).

Façading includes showing or presenting a façade or an outer appearance and will influence other people's interpretations and subsequent impressions. Façading is similar to management of masks, front or face and is used as a figure of speech to describe the "face" that people show other people when they, for example, façade cultural, religious or social identities. This façade or outer appearance is sometimes deceptive and at other times just misleading in the sense that it shows only parts of the truth, presenting oneself in a certain way and concealing other aspects, for example hiding vulnerability and sadness and façading strength (IV). The façade can have different degrees of permeability; sometimes it can include cracks through which one can catch a glimpse of what it conceals.

Façading can be done using verbal and nonverbal communication; the latter includes signs and facial expressions, behaviours, clothing and other attributes.

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2 Rules and norms guide all interactions (Strauss, 1969) and according to "symbolic interactionism", people act toward things on the basis of the meaning those things have for them—these meanings emerge from social interaction—and meanings are modified and dealt with through interpretation. People interact with each other by interpreting each other's actions (Blumer, 1969).

3 This is to be compared with self-presentation and impression management, which includes conscious and unconscious attempts to influence and control other people's impressions of them (Goffman, 1990). The author presents a dramaturgical model with performers and audience and a front and a back region.

4 In the essay “Mirrors and masks – The search for identity” (Strauss, 1969) it is suggested that everyone presents oneself using masks and sees oneself in the mirror of others. The masks presented are related to the anticipation of other’s judgements of oneself.

5 The front refers to expressive equipment and personal front includes appearance and manner (Goffman, 1990).

6 Goffman (1955) defines the face as the social value claimed by a person in interpersonal interactions and as an image of self. In China the concept of face is central in social interaction and has two dimensions, including the image people project in public, and their personal integrity and moral character (Gao, 1998).
such as status symbols\(^7\). As language is central in the appraisal and presentation of self\(^8\), façading will be negatively influenced by linguistic obstacles (I).

The face that is presented through façading varies with the situation, that is; different façades are used depending on the context. The different contexts and cultures people live in influence their rules and norms for interactions. Transcultural care is a context where façading is more difficult and is often not understood, sometimes misinterpreted, on account of obstacles to communication (I); façading itself then becomes an obstacle to transcultural caring relationships, resulting in inequity in care (I).

Façading is how people show their social identities, status, roles and affiliation to social, cultural and religious groups. Every human being has several identities/roles and characters; for example, a person can be a husband/wife, a parent, a professional, come from a certain country, have a religion, a political orientation, a culture, a social status, and so on\(^9\). Different views on these identities and roles can become cultural and religious, as well as social obstacles to transcultural caring relationships (I). Social identities and façades are shaped by memberships of different groups and are connected to social hierarchic systems, educational levels and financial situations and will influence power relations (I). The identities and status that are shaped by memberships of different groups can contribute to feelings of safety and belonging. This can be done by using, and sometimes hiding behind, certain attributes of the group in question, for example work clothes or uniforms that can help to protect professional composure (III) and maintain a professional façade. Social identities and groups can hinder the interaction between people in different groups, obstructing transcultural caring relationships (I) and support-seeking (IV) across groups. For example, foreign-born parents often felt excluded from supportive relationships with staff and other parents at the ward because of their foreign background (IV).

Façading also occurs in organizations\(^10\), sending messages about, for example, what is prioritized and seen as important in the organization. Organizational choices will send messages to consumers. An example of an organizational ‘choice’ that can constitute an organizational obstacle to transcultural caring relationships (I) is not using organizational tools such as time allocating for bridging obstacles to transcultural caring relationships, for example, interpreter-relying (II) for nursing communication and caring conversations.

\(^7\) Status symbols are means of displaying one’s social position (Goffman, 1951), including occupational and class symbols.

\(^8\) The relationship between language and identity is considered at greater length in Strauss’ chapter on this issue (1969, pp. 15-30).

\(^9\) According to Mead (1934), the self is composed of two components, “I” and “Me”. The I is the active, dynamic interpreting component of the self. The Me is the object of self-reflection; each individual has multiple Me’s, such as mother, daughter and so on.

