

The Nature of Family-Centred Care in Thailand:

A Case Study

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Abstract

Thalassemia is a long-term condition that is highly prevalent in children in northern Thailand and the management of this disease requires a strong input from families. Family-centred care is a key philosophy in the nursing care of children and their families, especially as parents play a key role in the health and well-being of a child. However, the concept of family-centred care is a western one and there is limited literature on its use in Thailand. The aim of this study is to explore the characteristics of family-centred care in one hospital in Thailand and the factors that influence the nature of the nursing care.

Using a qualitative case study approach, data was collected by non-participant observations, semi-structured interviews of five families, four nurses, a medical doctor and a Buddhist monk and the analysis of documentation in 2010. The data was initially analysed deductively using a recognised framework of family-centred care and this was followed by a thematic inductive analysis.

The results showed that all the elements of the framework of family-centred care existed in varying degrees although the concept was not recognised as shaping the nature of this care. The nature of this care was influenced by three factors: the family, the hospital and Thai culture with its strong religious traditions. These factors were incorporated into a model of family-centred care that could be applied to other institutions in Thailand.

This study has shown that the family-centred care model is practiced but it requires a strong commitment and input from healthcare professionals. Strengthening and formalising the use of this concept can be a very useful strategy to ensure that the needs of the child and family are recognised, valued and met.

KEYWORDS: Family-centred care/ Family-centred care/ Case study/
Children with Thalassaemia/ Family participation/ Thailand

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Chapter 1

Introduction

This thesis explores the nature of nursing care provided for children with thalassaemia in northern Thailand. Its aim is to examine the congruence of this care with the model of family-centred care. The study is set in the context of care at the tertiary level of the healthcare system in Thailand (Hanucharunkul, 2007) taking the perspectives of healthcare professionals, children and their families within the Thai context into account.

1.1 Structure of the thesis

Creswell (1994) suggests that the format for composing and reporting qualitative research is much less standardised than for quantitative studies or clinical trials and that there is no consensus about the form in which a case study is reported. Consequently, the structure that I have adopted for this thesis is unique and is set out in a format that will enable the reader to gain a contextual appreciation of the subject matter (thalassaemia) and the geographical location of the thesis (Thailand) before proceeding to the body of the thesis. To achieve this aim, this chapter contains an overview of thalassaemia which is followed by an overview of Thai culture and society and the province Lampang where this study was undertaken. This chapter concludes with information about myself and my rationale for selecting this topic. Chapter Two commences with an overview of the theoretical basis of family-centred care before a literature review of the use of family-centred care is presented. It concludes by highlighting the strengths, limitations and gaps in the literature which is followed by a presentation of the aim and research questions of this thesis. Chapter Three contains the methodology and methods used in this work. It provides the theoretical basis of the research design adopted for this study and contains the justification for the design and the discussion of data collection methods used. In order to contextualise this study, a description of the hospital where the data collection took place will also be provided. The ethical principles that underpinned this study will also be discussed here and its impact on the recruitment of participants and the data collection methods will be discussed. The chapter concludes by examining the criteria used for assessing the quality of qualitative research, which will then be applied to this thesis. Chapter Four contains the results

from the collected data which are presented in two sections: findings from the deductive and from the inductive analysis. Chapter Five contextualises the findings of the study with the theory of family-centred care and discusses a model of family-centred care that is pertinent in Thai culture and may be used to enhance the care of children with thalassaemia and other long-term conditions. The final chapter, Chapter Six, provides the conclusion of the study by revisiting the aims stated at the beginning and examining how well it has answered the research questions. Recommendations for practice and further research will be presented followed by a personal reflection on the research process which will demonstrate my personal and professional growth during this research project.

Within the literature, there are many arguments posed on whether qualitative studies should be written in the first person (Webb, 1992). Whilst this may be an argument about styles of writing, there are philosophical and methodological viewpoints that also need to be considered and having weighed up all the options, the first person will be used in this thesis when the data collection process is being described and an 'academic' style will be used in the remaining sections.

1.2 General information about thalassaemia

Thalassaemia refers to a group of blood disorders caused by mutations in the genes that regulate the production of haemoglobin which is necessary for the creation of red blood cells (Bryant, 2003). In people who suffer from thalassaemia the bone marrow does not produce sufficient haemoglobin which results in a reduced oxygen-carrying capacity of the cells causing anaemia (Sabloff et al., 2011). If the body does not receive sufficient oxygen, a person may feel tired, breathless, drowsy and faint. More severe types of thalassaemia can cause other complications, including organ damage, restricted growth, liver disease, heart failure and death (Bryant, 2003).

Cases of thalassaemia occur across the globe but are most prevalent in South-East Asia, South Asia, the Middle East, and the Mediterranean (Vanichsetakul, 2011). Over the last two decades there has been considerable improvement in the control and management of thalassaemia in developed countries, such as Canada (Weatherall, 2010). Other countries, especially developing and under-developed ones, have found it difficult to control and manage the illness due to a lack of

knowledge of its true prevalence, inadequate medical services and insufficient support from their governments and international health agencies (ibid.).

However, there has been some progress recently in addressing these problems in some regions and there are several ways in which the health of children with thalassaemia in less wealthy countries has improved. In Canada, genetic screening commences during high school and the incidence rate of newly-diagnosed cases has fallen by 90% since the beginning of The Montreal Thalassaemia Screening Program (Capua, 1998). In Thailand, there has been a reduction in the numbers of births of babies with thalassaemia and major improvements in the care of children with thalassaemia. There is now comprehensive care but it is still inadequate. In addition, the data available to the government is unreliable and does not give a realistic indication of the total dimension of the disease (Weatherall, 2010).

1.2.1 Types of thalassaemia

There are two different types of thalassaemia – alpha thalassaemia and beta thalassaemia. Haemoglobin is made up of matching chains of proteins. Red blood cells contain haemoglobin consisting of alpha chain and beta chain proteins. A defect in the alpha chain causes alpha thalassaemia, and a defect in the beta chain causes beta thalassaemia (National Heart Lung and Blood, 2013).

Alpha thalassaemia is found mainly amongst people of South Asian, Southeast Asian and Mediterranean descent (Bryant, 2003). The alpha chain is produced by four genes, two on each chromosome 16, and the severity of the condition depends on how many of these genes have mutated (Kumar et al., 2007). If only one gene is defect, it causes little or no harm to human life. Symptoms of mild anaemia can appear if two genes are significantly mutated and this is known as the alpha thalassaemia trait. The severity increases when three genes are mutated. This condition is referred to as haemoglobin H disease. People suffering from haemoglobin H disease have chronic anaemia and may require regular blood transfusions throughout their life. The most severe form is when four genes are mutated, which is known as alpha thalassaemia major. Infants with this condition are unable to produce normal haemoglobin and death at birth is very likely (Vanichsetakul, 2011).

Beta thalassaemia or Cooley's anaemia can range from moderate to severe (Bryant, 2003). The most severe form of the condition is known as Beta Thalassaemia Major (BTM) and people with BTM require transfusions early on and then regular blood transfusions throughout their lives. It is similar to haemoglobin H disease. The milder form is called Beta Thalassaemia Intermediate (BTI) and its symptoms are varied: some patients experience symptoms of mild anaemia and do not require blood transfusion, while others require regular treatment (ibid.). The main onset of thalassaemia symptoms can appear during late infancy or early toddlerhood and it causes anaemia and delayed physical development.

1.2.2 Treatment and prevention of thalassaemia

Thalassaemia services in countries such as Canada and the United Kingdom currently provide the highest quality treatment and the care is comprehensive. It includes biomedical, psychological care and educational services (Yardumian et al., 2008; Odame et al., 2013; Cappellini et al., 2008). In addition, there is a network of other mechanisms that can lead to a wider access to specialised clinics which provide constant and rigorous support (Yardumian et al., 2008). Patients who are diagnosed with thalassaemia receive courses of treatment delivered by qualified and experienced professionals. The severity of each case is identified carefully and managed by a general practitioner (GP) through the local support organisation or another patient. People who are carriers or who have the alpha or beta thalassaemia trait develop only mild or no symptoms and may require little or no treatment (Bryant, 2003). They are offered an early examination at the most convenient specialist centre, where they can be provided with appropriate transfusion services if needed and constant treatment and high quality care are ensured.

Patients with thalassaemia need to be cared for by specialists to ensure optimal routine care. Tertiary-level medical centres managed by an experienced haematology specialist provide advice, treatment and care for children and adults, who are suffering from anaemia (Yardumian et al., 2008; Odame et al., 2013). Three types of treatments are used for moderate and severe forms of thalassaemia: blood transfusions, iron chelation therapy, and folic acid supplements (Vanichsetakul, 2011). In the chelation therapy Desferrioxamine is administered as a slow infusion, either subcutaneously or intravenously over an 8–12 hour period 5–

7 times per week (Delea et al., 2007). The transfusion of red blood cells is the main treatment in Thailand for people who have moderate or severe thalassaemia (Vanichsetakul, 2011). This treatment gives the patient healthy red blood cells which contain normal haemoglobin. The procedure usually takes between 1 to 4 hours and the red blood cells are active for about 120 days, after which patients need further transfusions for a new supply of healthy red blood cells.

People with haemoglobin H disease or Beta Thalassaemia Intermediate may need blood transfusions occasionally, usually after they have developed an infection or illness or suffer from severe anaemia which causes tiredness (Bryant, 2003). Patients with Beta Thalassaemia Major need regular blood transfusions, often every 2 to 4 weeks. These transfusions help the patient maintain normal haemoglobin and red blood cell levels. With regular blood transfusions people with thalassaemia are able to lead normal lives, perform the same activities as others and have a normal life expectancy (Vanichsetakul, 2011).

The only known cure for thalassaemia is a bone marrow transplant from a person who does not have thalassaemia or an umbilical cord blood transplantation, which uses blood cells taken from an unborn baby carried by a mother who also has an older affected child. These treatments can cause other complications and are therefore not suitable for every patient (Cappellini et al., 2008 and Vanichsetakul, 2011).

