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PARENTS' EXPERIENCES OF NURSES' CULTURAL COMPETENCE IN SWEDISH PAEDIATRIC CARE

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*Parents' experiences of nurses' cultural competence
in Swedish paediatric care*

THESIS FOR LICENTIAT DEGREE

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ABSTRACT

Due to global migration, Sweden, as is the case for many other countries in Europe, has become a multi-ethnic society. The multi-ethnic composition of the Swedish population has led to an increasing diversity of patients and health staff in health care. The increased diversity in Swedish healthcare creates challenges for the staff of ethnic Swedish as well as the staff of minority ethnic, in terms of working together and working with diverse patient groups. The challenges are mainly related to communication with people who share neither the same native language nor the same cultural values or health beliefs. In relation to healthcare, the need for culturally competent care to overcome these challenges is reported in almost all studies about the caring relationship in the multi-ethnic societies.

The overall aim of this thesis was to explore the experiences and expectations of culturally competent care and the cross-cultural care encounters among parents of hospitalized children in Swedish paediatric care.

The thesis is based on two qualitative studies carried out from the perspective of parents of hospitalized children in Swedish paediatric care. Study I addresses ethnic Swedish parents' experiences of minority ethnic nurses' cultural competence and the care provided by them. Study II addresses the expectations and experiences of cross-cultural care encounters among minority ethnic parents in Swedish paediatric care. The sample in Study I consisted of 14 parents of ethnic Swedish background while the sample in Study II consisted of 12 parents of ethnic minority backgrounds whose children were being cared for at a children's hospital in the Stockholm County Council. The data for both Study I and Study II were collected by semi-structured interviews and analysed using content analysis.

The nurses' cultural competence was described by the ethnic Swedish parents and the minority ethnic parents in terms of the nurses' ability to provide professional and sensitive care based on their professional knowledge and their respect for the human being. The parents' experiences of the care relationship and the cross-cultural care encounters, as well as their expectations of the nurses' cultural competence, were affected by various factors and were also described at different levels. The importance of the nurses' professional approach, a well-functioning communication and the significance of organizations for the parents' experience of cross-cultural care encounters were identified in both Study I and Study II. This thesis confirms some of the constructs in the cultural competence models, such as cultural sensitivity and cultural encounter. However similarities with the definition of patient-centeredness care, such as the importance of a personal care relationship and the importance to being treated and respected as a unique individual and not as a part of a culture group, have also been emphasized. Culturally competent care is about professional and sensitive care based on respect for the patient as a unique individual. The challenges involved in cross-cultural care encounters are mainly related to lack of familiarity with language, culture and diversity rather than to differences between cultures. It is important to overcome the challenges of language and communication obstacles in cross-cultural care encounters. The healthcare system has a significant role in facilitating the provision of culturally competent care.

Keywords: cultural competence, cross-cultural care encounters, parents' experiences, paediatric care, minority ethnic, manifest analysis, content analysis, qualitative method

LIST OF PUBLICATIONS

This thesis is based on the following qualitative studies, which will be referred to in the text by Roman numerals.

- I. Tavallali, AG., Kabir, ZN., & Jirwe, M. (2014). Ethnic Swedish Parents' experiences of minority ethnic nurses' cultural competence in Swedish paediatric care. *Scandinavian Journal of Caring Sciences*. 28 (2)-255-63.
- II. Tavallali, AG., Jirwe, M., & Kabir ZN. Cross-cultural care encounters in paediatric care - minority ethnic parents' experiences. Submitted for publication.

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1 PREFACE

My interest in the cultural issues involved in caring relationships derives from my experience not only as a nurse but also as a minority ethnic nurse working in paediatric care in a multi-ethnic society. As a paediatric nurse, I have met many children and parents of both ethnic Swedish and minority ethnic backgrounds. In my contact with minority ethnic parents in paediatric units, I had the feeling that these parents felt an affinity with me having a minority ethnic background myself and that they preferred to turn to me with questions or concerns about their children, even though we did not share a common language. It seemed that the parents felt that I could understand them in a better way than could my ethnic Swedish colleagues. This could be related to our similar experience of migration. In my contact with ethnic Swedish parents, I always wondered if I could satisfy their cultural needs and what expectations they had of me as a minority ethnic nurse. During the time I was working as a paediatric nurse, I had many questions and thoughts about the care relationship and cross-cultural care encounters, which I was not able to explore at that time.

In addition, I have always been interested in the patient's perspective on the caring relationship. My master's thesis (2006) addressed parents' experience of information in relation to neurosurgery for brain tumours in children. And when I started working at Karolinska Institutet as a lecturer, I became familiar with the concept of cultural competence. In this current thesis, I had the opportunity to study parents' experiences and expectations of culturally competent nursing care in order to explore the cultural challenges in the caring relationship from the parents' perspective.

2 BACKGROUND

Due to global migration, Sweden, as is the case for many other countries in Europe, has become a multi-ethnic society. Today, the population of Sweden, which is almost 9.7 million people (Statistics Sweden, 2014), is a diverse group of almost 200 nationalities from different countries mainly from Asia, Africa and Europe (Statistics Sweden, 2013a). The multi-ethnic composition in the Swedish population has led to an increasing diversity of patients and health staff in health care. Today, almost 12% of the nurses in Sweden are of minority ethnic background (Statistics Sweden, 2012).

The increased diversity in Swedish healthcare provides challenges for the staff of ethnic Swedish as well as the staff of ethnic minority in terms of working together (Olt, Jirwe, Saboonchi, Gerrish & Emami, 2014) and working with diverse patient groups (Berlin Johansson & Tornkvist, 2006; Jirwe, Gerrish & Emami, 2010; Nkulu Kalengayi, Hurtig, Ahlm & Ahlberg, 2012). The challenges are mainly related to communication between people who share neither the same native language (Berlin et al., 2006; Jirwe et al., 2010; Nkulu Kalengayi et al., 2012; Pergert, Ekblad, Enskär & Björk, 2007) nor the same cultural values or health beliefs (Nkulu Kalengayi et al., 2012).

The thesis will start with a description of the terms and concepts that have been used in the two studies – that is, what cultural competence is, how the concept has been described in the scientific literature, and how it has developed and expanded over time.

2.1 What is cultural competence?

2.1.1 *The concept of cultural competence*

Cultural competence as a concept has been applied in many disciplines including nursing (Shen, 2014). It refers to the knowledge, skills and attitudes that are required in order to meet patients' cultural, social and linguistic needs, and the ability to provide effective care for patients of different cultural and ethnic backgrounds with diverse beliefs and values (Betancourt, Green & Carillo, 2002; Campinha-Bacote, 2002; Leininger & McFarland, 2002). Although the concept is quite new in the academic world it has received considerable attention from many researchers and theorists over the last few decades (Shen, 2004, 2014, Balcazar, Suarez- Balcazar & Ritzler, 2009a). In relation to nursing, the term cultural competence was first used by Leininger in her theory of cultural care diversity and universality. The focus of the theory was on human caring and cultural relationships and it highlighted cultural differences and similarities (Leininger, 1991, 2002a). Thereafter, many researchers have developed their own cultural competence models and frameworks (Campinha- Bacote, 2002; Papadopoulos, 2006; Purnell & Paulanka, 2003) as well as cultural competence assessment instruments and guidelines based on her theory (Andrews & Boyle, 2008; Campinha-Bacote 2003; Giger & Davidhizar, 2008). However, Leininger (1991) used the concept of cultural competence under the term 'culturally congruent care'. She has described culturally congruent care as care that fits the patients' and their families' cultural beliefs and lifestyle (Leininger, 1991, 1995, 2002a). The term 'culturally congruent' is conceptually very close to or synonymous with cultural competence and has been used interchangeably with it by Leininger (Andrews & Boyle, 2008; Burchum, 2002). However, cultural competence as a concept consists of two sub-concepts; culture and competence and they will both be described below.

2.1.1.1 Culture

Culture as a concept has been defined and used in many disciplines such as anthropology, nursing science (Leininger, 2002b) and sociology (Dunn, 2002). Although the concept has many definitions, there are common elements in most of the definitions. The most common element in the definitions of the concept of culture is the idea that “*culture is dynamic, shared, symbolic, learned and integrated*” (Dunn, 2002, p, 105). According to Dunn (2002), the most important aspect of culture is that it is dynamic, which means that it is constantly evolving and changing.

According to Kleinman and Benson (2006), culture is not just one variable but rather consists of multiple variables (economic, biological, political, etc.), which affect different aspects of experience. Culture describes a process. The process differs within and outside the same cultural group. This is due to differences in, for instance, age, class, religion and personality. The term has often been used as synonymous with nationality and ethnicity (Kleinman & Benson, 2006). According to Suh (2004), the concept of culture takes on different meanings and interpretations depending on the specific context and/or situation. For example, the concept may be used in relation to the culture of an ethnic group or in relation to the culture of an individual (Suh, 2004).

In relation to nursing, Leininger has 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, 2002b, p 9).

Culture and cultural background have an essential effect on many aspects of people’s lives. For example, they affect their understanding of and attitudes toward health and illness (Brusin, 2012; Golizadeh, Davidson, Hydari & Salamonson, 2014; Helman, 2007; Leininger, 2002 b), their expression of pain and discomfort (Brusin, 2012), and their treatment-seeking behaviour (Golizadeh et al., 2014). Culture and cultural background are therefore highly significant factors in people’s health (Helman, 2007) and must always be considered in clinical work and medical treatment (Golizadeh, et al., 2014).

2.1.1.2 Competence

Depending on the context, there are various definitions of the term competence (Laibhen-Parkes, 2014). Basically, the word competence derives from the Latin *co’mpeto* and is seen as synonymous with knowledge, ability and qualification (Hammare, 2004). Competence has been described as a performance that is adequate, correct and appropriate (Burchum, 2002). The concept of competence, which was initially limited to describing formal qualifications, has become a multidimensional concept that by definition includes the capacity to combine and integrate knowledge, skills, personal qualities and attitudes with the aim of developing an ability or activity in a specific and definite context (Korthagen, 2004).

In relation to nursing, competence refers to the nurses’ ability to practically, safely and professionally perform a task by applying their knowledge and skill. It requires nurses to have the ability to meet and satisfy patients’ basic and specific care needs, to respond to patients’ physical, psychological, social and cultural needs, and to also meet the needs of the patients’ relatives (The National Board of Health and Welfare, 2005).

