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**Communication over language barriers in
paediatric oncology care –
A prerequisite for equity in care**

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Communication over language barriers in paediatric oncology care – A prerequisite for equity in care

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To my family with love

“Why make it simple, when you can make it so beautifully complicated?”

Confucius

ABSTRACT

Background: Out of Sweden's more than two million children under the age of eighteen, 23% have a foreign background, which means that every fourth child has a foreign background. We know that migration and the mixed population are reflected in all healthcare settings nationwide and are naturally also reflected in paediatric oncology care. Paediatric oncology care is a complex communication and information context in which effective and patient-safe communication between specialist nurses and other healthcare personnel and patients and their families is of particular importance in order to avoid the risk of miscommunication that could threaten patient-safe care. The use of professional interpreters is an essential tool for achieving adequate clinical practice with patients with limited Swedish proficiency. Despite the fact that research shows that using interpreters improves care and increases patient safety, research also shows that the use of interpreters is still limited and threatens children's right to equity in care. Thus, there is a need to gain a deeper understanding of how communication over language barriers is performed and enabled in a paediatric oncology care context, and what factors limit the use of interpreters.

Aims: The overall aim of this research project was to investigate communication over language barriers among healthcare personnel in paediatric oncology care and the use of interpreters and other communication tools to overcome language barriers. The specific aims were: a) exploring interpreters' experiences of interpreting between healthcare personnel and patients/families with limited Swedish proficiency in paediatric oncology care (Study I), b) exploring interpreters' perceived strategies in interpreted-mediated consultations between healthcare personnel and patients/families with limited Swedish proficiency in paediatric oncology care (Study II), c) developing and validating the Communication over Language Barriers questionnaire (CoLB-q) (Study III), and d) investigating communication over language barriers among healthcare personnel in paediatric oncology care (Study IV).

Methods: Study I & II had an inductive exploratory qualitative design using semi-structured interviews with eleven interpreters with experiences of interpreting in paediatric oncology care. Study III was a methodology study in questionnaire development using cognitive and focus groups interviews, a pilot test and a test-retest, and Study IV was a national multisite cross-sectional survey using the CoLB-q.

Key findings: The interpreters in Study I struggled to establish a meeting point of understanding including all parties in the interpreter mediated consultation. In Study II the key findings were that in order to carry the bilingual conversation; the interpreters used strategies clearly outside their assignment, as for example by alleviating and adapting words

and phrases. Study III showed that the CoLB-q had sufficient content and face validity and, regarding reliability; the test-retest showed that the results were stable. In Study IV, almost 90% of the participants believed that the use of interpreters is important for the patients' involvement in care and patient safety. Nevertheless, this belief did not translate into the actual use of professional interpreters among the healthcare personnel in paediatric oncology care.

Conclusion: Language barriers negatively affect specialist nurses' and other healthcare personnel's ability to communicate effectively with their patients and thereby have a negative impact on the provision of appropriate, patient-safe and effective care. Due to its direct impact on health outcomes and equity in healthcare, high-quality interpreting should be a priority. Efficient professional interpretation is an important part of effective and patient-safe communication and a vital foundation for equity in healthcare.

SAMMANFATTNING PÅ SVENSKA

I Sverige idag lever mer än två miljoner barn under 18 års ålder. Av dessa barn har 23% utländsk bakgrund, vilket innebär att ungefär vart fjärde barn har en utländsk bakgrund. Vi vet att en blandad befolkning finns representerad inom alla instanser i vårt samhälle, liksom den finns representerad inom hälso- och sjukvården och förstås även inom barnoncervården. Barnoncervården är en komplex vårdssituation som kräver mycket information till barnen och deras föräldrar. Patientsäker kommunikation och information mellan specialistsjuksköterskor och annan hälso- och sjukvårdspersonal och barnen och deras familjer är därmed av stor betydelse för att minimera risken för allvarliga kommunikationsbrister och missförstånd. Kommunikationsbrister som kan hota en patientsäker vård. Att använda sig av professionella tolkar är ett viktigt verktyg för att undvika kommunikationsbrister mellan hälso- och sjukvårdspersonalen och barn och deras familjer som har begränsade kunskaper i det svenska språket. Men trots att forskning visar att tolkanvändning förbättrar vården och ökar patientsäkerheten visar den också att tolkar inom hälso- och sjukvården inte alls används i den uträkning att kommunikationen är patientsäker och hotar därmed barnens rätt till en patientsäker vård på lika villkor.

Syftet med den här avhandlingen har varit att få en djupare förståelse för hur kommunikation över språkbarriärer hanteras av hälso- och sjukvårdspersonalen inom barnoncervården och hur och när tolkar används i det kliniska arbetet. De specifika målen var att a) undersöka tolkarnas erfarenheter av att tolka mellan hälso- och sjukvårdspersonalen och barn och deras familjer med begränsade kunskaper i svenska språket (studie I), b) undersöka tolkarnas egna strategier i hur de hanterar det tolkade samtalet mellan hälso- och sjukvårdspersonalen och barn och deras familjer med begränsade kunskaper i svenska språket c) att utveckla ett frågeformulär om kommunikation och språkbarriärer inom barnsjukvård (CoLB-q) (Studie III), samt d) att kartlägga hur kommunikation över språkbarriärer hanteras bland hälso- och sjukvårdspersonal inom barnoncervården med frågeformuläret som utvecklades i studie III (Studie IV) .

Den metod som användes i studie I & II var en kvalitativ intervjustudie med 11 tolkar med erfarenhet av att tolka inom barnoncervården. Studie III var en metodstudie i frågeformulärsutveckling där vi använde både individuella- och fokusgruppsintervjuer, ett pilot-test och ett test-retest, och studie IV var en nationell tvärsnittsundersökning med frågeformuläret CoLB-q.

Resultatet visade att tolkarna i studie I kämpade för att skapa en mötesplats för förståelse och att alla parter i tolksamtalet måste vara delaktiga i detta. Studie II visade att tolkarna kämpar

med att axla den tvåspråkiga konsultationen och att de använder strategier för att göra det och som ibland är utanför deras tolkuppdrag, till exempel genom att lindra och anpassa ord och fraser i tolksamtalet. Studie III visade att frågeformuläret CoLB-q är tillförlitligt och har hög giltighet och därmed kunde användas för kartläggningen i studie IV. I studie IV rapporterade nästan 90% av respondenterna att användningen av tolkar är av stor betydelse för barnens och familjens delaktighet i vård och för att öka patientsäkerheten. Trots denna övertygelse rapporterade respondenterna att de inte alltid använder tolkar i kommunikationen med barnen och familjen.

Slutsatsen är att språkbarriärer påverkar specialistsjuksköterskors och annan hälso- och sjukvårdspersonals möjlighet att kommunicera patientsäkert med barnen och deras familjer med begränsade kunskaper i svenska språket. Genom språkbarriärerna riskeras den patientsäkra kommunikationen och därmed borde användandet av professionella tolkar bli en självklar del av vården av barnet och därmed säkerställa barnens rätt till en patientsäker vård på lika villkor.

LIST OF SCIENTIFIC PAPERS

This doctoral thesis is based on the following four original papers, which are referred to in the text by their Roman numerals (I–IV):

- I. Creating a meeting point of understanding: Interpreter's experiences in Swedish childhood cancer care
Johanna Granhagen Jungner, Elisabet Tiselius, Kim Lützén, Klas Blomgren & Pernilla Pergert
Journal of Pediatric Oncology Nursing, 2016, Vol. 33(2), pp. 137–145
- II. The interpreter's voice: Carrying the bilingual conversation in interpreter-mediated consultations in paediatric oncology care
Johanna Granhagen Jungner, Elisabet Tiselius, Klas Blomgren, Kim Lützén & Pernilla Pergert
Accepted in Patient Education and Counseling, October 2018
- III. Development and evaluation of the Communication over Language Barriers questionnaire (CoLB-q) in paediatric health care
Johanna Granhagen Jungner, Elisabet Tiselius, Marika Wenemark, Klas Blomgren, Kim Lützén & Pernilla Pergert
Patient Education and Counseling, 2018, Vol. 101(9), pp. 1661–1668
- IV. Language barriers and the use of interpreters – A national multisite cross-sectional survey in paediatric oncology care
Johanna Granhagen Jungner, Elisabet Tiselius, Klas Blomgren, Kim Lützén & Pernilla Pergert
Submitted

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LIST OF ABBREVIATIONS

| | |
|--------|--|
| CoLB-q | Communication over Language Barriers questionnaire |
| RN | Registered Nurse |
| MD | Medical Doctor |
| NA | Nursing Assistant |

LIST OF DEFINITIONS

| | |
|-----------------------------|--|
| Children | Used in this thesis. Includes children and adolescents from 0 to 18 years in accordance with the United Nations Convention on the Rights of the Child. |
| Family | Used in this thesis. Any member of a child's family such as parents or other guardians, siblings and other key persons in proximity to the child. |
| Interpreter | A person who interprets on site or via telephone/video, booked through an interpreting agency. |
| <i>Ad hoc</i> interpreter | An individual who translates (i.e. a relative, sibling, etc.). |
| Intercultural communication | Emphasises the interactive side of communication and information sharing between different cultures and/or social groups. |
| Equality | Equality is the condition of being equal. |
| Equity | Equity is the absence of avoidable and remediable differences among groups of people; in this thesis, children. |
| Foreign background | Individuals born abroad or born in Sweden but with two foreign-born parents. |
| Culture | The way of life, especially the general customs and beliefs, of a particular group of people, at a particular time. |

1 INTRODUCTION

“Not long ago, I was caring for a 9-year-old boy who was very ill. His father was with him all the time but could speak neither English nor Swedish. In the daily care of the child, the child himself had to translate between his father and the registered nurses, medical doctors and nursing assistants. The child assumed responsibility for translating questions about treatment, medication, medical examinations and procedures. I felt this was extremely unethical and far removed from the patient-safe care we were all taught from the first day of our specialist training. From my perspective as a specialist nurse student, I couldn’t understand how this could be acceptable among colleagues in a highly-specialized paediatric hospital.”