\(^10\) According to Goffman (1990) any individual or organization must maintain a proper front to influence the impressions that others receive of them so that they are congruent with the perceptions they want to convey.
Façading to Protect

Façading is often done in order to protect oneself and/or others. For example, foreign-born parents who are staying strong are concealing vulnerability and façading strength in order to protect (IV). Furthermore, protecting self-interest in health care (IV) includes approaches in interaction with healthcare staff that will be shaped, not only by the personality of the parent, but also in the transcultural interaction with healthcare staff; that is, what healthcare staff are façading and how this is interpreted by foreign-born parents. Trustful cooperation implies façading trust and cooperativeness, while fighting implies façading strength and conviction (IV).

Another example would be when nurses protect professional composure, presenting a professional façade in order to protect themselves and others from overwhelming emotional expressions of anger and wailing (III). This includes using various strategies such as controlled expression and power display which are about façading calm, control and power (III). Also management of space is done to protect from overwhelming emotional expressions and in order to façade calm in the care situation. Furthermore, when nurses use the strategies of escape/avoidance and distancing, they are often presenting a busy and professional façade to protect themselves (III). Façading to protect includes the subcategories emotional façading and façading sensitive issues.

Emotional Façading

How people express or façade emotions differs between cultures, genders and individuals (III), resulting in differences in emotional expressions, which has been identified as an obstacle to transcultural caring relationships (I). The Swedish norm is that emotions should be controlled and expressed more calmly (III), thus façading control and calm. Façading grief varies; overwhelming emotional expressions of grief have been categorized as wailing (III). In study III, overwhelming emotional expressions of anger and wailing have been found to override nurses’ professional preparedness and they continuously resolve this by protecting professional composure. Professional composure (III) is part of the nursing culture and implies façading professional calm despite strong reactions. Protecting professional composure involves strategies for protecting oneself and others from overwhelming emotional expressions; one of these strategies is controlled expression, which is about façading professional calm (III).

Overwhelming emotional expressions could be seen as acts resulting in loss of face and dignity (Goffman, 1955) in that rules (Swedish norms) for social interactions and expressive orders are not respected. To lose face is to be in a wrong face, out of face or shamefaced and to avoid this; particular expressive orders, consistent with the face, need to be sustained (Goffman, 1955).

In the words of Goffman (1955) this could be called face-saving practices.
**Façading Sensitive Issues**

This is about managing others’ impressions of a sensitive issue. It can sometimes be deceptive, at other times just misleading, in the sense that only parts of the truth are presented and other aspects are concealed. There are different levels of façading sensitive issues, which is similar to different levels of truth-telling. Truth-telling differences concern different views and practices regarding conveying difficult and sensitive information to the patient and can differ between individuals and cultures. In the context of pediatric oncology, the ‘truth’ concerns honest communication about the disease, treatment and prognosis. Those who favour truth-telling believe that it is a prerequisite for honesty, trustworthiness and also to the patient’s ability to prepare for and cope with the situation. One reason for this is the belief that it is usually just the verbal communication of the ‘truth’ that is silenced, while nonverbal communication keeps telling the truth and non-verbal communication can be very powerful. The verbally communicated message may be contradicted by non-verbal façading, which might suggest ‘betrayal’. For example, if parents of a dying child have a low level of truth-telling/high level of façading sensitive issues, nonverbal communications from parents and staff will reveal the ‘truth’ to the child and, most importantly, the child’s disease will inform the child, who may be lonely in this knowledge. Furthermore, the child’s fantasy may interpret these façades and imagine a worse and more horrifying picture of what is happening.

Those who do not in favour of truth-telling believe that it can weaken the spirit, destroy hope and cause the patient further suffering, fear, anxiety, or even deterioration in health. There are different façading strategies; furthermore, there is a difference between knowing and saying. Different levels of façading sensitive issues are used in all interactions. The truth is seldom conveyed bluntly; people try to avoid being harsh, mitigating the truth and giving it in portions to make it bearable. Thus, it is not either/or—the whole truth and nothing but the truth versus withholding the truth—but rather different levels of and different strategies for façading sensitive issues.