Family genetic studies can detect whether people have the mutated haemoglobin gene that causes thalassaemia. Pre-natal diagnosis is the most effective way to identify any abnormality in the genes of a foetus (Vanichsetakul, 2011). Therefore, thalassaemia can be prevented because these pre-natal tests can detect the disorder before birth. It needs to be noted that some individuals are silent carriers and may not experience any symptoms despite having the gene. Counselling for parents and couples who are at-risk is key in the successful prevention following pre-natal diagnosis (ibid.). If the genes are present parents need to decide whether to have a family.

1.2.3 Effect of thalassaemia on children and their family

The diagnosis of a chronic illness in children leads to significant changes in the lives of family members and to long-term relationships with healthcare personnel. Nuutila and Salanterä (2006) identified a number of variables that can influence a parent's cooperation in the care for their chronically ill child. These variables include the perception of family involvement, the treatment programme and the healthcare system's potential to facilitate family decision-making and a trusting relationship. Nuutila and Salanterä (2006) established that a high quality of healthcare can increase parents' health awareness and competence. This means that nurses should ideally change their focus from the medically-dominated model of care to a more equal approach that includes communication, respect, trust, sharing of information and parental empowerment as the essential characteristic (Hunter and Perkins, 2014). The skills that nurses possess mean that they are the most important people to support and enhance parents' competence to care for their child.

Children with the abnormal gene now live longer and with fewer complications due to better treatment, but for many the illness still reduces their quality of life. Fluctuating haemoglobin levels impair oxygen efficiency which, depending on the severity of the disease, requires regular blood transfusion and some children develop physical deformities (Thavorncharoensap et al., 2010).

As this is a chronic disease, patients with thalassaemia experience on-going treatment and the uncertainty of complications may lead to a psychosocial burden. Children (mean age 14.6 years) with medium or severe thalassaemia report experiencing pain, impairment in feelings, additional illnesses and a lack of social support (Pakbaz et al., 2005). Similarly, Shaligram et al. (2007) suggest that the impaired quality-of-life experienced by some children is due to the severity of symptoms and the side-effects of treatment. Aydinok et al. (2005), for example, found that children who were treated with Desferrioxamine were significantly more affected than those that received a different treatment.

In addition, thalassaemia also affects other aspects of the young patients' lives, including a delay in completing their education due to taking time off from school and reduced sports activity. The children often feel different from their friends and siblings, and their social interactions and the family's adjustment to the illness were perceived negatively. They also experienced feelings of anxiety, isolation, and stigmatisation. Gharaibeh et al. (2009) found a significant link between the family

background and the occurrence of psychosocial burdens. They recommend that families with children with thalassaemia need psychological as well as medical support. Healthcare professionals have to assess the psychological status of children and their families in order to help them manage their distress. In addition, nurses should provide psychosocial support for children with thalassaemia and encourage other family members to assist in providing them with support (Bryant, 2003; Aydinok et al., 2005).

Mednick et al. (2010) assessed the prevalence of symptoms of depression and anxiety in adolescent and adult patients with thalassaemia as these symptoms were associated with treatment difficulties and quality of life. They found that symptoms of anxiety and depression were highly correlated with the Desferrioxamine treatment and associated with a low quality of life. It is, therefore, essential to provide a child suffering from thalassaemia with psychological support that aims to enhance their emotional and physical health (Mednick et al., 2010).

The increased risk of psychosocial and behavioural problems in children with thalassaemia and their parents emphasises the importance of a lifelong psychosocial support that accompanies the physical treatment and prevents mental health problems (Aydinok et al., 2005). Aydinok et al. (2005) found that although children and their parents who were more conscious of the illness were also more anxious. They complied more with the therapy but needed more psychological support.

The most common complication of blood transfusions is the high level of iron in the blood system, which can lead to a significant morbidity and multiple organ dysfunction (Mathews et al., 2009). In a healthy child iron carries a protein called transferrin into certain tissues and because it is bound to this protein, other tissues are protected from the toxic effects of free iron. Children who have thalassaemia and who receive regular blood transfusions rapidly acquire much more iron than can be carried by transferrin and consequently free iron levels increase in the circulating blood. This free iron, called non-transferrin bound iron, is transported around the body and is toxic to the heart, liver and other organs, which can cause serious medical problems (Chan et al., 2004). Splenomegaly (enlarged spleen) in patients with B-thalassaemia major is often a symptom in an advanced stage of the disease and is also associated with frequent blood transfusions. These patients may need a splenectomy (removal of the spleen) if the patient develops significant abdominal

discomfort, splenic infarction, or symptomatic splenomegaly (Mathews et al., 2009). Many patients may experience pain from the medical treatments and those with Beta-thalassaemia major require regular blood transfusions to sustain their life (Chan et al., 2004).

Due to the complexity of symptoms, a variety of nursing strategies are needed for the child with thalassaemia and the parents. These include promoting compliance with transfusions and chelation therapy, supporting the child to cope with the symptoms of the disease and the side-effects of the treatment, helping the child and its family to make adjustments to living with thalassaemia, and to prevent complications of prolonged blood transfusion (Bryant, 2003). In order for these strategies to be successful, the nurse needs to be involved in several nursing actions.

Firstly, the nurse should inform the child and its parents in detail about the treatment programme and the treatment plan. The information will help them understand thalassaemia and anaemia. The family also needs to be taught to administer chelation and other treatments and to supervise the child's care.

Secondly, the nurse should seek to implement actions that enhance the quality of life of the child and its family. The impact of the disease on the physical appearance of a child living with thalassaemia needs to be taken into consideration as it might develop changes in the bone structure, delayed physical development and sexual immaturity and many patients might find this embarrassing and distressing (Bryant, 2003). These children need assistance in coping with the effects of the disease and it is important to inform them about the delayed and altered transition to adulthood (ibid.). The nurse can also assist in the improvement of their quality of life by ensuring that blood transfusions do not interfere with the children's activities. Their treatment and health conditions should be adjusted to suit their everyday life where possible.

Finally, the nurse needs to ensure that the child and family are aware of the need to prevent possible complications of prolonged blood transfusions. They should be offered comprehensive and age-appropriate education about thalassaemia. In addition, specialist opinions should be provided on the management of complex issues, including chelation regimens, problems with compliance, peri-operative management, management of complications, issues of bone marrow transplantation, and complex psychosocial issues (Yardumian et al., 2008).

1.2.4 Thalassaemia in Thailand

At least 2% of children in northern Thailand are born with severe thalassaemia and many die at birth, while others are born with physical problems such as low birth weight and anaemia (Lemmens-Zygulska et al., 1996; Traisrisilp et al., 2009). According to Tanphaichitr (1999), 30 to 40% of the Thai population carry the thalassaemia gene and of these, approximately 600,000 people of the Thai population require treatment. The majority of these patients are found in the north and northeast of the country and this region also has the highest number of thalassaemia cases in the world (Fuchareon and Winichagoon, 1987). Due to the high number of affected people, thalassaemia is considered to be a public health issue in Thailand. The Thai Ministry of Public Health (MOPH) aims to provide services that manage and treat thalassaemia so as to maintain the affected child's health and development (Ministry of Public Health, 2007).

Within the Thai healthcare service, thalassaemia children are usually cared for in hospital outpatient departments and only admitted to hospital when blood transfusions are required. Whilst in hospital the children are largely cared for by their parents, but only a few studies have focused on the importance of the family as care providers (Pongjaturawit and Harrigan, 2003). In addition, many centres employ the model used to counsel patients with Human Immunodeficiency Virus (HIV) or Acquired Immunodeficiency Syndrome (AIDS) as a template for thalassaemia counselling, even though this was found to be ineffective as these models focussed on the psychological aspect of the disease and ignored the genetic aspects (Dhamcharee et al., 2001).

The treatment and management of the care provided for children with thalassaemia and their families is similar in Thailand to the approach in other countries and includes physical treatment, blood transfusions, prevention of complications and the prevention of new cases (Vanichsetakul, 2011). The blood transfusion and iron chelation therapy to manage anaemia and reduce high iron in the body are provided in hospital and they require care by experienced nurses (ibid.). The prevention of new cases is managed by haematologists and physicians who are experts in thalassaemia, and who are able to identify thalassaemia-carrier couples at risk, and then provide family planning advice and counselling (Aydinok et al., 2005).

Four major issues impact on the care that is provided for children and their families in Thailand. The first is that thalassaemia is not seen as a priority and many hospitals do not have specialised clinics. The care is expensive and although it is partly funded by the government, the majority of Thai people have a low income and cannot afford the cost of treatment and the additional money that is needed to travel to hospital and other related expenses (Dhamcharee et al., 2001). Secondly, existing services are run by interested paediatric haematologists or obstetricians and there appears to be little coordination between them, leading to a lack of teamwork within a hospital, which contributes to an ineffective control of thalassaemia births (ibid.). Thirdly, blood supplies for transfusions are sometimes erratic, the screening of donors might not be sufficient, and iron chelation and necessary equipment might be unaffordable. The final issue is the lack of knowledge about thalassaemia amongst Thai people. Since there is no Thai word for “thalassaemia”, it is very difficult to help them understand this disease. Dhamcharee et al. (2001) found that this deficit in knowledge had a strong impact on genetic counselling and contributed to a lack of preventative measures.

The MOPH has recommended the establishment of a national policy to provide information about thalassaemia to hospital administrators and to promote a thalassaemia awareness campaign (ibid.). This is necessary as there are currently no national guidelines for the management of thalassaemia in Thailand, although the The Queen Sirikit National Institute of Child Health (2007) has recently published guidelines to support its care. The Institute was established in 1951 by the Department of Medical Services, MOPH. It has over 400 beds, and can accommodate 15,000-20,000 inpatients and more than 35,000 outpatients per year.

By Royal Decree B.E. 2539 (1996), the Institute is regulated by the MOPH and is responsible for a number of functions: study, analyse, research and develop medical knowledge in paediatric diseases; share knowledge and technology; improve the training of doctors, resident interns, medical students as well as public health personnel so as to develop experts in the field; be a referral centre for all paediatric subspecialties in diagnosis, investigation, rehabilitation and prevention of childhood diseases and finally to collaborate with other related sectors.