(Specialist nursing student during clinical clerkship, May 2017)

Working as a specialist nurse in paediatric healthcare requires expert knowledge about paediatric diseases, treatment and a broad knowledge of children’s development and how to communicate with children. Working in paediatric healthcare also includes close contact and communication with the patient’s family. Communication is one of the main foundations of paediatric healthcare and language barriers negatively influence the ability of children and parents to participate in care and to interact with specialist nurses and other healthcare personnel. Language barriers threaten patient safety and quality of care, i.e. patients are at significantly greater risk of developing serious medical complications and patient-safe communication is vital for the patient’s treatment and recovery.

The four papers included in this thesis deal with communication over language barriers in paediatric oncology care from different perspectives, i.e. from the perspectives of interpreters and healthcare personnel. The overall aim of the research project was to investigate communication over language barriers in paediatric oncology care and the use of interpreters and other communication tools in relation to language barriers.

2 BACKGROUND

2.1 THEORETICAL FRAMEWORK OF NURSING PRACTICE

The metaparadigm of nursing was developed to define what nursing is always about, no matter what the context or where in the world nursing takes place. This metaparadigm comprises four core concepts: the human being, the environment, health and nursing (Fawcett, 1984). These concepts are the foundation of an abstract, global and all-encompassing paradigm of nursing and the nursing profession (Fawcett, 2000) and provide the basis for nursing from a patient-centred and holistic perspective. According to the International Council of Nurses (ICN), the fundamental responsibilities of nursing are: to promote health, prevent illness, restore health and alleviate suffering. The ICN defines nursing as the encompassing, autonomous and collaborative care of individuals of all ages, families, groups and communities, ill or healthy and in all settings (International Council of Nurses, 2002).

The International Council of Nurses' (2012) Code of Ethics defines the core of nursing to be respect for human rights as defined by the World Health Organization (WHO), including cultural rights, the right to choose and be listened to, the right to dignity and the right to be treated with respect. Nursing care is respectful of and unrestricted by, for example, considerations of age, ethnicity, culture, disability or illness, gender, sexual orientation, nationality or social status (International Council of Nurses, 2012). A nurse is obliged to ensure that the individual patient receives accurate and adequate information in a culturally-appropriate manner upon which to base consent for care and treatment and to advocate for equity in healthcare (a.a.).

2.1.1 The nursing profession in paediatric healthcare

Healthcare involving children is special because of the family's role in relation to the care of the child. The family is required to be present and involved in the care, as well as in decisions about the treatment of the child (Wettergren, Blennow, Hjern, Soder, & Ludvigsson, 2016). Paediatric healthcare is also unique because the care is based on children's rights to have their views and wishes respected according to their age, developmental level, as well as growing autonomy (Ministry of Social Affairs, 2018).

The nursing profession in paediatric healthcare in a Swedish context comprises different levels of higher education. Working in paediatric healthcare requires a Postgraduate Diploma

in Specialist Nursing – Paediatric Nursing with a Degree of Master of Medical Science with a Major in Nursing (Ministry of Social Affairs, 2018).

Paediatric healthcare is a broad medical field of knowledge that includes diseases and health conditions in children, adolescents and the neonatal period. This specialist field requires deep knowledge of children’s physiology, developmental psychology and cognitive abilities, as well as knowledge about how to respond to and communicate with children based on their level of maturity and how to treat and care for children and their families in vulnerable situations (National Associations of Paediatric Nursing, 2017). The paediatric patient group is heterogenic in the sense of its broad differences in cognitive maturity, physiological development and differences in symptoms and diagnoses compared to adult patients.

Children diagnosed with severe diseases are treated during prolonged periods at hospital together with their families. Some children have a limited ability to express their needs and wishes. To be able to address this complex and highly-specialized care situation, the specialist nursing profession requires specific knowledge, skills and competence in communicative abilities and also requires the skills and competence to handle children with trust and confidence based on what is best for the child (Ministry of Social Affairs, 2018; National Associations of Paediatric Nursing, 2017).

2.2 ACTS AND REGULATIONS IN PAEDIATRIC HEALTH CARE

The United Nations Convention of the Rights of the Child concerns child-specific needs and rights, and states that every child has the right to life and basic needs. Children have the right to development, protection and the right to participate in matters concerning themselves (United Nations Convention on the Rights of the Child, 1989). More specifically, Article 2 concerns non-discrimination, which means that every child should be treated with equity right regardless of their age and level of maturity and should be able to express their opinion and be listened regardless of their ethnicity, colour and language background; Article 12 concerns the right to express one’s opinions and the right to be listened to. Children have this to in all matters that affect them. Also, Article 17 states that children have the right to receive information about what is important for their health and well-being.

If we look more closely at our own societies and the rights about understandable information and non-discrimination, we could state that all Nordic countries have legislation on the right

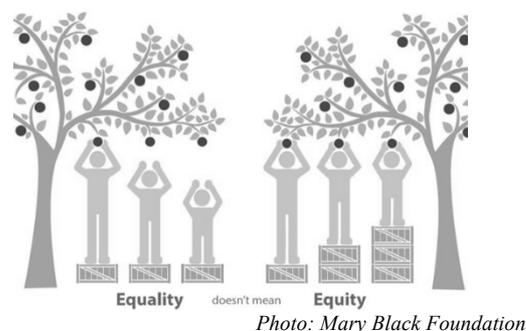
to understand and be understood in healthcare. In Finland (Riksdagen, 1992), Denmark (Folketinget, 2005) and Iceland (Alltinget, 2015) have special provisions regarding interpreters in healthcare. In Sweden (Riksdagen, 2014) and Norway (Helsedirektoratet, 1999) the acts have a general formulation with regard to language background. This means that specialist nurses and other healthcare personnel in paediatric healthcare in the Nordic countries are required by law to provide individually-tailored information regardless of a patient's age, level of maturity and language background, as well as ensure that the patient understands the information.

2.2.1 Equity and equality in healthcare

Equality is the basic right of all human beings and equity applies to those who do not have the same opportunities, as stated by the World Health Organization: equity is the absence of preventable differences among groups of people (World Health Organization, 1948). This means that children, just like any group of people, have the right to equity in healthcare.

The concept of equity in healthcare considers different conditions and is defined from three different perspectives: a) equal access to care, b) equal use, and c) equal quality of care (Black, 2016; Butts, Rich, & Rich, 2005; Whitehead, 1991). In other words, equity requires equal treatment in equal situations and different treatments in unequal situations, i.e. patients are supported in different ways depending on their different needs.

From a nursing perspective, this is fully in line with the professional assignments as a specialist nurse in paediatric healthcare. The nurse ensures respectful, individualized and equal care regardless of age, ethnicity, socio-economic background and language background, and advocates for equity in healthcare.



2.3 LANGUAGE BARRIERS AS OBSTACLES FOR EQUITY IN HEALTHCARE

One of the main obstacles for children's right to equity in healthcare is when the child/family has limited proficiency in the majority language. Language barriers obstruct the provision of effective healthcare; language barriers have adverse effects on accessibility, quality of care, patient satisfaction and patient health outcomes (Bischoff, Perneger, Bovier, Loutan, & Stalder, 2003). In fact, language barriers have been identified as being the primary obstacle in providing effective, equitable and patient-safe care to patients with limited proficiency in a country's majority language (Bischoff & Hudelson, 2010; A. L. Cohen, Rivara, Marcuse, McPhillips, & Davis, 2005; Flores, 2005; Schenker, Wang, Selig, Ng, & Fernandez, 2007; van Rosse, de Bruijne, Suurmond, Essink-Bot, & Wagner, 2016; Wilson, Chen, Grumbach, Wang, & Fernandez, 2005)

Despite the fact that providing understandable information is regulated by acts in the healthcare sector in all Nordic countries and in the United Nations Convention on the Rights of the Child (Alltinget, 2015; Folketinget, 2005; Helsedirektoratet, 1999; Riksdagen, 1992, 2014; United Nations Convention on the Rights of the Child, 1989), we know that when it comes to communication over language barriers, such barriers present a major challenge to healthcare personnel, as well as patients/families with limited proficiency in the country's majority language (Hernandez et al., 2014; Margolis, Ludi, Pao, & Wiener, 2013; Massimo, Wiley, & Caprino, 2008; Pergert, Ekblad, Bjork, Enskar, & Andrews, 2016; Pergert, Ekblad, Enskar, & Bjork, 2007; Steinberg, Valenzuela-Araujo, Zickafoose, Kieffer, & DeCamp, 2016).