The term competence has been described by nurses themselves as the context-specific knowledge of nursing, the nurses’ personal qualities, the ability to manage, teach, coach and to make decisions (Meretoja, Leino-Kilpi & Kaira, 2004), and the ability to draw rapid

and adequate and appropriate conclusions in a clinical situation (Reischman & Yarandi, 2002).

In relation to culture, competence refers to the ability to understand and effectively interact with people from different cultures. In relation to cultural care, competence refers to the ability to provide care that is meaningful and is adjust to patients' cultural values and health beliefs (Leininger, 2002a).

2.1.2 The definition of cultural competence

There are several definitions of the concept of cultural competence and the concept has been defined in many professions and in different ways (Shen, 2004, 2014). For example, in the social work profession, the term cultural competence has been described as a set of behaviours, attitudes, and policies that combine to enable the staff to work effectively in a system in cross-cultural situation (Cross, Bazron, Dennis & Isaacs, 1989).

In relation to healthcare, the term is described as the ability of healthcare systems to provide care to patients of diverse backgrounds (Betancourt et al., 2002). In relation to nursing, cultural competence refers to the knowledge and skills that care providers should have in order to care for and effectively communicate and interact with patients of different cultural backgrounds (Betancourt et al., 2002; Caminha-Bacote, 2002; Emami, 2000; Leininger & McFarland, 2002).

Leininger (2002a) refers to culturally competent nursing care as being “*the explicit use of culturally based care and health knowledge that is used in sensitive, creative, and meaningful ways to fit the general lifeways and needs of individuals or groups for beneficial and meaningful health and well-being or to face illness, disabilities, or death*” (p. 84).

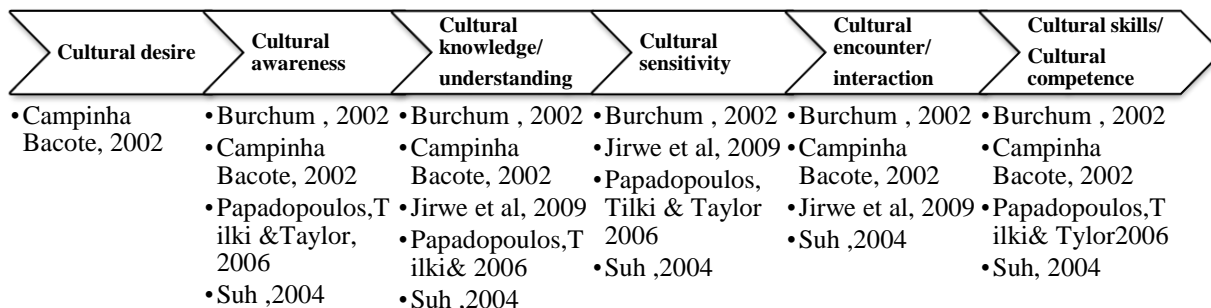
2.1.3 The models of cultural competence

Several frameworks, instruments, theories and models of cultural competence mainly from North America and Europe have been constructed during the past decade with the aim of describing cultural competence in healthcare (Balcazar et al., 2009a; Shen, 2004, 2014). According to a literature review carried out by Shen (2014), cultural competence models in nursing have been identified and presented using two approaches; theoretical and methodological approaches. As previously mentioned, the concept of cultural competence includes two components – culture and competence. The differences in the two approaches depend on which of the two components of cultural competence the models include (Shen, 2014). One approach focuses on culture, the other on competence. For example, models of cultural competence that are based on a theoretical approach focuses on competence –that is, knowledge, skills, awareness and sensitivity (Burchum, 2002; Campinha-Bacote, 2002; Jeffreys, 2010; Jirwe, Gerrish, Keeny & Emami, 2009; Papadopoulos, 2006; Suh, 2004). Methodological models, on the other hand, focus on the culture component of cultural competence and refer to the domains of religion, cultural values, cultural context, beliefs and lifestyle, health beliefs, communication, and family roles and organization (Leininger, 1991; Pacquiao, 2001; Purnell & Paulanka, 2003).

The definitions of cultural competence in the above models have mostly been provided by nurse researchers. The similarity between the models of cultural competence is that cultural competence is seen as an ongoing process that integrates and includes skills in all scopes and dimensions, that is, cognitive, behavioural and practical (Burchum, 2002; Campinha-Bacote, 2002; Jeffreys, 2010; Jirwe et al., 2009; Papadopoulos, 2006; Suh, 2004).

In addition, primarily theoretical models of cultural competence include similar constructs or domains in their definition of cultural competence. According to several systematic literature studies, the most common constructs used in these models are: cultural awareness, cultural knowledge, cultural skills, cultural sensitivity, cultural understanding and cultural encounter or interaction (Balcazar et al., 2009a; Shen, 2004, 2014). These constructs are illustrated in figure 1.

Figure 1: The constructs/attributes/core components of the theoretical models of cultural competence.



The above constructs are described by the researchers as follows: cultural awareness, considered the first step in the process of cultural competence, refers to becoming aware of one's own beliefs, feelings, values; to reflecting on our personal biases toward other people; to becoming knowledgeable about other cultures (Campinha-Bacote, 2002, Giger, Davidhizar, Purnell, Harden, Phillips & Strickland, 2007); to becoming aware of and understanding the differences between people from different cultural backgrounds as well as the individual differences between people of the same cultural background (Papadopoulos, 2006). Cultural knowledge, the ability to understand different world views, means being knowledgeable about and familiar with patients' cultures, traditions, behaviours and values (Campinha- Bacote, 2002; Jirwe et al., 2009). Cultural skills refer to the ability to communicate effectively and make cultural assessments. Cultural encounters relates to the relationship and face-to-face cultural interaction (Campinha- Bacote, 2011). Cultural desire is about being willing to engage in the subject and is described by Campinha-Bacote, (2002, 2007) as being the key to the process. Cultural sensitivity is about the nurse-patient relationship based on respect, trust (Papadopoulos, 2006) and respect for human beings (Jirwe et al., 2009).

However, while Campinha-Bacote (2002) describes cultural competence as an individual ongoing process, Papadopoulos, Tilki and Tylor in their model for developing cultural competence (PTT model) describe cultural competence both as a process and as an output. Their model also includes cultural competence as a construct or stage within the model. Cultural competence as a construct is presented as the outcome of the synthesis of nurses' cultural awareness, knowledge and sensitivity. It refers to nurses' clinical, practical and diagnostic skills and to their ability to provide care by taking the patient's cultural beliefs into consideration in the nursing process. The model also addresses prejudice, discrimination and disparities in healthcare (Papadopoulos, 2006).

In contrast to Leininger's cultural care theory from 1991, which was based on theories from nursing and anthropology, Purnell's model of cultural competence was based on theories from multiple disciplines such as political science, communication, sociology and pharmacology (Purnell, & Paulanka, 2003). In addition, in Purnell's model of cultural competence culture is not limited to patients or their families but also includes organization. This model includes workforce issues that can be used to assess and reflect on cultural issues among the staff and in the organization. Purnell & Paulanka (2003) have noted the importance of nurses' possessing "*cultural-general and cultural-specific information*" for their ability to provide sensitive and culturally competent care. The domains in the model move from more general phenomena – for example, overview, heritage, communication, family roles and organization – to more specific phenomena – such as nutrition, death rituals and spirituality.

2.1.3.1 The evolution and expansion of the models

While the early conceptual models of cultural competence focused on culture-specific knowledge (Leininger, 1991; Papadopoulos, 2006) the later models and research have focused on the encounters. This allows the nurse to see, connect and interact with the patient as a unique individual, rather than as a categorisation and a stereotype of a cultural group (Campinha-Bacote, 2011, Jirwe et al., 2009). For example, Jirwe et al. (2009) emphasized cultural understanding, cultural encounter and cultural sensitivity rather than cultural knowledge in their identification of the core components of cultural competence in nursing.

In addition, the models of cultural competence were expanded beyond the interpersonal domain to include the healthcare system as a whole, that is, organization, education and communities. For example, Jeffrey (2010), in her cultural competence and confidence (CCC) model focused on the multidimensional teaching–learning process. The model is based on theories from transcultural nursing, psychology and education.

Moreover, in the past few years, many researchers have compared the conceptual models of cultural competence and patient-centeredness, highlighting the similarities between cultural competence and patient centeredness. Even though the concepts of cultural competence and patient-centeredness have different focuses, implications and histories, the core components are the same and aim to improve and increase the quality of healthcare for the individual and aim to seeing the patient as an individual (Nielsen, Angus, Howell, Husain & Gastaldo, 2014; Saha, Beach & Cooper, 2008).

The concept of cultural competence has been criticised by some researchers as entailing a risk of stereotyping when the patient is assumed to belong to a cultural group (Kleinman & Benson, 2006; Ramsden, 2002). It has also been criticised for entailing a risk of stigmatisation, since the method focuses on cultural differences rather than similarities (Lee & Farrell, 2006), and for the difficulty of applying cultural competence in clinical and practical training (Kleinman & Benson, 2006). According to Lee and Farrell (2006) there is a tendency in the scientific literature on cultural competence, especially the North American literature, to use race synonymously and interchangeably with culture and ethnicity. According to Kleinman and Benson (2006) cultural competence has been related to particular groups. In the North American literature the concept of cultural competence has been used in relation to an established ethnic group, for example, African Americans, while in Europe cultural competence has mostly been used in relation to diversity of culture, ethnicity, language, etc. (Kleinman & Benson, 2006).

In summary, while there are several theories and models of cultural competence, there is still no general, unified definition and a limited number of validated conceptual frameworks applicable to all care contexts. Most of the models only evaluate the cultural competence of healthcare staff. The patient and health outcomes are not reflected or addressed in these models (Balcazar, et al., 2009 a; Balcazar, Suarez-Balcazar, Wills & Alvarado, 2009,b).

2.1.4 Cultural competence in the Swedish care context

In Sweden, the concept of cultural competence has been studied in different ways and in different care contexts. Cultural competence in elderly care has been studied by Emami (2000), in order to explore immigrants' perceptions and experience of culturally appropriate care. Healthcare providers' perception of diversity and cultural competence in elderly care has been studied by Olt (2013). Cultural competence in primary child healthcare focusing on the interaction between the nurses and parents of foreign origin and their children has been studied by Berlin (2010). In addition, in order to explore and analyse how cultural competence was understood in relation to the Swedish care context, the concept was also studied from the perspectives of nurses, nurse educators, nurse researchers (Jirwe et al., 2009) and nursing students (Jirwe et al., 2010). The perspective of patients and their relatives on the concept of cultural competence in the Swedish context is missing in these studies.