The Queen Sirikit National Institute of Child Health (2007) has developed five strategies for thalassaemia care. These focus on prevention, diagnosis and medical

treatment of thalassaemia and include the provision of appropriate laboratory systems, as well as research and technology to support its prevention and control (Queen Sirikit National Institute of Child Health, 2007). In addition to this, there is now a Thalassaemia Foundation of Thailand which produced a National Strategy for Thalassaemia (2007-2012). Its aim is to promote prevention and research in thalassaemia care. The strategy focuses on the screening of patients and also suggests an increase in the competence levels of registered nurses, allowing them to play a greater role and facilitate the participation of the family in all aspects of nursing care.

The World Health Organisation (WHO, 2010) provides principles for the care of people with chronic/long term conditions and it suggests that effective management of this group of individuals requires collaboration with the family, encouragement of self-care, active follow-up and maintaining the individuality of the person (Korff et al., 2002). In order to achieve these goals and to ensure that hospitals provide care in accordance with the WHO principles, the hospital environment needs to change and shift from medically-centred care (medical model) to family-centred care. This can be a challenge for nurses because the environment and facilities of the healthcare services can be a limitation and inhibit the delivery of individualised care.

The MOPH deploys strategies to manage thalassaemia by developing systems for its control and care. It has developed efficient diagnostic laboratory facilities and expanded the service area. It has also funded research, development and evaluation to improve the knowledge of thalassaemia care. The main implemented approaches to treatment consist of blood transfusions, iron supplements, splenectomy (removal of the spleen), and self-care. These are recognised treatments which indicates that thalassaemia care in Thailand is comparable to the care provided in other countries. However, the thalassaemia health care services struggle with the high cost of treatment, which has been estimated between 1,260,000 Baht to 6,600,000 Baht per person per year (approx. £26,250- £137,500 per person) (The Bureau of Policy and Strategy, 2011). As in other countries, genetic screening of the new born is now being introduced but this scheme has encountered some problems. For example, the results of the screening programme found that when married pregnant women were screened, their husbands did not always participate in the screening because it is not compulsory to do so (Tongsong et al., 2000). As a result the overall birth rates of children with thalassaemia remained unchanged.

The MOPH has the responsibility to provide thalassaemia care to improve patients' quality of life as, so far, there had been an emphasis on biomedical treatments only. Healthcare professionals are asked to abide to this new policy and their performance is monitored. The current treatment programme does not only rely on the use of medication and blood transfusions to control anaemia and the symptoms of thalassaemia and the prevention of infection, but also includes the education of the patient/child and its family. This is due to the realisation of the need for them to understand the disease, its treatment and the process of healthcare as they need to interact with the healthcare system. In addition, the effectiveness of care for children with chronic diseases depends on the co-operation of the family since the nurse has only a limited amount of time and resources for each patient.

1.3 The context of the study

This study was conducted in the Lampang Province in Northern Thailand and in order to appreciate this context, the following section provides general information about Thailand, the Thai healthcare system and the Lampang Province.

1.3.1 Location and population

Thailand is located in Southeast Asia and covers an area of approximately 514,000 square kilometres (Figure 1). It has borders with Myanmar (Burma) in the east, the Lao People's Democratic Republic in the north-east, Cambodia in the west and Malaysia in the south. The coast line is 2,420 kilometres long on the Gulf of Thailand and the Andaman Sea. The current Thai population consists of around 64,456,695 with an expected annual growth of 0.3% (National Statistic Office, 2013).

Figure 1 Thailand Maps provided by www.hollywoodgeography3.wikispaces.com



1.3.2 Language and dialect

The official and national language is Thai and 100 per cent of the population are using it in their spoken and written communication. Although Thai is the main language, there are several dialects of Thai. An official dialect is widely used and understood throughout the country and is the main dialect spoken in central Thailand. It is also the dialect used in education, communication, entertainment and by the government. However, there are also several regional dialects that people use when interacting with their family members, friends or within their local environment and neighbourhood. These consist of three main dialects: the people in the North-East speak "Isan" which shares many similarities with the Lao language. The dialect in Northern Thailand is "Lan Na" or "Kum Muang," while the one in Southern Thailand is "Lang Tai" or "Southern Thai." A significant feature of the Thai official language and the regional dialects is that they all have particular words, phrases and rules to demonstrate politeness that must be adhered to during formal interactions. In addition to the regional dialects, there is also one that is used by Thai royalty which contains "Royal words". It is used exclusively by the royal family

on special occasions. Finally, monks speak a 'religious' dialect during religious services and rituals.

1.3.3 Political system

Thailand is a constitutional monarchy with a king as the head of state. The current monarch is Bhumibol Adulyadej. He is very powerful and is very highly respected by Thai people. Most of the King's powers are exercised by the elected government in accordance with the Constitution of Thailand. The political system in Thailand is such that there is a national government consisting of a Prime Minister and a Cabinet. The country is divided into 76 provinces that are administered by appointed governors. The provinces are further divided into districts (*Amphurs*), sub districts (*Tambons*) and villages (*Moo Bans*).

The key component of Thai economy has rapidly changed from agriculture to the service industry and manufacturing, a change that was influenced by a number of social, economic and political factors. In 1961, the Thai government published its first five-year National Economic and Social Development Plan for the period between 1961 and 1966. The key aim of the plan was to address the issue of the country's heavy reliance on the agricultural sector. This first plan was followed by several other updated versions and the country is now working within the Eleventh National Economic and Social Development Plan 2012-2016. The success of these Plans can be seen in the rate of economic growth, which has been impressive for more than three decades and is based on a shift away from agriculture to other industries. However, this increase suffered a setback during the economic crisis that occurred in 1996-1997 and led to a recession. Thailand recovered from it and is now back on track to regain its economic successes.

The National Economic and Social Development Office provides the vision, mission, objectives and targets for the Thai economy by setting monetary and fiscal measures. These also cover the healthcare system with the aim that it should be managed in an efficient and sustainable manner.

For the healthcare system the current Eleventh Plan contains a number of targets which include a reduction of risk factors in health, with the aim to promote physical and mental well-being. The emphasis is on ensuring that knowledge and skills in

healthcare are provided on an individual, family and community level, and on creating a national health database. Citizens are encouraged to participate in formulating public policies related to healthcare and the health services is improved through the provision of high quality care accessible to all citizens. The use of alternative medicines is also promoted. The current Plan also sets a target for the supply of the healthcare workforce with the aim to redistribute qualified medical staff more equally across the country.

1.3.4 Educational system

According to the Thailand National Plan, lifelong learning should be essential for all Thai citizens and learning habits should be instilled in everyone from an early age on (National Economic and Social Development Board Office of the Prime Minister, 2012). In the educational system in Thailand basic education is available for free for all children at primary, lower level secondary and high level secondary school. This is commonly known as the 6-3-3 system, reflecting the number of years spent on each level. In addition to gaining subject knowledge, children learn the values of their country as well as the need for social respect and the respect for authority. The emphasis on the latter increases with the level of education.

Education is highly valued in Thailand and the educational system and its impact on citizens' lives has been improved through a series of reforms and investments. At present, 95.1% of the Thai population are educated on at least the primary level and only the remaining 4.9% appear not to have any educational qualifications (National Statistic Office, 2013). It is interesting to note that the level of educational achievement in northern Thailand (the location of this study) is below the national average. Over half of the population have only completed the primary level, a further 14% have only completed the lower secondary level, a quarter have completed the higher secondary level and only 5.7% have completed higher/university level education (*ibid.*). These figures imply that, on the whole, most people in northern Thailand only achieve compulsory education. They occupy, therefore, less-skilled employment and have consequently lower incomes.

The Office of the Education Council regulates higher education at the diploma, associate, and degree levels which are taught in universities, educational institutions, colleges, community colleges, and other types of institutions (The Office of the Education Council, 2013). Higher education is not free and consequently only

accessible to a limited number of people. As in other education systems, associate degrees or diploma level education requires two years of study, while programmes leading to a degree require a further two years of study beyond the diploma level.

1.3.5 Religious beliefs in Thailand

According to the national census in 2005 Buddhism is the professed faith of 93.9% of the population (National Statistic Office, 2013). It is the foundation of Thai society and follows parental and ancestral traditions. The influence of Buddhism is apparent in many aspects of Thai life and in other areas, such as language, arts, architecture, traditions and behaviour (Plamintr, 2003). The central aim of Buddhism is to promote peace and happiness at an individual, communal, societal and global level. The main elements of Buddhist teaching are *goodness*, *making merit*, the *middle way* and *kamma* or *karma*.

Goodness is the peaceful state of mind most Buddhists aim for as individuals. Goodness includes love and forgiveness, sacrifice, generosity and tolerating evil (Thongthammachart et al., 2002). Chandoko (2011) explained that the path to enlightenment is brought about by elements of the Eightfold Path of Rights: understanding, aspiration, speech, action, livelihood, effort, mindfulness and concentration. Peace of mind is considered to lead to ultimate happiness and is combined with a willingness to help others, live the middle way, believe in goodness and do good deeds to achieve peace and happiness.

‘Making merit’ is a ritual that most Thai people perform and consists of giving an offering to Buddhist monks when they leave the temples in the early morning or at midday. Thai people also ‘make merit’ at Buddhist holy day ceremonies and offer alms to monks. They practice Dharma rituals that include chanting, listening to sermons, observing religious rites and meditating. Such activities remind Buddhists of the need for sacrifice in order to achieve happiness. This idea of ‘sacrifice’ is also lived out by helping and sharing, for example by giving food or money to poor people as a good deed. Although it is a Buddhist belief, making merit is also a way of life in Thailand in general (Santina, 1984) and the practice is believed to increase morale by inducing relaxation and a sense of calm. Making merit is not only a ritual but also reflects the idea of coping. As a result, some people choose to look after

themselves when they are ill and cope on their own without any help from healthcare professionals.

The middle way means life must be lived between the extremes of self-denial and self-indulgence. It is the recommended way of living one's life according to the Buddhist way of thinking and is also linked to Dhamma. It includes accepting things the way they are and understand their nature or be enlightened by it (Santina, 1984).