2.3.1 Intercultural communication over language barriers

Communication is different from providing information. Communication includes an active interaction, while information is an isolated unilateral action (Linell, 1998). Information is the transmission of a message from a sender to a receiver; the content of the message refers to "objective" facts and is codified independently from the human relationship between the informer and the informed (Heath & Bryant, 2013; Linell, 1998).

The research field of communication over linguistic and cultural barriers in healthcare has a broad variety of definitions and meanings. One well-defined area is transcultural nursing, which touches upon the subject of transcultural communication. The prefix "trans" means "over" or "across". However, in our research we have chosen the term *intercultural communication* with the prefix "inter" to highlight the interaction between the caregiver and

the care recipient. Intercultural communication theory stresses the interactive side of communication and information sharing between different cultures and/or social groups (Gudykunst, 2005).

Intercultural communication is a way of overcoming cultural differences, both on a macro level (e.g. in society) and a micro level (e.g. in the workplace) and good intercultural communication leads to greater understanding (Gudykunst, 2005). Our linguistic proficiencies constrain the identities we can perform and, at the same time, our embodied identities constrain the ways in which our language proficiency is perceived (Piller, 2017). In a healthcare context, language proficiency is extremely important because of the narrative and the interpersonal relationship between healthcare personnel and the patient and is the key to the healthcare interaction (Hull, 2016).

A lack of language proficiency creates discrimination and language proficiency is related to equality. Language proficiency is not only about understanding, but also about revealing who you are (Piller, 2017).

2.3.2 The use of interpreters in healthcare

Interpreters procured by an agency in Sweden are required to abide by the Swedish guidelines (Good interpreting practice) for interpreters (Kammarkollegiet, 2018). The guidelines state that it is the interpreter's task to enable communication between individuals who do not share the same language and that an interpreter shall render, into the other language, all provided information (Kammarkollegiet, 2018). The interpreted-mediated consultation is a three- (or more) party conversation. The interpreter's task is to render and co-ordinate another person's speech. Apart from rendering a message into another language, this also includes monitoring turn-taking, feedback (Wadensjö, 1992), and handling the mutual and multilateral dependency on the interpreter (i.e. both the user and the interpreter ensure that a sufficient level of understanding has been achieved) (Skaaden, 2014). Optimal communication, the highest level of patient satisfaction, the best outcomes and the fewest errors with potentially clinical consequences are possible when patients with limited proficiency in a country's majority language have access to trained professional interpreters or bilingual healthcare providers (Flores, 2005; Ngai et al., 2016).

There appears to be a tendency among healthcare personnel for professional interpreters to only be used in the absence of other available options: that *ad hoc* interpreter is “good enough” even while acknowledging the quality differential between trained and untrained interpreters (Bischoff & Hudelson, 2010). However, merely making professional interpreters available to healthcare personnel is not the only solution for guaranteeing the use of professional interpreters (a.a.). Even though the presence of an interpreter is important for bridging language barriers, there are major differences in the quality of the interpreted medical consultation (Abbe, Simon, Angiolillo, Ruccione, & Kodish, 2006; Butow et al., 2011; Schenker, Perez-Stable, Nickleach, & Karliner, 2011).

It has been clearly stated that healthcare personnel need to use interpreters more frequently to facilitate trustful cooperation, persuasive communication and significantly improve quality and patient-safe care in clinical settings (Flores, Abreu, Barone, Bachur, & Lin, 2012; Pergert, Ekblad, Bjork, Enskar, & Andrews, 2012; Schenker et al., 2011). The proper use of qualified interpreters reduces costs and improves the care situation and medical safety (Bischoff & Denhaerynck, 2010; Flores, 2005). Lindholm, Hargraves, Ferguson, and Reed (2012) also support that conclusion that there is a clear correlation between the lack of using qualified interpreters and increased healthcare costs and that there is a need for education to ensure that healthcare personnel develop cultural awareness, knowledge and communication skills (Klassen et al., 2012).

The importance of patient-safe, intercultural communication using interpreters in healthcare consultations is also supported by Ribera, Hausmann-Muela, Grietens, and Toomer (2008). They states that professional interpreters reduce the risk of medical errors related to incorrect translations, increase the understanding of medical recommendations and increase trust and motivation among patients with limited proficiency in a country’s majority language, as well as being cost-effective (Ribera, Hausmann-Muela, Grietens, & Toomer, 2008). The use of professional interpreters in healthcare improves equity and quality of care for patients with limited proficiency in a country’s majority language (Ribera et al., 2008).

2.4 PAEDIATRIC ONCOLOGY CARE AND LANGUAGE BARRIERS

Around 300 children up to 14 years of age are diagnosed with cancer every year in Sweden (Gustavsson, Kogner, & Heyman, 2013). In recent decades there has been a dramatic increase in survival rates. Today more than 80% of the diagnosed children survive due to advances in

care and treatment (a.a.). Paediatric oncology care in Sweden is centralized to six specialized paediatric oncology centres.

Having a child who is suffering from a life-threatening disease puts a family in a difficult and vulnerable situation. Research shows that families need a great amount of support from healthcare personnel in their struggle to be able to both handle the situation and to support the sick child (Bjork, Wiebe, & Hallstrom, 2009). In order to get through a chaotic and stressful situation, the family will ask for information and will also ask to be involved in the care of the child (Bjork, Wiebe, & Hallstrom, 2005). By learning more about the disease and treatment, as well as what to expect and what to demand, parents feel the sense that they are coping with the situation (Bjork et al., 2005; Ringner, Jansson, & Graneheim, 2011). Also, Goldbeck (2001) has shown that parental ability to cope with a diagnosis of paediatric cancer is supported by seeking information together with communication with healthcare personnel and/or reading about the disease (Goldbeck, 2001; Pergert et al., 2016).

To support parental coping strategies, healthcare personnel must pay extra attention to the parent's informational needs (Ringner et al., 2011), especially during periods when treatment ceases or there is a relapse of the disease. Ringner et al. (2011) suggest that continuing information meetings beyond the early phases would optimize the information flow and increase the parent's sense of control over the situation.

There are no figures that indicate how many children/families from a foreign background with limited Swedish proficiency are diagnosed with cancer each year. Currently, 18.5% of Swedish inhabitants come from a foreign background (SCB, 2017) and 26% of inhabitants of Stockholm County (SCB, 2017) come from a foreign background. Of Sweden's more than two million children under the age of eighteen, 23% have a foreign background, meaning that every fourth child has a foreign background. We know that migration and the mixed population are reflected in all healthcare settings nationwide and are naturally also reflected in paediatric oncology care.

Several studies show that parents with a foreign background find it difficult to assimilate information about their child's illness and treatment and that they are particularly vulnerable when it comes to factors that hinder communication (Gulati et al., 2012; Pergert et al., 2007; Ringner et al., 2011). Language barriers challenge the ability of healthcare personnel to provide adequate information to parents about their child's condition, treatment and

prognosis (Davies, Contro, Larson, & Widger, 2010; Pergert, 2008). Language barriers also restrict the ability of healthcare personnel to discern the parent's understanding and emotional responses. The consequence of this is that parents with limited proficiency in a country's majority language are unable to participate in their child's care because they cannot communicate their needs, questions and concerns (a.a.). This is also supported by Gulati et al. (2012), whose research shows that communication challenges influence the parent's role in caring for their child. Learning about childhood cancer is hard for parents because of complex medical terminology and complicated treatment protocols (Klassen et al., 2012). Language barriers make it less likely that parents will engage on equal terms with the healthcare personnel team in the care of the child (a.a.).

Paediatric oncology care is a complex communication and information context in which effective and patient-safe communication between specialist nurses and other healthcare personnel and the patients and their families is of particular importance in order to avoid the risk of miscommunication that could threaten patient-safe care. The use of professional interpreters is an essential tool for adequate clinical practice with patients with limited Swedish proficiency. Despite the fact that research shows that the use of interpreters improves care and increases patient safety, research also shows that the use of interpreters is still limited. Thus, there is a need for a deeper understanding of how communication over language barriers is conducted and enabled in a paediatric oncology care context.

The starting point of the research project was clinical experiences in paediatric healthcare in conjunction with research by Pergert (2008), which showed that specialist nurses and other healthcare personnel in paediatric oncology care did not use interpreters to the extent to which effective and patient- safe communication with patients/families with limited Swedish proficiency was guaranteed. This situation occurred despite the fact that interpreters appeared to be available and that the attitude towards interpreters was generally positive.

3 AIM

3.1 OVERALL AIM

The overall aim of this research project was to investigate communication over language barriers among healthcare personnel in paediatric oncology care and the use of interpreters and other communication tools to overcome language barriers.

3.2 SPECIFIC AIMS

The specific aims were:

- To explore interpreters' experiences of interpreting between healthcare personnel and patients/families with limited Swedish proficiency in paediatric oncology care (*Study I*)
- To explore interpreters' perceived strategies in interpreted-mediated consultations between healthcare personnel and patients/families with limited Swedish proficiency in paediatric oncology care (*Study II*)
- To develop and validate the Communication over Language Barriers questionnaire (CoLB-q) (*Study III*)
- To investigate communication over language barriers among healthcare personnel in paediatric oncology care (*Study IV*)

4 METHODS

4.1 DESIGN

Study I & II had an inductive exploratory qualitative design. Study III was a methodology study in questionnaire development and Study IV was a national multisite cross-sectional survey (see Table 1).