2.2 The challenges of providing culturally competent care

The main challenges involved in providing culturally competent care are related to language barriers and the challenges of interacting with people who do not share one's own language, background, culture or values. For example, Betancourt, Green and Carrillo (2000) emphasized the language barrier as the first challenge, social and cultural differences between the care providers and patients as the second challenge, and understanding the patients in their social context as the third challenge in cross-cultural care encounters. The challenges have also been related to understanding and respecting the patients' values and feelings, diversity in the population, lack of resources (Hart & Marenó, 2013), prejudices and biases (Betancourt et al., 2000; Hart & Marenó, 2013; Schouten & Meeuwesen, 2006). The challenges mentioned included caregivers' unfamiliarity with diversity and patients' unfamiliarity with the healthcare system (Nkulu Kalengayi et al., 2012).

The cultural challenges in healthcare have been divided and presented on different levels (Hart & Marenó, 2013; McGee & Johnson, 2014; Nkulu Kalengayi et al., 2012). For example Nkulu Kalengayi et al. (2012) have presented four levels of challenges. On the individual level, the challenges are related to socio-cultural diversity, for example, migration, gender, health beliefs and the caregiver attitudes toward immigrants. On the interpersonal level, the challenges are related to differences in health beliefs, practices and language barriers. On the institutional level, the challenges are related to the structure, policies and organization of the healthcare system, and finally, on the societal level, the challenges are related to the general diversity –particularly the cultural diversity – policies and guidelines in the system. According to Nkulu Kalengayi et al. (2012) these four levels interact with and affect each other and should be reflected on by the care provider in order to improve the delivery of care for immigrant patients. Moreover, as Betancourt et al. (2000) have highlighted, it is important that the challenges be handled correctly in order to avoid the negative effect of the challenges in clinical interaction. The challenges will be discussed below.

2.2.1 The challenges at the individual level

2.2.1.1 Biases and prejudices

The existence of discrimination and prejudice has been reported in many studies about nurses' and patients' experience of the caring relationship in a multi-ethnic society. Experiences of discrimination have been reported both in the studies about ethnic minority nurses' experiences (Alexis, Vydellingum & Robbins, 2007; Johansson, Jones, Watkins, Haisfield-Wolfe & Gaston-Johansson, 2011) and ethnic minority parents' experiences of the care relationship in the multi-ethnic society (Davies, Larson, Contro & Cabrera, 2011; Rydström & Dalheim-Englund, 2014). The participants in these studies related the experiences of discrimination mainly to their cultural and ethnic backgrounds (Rydström & Dalheim Englund, 2014). Nurses' biases and prejudices (Hart & Mareno, 2013) and caregivers' discriminatory attitudes (Nkulu Kalengayi et al., 2012; Schouten & Meeuwesen, 2006) were reported as challenges for caregivers' ability to provide culturally competent care to patients of immigrant background. These discriminatory attitudes were partly related to the nurses' expectations of patients regarding their adaptation to the culture of the country of reception (Hart & Mareno, 2013) and partly to the nurses' unfamiliarity with diversity (Nkulu Kalengayi et al., 2012).

The first step in overcoming these challenges so as to be able to provide culturally competent care is to overcome biases and prejudices, by becoming aware of one's own biases (Jirwe et al., 2009; Campinha-Bacote, 2002) and developing self-awareness (Wilson, 2010) and self-reflection (Blackman, 2011). These elements as well as knowledge of others and the skill to manage difference, have also been described, by McGee and Johnson (2014), as the main elements required to develop cultural competence.

2.2.2 The challenges at the interpersonal level

2.2.2.1 Understand the patients values and feeling

The challenges in cross-cultural care encounters are related to the individual differences in health beliefs and care practices and also the differences in the expectations of the health care system (Nkulu Kalengayi, et al., 2012; Schouten & Meeuwesen, 2006). To understand the patients who have different views of health and illness and different expectations regarding the professional competence has been reported as being problematic in clinical care encounters by care providers in Sweden (Nkulu Kalengayi, et al., 2012).

The other cultural challenge experienced by nurses was related to understanding and respecting patients' cultural values, beliefs and feelings (Hart & Mareno, 2014). The key elements of meeting these challenges are nurses' willingness to become culturally competent and their sensitivity to cultural differences. These elements are referred to as 'cultural desire' and 'cultural sensitivity' in the model of cultural competence identified by Campinha-Bacote (2002).

2.2.2.2 Communication and language barrier

As discussed above, the language barrier and the challenges of communication with people who do not share the same background and language have been reported as the main, most obvious challenges in cross-cultural care encounters as has the provision of culturally competent care in several international (Betancourt et al., 2000; Flores, Rabke-Verani, Pine & Sabharwal, 2002; Hart & Mareno, 2014; Kai, Beavan & Faull, 2011; Lindsay, King, Klassen, Esses & Stachel, 2012) and Swedish studies (Berlin et al., 2006; Jirwe et al., 2010; Nkulu Kalengayi et al., 2012; Pergert et al., 2007). According to a literature study carried out by Flores et al. (2002), language issues have been reported by both nurses and

patients as being the major problem in the emergency care of children. Language problems can affect many aspects of healthcare – such as patient satisfaction and access to care. In a study about nursing students' experience of communication in cross-cultural care encounters Jirwe et al. (2010) reported difficulties in communication due to the lack of a common language which sometimes led to problems both for caregivers and patients. The problem was related to the risk of giving limited information about the medical, clinical and technical aspects of the procedures, and it was also due to the risk of misunderstanding patients' messages. Hart and Mareno (2014) in their study on cultural challenges from the nurses' perspective also reported language barriers as being the biggest challenge for the nurses, reducing the likelihood of a trustful nurse–patient relationship. Betancourt et al. (2000) had similar findings, emphasizing the language barrier as the first and most obvious challenge in cross-cultural care encounters between care providers and patients.

Moreover, many studies show that language and communication barriers can be overcome by using medical (Brusin, 2012) and professional interpreters (Brämberg & Sandman, 2012; Flores, et al., 2002; Jirwe et al., 2010; Nkulu Kalengayi et al., 2012; Plaza Del Pino, Soriano & Higginbottom, 2013; Pergert, Ekblad, Enskär & Björk, 2008). Pergert et al., (2008) highlighted the importance of using interpreters for both medical information and nursing communication, to bridge the linguistic divide if necessary (Pergert et al., 2008). Jirwe et al. (2010) reported using an interpreter as a communication strategy and as a way to enhance cross-cultural communication. In contrast to the researchers named above, some researchers reported difficulties in being able to connect with patients when using an interpreter (Hart & Mareno, 2014; Kai et al., 2011).

2.2.3 The challenges at the institutional level

2.2.3.1 Communication

Communication challenges exist not only on the interpersonal level but also on the institutional level. For example, non-face-to-face forms of communication prevalent in the Swedish healthcare system, such as email and voicemail, can have an effect on cross-cultural care encounters (Nkulu Kalengayi et al., 2012).

2.2.3.2 Unfamiliarity with the health-care system

Immigrant patients' previous experiences of health-care systems and health-care relationships, their unfamiliarity with the new healthcare organization and their expectations with respect to the care relationship affect the cross-cultural care encounter. For example, many immigrant patients are not used to being involved in medical or nursing decision-making due, to previous experience in their homeland of hierarchy and authority in the care relationship (Nkulu Kalengayi et al., 2012) or to their verbal behaviour (Schouten & Meeuwesen, 2006).

According to Brusin, (2012) and Nkulu Kalengayi et al. (2012), immigrant patients should have the opportunity to receive information and guidance so as to become familiar with and learn to navigate the new healthcare system. Gholizadeh et al. (2014) highlighted the importance of attention to the effect of cultural and linguistic factors in clinical work and medical treatment.

2.2.3.3 Training in cultural competence

Lack of training in cultural competence and a lack of knowledge about particular groups are also reported as major challenges to providing culturally competent care (Berlin, et al 2006; Hart & Mareno, 2014; Papic, Malak & Rosenberg, 2011). Access to a validated conceptual framework (Balcazar et al., 2009a,b; Bäärnhielm & Mösko, 2012; Loftin, Newman, Gilden,

Bond & Dumas, 2013) and training in cultural competence can improve implementation of the models in clinical work, which can in turn facilitate the provision of culturally competent care (Beach et al., 2005; Berlin, Nilsson & Tornkvist, 2010; Bäärnhielm & Mösko, 2012; Frintner, Mendoza, Dreyer, Cull & Laraque, 2013; Haack & Phillips, 2012; Hawala-Drury & Hill, 2012).

In a study about the effect of training in cultural competence, Berlin et al. (2010) reported that training had a significant effect on nurses' cultural competence, and on alleviating nurses' difficulties and concerns. This resulted in an improvement in the nurses' working conditions, which in turn could improve the quality of service provided to the children of immigrant parents in Swedish healthcare. Dellenberg, Skott and Jakobsson (2012), while reporting on the importance of training in cultural competence to improve the care encounter, also emphasized the importance of maintaining a discussion around culturally related subjects in all medical units.

2.2.4 The challenges at the societal level

The greatest challenges to healthcare encounters on the societal level are related to the rapid growth of diversity in healthcare. These challenges are related to the provision of care to a heterogeneous group with different backgrounds, cultures, values, education, experience and expectations. These differences affect the care relationship. The patient's country of origin and the reason for his or her immigration can also influence the care encounters (Hart & Mareno, 2014; Nkulu Kalengayi et al., 2012). However, as Dunn (2002) describes, to overcome this challenge and to be able to provide culturally competent care, both care providers and patients should change their *world view* (Dunn, 2002).

2.3 The diversity of the Swedish population

Sweden has experienced a long history of immigration. People from Europe, especially from Finland and Romania, were among the first groups to immigrate to Sweden to work, as early as the 15th century, while most of the people who have moved to Sweden in the past decade have been asylum-seekers from mainly Syria, Eritrea, Somalia, Iraq, Iran, Serbia and Kosovo. However, people have moved to Sweden for many different reasons. Some people have moved to Sweden to seek asylum due to the situation in their country of origin primarily on account of war or lack of political or religious freedom. There are also some who have moved voluntarily – to study or work in Sweden, for example (Migrationsverket, 2014a). Whatever the reason for the move, almost 20 per cent of the Swedish population is today, of foreign origin (Statistic Sweden, 2013a). Moreover, for most immigrants, migration results in a long period of uncertainty, due mainly to their unfamiliarity with the system in the country of reception (Hjern, 2012).