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13 This is to be compared with ‘veiling sexualities’, which is about nurses hanging a veil of silence around the taboo topic of iatrogenic sexual dysfunction by withholding information from psychiatric patients (Higgins, Barker, & Begley, 2006). Veiling is done in order to protect nurses from discomfort and embarrassment but also as a ‘protective withholding of information’ from patients to enhance their compliance with medication.

14 “The Western ideals of honesty and integrity are often incongruent with culturally informed needs to ‘save face’, avoid ‘shame’ or prevent ‘shock’” (Oliffe, Thorne, Hislop, & Armstrong, 2007, p. 12).

15 In several studies, concern for a negative impact on patients, including taking away their hope, has been found to be a reason for healthcare professionals withholding information on prognosis (Hancock et al., 2007) from adult patients with advanced life-limiting illnesses.

16 This has also been found in a study on truth-telling at the end of life (Deschepper et al., 2008).
**Façade-interpreting**

This involves how a façade is perceived and understood by observers and what impressions they receive\(^{17}\). It often entails unconscious processing of the information that is provided through façading. Façade-interpreting includes acknowledging identities and a categorization of the person\(^{18}\) and may be difficult across cultures on account of different meanings of façading.

In the interpretation of a person’s façade, it is often the case that only some roles or identities are acknowledged and become dominant. The parts that are acknowledged are of contextual importance, for example being a parent in childhood care, but also what is seen as different, for example foreign-born. When an identity/façading is not familiar and comprehensible on account of cultural differences\(^{19}\), there is a great risk of stereotyping\(^{20}\) and applying familiar roles or identities provided by, for example, the media to make it more understandable. The categorization\(^{21}\) of people into groups is an important part of façade-interpreting and can build walls between people and between “us and them”. These groups are interpreted differently and are ascribed different properties. Thus, categorizing people into social, cultural and religious groups can result in *obstacles to transcultural caring relationships* (I). Foreign-born is a status and façade that can be interpreted and ascribed different characteristics and qualities such as problem versus asset.

Façades are interpreted differently between cultures and individuals. Thus, a given action or a symbol used in façading may have a different meaning\(^{22}\) and be interpreted differently and can easily be misinterpreted and misunderstood by a person from a different country, social or cultural group. Thus, in the context of transcultural care, façade-interpreting itself becomes an *obstacle to*

\(^{17}\) This is to be compared with impressions of self-presentation (Goffman, 1990) and modifying and dealing with meanings of social interactions by interpreting each other's actions (Blumer, 1969).

\(^{18}\) For more about naming and classification in relation to identity, see Strauss’ writings on this issue (1969, pp. 15-30).

\(^{19}\) This difficulty of façading and façade-interpreting in transcultural encounters has been expressed by Berreman (1962) in the following way: “The task is especially difficult and tedious when the cultural gap between participants and audience is great. Then the impression [interpretation] that a given action [façading] will convey can not be predicted; audience reaction is hard to read and performance significance is hard to judge. Misinterpretation occurs frequently and sometimes disastrously so in such circumstances. Anyone who has been in an alien culture can cite faux pas [blunders] resulting from such misinterpretation. Inadvertent disrespect is a common type (p. 12).”

\(^{20}\) Stereotypes are applied when trying to interpret the cues given by an unfamiliar individual and references are used from previous interactions with similar individuals (Goffman, 1990).

\(^{21}\) The tendency to categorize, stereotype and oversimplify is thoroughly human (Strauss, 1969).