Kamma denotes the cycle of cause and effect and belongs to faith in the circle of action and reaction. It consists of three elements: good thinking, good practice, and good speaking (ibid.). People who practice these elements are believed to receive good results. Kamma embraces human action whether it happens in the past or present (Mahathera, 1982). The belief in this concept is not an obligation or a rule although many do believe and practice it. A belief in Kamma does not protect the rich or comfort the poor by promising illusory happiness in an after-life (ibid.) but it influences the morals and behaviours of Thai people (Santina, 1984).

1.3.6 Healthcare system in Thailand

Healthcare in Thailand is provided by public and private institutions. Public health facilities rapidly expanded throughout the country following the launch of the first Thai National Economic and Social Development Plans (1961 - 1966). All public hospitals in Thailand are under the administration of the Ministry of Public Health (MOPH) while private hospitals are regulated by the Medical Registration Division which is within the MOPH's Department of Health Service Support and regulated by the Sanatorium Act, B.E. 2541. Other government units and organisations such as the military, universities, local governments and voluntary organisations, e.g. Red Cross, also run hospitals and these adhere to the governance of the Ministry of Public Health as well. At present, there are 1,002 hospitals and 9,765 health care services in the country (The Bureau of Policy and Strategy, 2011).

Healthcare policies and the infrastructure to support universal coverage expanded greatly over the years and every province now has a provincial hospital, every district (*Amphurs*) has a community hospital and sub-districts (*Tambons*) have health centres. Some provincial hospitals have expanded to become regional hospitals and are the referral centres for other provincial hospitals but there are very

few specialist centres/hospitals at the provincial level as most of these are located in the bigger cities like Bangkok (Weatherall, 2010).

People are able to access healthcare services wherever it is most suitable for them but this access is restricted by the capacity of healthcare services. Their capacity depends on the size and location of the individual hospital. The Ministry of Public Health categorises hospitals into 4 types. The first are regional hospitals, which are located in the provincial capitals and have a minimum of 500 beds. They are able to provide complex care and have a considerable range of physical facilities, medical equipment and a workforce which specialises in the treatment of numerous diseases (Nuntaboot, 1994). The second type is the general hospitals which are also located in the provincial capitals and have a capacity of between 200 and 500 beds. General hospitals are mainly frequented by people in the immediate area of the provincial capital, while the bigger regional hospitals serve as the place to go for the population in their respective regions. The third are community hospitals which are situated in districts and have a capacity of between 10-150 beds. Community hospitals offer comprehensive health services and possess the facilities to support a range of healthcare activities and public health programmes in the districts where they are located (ibid.). However, a community hospital can also serve as a referral centre for small hospitals which are the final category. They typically have about 10 beds, are usually limited to providing less complex and primary care and a number of them only have the services of a doctor for a few hours a week.

In addition to the small hospitals, there are health centres in the community which are called primary healthcare units (PCUs). The emphasis here is on providing primary healthcare and promoting self-care. These PCUs are staffed by nurses and have no permanent medical doctor. As a result, the PCUs are limited in the type and range of healthcare they can provide and they operate as a referral system to transfer patients to the secondary and tertiary hospitals. In addition to receiving patients from the PCU, the regional and provincial hospitals provide support and staff to the PCUs. This is provided in form of healthcare professionals and nurses but also through the PCUs network of community volunteers, who offer simple first aid and medical care. These volunteers also function as co-ordinators between the PCU and residents in each village by distributing health information and offering basic care to the villagers under the supervision of the PCUs.

A major issue for the healthcare centres is the lack of both sufficient funds and health professionals to meet the needs of the rural population. This led to a re-organisation of primary care services with healthcare centres being re-organised into a series of networks and the regional hospitals acting as the hubs of the network. A consequence of this re-organisation was that funding for healthcare centres was provided by the Ministry of Public Health. Despite this re-organisation, the number of services available to the people who live in rural areas is significantly lower than those available in urban areas and health care centres continually struggle with insufficient budgets to meet the needs of the population.

The National Health Security Office (NHSO) of the MOPH distributes funding for healthcare through the universal healthcare programme which was introduced in 2001. It is divided into different schemes: the civil service welfare scheme for civil servants and their families, the social security scheme for private employees, and the universal health care scheme for all other Thai citizens (Damrongplasit and Melnick, 2009). The key aim of the programme is to ensure that healthcare services are available to all, especially those in the lower socio-economic groups who fall into the universal healthcare scheme or “30 Baht scheme” - patients who are not expected to pay more than 30 baht (approximately 60 pence) per visit for all the care received in outpatient departments or in a hospital.

Although the programme ensures that healthcare is available to all Thai citizens, an additional payment is expected from those who can afford it. Children under 12 years of age also benefit from the 30 Baht scheme and their parents are not expected to pay anything. Thai people are issued a gold card that gives them access to healthcare and they can be referred to specialists and regional hospitals if necessary. The funds for the universal healthcare programme come from public revenues and are distributed to the regions on a formula based on the size of the population within the region.

There are exemptions to the services that can be accessed through the universal healthcare programme and this includes cosmetic/plastic surgery, obstetric care beyond two pregnancies, organ transplantation, and haemodialysis (Damrongplasit and Melnick, 2009). The effectiveness of these exemptions has an impact on the health of the poor and the elderly because they are the main influences on the choice of health facilities used by these two groups (Coronini-Cronberg et al., 2007).

The universal healthcare programme was successful because it involved a collaboration between all the healthcare sectors. At the moment, however, it is facing major challenges due to rising costs, limited resources to meet patient's needs and the fact that healthcare facilities are already working at maximum capacity (Damrongplasit and Melnick, 2009). In order to try and alleviate these pressures, private hospitals now collaborate in the schemes, although the impact of this change is as yet unclear. The treatment for patients with thalassaemia is part of the scheme and it includes the cost of blood transfusions.

1.3.7 The profession of nursing in Thailand

Thai individuals can become registered nurses in two ways. The first is by attending and completing a course at a university that is regulated by the Ministry of Education. In order to gain a place at a university, individuals have to pass an entry examination and then undertake a four-year under-graduate programme. Competition to gain entry into a university is high as there are limited places available (Anders and Kunavikikul, 1999).

The second way is through attending a nursing college that is regulated by the Ministry of Public Health and there are currently 35 nursing colleges across the country. These colleges are affiliated to a university and in order to successfully complete the nursing degree, a student must pass the examinations that are set by the affiliated university even though the degree is awarded by the college (*ibid.*). In both cases the student must also pass the examination set by the Thai Nursing Council before they can become registered nurses and be licenced to practice.

The undergraduate course in nursing includes a generic training consisting of core competencies in adult, paediatric, psychiatric, midwifery and community care. Consequently, nurses in Thailand can work in all areas of healthcare. This is different from the UK system, in which student nurses select a specialist field (adult, child, mental health or learning disability) and spend 3 years studying that speciality. Midwifery is also a separate course in the UK.

Although there is no difference in the examination or the curriculum, a university degree is perceived as being superior and more prestigious compared to a college degree. Due to the high demand for their skills, registered nurses from either educational institution are able to find employment almost immediately in either a

government institution or with a private healthcare provider, in a community, secondary or tertiary care setting.

Nursing practice in Thailand is regulated by the Professional Nursing and Midwifery Act B.E.2528 (1985) which is a revision of the Act B.E.2540 (1997). It requires that the practice of nursing should be based on scientific principles and the art of nursing. The role of the nurse is defined by the Thai Nursing Council as well as the local employer as being responsible for the care and well-being of ill as well as healthy people. Although the profession of nursing has evolved and changed in Thailand over the years, the role is still limited and restricted to working under the direction of a doctor. However, in recent years, Thailand has introduced the nurse practitioner as a role recognised and licensed by the statutory body for nursing. Nurse practitioners perform highly skilled, autonomous and complex nursing care. Many work closely with doctors although some manage their own case load. They also work in community settings where their role is autonomous because of the limited availability of doctors and medical support (Hanucharunkul, 2007). Since the law restricts the role of nurse practitioners in some aspects of care, those working in the community work within guidelines and protocols and are thus able to access the support and advice of doctors when they face complex problems or are uncertain about treatments (ibid.). Nursing regulations in Thailand require that those who work in the community possess post-qualification training for an enhanced role which encompasses undertaking some of the skills of a doctor (Hanucharunkul, 2007).

The latest figures indicate that between 9,000 and 10,000 nurses are trained annually but these numbers remain insufficient for meeting the country's healthcare needs (Sawaengdee, 2008). Whilst there were approximately 97,900 registered nurses in Thailand in December 2005 (ibid.), it has been estimated that only about 88,440 or 90.3% of them are in current employment. The Ministry of Public Health employs about 60% with the remainder working in the private sector. In 2010 the ratio of nurses in Thailand was 14 per 10,000 people which is half of the global ratio (28 nurses per 10,000) and much less than the ratio in Europe (68 nurses per 10,000) (WHO, 2010). Figures from the Thai health organisations puts the ratio at 1 nurse to 531 people (The Bureau of Policy and Strategy, 2011). The main reason for this low ratio is the economic crisis in 1997, which led to cuts in expenditure on health and consequently to a decrease in the number of nurses (Anders and Kunavikikul, 1999).

The nurse's role in Thailand has changed and they are now expected to provide healthcare as per the national health insurance scheme that emphasises health promotion and patient satisfaction. Although the health reforms aim to improve the healthcare system, nurse shortages in public health facilities and hospitals are still severe and the increased expectations have a serious effect on nurses' workload which affects their ability to fulfil their role. Their lack of preparation for these changes is the result of a lack of knowledge, skills and abilities which leads to a lack of confidence and could result in role confusion and conflict within the team (Kunwat, 2002).