In Sweden, in relation to population the terms 'foreign' and 'Swedish background' are used by Statistics Sweden (Statistics Sweden, 2013 b). According to the *Reports on Statistical Co-ordination for the Official Statistics of Sweden* (2002:3) 'foreign background' refers to "persons born abroad or born in Sweden with two parents born abroad" and 'Swedish background' refers to "persons born in Sweden with one or two parents born in Sweden" (Statistics Sweden, 2002, p 23).

2.3.1 Diversity in Swedish healthcare

The mass migration of nurses and other healthcare professionals across Europe has in turn increased the number of minority ethnic healthcare staff caring for majority groups (Hancock, 2008). This also applies to the Swedish healthcare system since there has been significant migration to Sweden over the last few decades (Migrationsverket, 2014b; Swedish Statistic, 2012). This increased diversity in Swedish health care caused that the

care encounters take place between the nurse and the patient in several formations: for example the care encounter between an ethnic Swedish nurse and a patient of an ethnic minority; between a nurse of an ethnic minority and an ethnic Swedish patient or between a nurse of ethnic minority and a patient of ethnic minority. As mentioned before, several factors among others communication difficulties and cultural differences, affect the cross-cultural care encounter. Knowledge and skills in the cross-cultural care encounter in Swedish health care are a necessity due to the great diversity of the Sweden population.

2.4 Swedish paediatric care

Nurses' clinical work in paediatric care in Sweden is based on the principles of the United Nations Convention on the Rights of the Child (UN Human Rights, 2014), as well as on national regulations and legislation, acts and guidelines (SFS 1982:763). The purpose of these laws and regulations is to ensure that the child's rights and needs are upheld. The aim of the healthcare service in Sweden is to provide good-quality equitable healthcare for all (SFS 1982:763). This aim informs the healthcare system generally as well as paediatric care.

Paediatric care in Sweden also follows guidelines laid down by the European Association for Children in Hospital (2014) and the National Association of Paediatric Nurses (2014). According to these guidelines, nurses who care for children should have the competence to respond to and satisfy the child's and its family's physical and mental as well as social and cultural needs (European Association for Children in Hospital, 2014; National Association of Paediatric Nurse Practitioners, 2014). According to a report from the National Board of Health and Welfare in Sweden, most parents feel that they and their children are treated in a respectful way by healthcare providers (The National Board of Health and Welfare, 2014).

2.5 A child's hospitalization

A child's hospitalization creates a stressful situation for its parents in terms of uncertainty and anxiety related to the child's illness and diagnosis (Comp, 2011; Fisher & Broome, 2011). The child's illness and hospitalization also cause the family to be dependent on others, especially healthcare providers (Björk, Wiebe & Hallström, 2005). A sense of powerlessness has been reported in some studies on parents' experiences in Swedish paediatric care. This feeling of powerlessness was reported not only in relation to the child's illness and diagnosis but also in relation to the relationship with the nurses and other professional staff (Björk et al., 2005; Povlsen & Ringsberg, 2009; Pergert, Ekblad, Björk, Enskär & Andrews, 2012). The feeling of powerlessness is more common among foreign-born parents, especially if there is mistrust or a perception of racism and discrimination (Pergert et al., 2007; Pergert et al., 2012; Rydström & Dalheim Englund, 2014). In addition, studies on immigrant parents' experiences of their child's hospitalization show that their experiences are complex and varied. They also depend on and are affected by the parents' previous experiences of healthcare (Povlsen & Ringsberg, 2009; Rydström & Dalheim-Englund, 2014). Experiences of both the benefits and the shortcomings of the Swedish healthcare system have been reported by immigrant parents of children with asthma (Rydström & Dalheim Englund, 2014). The immigrant parents' experiences of shortcomings were related to language and communication problems, to the perception of discrimination, to a lack of confidence regarding care providers' behaviour and competence (Rydström & Dalheim Englund, 2014), and to a sense of powerlessness in the interaction with the care providers (Pergert et al., 2012; Povlsen & Ringsberg, 2009).

3 RATIONALE AND AIM

3.1 Rationale

Nurses around the world are challenged in today's healthcare systems to provide care to a heterogeneous group of patients with different backgrounds, languages, cultural beliefs and values, as well as different experiences and expectations of the healthcare system (Hart & Mareno, 2014; Kai et al., 2011; Lindsay et al., 2012; Nkulu Kalengayi et al., 2012). According to Betancourt et al. (2000) the challenges appear in the cross-cultural care encounter in the form of communication difficulties and mistrust due to sociocultural differences. In relation to healthcare, the need for implementation of culturally competent care in order to overcome the challenges is reported in almost all studies on the caring relationship in the multi-ethnic societies (Betancourt et al., 2002; Caminha-Bacote, 2002; Emami, 2000; Leininger, 2002a).

Although the literature is rich with strategies, theories and models of cultural competence aiming to improve care-providers' ability to deliver culturally competent care to patients from diverse backgrounds, (Caminha-Bacote, 2002; Papadopoulos, 2006) the number of studies addressing cultural competence from the patients' perspective is limited. In addition, the most difficult part of addressing cultural competence is implementing the models in clinical practice in such a way that it involves the whole healthcare system (Balcazar et al., 2009b). A way to improve care providers' ability to understand patients from diverse backgrounds is to incorporate the patients' point of view in care provision. Knowledge of patients' and their families' perceptions of the challenges involved in delivering healthcare in a multi-ethnic society is necessary in order to overcome the cultural challenges in healthcare and provide culturally competent care. This also applies to the Swedish society with its population of 9, 7 million (Statistics Sweden, 2014) including two million persons with foreign background (Statistics Sweden, 2013a).

This thesis will explore the challenges involved in the cross-cultural care encounter as experienced by parents of hospitalized children and their expectations regarding culturally competent care in a multi-ethnic society. Previous studies have focused mainly on the concept of cultural competence and the challenges of the cross-cultural care encounter from the caregivers' perspective. There are few studies in this area that apply the patients' or patients' relatives' perspectives. In the current thesis the subject has been studied from the perspectives of both minority ethnic parents and ethnic Swedish parents. This will provide a broader view of the cultural challenges involved in paediatric care and new knowledge in relation to culturally competent care.

3.2 The overall aim

The overall aim of this thesis was to explore the expectations and experiences of nurses' cultural competence and cross-cultural care encounters among parents of hospitalized children in Swedish paediatric care.

The specific aims were as follows:

Study I. The aim of this study was to explore ethnic Swedish parents' experiences of minority ethnic nurses' cultural competence and the care provided in the Swedish paediatric care context.

Study II. The aim of this study was to describe the expectations and experiences of cross-cultural care encounters among minority ethnic parents in Swedish paediatric care.

4 METHOD

In this thesis, nurses and parents who were not ethnic Swedes are termed ‘minority ethnic’. This is a commonly used term in the international nursing literature. For the purpose of this thesis, ‘minority ethnic’ is used in order to bring together different ethnic groups into one. In the Swedish statistics the term ‘foreign background’ is used instead of ‘minority ethnic,’ referring to those who were born abroad or who were born in Sweden with both parents born abroad (Statistics Sweden, 2002).

4.1 Design

The thesis includes two studies, both based on the same methodological approach, that is, qualitative design. According to many researchers, the qualitative method is one of the most commonly used methods in health and nursing research (Polit & Beck, 2010; Sandelowski, 2000; Thorne, 2011). This is due to its relevance for identifying the human dimension and subjective experiences of a healthcare-related situation or condition and extracting the clinical and practical knowledge in the situation and condition (Thorne, 2011).

A summary of the method is illustrated in Table 1.

Table 1. The methods applied in Studies I and II

Study	Design	Participants	Data collection	Data analysis
I	Qualitative design	n=14 Ethnic Swedish parents (7 mothers, 7 fathers)	Semi-structured interviews	Qualitative content analysis according to Elo and Kyngäs, (2008) Latent
II	Qualitative design	n=12 Minority ethnic parents (9 mothers, 3 fathers)	Semi-structured interviews	Qualitative content analysis according to Graneheim and Lundman, (2004) Manifest

4.2 Participants

Data were collected on a neuropaediatric ward at a children’s hospital in Stockholm. Neuropaediatric care involves the care and treatment of children and adolescents suffering from neurological diseases and developmental abnormalities. Therefore, the length of the child’s hospitalization can vary greatly depending on the child’s condition. Usually, however, these children are hospitalized for at least 2-3 days during each visit.

Every Monday and Friday between October 2011 and March 2012, parents of children who had been admitted to the neuropaediatric unit at the Children's Hospital in Stockholm were provided with written and verbal information about the aim of the studies.

The information was given to these parents on the child’s discharge in order to avoid a disturbance for the parents during their child’s hospitalization. The information letter was in Swedish. All parents who had given their consent to participate in the studies were

contacted one to two weeks after their child had been discharged from the hospital to ask if they wanted to participate and if they had any further questions about the study. If they agreed to participate, an appointment for the interview was made. The place for the interview was selected by the parents. Half of the interviews were conducted in the hospital and half either at the parents' home or over the telephone. The participants in the studies in this thesis included 26 parents of hospitalized children, 14 ethnic Swedish parents (Study I) and 12 minority ethnic parents (Study II).

4.2.1 Study I

A total of 14 ethnic Swedish parents whose child had been admitted to the ward between October 2011 and December 2011, gave their consent to participate in the study. The sample consisted of 7 mothers and 7 fathers. The length of the child's hospitalisation varied greatly dependent on the children's diagnosis and care requirements. The parents' ages varied from 31 to 49 years of age (age of three parents is not known).

Inclusion criteria: ethnic Swedish parents who had been in the hospital with their child during the child's hospitalisation.

The interviews were conducted either at the parents' home (N= 4), at the hospital (N=5), or over the phone (N=5).

Table 2. Demographic background of the participants and the place of data collection

Interview	Relationship with child/patient	Age	Length of child's latest hospitalization	The place for interview
1	Mother	41	6 days	Hospital
2	Father	Unknown	6 days	Hospital
3	Father	49	2 days*	Hospital
4	Father	31	5 days	Home
5	Mother	41	7 days	Phone
6	Mother	Unknown	4 days	Phone
7	Mother	37	3days	Home
8	Father	39	2 days	Phone
9	Father	42	3 weeks*	Home
10	Mother	49	Every third month	Hospital
11	Mother	35	3 days*	Home
12	Father	Unknown	6 months	Phone
13	Mother	37	5 days*	Phone
14	Father	46	Once a week	Hospital

* The child has been hospitalized several times before

4.2.2 Study II

Study II included 12 parents, 9 mothers and 3 fathers (including one couple) of minority ethnic background whose child had been admitted to the ward between October 2011 and March 2012. One mother and one father were second-generation immigrants while the others were first-generation immigrants. The interviews were conducted either at the parents' home (N= 4) or at the hospital (N=8).