\(^{22}\) One example is the headscarf (veil), a public symbol used in façading to communicate a Muslim identity that often is interpreted and given different meaning by observers, depending on their cultural background. The headscarf can be perceived as a symbol of freedom and modern pluralism of identity or as traditional, backward, oppressing and detrimental of women (Kulenovic, 2006).
transcultural caring relationships (I). For example, the interaction between genders is a possible problem in transcultural care and an example of cultural and religious obstacles to transcultural caring relationships (I). In study I the example is given of men born in a Muslim culture who refuse to shake the hands of women, which healthcare staff interpret as depreciating women. This might be a misinterpretation of the façading/action of those Muslim men who are simply following their beliefs or religious rules regarding the public interaction between genders. Furthermore, healthcare staff have a professional preparation (III), which includes education and previous experience, providing them with hypotheses about possible reactions and expressions. Differences in emotional façading, including overwhelming emotional expressions, have been found to override professional preparedness; that is, they refute hypotheses about expected reactions (III). Transcultural care is a context in which nurses can encounter reactions and expressions that are unexpected and overwhelming and thus difficult to interpret.

A façade may or may not constitute an obstacle, depending on how it is interpreted. Perceived differences become obstacles and the more significant the differences, the greater the obstacles to transcultural caring relationships (I). Lack of awareness of one’s own façading and possible interpretations can likewise constitute obstacles to transcultural caring relationships (I).

Bridging Obstacles to Transcultural Façading and Façade-interpreting

Façading is, as stated, a behaviour used to resolve the main concern of protecting self-interest, which can be difficult in the context of transcultural care. Differences in façading and façade-interpreting constitute obstacles to transcultural caring relationships, and bridging could be used to overcome these obstacles and to see past the surface and prejudice in transcultural encounters.

Communicational Tools

This includes non-verbal communicating and interpreter-reliance (II). An awareness of one’s own non-verbal communicating in façading and possible interpretations could help overcome obstacles to the same. Furthermore, using the tool of interpreter-reliance could enable some interpreters to also function in transcultural-linking and help in understanding culturally relevant interpretations of one’s own façading and also assist in façade-interpreting.

Transcultural Tools

These tools can facilitate transcultural understanding and will make it possible to see beyond façades and make informed interpretations. Transcultural learning is a continuous process (II) and includes learning about the meanings of façading in different cultures and religions, as well as possible interpretations of one’s own
façading. This should also be combined with specific knowledge about the individual patient’s façading and an awareness of the risk of stereotyping. Transcultural reflecting is an approach (II) that could be used in façade-interpreting to facilitate informed interpretations of social, cultural and religious façading. It could also be used to create awareness of one’s own façades and possible interpretations of others and thereby facilitate interaction. Transcultural linking is the process whereby a person functions as a mediator (II) and that person can be used in façade-interpreting.

Organizational Tools

This is about the leadership of an organization providing necessary resources and conditions for bridging obstacles to transcultural caring relationships, including time-allocating and transcultural training (II). If they are or are not doing so, the organization is façading its priorities, and they need an awareness of its communication through façading and possible interpretations as this could help overcome obstacles in transcultural care.
DISCUSSION OF FAÇADING

Façading emerged as the latent pattern of behaviour that unifies the present studies. Façading is a natural part of every human interaction, used to present, impress, cope and protect. The main concern that emerged in the present study is the protection of self-interest. It is used in hiding parts of ourselves or sensitive issues behind a façade as a way of coping but can also be limiting and hindering in social interactions. Healthcare staff need to be aware of façading and façade-interpreting and use that awareness; if a glimpse is caught of what is concealed behind the façade of parents, that is something which should be handled with caution and respect.

It has been suggested that nurses protect the self by developing a working persona which facilitates the possibility of switching off (Mackintosh, 2007). This working persona is similar to a professional façade that nurses use. But while Machintosh (2007) argues that the working life is distinguished from the personal self, it could be argued that these different roles/facades are different parts of the person or, in the words of Mead (1934), different Me’s are parts of the self.

Emotional labour has been defined as the induction or suppression of feelings in order to maintain an outwardly calm appearance; suggested strategies include surface and deep acting (Hochschild, 1983), which is similar to façading emotions. This led to a discussion in nursing about authenticity and whether acting is the same as faking (de Raeve, 2002; Smith & Lorentzon, 2005). It is argued that nurses can learn acting techniques to manage the emotions of patients and themselves (Smith & Lorentzon, 2005). If this acting were compared with Goffman’s (1990) dramaturgical model in his theory on impression management, perhaps it would make the discussion of authentic versus fake less acerbic, as it is suggested to be a natural part of all interaction.