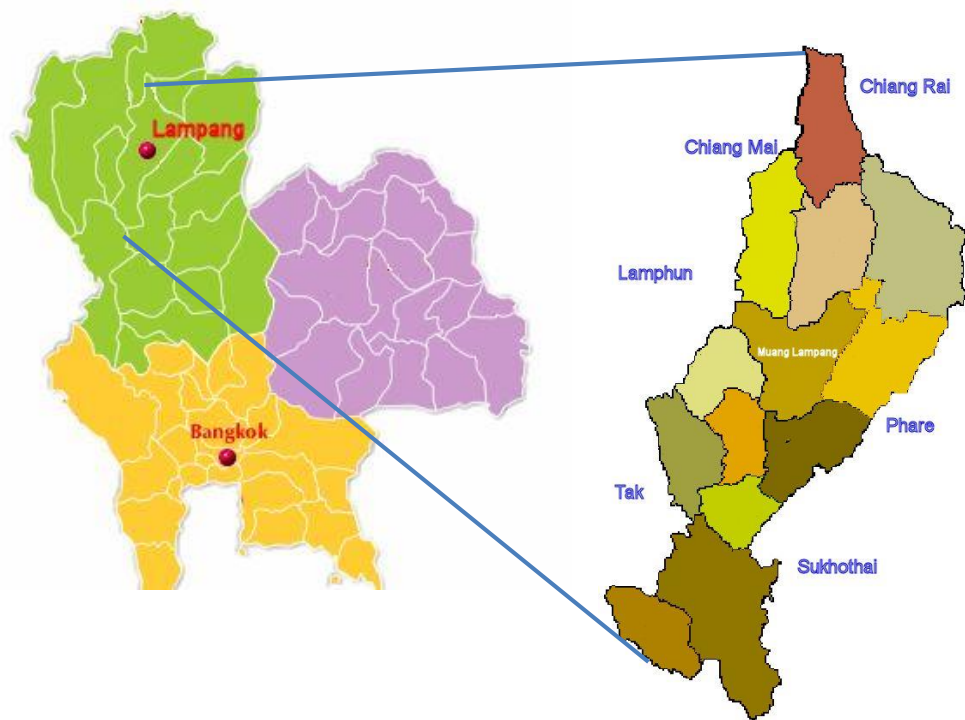
1.3.8 General Information of the Lampang province

This study was undertaken in Lampang, which is situated in Northern Thailand and covers an area of 12,534 square kilometres. It is the fifth largest province in the north after Chiang Mai, Tak, Mae Hongson, and Phetchaboon. It is located approximately 600 km to the north of Bangkok (Figure 1.2a) and can be accessed by road, railway and air. A flight from Bangkok to the nearest regional airport, situated in Muang Lampang, takes about 45 minutes.

Lampang lies next to a mountain range that runs from the north to the south with a plain in the middle. It is surrounded by 7 provinces: Chiang Mai, Chiang Rai, Phayao, Tak, Phrae, Sukhothai and Lamphun (Figure 1.2b) and is divided into 13 districts (Figure 1.2b), 100 sub-districts and 912 villages. The district with the highest population rate is the capital of the province Muang Lampang with 229,947 residents.

Figure 2: Map of Lampang (a) and the districts in the Lampang region (b)

source: <http://www.mapofthailand.org/> and <http://www.lampang.go.th/>



1.3.9 Population and economy of Lampang

The population in Lampang was 761,949 in 2009 (National Statistical Office of Thailand, 2009). 102,179 families or 41% of the adult population in the province work in the agricultural sector in farming, gardening, and cultivation. The remainder are distributed in occupations in the retail trade (18.49%) (National Statistical Office of Thailand, 2009).

In 2009, the average income of the Thai population was 7,149 Baht per month compared to 5,678 Baht month (approximately £115) in the Lampang province. Interestingly, the average income of residents in Bangkok was 11,829 Baht per person/month in that year, which is more than twice the income in the Lampang province. Consequently, the Lampang province is rated as being 51st of the 73 provinces in Thailand in terms of income (ibid.).

1.4 My rationale for conducting this study

I was a lecturer in children's nursing at the Boromarajonani College of Nursing, in Chiang Mai, which is situated in Northern Thailand. The College of Nursing operates

under the auspices of the Thai Ministry of Public Health (MOPH) and works in partnership with several hospitals and health centres across the region. Some of the subjects that I used to teach related to the theory of children's nursing and information technology used in nursing.

In the Thai nurse education system, there are two types of nurse educationalists: instructors, who work exclusively within practice areas, and lecturers, who work in both classroom settings and in practice areas. This format means that the theory of nursing is taught in the classroom and then always applied in practice. I was an instructor for 19 years and worked in the Suratthani Province from 1993 until 1997. In 1998 I moved to the Lampang Province. Although I was then employed as a lecturer, I continued to work in a clinic since it is a requirement that all lecturers in the Boromarajonani College of Nursing work as instructors to supervise student nurses who are undertaking their placements. Both roles require extensive and comprehensive knowledge and skills in all aspects of care.

Although the curriculum for children's nursing addresses the short-term/acute nursing care needs of children, it also places an emphasis on long-term illnesses and the problems which are typical for children with long-term illnesses. The latter is the area of my teaching expertise. I selected this topic for my doctoral studies because I realised that long-term illnesses can have a profound impact on a child's well-being. Their engagement in daily activities is restricted and they encounter a number of psychosocial problems which have an impact on their emotional wellbeing. In addition, their progress in education tends to be severely affected and they are likely to drop-out of school (Gerhard, 2002). The symptoms and effects of a long-term illness may not be constantly noticed by the child but the family needs to ensure that it has sufficient rest so that its daily activities are not affected. Chronic illnesses also impact on the family of the child as they result in numerous social, educational, psychological and financial commitments in addition to the usual daily commitments of parenting.

At a personal level, the concept of the family is important to me as I have two children which has helped me to understand the role individual families play in the care of a child with a long-term illness. The family structure provides safety and a caring environment for the developing child who is vulnerable and depends particularly on its parents (Gerhard, 2002).

I am familiar with thalassaemia, its high incident rates and prevalence in certain regions and am aware on the many difficulties that it causes the child and its family. Although recent legislation has meant that Thai citizens are able to access the national healthcare system with minimal financial contribution, the cost of travel to and from hospital adds substantially to the family's financial burden. In addition, psychological problems may develop when the child notices that it develops an abnormal physical appearance which can lead to depression (Immelt, 2006). Mothers have to face an uncertain future for their child and concerns have been raised about the need for social support to help them cope with this uncertainty (Prasomsuk et al., 2007). They expect their child to receive a high standard of healthcare throughout its life. Some parents are also concerned about the physical pain associated with the disease and its impact on the physical and psychological development of their child, the progression of the disease and their family planning for the future. Shaligram et al. (2007) examined the Indian health care system and found examples of the psychosocial problems that caregivers/ families of children with thalassaemia in India experience. Their results suggest that children and their families in Thailand may have similar problems. This challenged me to explore the provision of care for children with thalassaemia and their families' experience with healthcare and the provided Thai health services.

To narrow down the focus of my research aim and questions, I reviewed the literature related to thalassaemia care, long-term care and the role of the family in it. Through this process I found that thalassaemia care is a vast and complex subject area. Long-term illness is a complex specialty that operates within a healthcare setting which can be a challenging environment. Recent research reveals that chronically-ill children lack knowledge of their disease and its symptoms (Hameen-Anttila et al., 2006). While this may be due to their age, maturity and prior experience, it places a burden on their parents who need education and support to manage the illness of their children appropriately (Warschburger et al., 2003).

The relationship between parents and nurses who are caring for the sick child is also significant and the degree of co-operation offers potential for an increase. The study will allow me to explore the wide range of this collaboration, the time necessary to initiate and sustain the relationship and the potentially increased benefits for the families (McIntosh and Runciman, 2008).

There are several of approaches to the involvement of the parents during a child's hospitalisation. Concerns have been raised that the management of children with a long-term illness highly depends on professional care, reducing the parents' role to making decisions about treatment (Pyke-Grimm et al., 2006), essentially rendering them powerless. This issue of power was examined in a Swedish study. The researchers concluded that the professionals held the most power and parental participation was not evident as the parents did not wish to disturb or bother the professionals, even if the parents were in need of a short break from their caring responsibilities (Ygge and Arnetz, 2004). In order to guarantee a successful involvement of parents in the care of their ill children, they need support, professionalism and responsibility.

In addition, parents need to be involved in the treatment as it has a direct effect on the child's health and can improve its quality of life (Prasomsuk et al., 2006). They asserts that co-operation between healthcare professionals and parents is necessary for school-age children. Both parents and children wish to be more knowledgeable about their health and how to improve it. When parents and healthcare professionals work together it also leads to an increased competence in self-monitoring and self-recording.

One study in Thailand examined the effectiveness of an education programme for parents of children with thalassaemia (Paholpak et al., 2006) and found that parents who participated in the programme were more knowledgeable about the illness and could provide better care for their child. Paholpak et al. (2006) found that although parents wanted to participate in the care, their potential and ability to do so was limited. They concluded by emphasising the importance of educational programmes about thalassaemia in enhancing this ability.

The role of the family is important in improving the care of the young patient which also influences how the science and the art of nursing care can be integrated to focus on a child's daily healthcare needs (Betz, 2006). Only the child and its family can verify if the care provided emphasizes holistic care and encourages parental participation. In addition, the family can report if the needs of the child are met and if the treatment fits with the values and the culture of the family (Galvin et al., 2000; Harrison, 2010). The crucial question is how a healthcare professional integrates the voices and views of parents into healthcare procedures so as to ensure that the care is family-sensitive, culturally competent, effective, compassionate, and

respectful (Betz, 2006). Therefore, the voice of family members and children need to be heard and nursing care should be adjusted to fit not just within the context of the healthcare services but also the norms of the family. It is also important to identify how nurses and parents perceive each other to understand their partnership in childcare. Sangnatesawang (2008) examined these perceptions and found there were differences in the perceptions of partnership which varied according to the types of healthcare units and the experience of the professionals.

The expectations people have of healthcare systems has changed since the Thai health reforms and the current systems may need to improve when parents increase their participation in child care (Pongjaturawit and Harrigan, 2003). However, Prasomsuk et al. (2007) found that Thai mothers lacked sufficient knowledge of thalassaemia which has consequences for their child's well-being. Mothers also struggle with psychosocial problems, experience financial difficulties, have concerns for their child's future, depend on extensive social support systems and are reliant on the effectiveness of the healthcare services. Thalassaemia is thus a major public health problem (Traisrisilp et al., 2009).