Table 1. Overview of design, number of participants, and data collection methods of the four studies

| <i>Study</i> | <i>Design</i> | <i>Participants</i> | <i>Data collection</i> |
|--------------|--|---------------------|----------------------------|
| I | An inductive exploratory qualitative design | n=11 | Semi-structured interviews |
| II | An inductive exploratory qualitative design | n=11 | Semi-structured interviews |
| III | A methodology study in questionnaire development | n=5 | Cognitive interviews |
| | | n=3 | Focus group interviews |
| | | n=35 | Pilot test |
| | | n=18 | Test-retest |
| IV | A questionnaire survey | n=267 | CoLB-q |

4.2 PARTICIPANTS

4.2.1 Study I & II (Interpreters' experiences/strategies)

In Study I and II the sample comprised eleven interpreters and the inclusion criteria for the interpreters were that they worked through agencies (with signed confidentiality agreements). We did not include *ad hoc* interpreters (i.e. family members, friends or healthcare personnel). Our specific inclusion criterion was experience of interpreting in paediatric oncology.

The selection of the interpreters was based on the invoice data from a paediatric oncology unit via the interpreters' agencies. All interviews were booked through the interpreters' agencies and conducted at a children's hospital in Sweden. There were eight females and three males covering ten different languages. The interpreters had between 1 and 23 years' experience and none of them were certified interpreters, neither at a basic level nor at a specialized medical level (see Table 2). It is quite common in Swedish healthcare for professional interpreters to not hold a formal certificate issued by the Swedish certification authority.

Table 2. Overview of participants' demographic background (Study I & II)

| Interview | Sex | General education | Interpreter training | Interpreter certification | Training for interpreting for children | Years of interpreting experience | Interpreting language |
|-----------|-----|------------------------|----------------------|---------------------------|--|----------------------------------|-----------------------------|
| 1 | F | Graduate | No | No | No | 18 | Romanian, English, French |
| 2 | M | Undergraduate | Yes | No | No | 23 | Arabic, Kurdish, Turkmenian |
| 3 | F | Upper secondary school | Yes | No | Yes | 10 | Romanian, French |
| 4 | F | Community college | No | No | No | 2 | Somali |
| 5 | F | Upper secondary school | No | No | No | 1 | Somali |
| 6 | M | Community college | Yes | No | No | 1 | Arabic, Kurdish |
| 7 | F | Upper secondary school | Yes | No | No | 2 | Tigrinya |
| 8 | M | Graduate | Yes | No | No | 4 | Arabic |
| 9 | F | Community college | Yes | No | No | 5 | Arabic |
| 10 | F | Undergraduate | No | No | No | 4 | Tigrinya, Amhari |
| 11 | F | Upper secondary school | Yes | No | No | 3.5 | Arabic, Assyrian |

4.2.2 Study III (Developing CoLB-q)

This study used a multiple-methods approach in the process of developing the Communication over Language Barriers questionnaire (CoLB-q) and was conducted in three phases: initial development (phase 1), testing validity (phase 2) and testing reliability (phase 3) (see figure 1).

Figure 1. Overview phase 1–3 in the developing process of CoLB-q.

| 1. Initial development → | 2. Testing validity → | 3. Testing reliability |
|--|--|---|
| <ul style="list-style-type: none"> • Literature search • Review committee: themes and question development | <ul style="list-style-type: none"> • Focus group interviews • Cognitive interviews • Pilot test • Review committee: validation | <ul style="list-style-type: none"> • Test - retest • Review committee: finalization |

4.2.2.1 Phase 1 – Initial development

The development of the questionnaire in phase one consisted of a review committee comprising three researchers with expertise in paediatric healthcare, childhood cancer

healthcare research and interpreting science. The review committee discussed the development of the questionnaire during all three phases. Decisions on the development of the questionnaire were made by consensus in the committee.

4.2.2.2 Phase 2 – Validity testing

Validity testing in phase two consisted of establishing content and face validity (Broder, McGrath, & Cisneros, 2007; Drennan, 2003), including focus group interviews (Bloor, 2001), cognitive interviews (Drennan, 2003) and a pilot test (Brown, 2010).

Three focus group interviews were performed on a convenient sample of healthcare personnel with diverse academic, clinical and subject expertise. There were a total of 11 participants with three to four members per group, all female.

Cognitive interviews were conducted with a convenient sample of registered nurses and nursing assistants (n=5) who worked in specialized paediatric care.

The pilot test was conducted on a national sample of two different groups of nurses (n=35) in different paediatric healthcare contexts. Participants in the first group were nurses (n=20) in a programme of specialist paediatric oncology nursing. The participants in the second group were registered nurses with a postgraduate diploma in specialist paediatric nursing (n=15) who worked in paediatric healthcare.

4.2.2.3 Phase 3 – Reliability testing

Establishing reliability in phase three included a test-retest of the questionnaire (McCurdy et al., 2015). For the test-retest, 27 registered nurses (n=27) in an educational programme in specialist paediatric nursing were invited to complete the questionnaire and 24 (n=24) accepted. They were between 25 and 45 years of age and had between three and 10 years of clinical working experience from different clinical contexts nationwide. There were 18 participants (n=18) for both the test and retest.

4.2.3 Study IV (CoLB-q survey)

Healthcare personnel working at six paediatric oncology centres in Sweden were invited to participate; 281 responded and 267 were included in our analysis as they matched our inclusion criteria, i.e. MDs (n=54), RNs (n=151) and NAs (n=62) with patient care in their assignment. Of the participants, 221 (79.2%) were female and 46 (20.8%) were male. Both genders were represented in all three professions; in the MD group the two genders were equally represented.

4.3 DATA COLLECTION

4.3.1 Study I & II (Interpreters' experiences/strategies)

In Study I and II data were collected using semi-structured interviews (DiCicco-Bloom & Crabtree, 2006). An interview guide was developed based on previous research regarding obstacles to intercultural caring relationships (Pergert et al., 2007). The questions focused on: a) experiences regarding complex interpreting situations; b) experiences of handling and rendering difficult information; c) experiences of interpreting for different healthcare professions; d) knowledge background of the family; e) equivalence of terminology; f) how to handle relationships with families, and; g) experiences of being cultural mediators. All interpreters were interviewed in Swedish by the author. The interviews lasted 40 to 60 minutes and were digitally recorded and transcribed verbatim by the author within one week of the interview.

4.3.2 Study III (Developing CoLB-q)

4.3.2.1 Phase 1 – Initial development

Identification of an initial pool of themes and issues relevant to the questionnaire were identified in the background literature and the research by Pergert (2008). Ten initial issues were identified: experiences of communication with patient/family with limited Swedish proficiency, different means of communication used, obstacles to prevent that the patient/family understand the information, experiences of the needs of interpreters, practical problems to resolve the needs of an interpreter, general problems when using interpreters in healthcare encounters, nurse-specific problems when using interpreters in healthcare encounters, frequency of the use of interpreters in general nursing, quality issues regarding healthcare interpreting services and quality issues (professionalism) regarding healthcare interpreters. These ten issues were then used for further development into themes, questions and items.

4.3.2.2 Phase 2 – Validity testing

In phase two, we conducted validity testing (see figure 1). The focus group interviews, cognitive interviews and pilot test were used to explore the questions and items in the questionnaire in order to establish content validity.

During the focus group interviews, participants were given instructions not to explicitly answer the questions but to refer to them during the discussion. They were encouraged to reflect on the relevance of the questions/items, how they understood them, and if they wanted to add any questions/items. The author moderated the focus groups and used open and

probing questions. The discussions lasted 30–45 minutes and were audio-recorded. During the discussion, the author took field notes on the questionnaire about the participants' comments. The field notes were elaborated using the recordings immediately after the interviews.

When conducting the cognitive interviews, participants were asked to “think aloud” while answering the questionnaire and then, by using retrospective probes, to engage in dialogue with the researcher on the clarity of the concepts and on their ability to understand and answer the questions. At the end of the session, they were asked about their overall impression of the questionnaire and the relevance of the items. Field notes were taken.

In the pilot test the participants were asked to submit written comments when responding to the questionnaire about how they perceived certain questions or items, whether anything was missing, and how they perceived the questionnaire's relevance, comprehensibility and ease of response.

4.3.2.3 Phase 3 – Reliability testing

To test reliability, we conducted a test-retest. The lapse between test and retest was set at two to four weeks, partially due to the convenient time frame for test-retest and partially due to the participants' use of interpreters, which could be assumed to have been fairly stable during the period. The participants in the test re-test comprised registered nurses in an educational programme in specialist paediatric nursing (n=18) and they returned to their ordinary workplace during the interval between the tests and answered the questionnaire when attending campus training. The dropout rate between test and retest was 25% (n=6) and item nonresponse was low (<10 %).

4.3.3 Study IV (CoLB-q survey)

Data collection in Study IV was conducted using the CoLB-q questionnaire that was validated in Study III. A total of 312 questionnaires were administrated by the research group to healthcare personnel (MDs, RNs and NAs) at six paediatric oncology centres in Sweden. 281 questionnaires were returned. Data collection was carried out between February and September 2016. In order to limit drop-outs, the research group visited all the paediatric oncology centres and the questionnaires were distributed during clinical meetings or training sessions to which all healthcare personnel at the centre were expected to attend. The research

group offered lectures as incentives after they had been given an opportunity to answer the questionnaire. The response rate was 90% (n=281/312).