Understanding the delicate matter of façading sensitive issues so that it can be received, interpreted and dealt with in a positive manner is essential in childhood cancer care. There is a need to try to understand the parent and the family and how our façading of sensitive issues is interpreted depending on world view, life style, values and beliefs (Leininger, 2002). Façading of sensitive issues needs to be individualized in each interaction, as forcing the truth on someone can be as insensitive as withholding it (Gold, 2004). Furthermore, verbal communication is central in Western cultures, while other means of façading sensitive issues may be more prominent in other cultures, that is, not withholding but façading in nonverbal ways and maybe also in slower pacing. Truth-telling has been viewed as a process that should be ‘dosed and gradual’ in a step-by-step approach (Deschepper et al., 2008, p. 3). In this approach it is essential to be aware of one’s own façading but also the parent’s and child’s meaning making and façade-interpretations. The level of façading sensitive issues should always be chosen with the best interests of the patient and family in mind, rather than motivated by protection of healthcare staff from difficult and embarrassing situations. Despite this, several studies have
found discomfort of healthcare professionals as a reason for withholding information (Hancock et al., 2007; Higgins et al., 2006). The attitudes of healthcare staff concerning truth-telling were explored in study I but it would also be interesting to study what they actually tell parents and children as studies in adult care have shown that, even though healthcare professionals are in favour of truth-telling, in practice they avoided the topic of prognosis (Hancock et al., 2007).

To label someone foreign-born or immigrant not only indicates that person’s background but also places him/her in a category (Strauss, 1969) and creates a distance between “us” and “them”. While some categorization can be used positively, the human tendency to stereotype needs to be avoided. In study II, the risk of cultural knowledge resulting in stereotyping and the importance of being aware of intra-group differences are discussed; this is also important to bear in mind when people’s façades are interpreted. In the 1950s-70s—when primarily European immigrants came to Sweden for labour market reasons (Swedish Migration Board, n.d.-a)—immigrants were often viewed as resources in society. Today, most immigrants are coming from non-Western countries; belonging to the group of people with a foreign background and having the social identity of “foreign-born” or “immigrant” is in Sweden often associated with problems (I). As people mirror themselves in other people’s judgment, the latter’s interpretation and appraisal will influence the former’s identity (Strauss, 1969). Once a person acquires a reputation, it seems to become a part of the face that person maintains (Goffman, 1955), thus making people’s judgements self-fulfilling. These stereotypes and negative associations of whole groups as well as individuals need to be challenged in healthcare situations and in society at large. Furthermore, racism and prejudice, which are consequences of social obstacles (I) and often misinterpretations of façades, could be prevented if the human being behind the façades of social and cultural identities was seen.

Below, important implications are suggested for the daily practice of healthcare staff, education and training, research and organizational policies.
IMPLICATIONS

Study I is an important first step that can contribute to an understanding of obstacles to transcultural caring relationships from the perspective of healthcare staff. As these obstacles are recognized, they can be used to guide practice. Furthermore, in order to ensure the provision of high-quality care to families with a foreign background, healthcare staff need to bridge obstacles to transcultural caring relationships, using and combining tools presented in study II. Experience and education in using the tool of interpreter-reliance (II) have high priority as this will improve the quality of communication and care for families experiencing linguistic obstacles (I). This is a prioritised area for further research. For example, an intervention study evaluating the use of printed information in different languages and interpreters for nursing communication, caring conversation and chatting, and in the development of transcultural caring relationships, would be of great importance. Education is also important in providing healthcare staff with tools for transcultural care and needs to be prioritized and implemented in the basic training of healthcare staff as well as in further education and adequate transcultural training of healthcare staff in the clinical context, including childhood cancer care, which is the employer’s responsibility. Healthcare organizations should provide resources to assist in bridging obstacles to transcultural caring relationships; organizational changes are prerequisites as this cannot be the sole responsibility of individual healthcare staff. Time allocation for transcultural care is one very important example. Furthermore, childhood cancer care has the organizational structures and networks that could be used on a national and international level in this important area: carrying through suggested interventional studies on a larger scale, implementing transcultural training, including training in interpreter-reliance, adjusting and changing policies and routines in order to achieve a congruent care for everyone irrespective of their language, religion, culture and social situation. For example, Swedish childhood cancer care has national nursing programs—updated and distributed by the Swedish organization for nurses in pediatric oncology (SIBO)—for several of the larger diagnostic groups as well as general programs for different areas such as nausea. A similar program needs to be developed for transcultural nursing in childhood cancer care, including a checklist for nursing conversation through interpreters. Furthermore, the International Society of Pediatric Oncology (SIOP) Working Committee on psychosocial issues has published a number of guidelines for the pediatric oncology community, addressing issues such as the therapeutic alliance between families and staff (Masera et al., 1998). Similar guidelines are needed for transcultural childhood cancer care.