Cultural awareness is a further challenge nurses have to face. They have to be aware of, appreciate, and become sensitive to the values, beliefs, ways of life, practices, and problem-solving strategies of the children's and their families' cultures (Campinha-Bacote, 2002). The aim of creating cultural awareness is to encourage the nurse to become aware of how his/her personal background and the family's background differ. Family-centeredness may be a challenge to the medical model in Thailand. Hunter and Perkins (2014) warn that cultural norms and behaviour can impact on the partnership because they influence the existing hierarchy of power and resources, status and style of leaderships.

This study will explore the characteristics of family-centred care and factors that influence family-centred approaches in thalassaemia clinics in the Thai socio-cultural context. The purpose of this research is to provide qualitative findings that can help nurses and healthcare professionals to understand and apply family centeredness in their care for thalassaemia children and their families.

1.5 The anticipated contribution of this study to the body of knowledge

This study has the potential to identify the characteristics of family-centred care within the context of the Thai healthcare system and Thai culture. This new insight is necessary for several reasons. Firstly, Thai Ministry of Public Health (2007) concentrates on the prevention and research of thalassaemia and omits the impact of the disease on the child and its family. Therefore, the results from this study will contribute to fill this gap in research. Secondly, most of the previous studies related to thalassaemia were designed to examine biomedical and psychological care, educational services, prevention and treatment (Delea et al., 2007; Yardumian et al., 2008; Odame et al., 2013; Cappellini et al., 2008). Studies in Thailand focussed on detection, management, prevention and curative treatment that were provided in pre-natal care and family planning (Vanichsetakul, 2011). Consequently, they did not focus on the severity of symptoms and the side-effects of treatments (Shaligram et al., 2007), such as pain, impairment in feelings, changes in health and lack of social support (Pakbaz et al., 2005), nor did they take into account that most of the thalassaemia treatment is provided in a tertiary-level medical centre (Yardumian et al., 2008; Odame et al., 2013). This study will examine the role the family plays to meet the physical and psychological needs of the child (Aydinok et al., 2005; Mednick et al., 2010).

A number of variables may influence a parents' role in the care of their chronically ill child (Nuutila and Salanterä, 2006) and these need to be explored. Some of these variables include the perceptions of family involvement, the treatment programme and the healthcare system's potential to facilitate family decision-making and a trusting relationship between family members and healthcare professionals. The perceptions of parents and healthcare professionals also influence the success in implementing family-centred care (Sangnatesawang, 2008) but the expectations of healthcare systems has changed since the Thai health reforms. The current healthcare system might need to improve if parents increase their participation in child care (Pongjaturawit and Harrigan, 2003). As parents care for a hospitalised child, there is a need for them to participate and work with the staff (*ibid.*) which might create new challenges for nurses (Prasomsuk et al., 2007). Thai society is largely Buddhist and Thailand is called the land of smiles. Religion and social norms need to be taken into consideration as the chronically ill child and their carers may be influenced by labelling. This research also aims to offer recommendations to

develop family-centred care and help healthcare providers and policymakers to understand and value this model of care for children with thalassaemia and their families. It is anticipated that knowledge developed from this study will contribute to a practical model of family-centred care specifically for the treatment of children suffering from thalassaemia in Thailand.

Using a case-study design facilitates the development of recommendations based on real events since the research design requires research to be undertaken with participants and findings are generated from the real experiences of children and their families, which gives the recommendations substantial credence and value.

1.6 Conclusion

This chapter has provided the background necessary to contextualise the study in its specific geographical and cultural setting. The description of thalassaemia facilitates an appreciation of the long-term and complex nature of this disease. An understanding of the political, social, and economic factors and health policy in Thailand (The Bureau of Policy and Strategy, 2011) helps the reader to understand that nursing practices and the care of children with thalassemia takes place in a complex environment and is influenced by these factors. The side effects of the illness and the treatment can reduce a child's quality of life and the effectiveness of health care services. Recent studies have focussed on both physical and psychological care but failed to take the context into account. Parents can contribute to the quality of care for a chronically ill child by getting involved in self-care management strategies. As the Thai healthcare system has to cope with a high number of patients, however, the role of the nurse in facilitating this contribution can be quite limited.

The following chapter will illustrate that family-centred care is a Western concept which has been developed and used extensively in Western countries. This study is one of the few that examines the role family-centred care can play in the care of children and families within a Thai context. Thai culture is strongly influenced by family ties, Buddhism and particular attitudes to health and this study examines the role these factors play in the way family-centred care is implemented.

Chapter 2

Literature Review

This chapter is divided into two sections: the first aims at analysing the concept of family-centred care (FCC) by discussing its history, definitions, philosophy and objectives before discussing its main elements. This will lead on to a discussion of the benefits of this type of care for ill children and their families.

In the second section, a review of the literature will be conducted. It also contains a description of the process employed to search for and retrieve the relevant literature together with a rationale for the types of literature that will be reviewed. This review will then proceed to highlight the strengths and weaknesses of the existing literature and explain how this thesis will address its limitations in the literature on the use of FCC in the care of children with thalassaemia in Thailand.

2.1 History of family-centred care (FCC) and development

In 1987, a group of healthcare experts developed a new approach to maternal and child care when Shelton and colleagues devised a framework known as family-centred care, which was comprised of 8 elements (Shelton et al., 1987):

- a) a recognition that a family is a constant in the child's life;
- b) the facilitation of parent/professional collaboration at all levels of healthcare;
- c) the recognition of a family's strength, individuality and respect for their methods of coping;
- d) the sharing of unbiased and complete information between parents and professionals;
- e) encouragement and facilitation of parent-to-parent support;
- f) an understanding and incorporating of the developmental and emotional needs of children and their families into the healthcare delivery systems;
- g) the implementation of appropriate policies and programmes that are comprehensive and to provide emotional and financial support to meet families' needs;
- h) an assurance that the design of healthcare delivery systems is flexible, accessible and responsive to families' needs

Subsequently, the American Academy of Paediatrics Committee on Hospital Care (APP) added one more element to Shelton et al.'s (1987) framework in 2003, which

was adopted for child healthcare in the United States. This additional element was that healthcare staff should be experts in family-centred care. In 2008, the Institute for Patient- and Family-Centred Care (IPFCC) proposed the adoption of the family-centred model for the care of children with chronic or long-term conditions so as to promote respect and dignity, participation, information sharing and collaboration. The IPFCC's (2007) model shared many similarities with the stages of the nursing process of assessment, planning, implementation and evaluation. However, it did not take the economic factors or the consistent presence of a family with a chronically ill child into account. IPFCC (ibid.) proposed the framework to be used for infants, children, and adolescents of all ages to ensure their well-being by enhancing the role of families. They suggest to do this by recognising the individuality of a family, allowing the family members to maintain their dignity, control and individuality.

The family-centred framework has been adopted as a philosophy of care for paediatric nursing in the United States of America (Harrison 2010; American Nurses Association and Society of Paediatric Nurses, 2003; Lewandowski and Tesler, 2003) and is now considered the main philosophy in paediatric care in Canada (King et al., 1999). It also underpins the principles of child care in the United Kingdom (Glasper et al., 2010), and aims to enhance a child's wellbeing by delivering care to it and its whole family (Hockenberry et al., 2013). The concept has become widely accepted as part of the philosophy of care giving in children's healthcare in hospitals and community settings in the United States (Franck and Callery, 2004). In addition, FCC has been adopted in developing as well as developed countries and one international comparative study of this kind of care system found that parents provided most of the care to their child and that the basic concepts of family-centred care were similar in the United State, the United Kingdom and Canada (Shields and Nixon, 2004).

The involvement of the family in the care of a child was first acknowledged in the 1960s and was based on the work of Bowlby (1969). Bowlby developed the attachment theory following research in a hospital in London in 1944 to measure behaviour in children. The results revealed a correlation between a child's behaviour and a history of maternal separation and deprivation. The theory developed from his work consisted of three components: attachment, separation, and loss (ibid.). Bowlby (1973) expanded his theory about attachment behaviours by developing the concept of availability, which was linked to a mother's access to the child. A lack of

this availability led to separation anxiety in children. According to Bowlby, this separation anxiety may be expressed in three phases which were first identified by Roberson (1970). The three phases were protest, despair and detachment. In the first phase, the child exhibits protest by crying, clinging and screaming. In the next phase despair a child becomes listless and shows a loss of interest in its environment and food. In the last stage detachment the child learns to interact with the current environment and caregivers and its behaviour is meant to show that it has lost interest in its mother (ibid.).

Bowlby (1980) also recognised that children can show grief and mourning during and after separation from their mother although he warns that children might hide these feelings. Bowlby suggests that in the absence of a mother, a child may see healthcare staff as attachment figures and start to develop a bond with them, but it might continue to protest because of the absence of the mother. Despite the presence of other attachment figures, Bowlby (ibid.) recommends that a child should not be separated from its family because of the strength of the emotional relationship between a child and its mother. Ainsworth and Bowlby (1991) recognised that this bond can be disrupted through separation, deprivation, and bereavement.

Bowlby's theory has been influential in children's nursing as it helps to explain the importance of maintaining an attachment between a child and its mother during hospitalisation because it can lessen the emotional impact. In order to minimise this separation, they found that having less-restrictive visiting times for parents had a positive effect on the psychological health of children in hospital. Flexible visiting hours became the norm in children's wards because hospitals acknowledged that parents were important participants in the delivery of care to their child (Robertson, 1970). Alsop-Shields and Mohay (2001) and Shields et al. (2006) suggest that the work of Bowlby (1970) forms the underlying theoretical principles of FCC and that his theoretical work still forms the rationale for today's practice of FCC.