4.4 DATA ANALYSIS

4.4.1 Study I (Interpreters' experiences)

In Study I, data were analysed using qualitative content analysis in accordance with Graneheim and Lundman (2004). Following Graneheim and Lundman, the content analysis process was divided into six different phases. When the interviews were completed and transcribed verbatim, the text was read through several times to obtain a sense of the whole (phase 1), the text was then divided into meaning units (phase 2), the meaning units were condensed into a description close to the text (phase 3) and, if possible, into an interpretation of the underlying meaning (i.e. the latent content) and coded for sorting (phase 4), the condensed meaning units were abstracted into sub-themes (phase 5) and the sub-themes were then unified into one theme (phase 6). It should be noted that, according to Graneheim and Lundman (2004), content analysis is not a linear process but a back-and-forth movement between the whole and parts of the text. Before discussing the themes jointly, the supervisors independently read the transcripts, together with the sub-themes, to increase their credibility and dependability.

4.4.2 Study II (Interpreters' strategies)

During the content analysis in Study I, different strategies reported by the interpreters were identified. In Study II we performed a secondary analysis to further explore the data regarding different perceived interpreting strategies in the interpreted-mediated consultation in paediatric oncology care.

In this study, data were analysed using qualitative inductive content analysis following the methodology of Elo and Kyngas (2008). The analysis phases in Study II comprised a preparation phase and an organizing phase. In the preparation phase, the first co-supervisor (Tiselius) conducted a retrospective reading of all the interview data to confirm the strategy reports by the interpreters that emerged from Study I. The preparation phase also consisted of selecting analysis units comprising different perceived interpreting strategies from the interpreters' perspective of the interpreted-mediated consultations.

In the organizing phase, the first author in conjunction with the first co-supervisor made an open coding to frame the different perceived interpreting strategies from the selection of

analysis units. The codes were then sorted and divided into groups. When all the data had been coded, the abstraction process started, during which the first author and the first co-supervisor created different levels of categorization in conjunction with the main supervisor (Pergert). In order not to risk losing the specific strategies the interpreters expressed using in the interviews, the analyses were kept on a descriptive level, staying close to the data. During the abstraction process, data were categorized by combining the perceived strategies that belonged together into sub-categories (Elo & Kyngas, 2008). The data were then abstracted further by combining the sub-categories with similar content into four generic categories. These generic categories were finally combined into one main category. The main category captures the core of the interpreters' perceived strategies in interpreted-mediated consultations between healthcare personnel and patients/families with limited Swedish proficiency in paediatric oncology care.

4.4.3 Study III (Developing CoLB-q)

4.4.3.1 Phase 1 – Initial development

The issues were discussed in the review committee and four overarching themes were identified: Experiences of language barriers [...], The use of interpreters [...], Interpreting services, and the professionalism of the interpreter. The review committee developed specific questions and items within each theme. Decisions on the questions and items included in the questionnaire were made by consensus in the review committee.

4.4.3.2 Phase 2 – Validity testing

For validity testing, the focus group interviews and the elaboration of each of the items were discussed in the review committee and used to refine the questions in the questionnaire. From the cognitive interviews, the participants' notes from the questionnaire together with the field notes were discussed with the review committee and used to further refine the questions. The pilot test was analysed using descriptive statistics for the closed questions in the questionnaire. The answers from the open-ended questions, together with the written comments, were analysed from the perspective of the participants' understanding of the questions and suggestions for further improvements of the questionnaire.

4.4.3.3 Phase 3 – Reliability testing

In phase three, the test-retest was analysed using descriptive statistics. Weighted kappa (Cohen, 1960, 1968) was applied to evaluate reliability. For the weighted kappa we used the Cicchetti-Allison weighting matrix (Cicchetti & Allison, 1971), which is a cautious weighting matrix. The Svensson method (Svensson, 2012) for paired ordinal data was used

to identify any systematic patterns of change on the group level, for example, whether the participants reported an increased use of interpreters between test and retest.

4.4.4 Study IV (CoLB-q survey)

In Study IV, which contained the main questionnaire data, descriptive statistical analyses were conducted with a focus on frequency distributions. Comparing the different professional groups, cross-tabulations were used, including nonparametric chi-square tests. When p-values were calculated in the cross-tabulation, statistical significance was set for a p-value of <0.05. All statistical analyses were performed using IBM® SPSS® Statistics Version 24.

4.5 ETHICAL CONSIDERATIONS

Studies I–IV were in accordance with the ethical standards of the ethical review board based on the 1964 Declaration of Helsinki and its subsequent amendments, or comparable ethical standards (the Ethical Review Act, 2003).

Ethical approval for Study I & II was obtained from the Regional Ethical Review Board in Stockholm, reference number [2011/992-31/5]. All participants were given verbal and written information regarding the aim of the study and were informed they had the right to cancel their participation at any time without giving any reason. The participants were also informed that the interviews would be recorded and handled confidentially.

Study III & IV contain ethical advisory statements with no ethical objections to the studies from the Regional Ethical Review Board in Stockholm, Sweden. Reference numbers [2012/389-31/4] and [2015/1783-31/5].

This research project has a multidisciplinary research approach and its participants are adult professionals (healthcare interpreters and healthcare personnel) in Swedish paediatric oncology care. The research is based on the four research ethical principles of the Swedish Research Council, which aim to balance the research requirements and the protection of individuals as participants in a research project. This is supported by the four main requirements: the information requirement, the consent requirement, the confidentiality requirement and the utility requirement (Swedish Research Council, 2017).

The information requirement was obtained by that the participants in the studies were informed about their task in the project, through both oral and written information. The consent requirement was obtained by that the participants in the studies were informed that

participation in the studies was completely voluntary and that they had the right to discontinue their participation whenever they wished and that in no way would this affect them or their work situation or employee. The participants in Study I & II received both written and oral information from the author and via the interpreter services. In Study IV, written information about the study was provided in the questionnaire (CoLB-q). A completed questionnaire was regarded as consent.

The confidentiality requirement means that all data are given the highest possible level of confidentiality and that any personal data is kept so that no unauthorized persons have access to them. Our data have been treated confidentially to ensure that participants cannot be identified. Collected data including audio files from the interviews is securely stored in fireproof cabinets. Only members of the research group have access to the cabinets. The utility requirement is obtained by the collected data is not or will not be used for any purpose other than research.

5 KEY FINDINGS

5.1 STUDY I (INTERPRETERS' EXPERIENCES)

The data analyses resulted in the main theme of “Creating a meeting point of understanding”. The main theme was constructed from three sub-themes: balancing between cultures, bridging the gaps of knowledge, and balancing between compassion and professionalism. The sub-themes bore witness to the linguistic, cultural and emotional challenges in the interpreter-mediated consultation. The interpreters struggled to establish a meeting point of understanding that included all parties in the interpreter-mediated consultation. The interpreters reported that language is complex and that “literal translation” does not really exist. Even though the interpreters stated that they were trying to pursue a literal translation, they believed that concepts and sentences must be adapted to context and culture, and that the language, as a part of a context, must be understood by both the interpreter and the person using the interpreter.

5.2 STUDY II (INTERPRETERS' STRATEGIES)

The main findings in Study II showed that the interpreters strived to carry the bilingual conversation. The main category of carrying the bilingual conversation was based on the four generic categories of perceived strategies, namely, strategies for maintaining a professional role, facilitating communication, promoting collaboration and improving the framework of

interpreting provision. The interpreters were the only participants in the multi-party consultations who had access to the whole linguistic context, both the foreign-language context and the majority-language context. This gave the interpreters a unique opportunity to carry the bilingual conversation, although they did not automatically have access to the specific context of the topic in question, such as the diagnosis or treatment. The key findings were that to carry the bilingual conversation the interpreters used strategies clearly outside their assignment, for example, by alleviating and adapting words and phrases.

5.3 STUDY III (DEVELOPING COLB-Q)

The findings in Study III focused on the development of CoLB-q. In regard to the CoLB-q's face and content validity, the cognitive interviews and the pilot test showed that the participants understood the questions in the questionnaire and that the questions had sufficient clarity and readability. In regard to reliability, the test-retest showed that the results were stable, although questions about using web-based translation tools or apps indicated a learning effect between test and retest. The final questionnaire (CoLB-q) comprised questions about the participants' demographic/background and two themes: 1) communication over language barriers and 2) the use of interpreters, which contain questions about communicating with families with limited Swedish proficiency, using interpreters in healthcare and using interpreting services. The CoLB-q contained a total of 27 questions, 10 demographic/background questions including linked items, 14 closed questions and three open questions.

5.4 STUDY IV (COLB-Q SURVEY)

The findings in Study IV were based on the results of the main data collection using the CoLB-q. The findings showed that all participants (n=267), to varying degrees, used family members or relatives to translate in situations where no professional interpreter was available. It was also quite common for all professions to use children as translators (see Table 3). All professions also reported that other healthcare personnel acted as interpreters on a regular basis.