The parents were from 7 different countries: Kurdistan, Iran, Iraq, Pakistan, Peru, Somalia and Syria. The parents' ages were between 27 and 45 years (age of two parents is not known).

Inclusion criteria: ethnic minority parents who had been in the hospital with their children during their hospitalization and ethnic minority parents who were able to express themselves in Swedish.

Table 3 Demographic background of the participants

Interview	The country of origin	Relationship with child/patient	Age	Number of years in Sweden	Length of child's latest hospitalization	The place for interview
1	Peru	Mother	27	17	2 days	Hospital
2	Somalia	Father	45	20	3 days	Home
3	Kurdistan	Mother	Unknown	17	1 week	Hospital
4	Somalia	Mother	41	15	4 weeks*	Hospital
5	Iran	Father	34	2	2 days*	Home
6	Iran	Mother	29	3	4 days*	Home
7	Born in Sweden	Father	35	Second-generation immigrant	2 weeks*	Hospital
8	Born in Sweden	Mother	35	Second-generation immigrant	2 weeks*	Hospital
9	Iraq	Mother	42	10	3 weeks*	Hospital
10	Pakistan	Mother	35	15	1 week*	Hospital
11	Syria	Mother	41	10	2 days	Home
12	Somalia	Mother	Unknown	5	4days	Hospital

*The child had been hospitalized several times before

4.3 Data collection

Data were collected for both Study I and Study II by using semi-structured interviews (Polit & Beck, 2010; Sandelowski, 2000). The interviews, which were conducted in Swedish, were recorded. Some of the children had been hospitalized several times but the focus in this study was the child's latest hospitalization. An interview guide was developed and it was used in both studies. The interview guide was based on the categories identified in the models of cultural competence, namely, cultural sensitivity, cultural understanding, cultural encounters, understanding of health, ill-health and healthcare, and social and cultural contexts identified by Jirwe et al. (2009). It also covered the parents' experiences and expectations of culturally competent care. Some examples of the questions in the interview guide were: *"How did you experience the care provided by the nurse? What knowledge and skills do you think nurses who work with persons from another cultural background should possess? How did you experience the relationship with the nurses? What characterizes a cultural encounter in healthcare for you?"* The interview guide is appended to this thesis (Appendix 1).

4.4 Data analysis

4.4.1 Study I

The data were transcribed. A qualitative content analysis based on the Elo and Kyngäs (2008) description was used to analyse the transcribed data. Content analysis has been described by Polit and Beck (2010, p.550) as “the process of organising and integrating, *narrative, qualitative information according to emerging themes and concepts*”. According to Elo and Kyngäs (2008) content analysis is usually used as an analysis method in nursing studies and their description of the method covers both inductive and deductive approaches. An inductive content analysis was chosen because the focus of the study was not to test the concept or models of cultural competence. In this study, the following analysis steps were used: preparation, organization and abstraction (Elo & Kyngäs, 2008).

The first step in the data analysis was to decide on the unit of analysis and make sense of the data by reading the transcribed data several times. The data were then organized by creating open coding and were thereafter sorted into different groups. The data were read through several times again, in order to identify similarities and differences, and to create the subcategories. An interpretation of the underlying meaning was involved in this step, which Kondracki, Wellman and Amundson (2002) describe as ‘the latent content’. Finally the subcategories with similar events/content were grouped together into the categories, and the categories with similar events were sorted into main categories. An example of the steps in the analysis process for Study I is presented in Table 4.

Table 4. An example of the different steps in the analysis process

Meaning unit	Condensed meaning unit	Open coding	Creating categories/	Sub category/ categories interpretation of the underlying meaning	Main Category
I cannot see any relationship between the nurse's background and also my experience of a good nursing care	Nurses' background and the experiences of a good nursing	Nurses' background/ Ethnicity Parents ' experiences	Nurses' ethnicity Good nursing care	Nurses' ethnicity doesn't matter Experiences of good nursing care	Influence of nurses' ethnicity
I personally think that foreign nurses are talented and also much warmer and personal. It felt very positive.	Foreign nurses are talented and are much warmer and personal. Positive feeling	Experiences Foreign nurse Personality Talented	Positive experiences of minority ethnic nurses	Experiences of minority ethnic nurses	Influence of nurses' ethnicity
No, I do not think there was any difference between Swedish and non-Swedish nurses	No difference between Swedish and non-Swedish nurse	Differences between Swedish and non-Swedish nurse	Nurses' ethnicity	Nurses' ethnicity doesn't matter	Influence of nurses' ethnicity

4.4.2 Study II

The transcribed data in Study II were analysed using manifest content analysis according to Graneheim and Lundman (2004) to categorise parents' experiences and expectations of the cross-cultural care encounter in Swedish paediatric care. A manifest approach was chosen for this study to reduce the risk of misinterpretation, since Swedish was not the participants' first language. The transcribed text was read several times to acquire overall clarity. The meaning units were marked and condensed and then referred to a code relevant to the context of the study. Thereafter, the codes were sorted into ten subcategories at a more descriptive level. These subcategories were then sorted and abstracted into three categories.

An example of the different steps of the analysis process for Study II is presented in Table 5.

Table 5. An example of the different steps in the analysis process

Meaning unit	Condensed meaning unit	Codes	Sub-category	Category
When you are in the hospital with your child, you have a lot of problems. you need a lot of reassurance.	The needs of ease and a sense of security	Sense of security and confidence	Sense of security, ease and confidence	Cultural sensitivity and understanding
You should be respected as a human being.	Being respected as a human being	Respect	Sensitive care	Cultural sensitivity and understanding
People have different values and beliefs about the death, care and the relationships between nurse and patient.	Differences in values and health beliefs	Respect for differences	Sensitive care	Cultural sensitivity and understanding
I think they should know about the major ethnic groups located in Sweden.	To be knowledgeable about the major ethnic groups	Cultural knowledge	Cultural knowledge	Cultural sensitivity and understanding

4.5 Trustworthiness

The concepts of credibility, dependability and transferability have been used in qualitative research to describe the different aspects of trustworthiness. Credibility concerns confidence in how well the sample is selected and if it represents the study population. Credibility also concerns how well the data collection and the analysis process addressed the projected focus. It also concerns confidence in the researchers' interpretation of the data. Dependability concerns the stability – that is, the reliability – of data over time and in different situations and conditions. Transferability concerns how findings can be transferred to other groups and other settings (Polit & Beck, 2010).

To achieve and increase the trustworthiness of these studies the following steps were followed: The studies' design, data collection process and the data analysis process were explained clearly. Participants of various backgrounds, ages and experiences were involved in the studies, which could increase the credibility of the studies (Graneheim & Lundman, 2004). In order to increase the credibility of the studies the questions in the interview guide had been discussed by all three authors involved in Studies I and II. The questions, which generally concerned the care relationship, were also culture-specific. This could also increase the credibility (Graneheim & Lundman, 2004). The participants in Studies I and II are representative in many aspects – for example, age, experience of cross-cultural care encounters, and experience of hospitalization. The sample in Study II, however, consists of minority ethnic parents who could speak Swedish. Therefore it cannot be argued that they are representative of all minority ethnic parents.

The interviews were conducted in Swedish, which in Study II was not the participants' native language. This could decrease the reliability. The use of an interpreter was avoided to minimize the risk of missing important data and of interpretation due to three-way communication. The interviewers' own ethnic background could also affect the participants and the data during the data collection. In addition the children's diagnoses, the length of their hospitalisation, and the number of years the parents in Study II had lived in Sweden, varied greatly. There is some risk that other factors affected parents' experience of cross-cultural care encounters. This could decrease the trustworthiness of the data.

The three authors involved in Studies I and II were involved in the studies' preparation, design and data analysis as well as in the development of the categories and subcategories, to increase the dependability of the results. The categories and subcategories were assessed and discussed by the three authors until agreement was reached. We were aware of the risk of making our own subjective interpretations during the data analysis and tried to avoid doing so. Some of the transcribed data were quoted in the text to show how the categories and subcategories were assessed. In addition, the focus of the studies and the context were explained clearly. The results are presented in a descriptive and vigorous manner and are illustrated with quotations which may increase the reliability of the study.

5. ETHICAL CONSIDERATIONS

Both studies, I and II, were approved by the regional ethical review committee in Stockholm (Ref.No: 2011/927-31/5) in June 2011. Permission was given by the head of the neuropaediatric department at the children's hospital for the researcher to be on the ward to recruit parents for the two studies. The parents received written and verbal information about the aim of the research, the estimated time required for the interview, and the researcher's name, phone number and email. In addition, they were informed that their participation was voluntary and their decision whether or not to participate in the studies would not affect their child's care in any way. They were also informed that the interviews would be in Swedish and would be recorded.

Only the three researchers involved in these studies had access to the data from the interviews. Information about the participants was not shared in these studies. The data were stored in a locked cabinet not accessible to others.

The participating parents provided their written consent to participate in the study. The parents' decision whether or not to participate was respected. No reminder letters were sent to the parents. The demanding situation the parents were in at the hospital was taken into consideration, and the information letter was therefore given to them on their child's discharge from the ward. The venues for the interviews were chosen by the parents.

6. RESULTS

6.1 Study I

The ethnic Swedish parents of hospitalized children included in this study described their experiences and expectations of minority ethnic nurses' cultural competence, the care relationship and the care encounter in Swedish paediatric care in a descriptive way. A cultural encounter was described by them as an encounter between different cultures, whether it was the care provider or the patient who comes from a different culture.

The influence of the nurses' ethnicity, significance of cross-cultural communication and cross-cultural skills and the importance of nursing education were identified as the main categories in this study. The nurses' ethnic and cultural background was reported not to be an important factor influencing the ethnic Swedish parents' experiences of the care provided to their child by minority ethnic nurses. The personal attributes of the minority ethnic nurses, however, were reported to be more important.