FCC is a philosophy which believes that the family is a potential member of the care team and through collaboration can provide comprehensive care for children (Glasper et al., 2010). As a result, children and their families should be at the centre of every decision made about the care for their child (Shelton et al., 1987; MacKean et al., 2005). FCC is an approach to the planning, delivering and evaluating of healthcare and while children and families are encouraged to collaborate with

service providers, the Institute for Patient and Family-Centered Care (2013) and Shelton and Stepanek (1994) suggest that the level of collaboration should take the ability of a family into account. Providing FCC means that the healthcare professionals can incorporate families into care processes and children will then receive higher quality care. Bowden and Greenberg (2009) take the rationale for the use of FCC further by suggesting that the child and family should be considered as one unit which should be the fundamental focus of all healthcare interventions. Haddock (1996) raised concerns about the lack of acknowledgement of the dignity of parents and children and that, while families may be similar in many respects, there are also differences and their individuality should therefore be respected. If nurses working within the family-centred approach show respect, it may lead to the provision of dignified care (ibid.). Glasper et al. (2010) sees the family as central for a child's wellbeing because the attachment of family members offers support. This requires healthcare professionals to have an understanding of family-centred care and to have a positive attitude toward the family.

The term FCC has been used interchangeably with the term parental participation, although the latter implies that the parents are the primary carers and are central as partners in all care and decisions involving their child (Helen, 2000). The terms FCC and family-centred services (FCS) have also been used interchangeably to describe the involvement of the family. Mikkelsen and Frederiksen (2011) suggest a range of other alternative terms such as family-oriented, family-participant, parental involvement, and parental participation as synonyms for FCC. In addition, FCC is an approach to healthcare that shapes policies, programmes, and facilities and the day-to-day interactions of hospital staff (Staniszewska et al., 2012). It has been suggested that using the approach can lead to better treatment results, better allocation of resources and greater patient and family satisfaction (Patient and Family-Centered, 2013).

The involvement of parents in the care of their child has attracted much attention in literature about nursing. Casey (1995) argues that this collaboration can occur in one of four ways. He calls the first type of collaboration "Communication/nurse-centred permission" (p.1060). The nurse is the leader in childcare and judges the parents ability to collaborate. Some parents are then allowed to collaborate in some but not all aspects of the care and the nurse retains control by supervising them. In this way, the nurse has power and authority over the parents and permission to collaborate in care processes is given to some parents but not all. The second is the

“Non-communicating/ nurse-centred exclusion” (Casey 1995; p.1060). In this category the nurse views parents as strangers to the hospital. The nurse performs all the care and parents are expected to watch, observe and learn. The nurse avoids collaborating with parents, even if they have experience of caring for their child and the nurse’s uniform is seen as sign for their power. Casey (1995) argues that the uniform is also used as a way of avoiding discussions and engagement with parents, which makes the latter feel powerless. The third category is “Non-communicating/person-centred assumptions” and here assumptions are made about the collaboration. Many of the assumptions formed are false as little communication between nurses and families actually occurs. When communication does occur, the nurse uses medical jargon or professional language in an attempt to complicate and confuse parents which leads to the parents not collaborating in the care of their child because of a lack of knowledge. The final category is the “Communicating/person-centred negotiation” (Casey 1995; p.1060) approach. A negotiation between parents and nurses takes place before participation occurs. In this negotiation, parents explain their needs and the nurse listens and shares appropriate knowledge and expertise with them. Through this negotiation parents gain confidence and start to influence the medical and nursing practices.

2.1.1 Framework and Stages of Family-Centred Care

2.1.1.1 Frameworks

Frameworks of FCC have been developed by Shelton et al., (1987), the American Academy of Paediatrics (Committee on Hospital Care, 2003) and the Institute for Patient- and Family-Centered Care (IPFCC, 2013). The following discussion will examine the similarities and differences between these frameworks and it begins with a summary of the models (Table 1) which is followed by a critique.

Critique of the FCC models

The family as a constant

All frameworks see the family as an important factor in the child's life which means that healthcare professionals must consider the family and support it because family members are the first people who are able to care for a child in the hospital and after it is released. Based on their ability and needs, the parents are encouraged to take the lead in healthcare (Shelton et al., 1987; Committee on Hospital Care, 2003; IPFCC, 2011). The parents are the intermediaries between healthcare professionals and the ill child as they are the only people who see the child all the time. Therefore, they play the key role of the expert who can observe the child and make recommendations for healthcare services. The healthcare provider's role is to consider the parents' opinion and to collaborate with them on all levels of healthcare services.

Family strength and individuality

Shelton et al. (1987) and Committee on Hospital Care (2003) agree that families have individual characteristics and varying degrees of strength. However, an illness can influence the strength of a family and effect the functions and roles of its members, although they still have the potential to care for a child's basic needs. Family strength is recognised as an important feature of a family which enables them to participate in the care of an ill child, although this varies in each case. It is important to note that a family's strength is based on the information they possess and this information is necessary for clinical decision-making.

Table 1: Frameworks of family-centred care

Shelton et al. (1987, p1)	Committee on Hospital Care (2003; p692)	IPFCC (2013; pVI)
<ol style="list-style-type: none"> 1. Recognition that a family is the constant in a child's life 2. Facilitating of parent/professional collaboration at all levels of healthcare 3. Recognising families' strength and individuality and showing respect for different methods of coping 4. Sharing unbiased and complete information 5. Encouraging and facilitating of parent-to-parent support 6. Understanding and incorporating the developmental and emotional needs of children and their families into the healthcare delivery systems 7. Implementing of appropriate policies and programmes that are comprehensive and provide emotional and financial support to meet families' needs 8. Assuring that the design of healthcare delivery systems is flexible, accessible and responsive to family needs 	<ol style="list-style-type: none"> 1. Recognition that the family is a constant in the child's life, whereas service systems and Respecting each child and his or her family 2. Honouring racial, ethnic, cultural, and socioeconomic diversity and its effect on the family's experience and perception of care 3. Recognizing and building on the strengths of each child and family, even in difficult and challenging situations 4. Supporting and facilitating choice for the child and family about approaches to care and support 5. Ensuring flexibility in organizational policies, procedures, and provider practices so services can be tailored to the needs, beliefs, and cultural values of each child and family 6. Sharing honest and unbiased information with families on an ongoing basis and in ways they find useful and affirming 7. Providing and/or ensuring formal and informal support (eg, family-to-family support) for the child and parent(s) and/or guardian(s) during pregnancy, childbirth, infancy, childhood, adolescence, and young adulthood 8. Collaborating with families at all levels of health care, in the care of the individual child and in professional education, policy making, and program development 9. Empowering each child and family to discover their own strengths, build confidence, and make choices and decisions about their health 	<ol style="list-style-type: none"> 1. Respect and dignity: Healthcare practitioners listen to and honour patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care. 2. Information Sharing: Healthcare practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making. 3. Participation: Patients and families are encouraged and supported in participating in care and decision-making at the level they choose. 4. Collaboration: Patients and families are also included on an institution-wide basis. Healthcare leaders collaborate with patients and families in policy and program development, implementation, and evaluation, in healthcare facility design, and in professional education, as well as in the delivery of care.

IPFCC (2013) see this element as part of allowing a family to keep their dignity by respecting their preferences and choices, while the frameworks of Shelton et al. (1987) and Committee on Hospital Care's framework see it differently. They argue that it offers healthcare professionals flexibility in potential parental involvement in care.

Facilitating of parent/professional collaboration at all levels of healthcare

All frameworks recognise that collaboration is important in the healthcare system and that healthcare professionals need to tailor their practices, policies and programmes in order to collaborate with parents (Shelton et al., 1987; Committee on Hospital Care, 2003 and IPFCC, 2013). This element is based on the notion that the family plays a key role the care for a child, but that it is the healthcare professional who controls collaboration and makes all the decisions.

Shelton et al. (1987) recommend that collaboration between parents and professionals should occur on all levels and in all stages of healthcare. In contrast, IPFCC (2013) states that healthcare professionals should collaborate with patients and families in some areas only. These include policy and programme development, implementation, and evaluation, healthcare facility design, professional education, as well as the delivery of care. They should also include the evaluation of patient and family knowledge, values, beliefs and cultural backgrounds. For the Committee on Hospital Care (2003) collaboration is at the organisational level of care rather than at the individual level, which is how Shelton et al. (1987) define it. All three frameworks offer the potential to measure the interaction between nurses and parents and other family members to gauge the level of collaboration.

Communication and information sharing

The ultimate goal of all frameworks in information sharing is to achieve a number of outcomes, such as improved quality of life, greater patient satisfaction, and increased safety in the context of a mutually beneficial partnership (Shelton et al., 1987; Committee on Hospital Care, 2003 and IPFCC, 2013). The sharing of information has been recommended in all three frameworks. It consists of unbiased, complete information and

knowledge and is important because it enables parents to undertake self-care independently (Shelton et al., 1987). It is important that every procedure and practice is explained and medical terminology needs to be modified to make sense to a layperson. Simple language allows parents and children to communicate with professionals. The Committee on Hospital Care (2003) recommends that relevant information related to a variety of issues, like medical information, resources, support groups and the effects of treatments, should be provided. IPFCC (2013), on the other hand, calls for complete and accurate information in order to enable parents to make decisions. It also suggests that parents should receive timely, complete and accurate information in order to effectively participate in the care and decision-making process (IPFCC, 2013). These choices might include culturally distinct or nonconventional options for treatment, sometimes referred to as complementary and alternative medicine.

All frameworks agree that information sharing is often underestimated by nurses. If parents are forced to share more information than they are comfortable with, they might refuse to participate in the information sharing process in general. All frameworks agree that providing information is the foundation of FCC. However, they are aware that this process can be influenced by a family's strength, power dynamics and techniques used by healthcare professionals.

Peer-to-peer support

This element highlights the importance of non-medical support for families and that the power of mutual support can compensate for a lack of support from healthcare professionals. Peer-to-peer support can also reduce the gap between healthcare providers and families concerning information and health literacy. Shelton et al. (1987) state that the sense of isolation can be reduced by talking to another family and this support is invaluable. Peer-to-peer support can contribute to the psychosocial well-being of the child and other family members, can lead to an exchange of individual perspectives on treatment and can lead to a discussion about innovative ideas and alternative treatments. Experienced families are able to support other parents with the burden of treatments (Shelton et al 1987).

Two frameworks, Shelton et al. (1978) and the Committee on Hospital Care (2003) regard peer support as crucial elements of the process of care. It

can be either formal in form of group meetings at regular times or informal with parents meeting on different occasions. The IPFCC (2013) does not include peer support in their framework and does not offer an explanation for this omission.