Table 3. Responses by healthcare personnel on different items in the question on communication over language barriers without an interpreter

| Items, number of respondents | Respondents, n=267 | | |
|---|--------------------|------------|-----------|
| | MDs, n=54 | RNs, n=151 | NAs, n=62 |
| Response alternatives | n (%) | n (%) | n (%) |
| <i>An adult family member or close relative translates, n=261</i> | | | |
| Never | 0 (0) | 0 (0) | 2 (3.3) |
| Seldom | 12 (22.2) | 17 (11.6) | 7 (11.7) |
| Sometimes | 30 (55.6) | 80 (54.4) | 31 (51.7) |
| Often | 12 (22.2) | 50 (34.0) | 20 (33.3) |
| <i>A child translates (e.g. the patient or a sibling), n=260</i> | | | |
| Never | 7 (13.0)** | 13 (8.8) | 3 (5.1) |
| Seldom | 30 (55.6)** | 48 (32.7) | 18 (30.5) |
| Sometimes | 17 (31.5)** | 70 (47.6) | 28 (47.5) |
| Often | 0 (0)** | 16 (10.9) | 10 (16.9) |
| <i>A colleague translates n=259</i> | | | |
| Never | 5 (9.3) | 27 (18.4) | 14 (24.1) |
| Seldom | 26 (48.1) | 55 (37.4) | 16 (27.6) |
| Sometimes | 22 (40.7) | 61 (41.5) | 27 (46.6) |
| Often | 1 (1.9) | 4 (2.7) | 1 (1.7) |
| <i>You speak the language in question (other than Swedish), n=256</i> | | | |
| Never | 6 (11.1)** | 68 (46.9) | 33 (57.9) |
| Seldom | 22 (40.7)** | 30 (20.7) | 9 (15.8) |
| Sometimes | 20 (37.0)** | 38 (26.2) | 11 (19.3) |
| Often | 6 (11.1)** | 9 (6.2) | 4 (7.0) |

**Due to rounding error, some of the percentages do not add up to 100%.

Among the different communication tools used to communicate over language barriers, the most common method was to use interpreters on site. This was reported by all professions (see Table 4). Telephone interpreters were to some extent also used regularly, but not as much as on-site interpreters. Written material in the language in question was used to a very low extent among all professions. This was also the case regarding the use of web-based translation tools or apps. However, RNs and NAs did use alternative communication tools to some extent. Of all the professions, MDs used interpreters the most ($p > 0.001$) (Table 4).

Table 4. Use of interpreters and other communication tools

| | Respondents, n=267 | | | Group comparison | | |
|---|--------------------|---------------------|--------------------|--------------------------|-------------------------|-------------------------|
| | MDs, n=54 n (%) | RNs, n=151 n (%) | NAs, n=62 n (%) | MDs vs. RNs, p-value* | MDs vs NAs, p-value* | RNs vs NAs, p-value* |
| <i>The use of interpreters on site, n=261</i> | | | | .002 | .007 | .200 |
| Never | 0 (0.0) | 5 (3.3)** | 5 (8.2)** | | | |
| Seldom | 1 (1.9) | 19 (13.0)** | 9 (14.8)** | | | |
| Sometimes | 18 (33.3) | 68 (46.6)** | 20 (32.8)** | | | |
| Often | 35 (64.8) | 54 (37.0)** | 27 (44.3)** | | | |
| <i>The use of interpreters via telephone, n=258</i> | | | | <.001 | .008 | .002 |
| Never | 1 (1.9) | 11 (7.5)** | 13 (22.0) | | | |
| Seldom | 6 (11.3) | 43 (29.5)** | 7 (11.9) | | | |
| Sometimes | 23 (43.4) | 69 (47.3)** | 24 (40.7) | | | |
| Often | 23 (43.4) | 23 (15.8)** | 15 (25.4) | | | |
| <i>The use of interpreters via video, n=248</i> | | | | | | |
| Never | 49 (96.1) | 135 (96.4) | 54 (94.7) | | | |
| Seldom | 2 (3.9) | 5 (3.6) | 2 (3.5) | | | |
| Sometimes | 0 (0.0) | 0 (0.0) | 1 (1.8) | | | |
| Often | 0 (0.0) | 0 (0.0) | 0 (0.0) | | | |
| <i>Communicate through written information, n=259</i> | | | | | | |
| Never | 20 (37.0) | 28 (19.2) | 14 (23.7) | | | |
| Seldom | 23 (42.6) | 53 (36.3) | 20 (33.9) | | | |
| Sometimes | 10 (18.5) | 57 (39.0) | 21 (35.6) | | | |
| Often | 1 (1.9) | 8 (5.5) | 4 (6.8) | | | |
| <i>Communicate via tools on the computer, n=261</i> | | | | | | |
| Never | 30 (55.6)** | 23 (15.6) | 12 (20.0)** | | | |
| Seldom | 19 (35.2)** | 47 (32.0) | 16 (26.7)** | | | |
| Sometimes | 5 (9.3)** | 66 (44.9) | 28 (46.7)** | | | |
| Often | 0 (0.0)** | 11 (7.5) | 4 (6.7)** | | | |
| <i>Communicate via translation app, n=261</i> | | | | | | |
| Never | 38 (70.4)** | 59 (40.1) | 23 (38.3)** | | | |
| Seldom | 11 (20.4)** | 44 (29.9) | 14 (23.3)** | | | |
| Sometimes | 5 (9.3)** | 38 (25.9) | 18 (30.0)** | | | |
| Often | 0 (0.0)** | 6 (4.1) | 5 (8.3)** | | | |

* p-value from Pearson's chi-square test

** Due to rounding error, some of the percentages do not add up to 100%.

The frequency of using an interpreter in different clinical tasks for the three different professions varied between the different professional groups (Table 5). Of the MDs, half of the group (47.2%) reported that they often use interpreters to take arrival status or medical history and the other half (47.2%) reported that they seldom or sometimes use interpreters

for this purpose. For RNs, 15.4% reported that they often use interpreters to take arrival status or nursing history. 62.3% do this seldomly or sometimes, and 22.4% not at all.

Table 5. Frequency of using an interpreter for different clinical tasks among healthcare personnel

| Items, number of respondents | Respondents, n=267 | | |
|---|--------------------|-------------|-----------|
| | MDs, n=54 | RNs n=151 | NAs, n=62 |
| Response alternatives | n (%) | n (%) | n (%) |
| <i>Take arrival status or medical history (medical or nursing), n=256</i> | | | |
| Never | 3 (5.7)** | 32 (22.4)** | 37 (61.7) |
| Seldom | 7 (13.2)** | 40 (28.0)** | 11 (18.3) |
| Sometimes | 18 (34.0)** | 49 (34.3)** | 9 (15.0) |
| Often | 25 (47.2)** | 22 (15.4)** | 3 (5.0) |
| <i>Inform about routines, n=262</i> | | | |
| Never | 2 (3.7)** | 10 (6.8) | 6 (9.8) |
| Seldom | 10 (18.5)** | 25 (17.0) | 9 (14.8) |
| Sometimes | 24 (44.4)** | 67 (45.6) | 22 (36.1) |
| Often | 18 (33.3)** | 45 (30.6) | 24 (39.3) |
| <i>Inform about procedures, n=261</i> | | | |
| Never | 1 (1.9)** | 7 (4.8) | 10 (16.7) |
| Seldom | 6 (11.1)** | 21 (14.3) | 16 (26.7) |
| Sometimes | 19 (35.2)** | 75 (51.0) | 14 (23.3) |
| Often | 28 (51.9)** | 44 (29.9) | 20 (33.3) |
| <i>Prepare for procedures/examinations, n=260</i> | | | |
| Never | 5 (9.3)** | 12 (8.2) | 12 (20.0) |
| Seldom | 15 (27.8)** | 46 (31.5) | 13 (21.7) |
| Sometimes | 21 (38.9)** | 54 (37.0) | 23 (38.3) |
| Often | 13 (24.1)** | 34 (23.3) | 12 (20.0) |
| <i>Hold patient or parent education, n=256</i> | | | |
| Never | 6 (11.5)** | 25 (17.2)** | 23 (39.0) |
| Seldom | 13 (25.0)** | 46 (31.7)** | 16 (27.1) |
| Sometimes | 19 (36.5)** | 54 (37.2)** | 12 (20.3) |
| Often | 14 (26.9)** | 20 (13.8)** | 8 (13.6) |
| <i>Supportive conversation, n=261</i> | | | |
| Never | 1 (1.9)** | 38 (25.9)** | 24 (40.0) |
| Seldom | 9 (16.7)** | 63 (42.9)** | 17 (28.3) |
| Sometimes | 30 (55.6)** | 35 (23.8)** | 10 (16.7) |
| Often | 14 (25.9)** | 11 (7.5)** | 9 (15.0) |
| <i>Small talk, n=262</i> | | | |
| Never | 28 (51.9) | 91 (61.9) | 33 (54.1) |
| Seldom | 14 (25.9) | 44 (29.9) | 18 (29.5) |
| Sometimes | 11 (20.4) | 8 (5.4) | 5 (8.2) |
| Often | 1 (1.9) | 4 (2.7) | 5 (8.2) |

** Due to rounding error, some of the percentages do not add up to 100%.

MDs (84.9%), RNs (88.4%) and NAs (85.5%) agreed that the use of interpreters increases the patients' and families' involvement in care considerably and also improves the care relationship considerably (Table 6). MDs also agreed that the use of interpreters increases patient safety considerably (92.5%). The same applied to RNs and NAs (both 91.1%).