In study III, concepts are presented that can help raise awareness of what happens in situations of overwhelming emotional expressions in transcultural care. Concepts can be used by healthcare staff and units to make changes and consciously prepare to meet overwhelming emotional expressions, especially in emotionally charged fields such as childhood cancer care. Furthermore, nurses
need to be aware of strategies for protecting professional composure, to use them in a positive and conscious manner, and this should be integrated in both their basic and their further education. A formal theory of protecting professional composure would be of value as this is a major element in the nursing profession and probably also in other professions. There also needs to be a shift in focus in research and practice from staff to the emotion-expressing parent. Studies need to be conducted with parents to understand underlying reasons and conditions for differences and similarities in emotional expressions and also how healthcare staff could best assist them in their struggle.

Study IV provides important insights into the human experience of being a parent dealing with childhood cancer and the extra strains on foreign-born parents. With a better understanding of the problems parents face, healthcare staff can adapt strategies and also improve their own understanding and anticipation of parents’ approaches. As foreign-born parents are often excluded from supportive relationships, special efforts need to be made to offer support to these parents and families, for example through an interventional study or a special program with, for example, “god-families”. Furthermore, struggling on has general implications, so a formal theory would be of great value.

The present thesis could help to make healthcare staff and organizations aware of their façading and possible interpretations but also different meanings of façading across cultures. Understanding the delicate matter of façading sensitive issues is essential in childhood cancer care. Façading of sensitive issues needs to be individualized in each interaction, and the complexities of truth-telling recognized in education and practice. Many years have passed since the study on awareness of dying by Glaser and Strauss (1965) and it would be interesting to do a similar study today and see what healthcare staff actually tell parents and children. Furthermore, tools, presented in the section on bridging obstacles to transcultural façading and façade-interpreting, need to be provided and used in health care to see beyond the surface and prejudice in transcultural encounters.
CONCLUDING REMARKS

This thesis is based on four studies that were conducted to explore the situation of families with a foreign background in childhood cancer care. Further a grounded theory was generated to unify these studies. Using GT, the aim was to study the main concerns of participants and how they resolve them. The behaviour resolving the main concern becomes the core. The core categories presented include bridging obstacles to transcultural caring relationships, protecting professional composure, struggling on, and façading. Studies II-III present different strategies used by healthcare staff in dealing with obstacles to transcultural caring relationships (I), and overwhelming emotional expressions (III). Study IV presents different approaches used by foreign-born parents as they are struggling on to achieve the best possible care for their child and protecting their family’s interests. Façading is the latent pattern of behaviour used by healthcare staff and foreign-born parents to resolve the main concern of protecting self-interest and is central in transcultural interactions, as it is often misunderstood. These studies provide insights into social processes and interactions in transcultural childhood cancer care that could be used to explain, interpret and predict. The results should be used to improve the situation of families with a foreign background in childhood cancer care.