The ethnic Swedish parents' experiences of minority ethnic nurses was varied. They reported experiencing both advantages and disadvantages in relation to minority ethnic nurses' cultural competence and the care provided by them. The advantages were mainly related to the minority ethnic nurses' personal attributes and professional knowledge; a disadvantage was perceived, however, in the cultural differences between the nurses and the parents, as it could negatively affect parents' experience of the care provided by the minority ethnic nurse. An example of this was minority ethnic nurses' authoritarian attitude toward to parents, which the parents attributed to the nurses' previous experience of the healthcare system in their homeland.

In contrast to nurses' ethnic background, their language skills, professional knowledge and clinical competence were identified as important factors in the ethnic Swedish parents' experience of the care provided by the minority ethnic nurses. The parents expected nurses who work in the Swedish healthcare system to adapt themselves to Swedish culture and norms. In connection with this, they stressed the role of nursing education in integrating minority ethnic nurses into Swedish culture in general and Swedish care culture in particular.

In summary, minority ethnic nurses' ability to have successful cross-cultural care communication with the ethnic Swedish parents, and minority ethnic nurses' cross-cultural skills, were reported by the ethnic Swedish parents as key to their perception of receiving culturally competent care. The parents expected the minority ethnic nurses to be sensitive to and respect their needs. The parents reported their own awareness of the diversity in the Swedish society and Swedish healthcare as being an important factor. They talked about the importance of mutual respect in all caring relationships.

6.2 Study II

Almost all of the minority ethnic parents expressed experiences of advantages with respect to the cross-cultural care encounter in Swedish paediatric care. In contrast with Study I, nurses' cultural and ethnic backgrounds did have an impact on the minority ethnic parents' experience of the care relationship. The parents talked about the care relationship with three groups of nurses: ethnic Swedish nurses, minority ethnic nurses, and minority ethnic nurses who were from their own country of origin. The parents attributed their experiences of cross-cultural care encounters partly to the nurses' personal and professional ability to make them feel safe and secure in the care relationship, and partly to their own limitations regarding the Swedish language and to differences in culture and care culture.

The parents identified the nurses' ability to show respect and the nurses' professional knowledge as being fundamental in the cross-cultural care encounter. The nurses' personal attributes, their ability to provide sensitive care and their cultural knowledge and understanding were all reported as significant for the parents' experience of the cross-cultural care encounters.

Communication and language barriers, the parents' unfamiliarity with Swedish culture and care culture, the nurses' experience of cultural differences and the availability of multi-ethnic and bilingual healthcare providers were all described as being influential in the minority ethnic parents' experience of the cross-cultural care encounter. Both the minority ethnic nurses' and the minority ethnic parents' limited knowledge of the Swedish language were identified by the parents as being influential factors in the cross-cultural care encounter.

Parents also recognized the importance of nurses' experience of working in a multicultural society. They noticed a clear difference in the ability to provide culturally competent care between nurses working in present-day Swedish healthcare, compared with those who worked in Swedish healthcare some years ago. The difference was attributed to nurses' personal attitudes and to their sensitivity to the cultural differences. Although the parents were satisfied with the ethnic Swedish nurses, they referred to the importance of a common language and cultural background in the care relationship and their desire for the availability of multi-ethnic and bilingual healthcare providers.

6.3 Synthesis of the results of Study I and Study II

Almost all of the ethnic Swedish and minority ethnic parents interviewed were satisfied with the care provided by the nurses in Swedish paediatric care. The nurses' cultural competence was described by the ethnic Swedish and minority ethnic parents as the nurses' ability to provide sensitive professional care based on their knowledge and respect for the human being. The parents' experiences of the care relationship and cross-cultural care encounters, as well as their expectations of nurses' cultural competence, were affected by many factors and described at different levels. The parents in both studies were aware of their own individual effect as well as the interpersonal and the organizational effects on the caring relationship, which will be described below:

6.3.1 Professionalism

The importance of the nurses' professional approach for the parents' sense of trust, security and confidence in the care relationship was stressed by the parents in both studies.

6.3.1.1 Nurses' ability to provide sensitive care

Regarding culturally competent care and a caring relationship, the parents' basic expectations were that they be respected, be understood and be able to have trust in the caring relationship. Nurses' personal attributes, described as openness, kindness and sensitivity to patients' needs and cultural differences were considered important by the parents in both studies (Study I and Study II). According to the ethnic Swedish parents in Study I, respect could be shown through a humble attitude, or by the nurse's readiness to listen to the parents. Parents in both studies referred to the importance of nurses being open-minded, compassionate, and confident and sensitive when asking questions (Study I & Study II).

It's about nurses' characteristics, it's about the person – being sensitive and respecting the individual. It's about nurses' being responsive and empathic and knowing what to say and what not to say. It's about showing interest. (Study I, mother, Interview 6)

6.3.1.2 Nurses' clinical knowledge and professional approach

All of the parents reported that the most important thing for them during their child's hospitalization was having a sense of security and being able to feel trust in the caring relationship (Study I & Study II). Nurses' medical and clinical expertise could make parents feel secure and confident about the care relationship, leading to a positive experience of the care encounters. The parents thought that the focus should be on the child's medical and nursing care and needs, not on the parents' cultural background or cultural needs.

Actually, I think that the nurse should project a humble attitude and respect for human beings and for differences, along with their medical expertise. In my experience, they have been like this. (Study I, mother, Interview 7)

6.3.2 Cross-cultural care encounters

Well-functioning communication was reported as the key component of and the first step in a caring relationship. The influencing factors described by parents of both ethnic Swedish and minority ethnic backgrounds as important for well-functioning cross-cultural care encounters in the Swedish care context were familiarity with the Swedish language, familiarity with Swedish culture and care culture, and familiarity with diversity.

6.3.2.1 Familiarity with the Swedish language

Nurses' familiarity with the Swedish language (Study I and Study II) as well as the parents' familiarity with the Swedish language (Study II) has been reported as essential to the parent-nurse relationship and to parents' satisfaction with the care provided in Swedish paediatric care. Ethnic minority nurses' language difficulties could cause frustration and insecurity for both ethnic Swedish parents and ethnic minority parents. This in turn could affect the parents' experience of the cross-cultural care encounter. Both ethnic Swedish parents and minority ethnic parents expected that the nurses who work in Swedish paediatric care could speak Swedish well (Study I & Study II).

I expect the same as I would expect of a Swedish nurse – that they can manage a lot. I want her to be able to cope with the language. The language must work...Communication is a big part of healthcare. (Study I, father, Interview 12)

6.3.2.2 Familiarity with Swedish culture and care culture

The importance of minority ethnic nurses' (Study I) and the minority ethnic parents' (Study II) familiarity with Swedish culture and care culture was reported to be a factor influencing cross-cultural care encounters. Lack of familiarity with Swedish culture and care culture can lead to conflicts, misunderstandings and misjudgement in the communication, information delivery, care relationship and nursing care (Study II), and could cause frustration and confusion for the ethnic Swedish parents, which in turn affected their experience of the cross-cultural care encounter (Study I).

You know, I haven't lived in Sweden very long and there is a lot about Swedish culture I don't know. For example, when I ask a question I don't know if it is a normal issue or if it feels weird or wrong for them (for Swedish nurses). They may misunderstand me. (Study I, mother, Interview 6)

Minority ethnic nurses' (Study I) and minority ethnic patients' (Study II) previous experience of the healthcare system was also reported as being a factor in the care relationship. Some

examples are: minority ethnic nurses' experience of authority in the healthcare system in their country of origin (Study I), and the usual ways of expressing caring and showing respect (Study II).

6.3.2.3 Familiarity with diversity

The parents' (Study I) and the nurses' (Study II) familiarity with diversity was stressed as a key factor in cross-cultural care encounters. As the parents in Study I reported, there are many parents and staff-members of diverse cultural and ethnic backgrounds in contemporary Swedish healthcare. There should be an acceptance of and respect for all cultures. As one father (Study I) said, there should be mutual respect and cultural understanding – that is, respect from people from other cultures toward Swedish-born individuals, and from Swedish-born individuals toward other cultures.

At the same time, the parents in both studies were aware of the great diversity in the Swedish population and no-one expected nurses to be familiar with all cultures and norms. This was pointed out as being an unreasonable demand. However, the minority ethnic parents in Study II did think the ethnic Swedish nurses should adapt themselves to the multi-cultural society.

6.3.3 Organizational significance

The parents in both studies stressed the importance of organizational policy in facilitating care relationships in the multi-ethnic society. They expected the healthcare system to be organized so as to facilitate cross-cultural care encounters.

6.3.3. Nursing education

The parents in Study I expected nursing education to be organized in such a way that minority ethnic nurses who graduated and were licensed in Sweden should be proficient in the Swedish language and familiar with Swedish culture and norms. As one father in Study I said, there are so many details and codes in Swedish culture, and nurses working in the Swedish healthcare system should know about them.

I don't know how nursing education is today, but this is something that should be a part of nurses' education. (Study I, mother, Interview 1)

6.3.3.1 Availability of multi-ethnic and bilingual healthcare providers

Although the nurses' cultural background per se had little impact on the parents' impression of the care relationship, a sense of connection with the nurses through a common background was mentioned as important for parents' sense of security and confidence in the caring relationship (Study I and Study II). As reported by some participants in both studies, it is always easier to relate to someone with whom you have something in common.