Table 6. The attitudes of healthcare personnel regarding the importance of the use of interpreters in respect of patients' involvement in care, increasing patient safety in care and improving the care relationship

| Items, number of respondents | Respondents, n=267 | | | | | |
|--|--------------------|--------|------------|----------|-----------|----------|
| | MDs, n=54 | | RNs, n=151 | | NAs, n=62 | |
| Response alternatives | n | (%) | n | (%) | n | (%) |
| <i>Increase involvement in care, n=254</i> | | | | | | |
| Not at all | 0 | (0.0) | 0 | (0.0)** | 0 | (0.0) |
| To a low degree | 1 | (1.9) | 3 | (2.1)** | 1 | (1.8) |
| Not so high degree | 7 | (13.2) | 14 | (9.6)** | 7 | (12.7) |
| To a high degree | 45 | (84.9) | 129 | (88.4)** | 47 | (85.5) |
| <i>Increase safety in care, n=255</i> | | | | | | |
| Not at all | 0 | (0.0) | 0 | (0.0) | 0 | (0.0)** |
| To a low degree | 0 | (0.0) | 2 | (1.4) | 2 | (3.6)** |
| Not so high degree | 4 | (7.5) | 11 | (7.5) | 3 | (5.4)** |
| To a high degree | 49 | (92.5) | 133 | (91.1) | 51 | (91.1)** |
| <i>Improves care relationship, n=254</i> | | | | | | |
| Not at all | 0 | (0.0) | 0 | (0.0) | 1 | (1.8) |
| To a low degree | 1 | (1.9) | 1 | (0.7) | 0 | (0.0) |
| Not so high degree | 8 | (15.1) | 26 | (17.9) | 11 | (19.6) |
| To a high degree | 44 | (83.0) | 118 | (81.4) | 44 | (78.6) |

** Due to rounding error, some of the percentages do not add up to 100%.

6 DISCUSSION

6.1 DISCUSSION OF KEY FINDINGS

6.1.1 Study I (Interpreters' experiences)

The findings from Study I which state that interpreters struggle to create a meeting point of understanding confirmed previous research by for example Bischoff, Kurth, and Henley (2012) showing that medical interpreters are sensitive to the different needs of the various parties and that these needs may clash, but it also added understanding to the role of the interpreter in the middle ground. The sub-category of Study 1 *balancing between cultures* showed that translating and transferring information is complicated by cultural issues that may result in misunderstandings and clashes.

Bischoff et al. (2012) concludes that interpreters must find a balance between the domestic and foreign side and that this unique position enables them to mediate between different cultures. Our key findings indicated that interpreters not only mediate between different cultures but also adjust the translation to the context, meaning that they balance different cultures and care issues in their multiple roles as a professional interpreter and also of a compatriot and cultural link. We have shown that these multiple roles are delicate and are often not natural for interpreters. There are difficulties associated with being a neutral interpreter in situations in which there is a need for a cultural link, see also Norris et al. (2005), Bischoff et al. (2012) and Suurmond, Lieveld, van de Wetering, and Schouten-van Meeteren (2017).

According to Norris et al. (2005), knowledge gaps in clinical encounters can directly affect the quality of care. Another important aspect of knowledge gaps and cultural differences is that some parents might not understand the right of their child to receive age-adapted information about her/his disease and treatment (Jaeger, Kiss, Hossain, & Zimmerman, 2013). Through the sub-category *bridging the gaps of knowledge*, our findings showed that interpreters have to handle the cultural knowledge of healthcare personnel, the knowledge level of the family and their possibility of understanding, as well as the continuity and competence of previous interpreters, which means that they actively contribute to counteracting the negative impact of care that results from the aforementioned factors. The interpreters in our study confirmed what Wiking, Saleh-Stattin, Johansson and Sundquist (2009) also report, namely, that the interpreters feel the need to adjust information to the patient's educational level. Our results showed that interpreters find that healthcare personnel

are too focused on providing information in a unidirectional way and this also affects the opportunity for the family to understand the information and gain knowledge of their child's illness and treatment.

The sub-category *balancing between compassion and professionalism* showed that there is a fine line between being a compassionate fellow human being and a professional interpreter. According to Norris et al. (2005), interpreters identify honesty and compassion as being basic professional skills and qualities. Yet our findings showed that interpreters struggle to follow the principle of neutrality in the ethical guidelines and that they want to reach out to families in distress. Based on our findings, we assume that for the interpreters in this study, the issue of neutrality becomes more apparent as they are interpreting for very sick children, which affects the interpreters emotionally.

In summary, the results of Study I highlights that interpreters often find it necessary to explain both the context and the cultural aspects in order to create a sustainable meeting point of understanding between families with limited Swedish proficiency and healthcare personnel in paediatric oncology care. Aiming for a literal interpretation of the message, in accordance with the Swedish guidelines for interpreters, good interpreting practice, in the interpreters' view, does not pave the way for a multi-dimensional understanding between the parties involved in the communication. Our key findings showed that an interpreted-mediated event is a complex communicative situation and that the interpreter is not solely responsible for the information transfer. All parties must take responsibility in order to enable families to understand the information and take control of the situation, thereby reinforcing the patient-safe care of their child.

6.1.2 Study II (Interpreters' strategies)

The findings of Study II indicate that the interpreter's struggle to carry the bilingual conversation is linked to the concept of discretionary power used as a theoretical framework by Molander and Terum (2008). The concept of discretionary power is the freedom to act according to one's own judgment within the legislative framework (Dworkin, 1978). This sphere of judgment means that the scope of action or sphere of autonomy depends to some extent on personal values and deliberations, and the judgment domain is an "open" area surrounded by a belt of restrictions. Professional interpreters, for example, must lean on professional ethical guidelines and norms such as neutrality while making immediate

decisions about their interpreting, the situational knowledge and their personal evaluation (Skaaden, 2014), as expressed by the interpreters in our data.

The interpreted encounter in health care is part of an institutional discourse, i.e. that the role structures and goals of the conversation are fixed (Wadensjö, 1992). The challenges in this type of interpreted institutional discourse in healthcare stem from the fact that in the multi-party conversation, the interpreter does not own the conversation but assumes responsibility for rendering and co-ordinating the bilingual communication beyond their professional responsibility for transferring messages.

Our results showed that the interpreters report that they use different strategies to fulfil their assignment. However, the interpreters also seem to take on an extended responsibility for the communication in their assignment. The interpreters stretch their discretionary power in order to carry the bilingual conversation by using strategies clearly outside their assignment, for example, by alleviating and adapting words and phrases. Other researchers confirm our findings by reporting that interpreters hid or omitted information in order not to worry the patients (Alanzeh, Ramjan, Kwok, Levesque, & Everett, 2018).

Interpreting in paediatrics is reported by other researchers as being emotionally challenging and demanding a high level of professionalism among the interpreters (Jaeger et al., 2013). Our findings showed that emotionally-challenging situations possibly force interpreters to stretch their discretionary power in order to carry the bilingual conversation. Our findings emphasized that the interpreters clearly identified several problem areas in the communicative situation. A strategic solution, they suggest, in order to improve the communication challenges, would be to be viewed and treated as being part of the healthcare team. They suggested that interpreters could also participate in medical rounds or be part of an employed ambulatory healthcare interpreting team. Other studies have also demonstrated the importance of approaching interpreters as members of the healthcare team with the shared goal of providing optimal care (Benjamin, Swartz, Chiliza, & Hering, 2016; Butow et al., 2012; Hsieh & Kramer, 2012). Other researchers report that there is a gap in training and support for both interpreters and healthcare personnel (Williams, Oulton, Sell, & Wray, 2018) and that there is a need for recognition of the interpreters' roles in the healthcare encounter (Brisset, Leanza, & Laforest, 2013). Other studies has also shown that participants in the interpreted-mediated consultation must be aware of the risk of misinterpretation and the risk of misunderstanding (Jackson, Diem, Hu, Harris, & Terasaki, 2011; Pham, Thornton,

Engelberg, Jackson, & Curtis, 2008; Pope et al., 2016; Sinow et al., 2017; Sleptsova et al., 2017).

Based on the results of this study, we would argue that healthcare personnel must be more aware of the complexity of using interpreters as language brokers and that they need to adopt greater skills and be more professional in the use of interpreters.

6.1.3 Study III (Developing CoLB-q)

Based on the findings of Study III, when developing systematized questionnaires, we would argue for the importance of being transparent and of following rigorous methods in developing and testing the validity and reliability of a questionnaire (Green, Rosu, Kenison, & Nze, 2018). The findings in Study III are mainly methodological and while it is challenging to develop a questionnaire that has been both validated and reliability tested, our results showed that this way of developing a questionnaire is very fruitful. The CoLB-q includes questions about the interpreters' function, the use of interpreters and the interpreters' impact on the patients/families' healthcare. The CoLB-q also covers other types of communication over language barriers and other aspects of the use of interpreters.

With regard to face and content validity, the cognitive interviews and the pilot test showed that the participants understood the questions in the questionnaire and that the questions had sufficient clarity and readability. With regard to reliability, the test-retest showed that the results were stable, although questions about translation tools indicated a learning effect between test and retest. Furthermore, several participants in the different testing phases stressed that the questions felt important to answer. One could also argue that the high response rate (90 %) in Study IV supports the claim that the CoLB-q is relevant.