The Swedish Health and Medical Service Act (Ministry of Health and Social Affairs, 2003) prescribes care on equal terms to the whole population and the National Public Health Commission (2000) in Sweden has developed a national health policy with a strong focus on reduction of health inequalities. Furthermore, ethical values in Stockholm County (Blomgren & Stockholm County Council, 2002) hold that all human life has an inherent value and dignity independent of personal qualities and functions in society, leading to the right to care on equal terms. However, the present studies indicate a discrepancy between policy and clinical practice and healthcare staff need education and experience in using strategies to better meet needs in transcultural care. The presented strategies and approaches could be used in achieving a more equal childhood cancer care for families with a foreign background.
Det övergripande syftet med avhandlingen var att utforska och få kunskap om vårdsituationen för familjer med utländsk bakgrund i barncancervården i Sverige. Att drabbas av barncancer innebär en långdragen, kumulativ stress för hela familjen. Dessutom har Sverige blivit ett allt mer mångkulturellt samhälle resulterande i ett behov av forskning och utbildning i transkulturell vård.

Avhandlingen består av 4 studier; I – III utgår från hälso- och sjukvårdspersonalens perspektiv medan studie IV utgår från utrikes födda föräldrar perspektiv. Dessa studier användes sedermera för att generera en integrerande grundad teori. För samtliga studier har metoden grundad teori (GT) använts eftersom den syftar till att upptäcka förklaringsmodeller för problemlösningar av informanternas huvudsakliga angelägenhet; förklarar beteendemönster som är problematiska och relevanta.

Studierna I & II inkluderade 5 fokusgrupps intervjuer med hälso- och sjukvårdspersonal och 5 enskilda intervjuer med sjuksköterskor inom barncancervården. I studie III utfördes 12 individuella intervjuer med sjuksköterskor från pediatrisk hälso- och sjukvård. I studie IV intervjuades 11 utrikes födda föräldrar varav 4 med tolk. Data analyserades med hjälp av den ständigt jämförande metoden GT.


Dessa studier ger en inblick i sociala interaktioner inom transkulturell barncancervård och kan användas för att förklara, tolka och förutsäga. Generella teorier på kärnkategorierna skulle vara av värde och presenterade strategier och tillvägagångssätt kan användas för att uppnå en passande och jämställd barncancervård för familjer med utländsk bakgrund.
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REFERENCES


ethnographic researcher in a familiar nursing context. *Nurse Researcher, 14*(3), 
25-35.

de Raeye, L. (2002). The modification of emotional responses: A problem for trust in 
nurse-patient relationships? *Nursing Ethics, 9*(5), 465-471.

Deschepper, R., Bernheim, J. L., Stichele, R. V., Van den Block, L., Michiels, E., Van 
perspective of patients and professional caregivers. *Patient Education and 
Counseling, 71*(1), 52-56.

An interview method for nursing research. *The Journal of Neuroscience Nursing, 
26*(3), 175-180.

Dohan, D., & Levintova, M. (2007). Barriers beyond words: Cancer, culture, and 
translation in a community of Russian speakers. *Journal of General Internal 
Medicine, 22 Suppl 2*, 300-305.

Ekblad, S., & Baarnhielm, S. (2002). Focus group interview research in transcultural 
484-500.

situation and problems as reported by children with cancer and their parents. 
*Journal of Pediatric Oncology Nursing, 14*(1), 18-26.

reports of changes and challenges that result from parenting a child with cancer. 
*Journal of Pediatric Oncology Nursing, 14*(3), 156-163.

Liber.

views on consultations with interpreters: A triad situation with complex issues. 
*Scandinavian Journal of Primary Health Care, 26*(1), 40-45.

*Textbook of palliative medicine* (pp. 111-116). London; New York: Hodder 
Arnold; Distributed by Oxford University Press.

Gao, G. (1998). An initial analysis of the effects of face and concern for "other" in 
Chinese interpersonal communication. *International Journal of Intercultural 
Relations, 22*(4), 467-482.

The use of interpreters in primary care nursing. *Health & Social Care in the 
Community, 12*(5), 407-413.


Sociology Press.

Qualitative Social Research [On-line Journal], 3*(3), Retrieved April 30, 2008, 
e.htm.

Qualitative Social Research [On-line Journal], 5*(1), Art. 7, Retrieved April 30, 
2004glaser-e.htm.

Sociology Press.