Relationships? Yes, it's perhaps easier with a Swede. I might be able to joke with a Swedish nurse but not if she's a Muslim. You never know if it's going to be considered offensive. (Study I, father, Interview 12)

While all of the parents who were interviewed for Study II spoke fairly good Swedish, they did say they would have appreciated the opportunity to have access to staff who spoke their own language. As the parents mentioned, there are a lot of bilingual nurses in Swedish paediatric care and the healthcare system should be organized in such way that this resource (bilingual nurses) is used in a better way. The parents felt that the healthcare system was not using this resource in the right way. A mother in Study II said:

There was a nurse who spoke Arabic. I saw her several times in the ward, but she never come up to us – I don't know why. It would have been nice if she'd come and talked to us. I think my daughter would have appreciated it. We speak Arabic at home. (Study II, mother, Interview 9)

7 DISCUSSION

Culture is a complex and complicated concept to understand and the research about culture, cultural challenges in healthcare and cultural competence highlights this complexity. For example, Leininger focuses in her model of cultural care diversity and universality on the complexity of the knowledge that nurses need to provide culturally competent care (Leininger & McFarland, 2002). Until now, research on culture and cultural competence in nursing has mainly focused on the models of cultural competence (Caminha-Bacote, 2002; Jirwe et al., 2009; Papadopoulos, 2006; Purnell & Paulanka, 2003) and on the conceptual analysis of these concepts (Burchum, 2002; Suh, 2004). In addition, studies on the cultural challenges in healthcare have mainly been from the perspective of the researchers and the health-care professionals (Betancourt et al. 2000, Hart & Marenco, 2014; Jirwe et al., 2009, Jirwe et al., 2010; Nkulu Kalengayi et al., 2012) and not from the patients and/or their family members. This thesis together with a few other studies (Garret, Dickson Young, Whelan & Forero, 2008; Wiebe & Young, 2011) involves the expectations and the experiences of care recipients or relatives, in this case parents of hospitalized children, with respect to culturally competent care. This thesis is also unique in that it illustrates the differences and similarities between the expectations of minority ethnic parents and the ethnic Swedish parents in regard to the culturally competent care and cross-cultural care encounters in paediatric care in Sweden. By comparing the similarities and differences between the experiences and expectations of culturally competent care reported by the two groups of parents who participated in the studies included in this thesis and comparing the study results to similar studies, it is possible to identify some domains, elements or attributes that are likely to lead to culturally competent care from the parents' perspective. The parents of minority ethnic and ethnic Swedish backgrounds have correlated culturally competent care with two competence areas. The first of these areas of competence was nurses' competence in providing professional and sensitive care. The second was nurses' competence in facilitating the cross-cultural care encounter. In relation to these competence areas, the parents also described the role of the healthcare system as a whole in supporting and facilitating the cross-cultural care encounter and the provision of culturally competent care, for example, by helping minority ethnic nurses learn Swedish and become familiar with Swedish culture and care culture.

7.1 Competence to provide professional and sensitive care

The most important expectations that both minority ethnic parents and ethnic Swedish parents had of culturally competent care was that it entails the provision of respectful and professional care. The parents reported that to be respected as a human being and to be treated as an individual was for them most important aspect of any care relationship. The parents commented that nurses' personal attributes are even more important in a cross-cultural care encounter – that is, when the encounter is between a nurse and a patient/patient's family from different cultural backgrounds. The parents also stressed the importance of respect for the patients' and the nurses' culture and cultural differences as well as the importance of seeing culture as an integral part of the individual. This indicates that a vital element for parents' expectation of culturally competent care was cultural sensitivity. The parents' views regarding the cultural sensitivity demonstrated in their experiences of culturally competent care confirms and enhances the constructs and categories identified in the models of cultural competence (Burchum, 2002; Jirwe et al., 2009; Papadopoulos, 2006; Suh, 2004).

The differences between the views of minority ethnic parents and ethnic Swedish parents regarding cultural sensitivity was that cultural sensitivity for ethnic Swedish parents was about minority ethnic nurses' sensitivity to the values and norms important in the Swedish culture. Parents of minority ethnic background described cultural sensitivity as nurses' ability to be sensitive to the diversity in healthcare and respect the differences in the cultures. None of the parents of ethnic Swedish background addressed religion as an element of culture. This is in contrast to the minority ethnic parents' expectation of cultural sensitivity. Some parents of minority ethnic backgrounds referred to sensitivity to the parents' religious needs as being part of cultural sensitivity.

Moreover, for the minority ethnic parents participating in Study II in this thesis, the most important factor, based on their experience of culturally competent care, was not nurses' cultural knowledge but rather a professional and sensitive care, described by the parents as fundamental to any care relationship. This finding confirms the findings of a study on immigrants in Canada that explored minority ethnic parents' perception of culturally congruent care. The result of this study shows that, nurses-patient relationship of trust and caring and also a respectful communication are more important rather than nurses' cultural knowledge for minority ethnic parents' perception of culturally congruent care (Wiebe & Young, 2011). The findings of these studies are in contrast to Study I in this thesis on ethnic Swedish parents' expectations of minority ethnic nurses' cultural knowledge. Parents in Study I expected minority ethnic nurses to be familiar with Swedish culture and norms and expected minority ethnic nurses to adapt to Swedish culture.

Cultural sensitivity is one of the categories and constructs identified in several models of cultural competence (Burchum, 2002, Jirwe et al., 2009; Papadopoulos, 2006, Suh, 2004). According to Jirwe et al. (2009) cultural sensitivity includes nurses' personal attributes and self-awareness. In relation to personal attributes, cultural sensitivity is described as nurses' ability to adopt a humanistic perspective, to show respect, to be empathic and to be open to patients' cultural differences (Jirwe et al., 2009). The parents in the present thesis also referred to personal attributes and self-awareness in their descriptions of nurses' cultural sensitivity, which strengthens previous models of cultural competence.

The findings of study I in this thesis confirm the result of other international (Cleveland & Horner, 2012; Garrett et al., 2008) and Swedish studies on minority ethnic patients' and families' expectations of care relationships in multi-ethnic societies (Hultsjö, Berterö & Hjelm, 2009; Rydström & Dalheim Englund, 2014). Garrett et al. (2008) reported the importance of staff attitudes and behaviour in patients' experiences of culturally competent care in Liverpool Hospital in Australia. The importance of the nurses' personal attributes and the importance of being met with respect have also been reported in Swedish studies of minority ethnic families' experiences of the care relationship (Hultsjö et al., 2009; Rydström & Dalheim Englund, 2014) and in international studies of minority ethnic parents' experiences of neonatal care in the USA (Cleveland & Horner, 2012) and Canada (Wiebe & Young, 2011).

7.2 Competence to facilitate the cross-cultural care encounter

Both patients' and nurses' health-related values and beliefs affect nurse-patient interaction (Andrews, 2008) and influence care encounters (Nkulu Kalengayie et al., 2012). The cultural encounter is one of the categories and constructs identified in several models of cultural competence (Campinha-Bacote, 2002; Jirwe et al., 2009; Suh, 2004) and is described as *“the process that encourages the health care provider to directly engage in cross-cultural interactions with clients from culturally diverse backgrounds”* (Campinha-

Bacote, 2002, p 182). An assessment of the patients' linguistic needs and language skills is included in the process of a cultural encounter (Campinha-Bacote, 2002; Jirwe et al., 2009).

The importance of well-functioning communication and language skills was reported by minority ethnic parents as well as ethnic Swedish parents in the studies included in this thesis. It affected not only parents' experiences of a well-functioning cross-cultural care encounter but also parents' feelings of security and trust. The negative effects of language barriers were expressed by both groups of parents based on their experiences of cross-cultural care encounters. The minority ethnic parents' and Swedish ethnic parents' perspective on the cultural encounter in their experiences of culturally competent care confirms the models of cultural competence in nursing. It also provides a reference to an important element that includes the unexplored part of the culturally competent care – that is, parents' perspective on the element identified in the models of cultural competence.

Communication and linguistic difficulties have also been cited by Pergert et al. (2007) as obstacles to the transcultural caring relationship. The transcultural caring relationship is described by them as a professional caring relationship across cultures, for example, between the healthcare providers from the majority culture and families of immigrant background (Pergert et al., 2007). Other studies also have reported language barriers as an impediment to effective communication that can lead to frustration, which in turn can affect the quality of care (Akhavan & Karlsen, 2013; Hultsjö & Hjelm, 2005; Jirwe et al., 2010).

Furthermore, communication has been identified as an important domain in the model of cultural competence (Purnell & Paulanka, 2003) and in cultural competence assessment instruments (Andrews & Boyle, 2008; Giger & Davidhizar, 2008). Both verbal communication and nonverbal communication are referred to as important factors in nurse–patient interaction (Andrews, 2008).

Moreover, according to Jirwe et al. (2009) cultural encounters are not just about communication and language skills. Cultural encounters are also about awareness of and skill in cultural encounters –that is, to understand the significance and the meaning of creating a trusting relationship with the patient and to be aware of one's own and the patient's influence on the cultural encounter (Jirwe et al., 2009). The parents who participated in the studies in this thesis also reported the importance of awareness of cultural differences and the creation of a trusting relationship with respect to their experience of cross-cultural care encounters. In addition, the parents who participated in Studies I and II were aware of the influence their own culture and cultural background had on their experiences of cross-cultural care encounters. For example, minority ethnic parents in Study II were aware of how their earlier understanding and experiences of the care relationship from their country of origin, in terms of how respect was shown and how they express their emotions, influenced later cross-cultural care encounters. This finding is also in line with an Australian study about patients' view of culturally competent care. The result of this study shows, for example, that the minority ethnic patient had a different expectation on family involvement and patient decision-making in care. This is due to the expectation of the family relationship in their country of origin (Garrett et al., 2008).

7.3 The role of healthcare system in facilitating cross-cultural care encounters

Although most of the parents interviewed reported positive experiences of the cross-cultural care encounter and the care provided by the nurses in Swedish paediatric care, the ethnic Swedish parents did associate certain negative events with minority ethnic nurses' lack of familiarity with Swedish culture, care culture and the Swedish language. In these contexts,

the parents stressed the importance of the healthcare system in supporting and facilitating the provision of culturally competent care. Some of the parents referred to the role of nursing education in helping minority ethnic nurses become familiar with the Swedish language and with Swedish culture and care culture (Study I), and that the healthcare system should be organized so as to make it easier for minority ethnic parents to navigate the system (Study II). The healthcare system needs to identify the challenges that exist and change its policies, guidelines and strategies to improve and facilitate the provision of culturally competent care. However, the parents described their expectation of cultural competence in a broader perspective. They viewed cultural competence as not limited to the nurses but also including the healthcare system as a whole (Study I & Study II).

According to the minority ethnic parents, one way for the healthcare system to influence the cross-cultural care encounters would be to make it easier for these parents to access bilingual healthcare staff. The minority ethnic parents in Study I appreciated having the option of accessing multi-ethnic and bilingual healthcare staff even though they could speak Swedish. This finding is in line with other international (El-Amouri & O'Neill, 2011; Garrett et al., 2008) and Swedish (Heikkilä, Sarvimäki & Ekman, 2007) studies about supporting and facilitating cross-cultural communication and culturally competent care. Access to nurses who have the same minority ethnic background and native language as the patient (Heikkilä et al., 2007) and the nurses' ability to speak several languages were reported as factors that can improve culturally competent care (El-Amouri & O'Neill, 2011). Garrett et al. (2008) reported that bilingual staff provided language facilitation for non-English speaking patients' experience of culturally competent care and the patients wanted bilingual staff to be available for daily assistance and to connect them with the healthcare system.