6.1.4 Study IV (CoLB-q survey)

In Study IV, we have shown that when communicating over language barriers in paediatric oncology care, it was not uncommon for other means of communication than interpreters to be used, for example, the patients themselves or the patients' parents, siblings, relatives or friends.

Our results showed that the most common way of using interpreters is on site, though this usage differed considerably among the three professional groups with, for example, 64% of MDs, 37% of RNs and 44% of NAs reporting that they used on-site interpreters frequently.

When comparing the groups, we noted significant differences between MDs versus RNs and MDs versus NAs and their use of interpreters on site, but no significant differences between RNs versus NAs. It may be that the reason why MDs and RNs differ in their overall use of interpreters is that interpreters are used for consultations deemed to be important or difficult (i.e. medical consultations) and not for other informational consultations or as support in caring encounters. The finding that RNs used interpreters less may also be due to the effect of RNs and NAs taking the opportunity to use an interpreter when she/he is already on site rather than booking a separate consultation (Pergert et al., 2007), while MDs were more inclined to call interpreters to the site when they needed to. In brief, MDs use interpreters on site when they need to; RNs and NAs use interpreters when they are available.

Our results about using interpreters for different clinical tasks also showed that RNs had a strikingly low frequency of using interpreters when taking arrival status (15.6% often and 34.4% sometimes). This was striking as it forms part of an RN's assigned clinical task. On the other hand, the figures were higher for RNs informing about routines (30.6% often and 45.6% always) and procedures (29.9% often and 51% always). A reason for the low frequency of using interpreters when taking arrival status may be that this activity does not take place in connection with the medical consultation with an MD. Presumably the RN does not book an interpreter for this consultation and this figure was therefore low. On the other hand, we assume that RNs take the opportunity to inform about routines and procedures when an interpreter is on site for a follow-up medical consultation and this figure was therefore higher. Lundin, Hadziabdic, and Hjelm (2018) and Williams et al. (2018) found that healthcare personnel wanted better routines to be developed for providing direct access to professional interpreters and for training both interpreters and users. Our findings support the idea that if routines like this were developed, interpreters would probably be used more in healthcare contexts.

We know that using professional interpreters results in a significantly lower likelihood of errors occurring than similar situations using *ad hoc* interpreters or no interpreters at all (Flores et al., 2012; Ribera et al., 2008). This correlates with the participants in this study, almost all of whom agreed that the use of interpreters is important for the patients' involvement in care and patient safety. More specifically, over 90% of the participants believed that the use of interpreters increased patient safety and over 80% believed that it increased the patient's and family's involvement in care and improved the care relationship considerably. Nevertheless, this overwhelming belief did not always translate into the actual

use of professional interpreters, which is also supported by several other researchers (Guerrero, Small, Schwei, & Jacobs, 2018; Mengesha, Perz, Dune, & Ussher, 2018; Watts et al., 2018). It could also be as Llopis (2015) highlights that healthcare personnel do not understand the risks involved in communicating through unqualified interpreters.

In any case, communication is identified as being one of the most important aspects of care provision and an essential component of the nurse's professional role (Ali & Watson, 2018). Failure to provide a qualified interpreter is both a professional error (Lundin et al., 2018) and an ethical issue (Kliche et al., 2018). Our results showed that healthcare personnel fail to uphold patient-safe communication.

6.2 METHODOLOGICAL DISCUSSION

This thesis includes four studies, all which have different methodological approaches. Study I and II were qualitative content analysis studies. Study III was a multi-methodological questionnaire development and Study IV was a national multisite cross-sectional survey.

To ensure the trustworthiness of Study I and Study II, the studies enhance credibility by triangulation and member checks, transferability by providing accurate information about the context in which the studies were conducted, dependability by involving external researchers not involved in the data collection and analysis process, and confirmability by reviewed by other researchers (Elo & Kyngas, 2008; Graneheim & Lundman, 2004; Korstjens & Moser, 2017).

Study I and II were based on two different theoretical concepts. The first study used the method in accordance with Graneheim and Lundman (2004) and the second study used the method in accordance with Elo and Kyngas (2008). In Study I, we wanted to be more explorative in order to capture the interpreters' experiences as in "What are they experiencing?" and in Study II we wanted to be more descriptive about the strategies the interpreters explained they used to handle their assignments in Study I. Through the inductive method in accordance with Elo and Kyngas (2008), we wanted to highlight the strategies by staying close to the data and not attempting to achieve a too high abstract level and conceptualization, answering the research question: "What are the interpreters doing to handle their assignment?".

In Study I, I would argue that the main theme “Creating a meeting point of understanding” is a form of conceptualization that is too stretched, as the main theme does not explain the interpreter’s “experiences” as our research question asked. The main theme should be closer to “the interpreters’ struggle to create a meeting point of understanding”. The interpreters’ experience is “the struggle” in conjunction with the three sub-themes: balancing between cultures, bridging the gaps of knowledge and balancing between compassion and professionalism. “Creating a meeting point of understanding” is what the interpreters are attempting to do. It answers the question “What are the interpreters doing to handle their situation?” and is more of a “main concern” in accordance with Grounded Theory. I would therefore argue that we reached a higher abstract level and conceptualization in Study I than we intended to and, in doing so, missed answering our research question. The benefit of our analysis was that we managed instead to answer the question: What is the interpreters’ main concern?

Other limitations of Study I and II are the small number of participants. However, the participants reported similar experiences and the results should therefore be seen as a description of the specific phenomenon of interpreter-mediated consultation in paediatric oncology care.

Study III was a real struggle and has a number of limitations. The sample size of the pilot test and test-retest was relatively small. The sample was also a convenient sample and not randomly selected, which may limit the study’s statistical power. The test-retest should not be expected to show a difference between the two tests, and for most of the questions it did not. However, for three of the questions our results seem to indicate that some participants had changed their behaviour, which we interpret as a possible learning effect between the test and the retest. The questionnaire was also mainly developed and evaluated in a paediatric healthcare context and with RNs and NAs as participants.

In Study IV the sample in the survey was relatively small, yet we would argue that the opportunity to survey healthcare personnel at all six paediatric oncology centres in Sweden strengthens this study. Most notable is that the data in Study IV cover the whole population of healthcare personnel at paediatric oncology centres in Sweden. Thus, due to the risk of inflation of type I error (i.e. false positives), we did not conduct any systematic calculations of p-values. Splitting the population into different professions makes the groups smaller, but this calculation was chosen to clearly demonstrate that the different professions handle

language barriers in different ways. Nevertheless, I would argue that it strengthens the study due to the possibility of comparing the different professions.

7 CONCLUSION

This thesis has contributed to a deeper understanding of communication over language barriers among healthcare personnel in paediatric oncology care and the use of interpreters and other communication tools to overcome language barriers.

The interpreted-mediated consultation is a complex communicative situation and the interpreter is not solely responsible for the information transfer. All parties in the consultation must take responsibility to enable the families to understand the information. As this research has demonstrated, the interpreters stretch their discretionary power in order to carry the bilingual conversation by using strategies clearly outside of their assignment, for example, by alleviating and adapting words and phrases. Healthcare personnel must be aware that interpreters could adapt the information in order to facilitate the communication.

As a result of developing the CoLB-q as a validated and reliable questionnaire, investigating communication over language barriers and the use of interpreters, as well as reporting the developing process, we can argue that the survey results have a high level of accuracy. Taking into account the fact that healthcare personnel believe the use of interpreters is crucial when caring for a patient/family; this study highlights the discrepancy between their belief and the actual use of professional interpreters. The results indicated that MDs use interpreters on site when they need to, while RNs and NAs mostly use interpreters when they are already available on site. This is in contrast to the ideal that the use of interpreters should, in all care contexts, be based on the patient's needs and not merely on the interpreter's availability. The use of interpreters must be based on the patient's ability to understand and be understood by healthcare personnel. By doing so, healthcare not only ensures patient-safe care but also maintains the legal right to equity in healthcare.

Communication is identified as being the most important aspect of care provision and an essential component of a nurse's professional role regardless of the clinical context. Language barriers negatively affect nurses' ability to communicate effectively with their patients and thereby have a negative impact on the provision of appropriate, patient-safe and effective care. Because of its direct impact on health outcomes and equity in health care,

high-quality interpreting should be a priority. Efficient professional interpretation is an important part of effective and patient-safe communication and a vital foundation for equity in healthcare.

The implication of this research project has been children's right to equity in paediatric oncology care and a prerequisite for equity in care is to strive for patient-safe communication between healthcare personnel and the patient/family with limited Swedish proficiency.

8 FUTURE RESEARCH

There is a need to further investigate the situation for children in multi-party consultations, for example, observational studies into how children handle language barriers in paediatric healthcare. It is also important to approach other difficulties in paediatric health care such as the child's perspective and patient participation in the decision-making process when there are language barriers.

By continuing to combine different research fields such as interpreting research and caring science there are some synergy effects that could increase knowledge of communication over language barriers in healthcare. For example, in interpreting studies, conversation analysis (CA) is a common tool for studying interaction in interpreter-mediated consultations. CA provides a micro perspective of communication over language barriers, but can contribute to providing a fuller picture of the macro perspective than this study has taken.

Other important questions for further research due to increased migration is how advancements in the new IT and AI technologies could be used to reduce language barriers that affect the quality of care provided to patients with limited proficiency in a country's majority language.

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11 APPENDIX