In summary, although the aim of the studies and the questions in the interview guide focused on the parents' experiences of the nurses' cultural competence, the parents perceived the nurses' cultural competence as their ability to provide professional care based on respect and their ability to see them as individuals rather than members of a particular cultural group. The expectations of the minority ethnic parents and the ethnic Swedish parents with respect to culturally competent care were quite similar. The question now is whether the key competence is really culturally competent care or patient-centred care. This subject has been discussed by many researchers during recent years (Beach, Saha & Copper, 2006; Campinha-Bacote, 2011; Nielsen et al., 2014; Saha, et al., 2008). Patient-centeredness is defined as *"perceiving and evaluating health care from the patient's perspective and then adapting care to meet the needs and expectations of patients* (Beach et al, 2006, p.vi). As mentioned in the background both culturally competent care and patient-centeredness aim to improve and increase healthcare quality for the individual (Saha et al., 2008). The differences between these approaches depend on what aspect of the quality of care they focus on. In the models of patient-centeredness the focus is on the personal relationship and it aims to improve and increase quality of care for all patients (Saha et al., 2008) while the aim of culturally competent care is to improve equity and decrease disparities for minority ethnic patients (Leininger, McFarland, 2002; Campinha-Bacote, 2002; Papadopoulos, 2006).

A new and an important finding in this thesis is that parents' experience of the challenges involved in cross-cultural care encounters affirm caregivers' experience of the cultural challenges involved in a multi-ethnic society. Both groups of parents, in the current thesis (Studies I and II) and previous studies involving care providers, described the challenges involved in cross-cultural care encounters on the individual, interpersonal and organizational levels, and both referred to the importance of communication difficulties,

cultural differences and a lack of familiarity with diversity as the main challenges in cross-cultural care encounters (Hart & Mareno, 2014; Nkulu Kalengayi et al., 2012).

7.4 Methodological considerations

This thesis includes two qualitative interview studies and as is the case with many other studies, have certain strengths, weaknesses and limitations in their approach, which will be discussed below. The participants, parents of minority ethnic and ethnic Swedish background who have had hospitalized children in the same ward at a children's hospital in Stockholm. The ward/unit selected for the data collection was suitable for these studies in the sense that the children's hospitalization in this ward often was for a longer period, that is, at least 2–3 days; consequently, the parents had time to experience cross-cultural care encounters. The length of the child's hospitalization, the number of occasions of hospitalization, the parents' previous experiences of healthcare and the parents' ages varied greatly. This variation could in part contribute to a broader view of the subject of interest, which could increase credibility (Graneheim & Lundman; Polit & Beck, 2010), and in part influence the parents' experience of the care relationship in general and the cross-cultural care encounters in particular.

The data for both studies was collected by using semi-structured interviews. An interview guide based on categories identified by means of a model of cultural competence (Jirwe et al., 2009) was used to facilitate data collection. To avoid imposing their own preconceptions on the interpretation of the data during the collection and data analysis, the researchers who conducted the studies were aware that the interviewer's preconceptions and foreign background could have an influence on the data collection. They tried to avoid any such influence by continuous discussion of and involvement in the whole process.

Although the participants in Study II could speak fairly good Swedish, the risk of not conducting the interviews in the parents' native language was that they might not be able to express themselves as effectively they would if the interviews were conducted in their native language. A rationale for not using an interpreter for Study II was to avoid the risk of three-way communication (Brämberg & Sandman 2012). A methodological decision made to try to avoid misunderstandings and misinterpretations during the analysis of the interview transcripts from Study II, was to use manifest content analysis.

The method, participants, data collection process, data analysis and ethical considerations for both Study I and II have been described and explained in as much detail as possible, in both the text and in the tables and figures, to avoid misunderstandings, which may increase the credibility of the studies. The results of both studies have been presented and illustrated using quotations from the interviews and have been discussed and compared with national and international studies on this topic.

The data were collected at a large hospital in the Swedish capital. The healthcare organization, the nurses and the parents of hospitalized children in a large city are likely to be more familiar with diversity than might be the case in smaller towns. This may limit the transferability of the results of the studies. In addition, both study samples were drawn from a single unit and caution should therefore be observed when drawing conclusions.

8 CONCLUSIONS

This thesis confirms some of the constructs in the cultural competence models, such as cultural sensitivity (Burchum, 2002; Jirwe et al., 2009; Papadopoulos, 2006; Suh, 2004) and cultural encounter (Burchum, 2002; Campinha-Bacote, 2002; Jirwe et al., 2009; Suh, 2004). However, similarities with the definition of patient-centeredness care such as the importance of a personal care relationship and the importance of to be treated and respected as a unique individual and not as a part of a culture group, have also been emphasized. Culturally competent care is about professional and sensitive care based on respect for the patient as a unique individual. The challenges involved in cross-cultural care encounters are mainly related to lack of familiarity with language, culture and diversity rather than to differences between cultures. It is important to overcome the challenges of language and communication obstacles in cross-cultural care encounters. The healthcare system has a significant role in facilitating the provision of culturally competent care. Access to multi-ethnic and bilingual healthcare staff is important to overcome a part of the cultural challenges involved in healthcare. There are great similarities between the perspectives of minority ethnic parents and those of ethnic Swedish background with respect to culturally competent care and also the challenges in cross-cultural care encounters.

9 IMPLICATIONS

To increase the quality of the care, it is important to evaluate healthcare from the care recipients' perspective. The results of these studies show that there is a need for expansion and evaluation of perceptions of and models of cultural competence. The challenges involved in the cross-cultural care encounter are no longer only related to patients of minority ethnic background. The great diversity nowadays in the healthcare systems of many countries, such as Sweden, implies that patients, care providers – for example, nurses – and the systems themselves are all facing new challenges. The provision of culturally competent care is no longer about having detailed knowledge of different cultures and cultural behaviours. It is about the ability to provide professional and sensitivity care to all people. It is about being aware of cultural differences and similarities. The challenges in the cross-cultural care encounter were mainly due to unfamiliarity with Swedish culture and care culture. It is important to create opportunities for parents and nurses of minority ethnic background to become familiar with Swedish care and Swedish care culture. The healthcare system plays an important role in facilitating the delivery of sensitive professional care. The focus in all care encounters should be on the patient as an individual, irrespective of his or her ethnic or cultural background and affiliation. The healthcare system of a multi-ethnic society should be organized in such a way as to satisfy the specific needs of all individuals.

The communication and language barrier is one of the challenges involved in cross-cultural care encounters. It is important to use bilingual professionals in a more structured way than has been done up until now by improving the possibility to access to bilingual professional for minority ethnic parents.

This thesis has reported on parents' expectations on and experiences of nurses' cultural competence and cross-cultural care encounters among parents of hospitalized children, to increase nurses' awareness of parents' expectations of culturally competent care. The similarities and differences in the perspectives of minority ethnic parents and ethnic Swedish parents in this thesis, and the similarities between the results of the studies here and previous studies on caregivers' perspectives on the challenges involved in cross-cultural encounters and in providing culturally competent care, can contribute to broadening our knowledge in this area, provide important insight into cross-cultural care encounters and promote a new way of thinking.

10 SUMMARY IN SWEDISH/SVENSK SAMMANFATTNING

Som ett resultat av den globala migrationen har Sverige, liksom som många andra länder i Europa, blivit ett multietniskt samhälle. Den multietniska sammansättningen av den svenska befolkningen har lett till en ökad mångfald bland såväl patienter som sjukvårdspersonal inom hälso- och sjukvården. Den ökade mångfalden inom svensk sjukvård leder till utmaningar för personalen, både för de med etnisk svensk bakgrund och för de som tillhör en etnisk minoritetsgrupp. Detta gäller i deras arbete tillsammans såväl som i arbetet med olika patientgrupper. Utmaningarna är huvudsakligen relaterade till kommunikation med människor som varken har samma modersmål eller samma kulturella värderingar eller hälso-övertygelser. När det gäller hälso- och sjukvård, är behovet av kulturell kompetent vård för att övervinna dessa utmaningar rapporterat i nästan alla studier om vårdande relationen i ett multietniskt samhälle

Avhandlingen baseras på två kvalitativa studier med föräldrar vars barn har vårdats på sjukhus i den svenska barnsjukvården. Det övergripande syftet med denna avhandling var att undersöka föräldrars erfarenheter av och förväntningar på kulturellt kompetent vård och av tvärkulturella vårdmöten. I studie I har 14 etniskt svenska föräldrar intervjuats om sina upplevelser av etniska minoritetssjuksköterskors kulturella kompetens och om den vård de har fått av sjuksköterskorna. I studie II har 12 föräldrar med etnisk minoritetsbakgrund intervjuats om sina förväntningar och upplevelser av tvärkulturella vårdmöten i den svenska barnsjukvården. Data för både studie I och studie II insamlades genom semistrukturerade intervjuer och analyserades med kvalitativ innehållsanalys.

Sjuksköterskans kulturella kompetens beskrevs av både föräldrar med etnisk svensk bakgrund och föräldrar med etnisk minoritetsbakgrund, som sjuksköterskans förmåga att ge en professionell och känslig vård utifrån sina professionella kunskaper och med respekt för människan. Föräldrarnas upplevelser av vårdrelationen och tvärkulturella vårdmöten, samt deras förväntningar på sjuksköterskans kulturella kompetens, påverkades av olika faktorer och beskrivs på olika nivåer. Betydelsen av sjuksköterskans professionella förhållningssätt, en väl fungerande kommunikation och betydelsen av organisationen för föräldrarnas upplevelser av tvärkulturella vårdmöten identifierats i såväl Studie I och Studie II.

Denna avhandling bekräftar några av komponenterna, såsom kulturell känslighet och kulturella möten, identifierade i modellerna av kulturell kompetens. Dock är likheter med definitionen av patientcentrerad vård, till exempel betydelsen av en personlig vårdrelation och vikten av att behandlas och respekteras som en unik individ, och inte som en del av en kultur grupp har också lyfts fram. Kulturell kompetent vård handlar om en professionell och känslig vård baserad på respekt för patienten som en unik individ. Utmaningarna i tvärkulturella vårdmöten är huvudsakligen relaterade till brist i kännedom om språk, kultur och mångfald än till skillnader mellan kultur. Det är viktigt att övervinna utmaningar som språk- och kommunikationshinder i tvärkulturella vårdmöten. Sjukvården har en viktig roll i att underlätta tillhandahållandet av kulturellt kompetent vård.

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