Flexibility of policy and practice

Two frameworks (Shelton et al., 1987 and Committee on Hospital Care, 2003) highlight the importance of flexibility of healthcare policies and practices, although there are differences in how this element feature within the frameworks. Healthcare policies should be dynamic and flexible on an individual level and services should provide care for the whole family and not just the individual child.

Shelton et al. (1987) expect the family to collaborate in policy making so as to ensure flexibility and effectiveness and that healthcare programmes are comprehensive. This ensures that a family's needs are met and should include emotional and financial support. The Committee on Hospital Care (2003) agrees that organisational policies, procedures and practices can be flexible and responsive to families' physical and psychological needs, background and ability on an individual basis and can vary over the span of an illness trajectory. Shelton et al. (1987) and the Committee on Hospital Care (2003) express the necessity to understand the child's needs and the healthcare professional should, therefore, integrate the developmental needs of infants, children, and adolescents and their families into healthcare delivery systems. The IPFCC (2013) offers patients and families the option to collaborate in the design of healthcare facilities, such as policy and programme development.

Respect and dignity

Despite the fact that IPFCC's (2013) principles include only four elements, it recommends that healthcare professionals should respect the child and its family's perspectives and choices. This element also appears in the principles of the Committee on Hospital Care (2003) and Shelton et al. (1987) who suggest that the child and family should be taken into consideration at all times. The family's needs are considered if a healthcare professional listens to and respects the child's and its family's perspectives and choices. All frameworks explain that respect and dignity

is maintained when a family's knowledge, values, beliefs and cultural background are incorporated into the planning and delivering of care.

Implementing programme development and addressing financial and emotional needs

This element focuses on the implementation of programmes that incorporate the developmental and emotional needs of the entire age-range of children and their families in the healthcare system (Shelton et al., 1987; Committee on Hospital Care, 2003). This implementation is achieved on an organisational policy level as well as on the individual level by acknowledging socio-economic issues. It requires that all healthcare professionals work collaboratively to interpret a child's behaviour in order to understand its development. Parents should also be actively encouraged to participate in facilitating a child's social and emotional development (Shelton et al., 1987), while healthcare staff can facilitate and promote the development and emotional state of children.

IPFCC (2013) does not discuss financial and emotional support and again there is no explanation. It does, however, offer the family to collaborate in the development of the educational programme for professionals.

Staff emotional support

The Committee on Hospital Care (2003) model was conceptually based on all of the elements of family-centred care identified by Shelton et al., (1987) and added emotional support for staff in order for family-centred care to be practiced effectively, resulting in nine elements of family-centred care. The emotional needs should be met by providing staff development policies and programmes that are comprehensive and which include the provision of emotional support to meet their needs. IPFCC (2013) and Shelton et al. (1987) do not include this element in their frameworks.

In conclusion, the framework of Shelton et al. (1987) is the original one and its principles are comprehensive and aim to meet the needs of children and their families. Comparing the core concept in Shelton et al. (1987) with the Committee on Hospital Care (2003) shows that the fundamental aspects of the framework are similar although they have been organised differently. Shelton et al.'s (1987) and the IPFCC's (2013) frameworks are based on

the understanding that children and their families are central for the health and well-being of people of all ages. Patients and their families are not passive consumers of healthcare services but should have their preferences, needs, and values integrated into their care. Their unique cultural backgrounds, motivations, knowledge, attitudes, experiences, and other strengths are key factors that drive decision making in the Shelton et al. (1987) and Committee on Hospital Care (2003) frameworks. Consequently, healthcare and healthcare programmes are not solely influenced by healthcare experts but by children and families who are empowered in a dignified and respectful manner to participate at the level that best meets their abilities and preferences. The family is a potential member of the care team who can collaborate to provide comprehensive care for children and families should be at the centre of every care decision. FCC is an approach to planning, delivering and evaluating healthcare and children and families are encouraged to collaborate with service providers while a family's ability is taken into account.

The foundation of FCC in Table 1 compares the core concepts of each framework and two of them focus on paediatric care (Shelton et al., 1987 and Committee on Hospital Care, 2003) while the IPFCC (2013) propose a framework for all age ranges. The framework of Shelton et al. (1987) is more comprehensive as it is more detailed and includes the economic aspects of care and the suggestion that healthcare practices should be evaluated for their effectiveness.

2.1.1.2 Stages of family-centredness

One of the major issues that arises in organisations that intend to adopt FCC is a lack of guidelines on its implementation and the nature of parent centeredness. In an attempt to address the second issue, Hutchfield (1999) extended the understanding of FCC by categorizing the practice into 4 sequential stages: parental involvement, parental participation, partnership with parents and family-centred care. Each stage determines the degree of cooperation between healthcare professionals and parents and the first stage is often considered as the beginning of the implementation of FCC. The following discussion will explore each of the stages.

Parental Involvement

Hutchfield (1999) explains that this early stage involves the development of a relationship between nurses and parents and the primary interaction between parents and child is often led by nurses. These interactions can occur either verbally or in writing so as to encourage parental involvement that recognises their individuality (Foster et al., 2010). Smith (2010) suggests that a process of negotiation is needed to develop a family's confidence in their ability to manage care. The nurse encourages the parents to participate by teaching them what they need to do in order to care for their child. Individuality is important when families negotiate and make decisions and it influences their ability to provide care (Green, 2008). Negotiations can help parents and nurses identify their needs and consider the views of each party, which leads to effective decision making for the child. Levenstein et al. (1986) point out that negotiations can lead to a change from a medically dominated model of care to one which values the contribution and involvement of the patient.

Parental Participation

Hutchfield (1999) defines parental participation as a collaboration between healthcare professionals and the parents. The latter's role at this stage is as a co-worker in the care for their child, undertaking nursing actions. Kemp (1998) suggests that parental participation can only occur after negotiations and decision-making in healthcare services have taken place so as to create confidence in the family. It is important to note that parental participation is voluntary although it is encouraged. Corlett and Twycross (2006) provide examples of a number of parents who wanted to participate in their child's care but were unable to do so.

In this stage, negotiation and communication are recognised as the basis of involvement in child care. Tyler and Horner (2008) explain that these negotiations continue to be determined by the healthcare providers. The negotiating process incorporates principles from well-established approaches about how to work with individuals. Green (2008) suggest that collaboration on every level of care can empower the family and strengthen it and communication between parents and nurses is essential to improve the quality of care. Law et al. (2005) state that effective communication is

an essential skill for a family-centred approach and that healthcare professionals have to learn and practice it. Communication skills allow them to listen effectively, monitor communication, build warm relationships, and support parents in an effective way (ibid.).

Therefore, it is important that nurses encourage parents to take part in the care process by using simplified medical terms to communicate so that they can be understood (Campbell and Glasper, 1995; Espezel and Canam, 2003). Doctors and nurses often use technical terms to communicate with each other but parents and children may not understand them (Wigert et al., 2008; Espezel and Canam, 2003) which leads to lower levels of participation from parents. Healthcare staff need to understand this effect and have adjusted their language to help parents to participate and to support their child. Frustrations with language barriers can create ineffective communication (Gance-Cleveland, 2006; Picton, 1995; Higman and Shaw, 2008).

Partnership with Parents

Hutchfield (1999) explains that the main element of this stage is the acknowledgement that parents are equal to nurses as care-givers because they are also knowledgeable and skilful. Collaboration with the family can reduce the stress levels of parents and give them the strength to care for their child (McCubbin et al., 1983; Kemp, 1998). Gilson (2003) explains that the provision of FCC requires both the family and nurse to recognise the importance of communication for the development of a relationship of trust. Trust is a decisive factor in the successful delivery of care for children (ibid.). Wigert et al. (2008) point out that partnership is an important function within FCC's objective and they give the example of providing parents with their own space in a critical care unit to allow them to feed their child undisturbed.

Family-Centred Care

The high level of co-operation that Hutchfield (1999) identifies in the relationship between nurses and parents at this stage consists of mutual respect and involves several family members. At this stage instead of nurses or service providers, parents will lead the care for their child and are

considered the experts in all aspects of this care. Law et al. (2003) agree that a positive outcome can be achieved by improving the relationship with others by negotiating effectively.

The nurses' role is that of a consultant or counsellor, while the parents have an extensive knowledge of a child's illness and also acknowledge the importance of treatment for their child. This stage can be referred to as parents' nursing because the technical skills of parents are respected and the communication at this stage usually revolves around policy making for the care of their child.

2.1.2 The role of the family and nurse in family-centred care

Role of family in family-centred care

It is important that parents understand the nature of family-centred care and have a positive attitude about participating in the care of their child. Palmer (1993) suggests that a parent can be a comforter and supporter and can also offer emotional support to their child when medical treatment is taking place. Dokken and Ahmann (2006) highlight the parents' role in family-centred care and argue that it is operating on several levels. Mitchell and Chaboyer (2010) also suggest that family involvement is closely linked to the nurses' support and the parents' role can be summarised as the following:

- 1) Readiness to assume; parents are ready to embrace new opportunities or a change in role; they should be flexible and adaptable when a child is ill
- 2) Support of healthcare professionals; parents collaborate in care of their children when they are encouraged to do so
- 3) Interaction with other families; it serves as an exchange of experiences and can lead to greater knowledge of child care
- 4) Identification of roles that best matches their interest, background and skill; parents may be keen to participate in the care but the level of their involvement depends on their knowledge and experience

- 5) Growing conviction of their ability to contribute to the care of their child in a holistic way
- 6) Negotiation in practice to agree on the level of parental participation, with a sharing of power and control

Nurse's role in Family-centred care

The nurses' role in their work with chronically ill patients consists of two parts: to promote the psychosocial adaptation and to promote the optimal potential for growth and development (Stevens, 1989). By promoting psychosocial adaptation, nurses support the families in gaining confidence and accepting the illness in order to overcome feelings of hopelessness, discomfort, frustration, powerlessness and incompetence (ibid.).

In the USA, the nurse's role in the treatment of chronic illnesses focuses on education, being a resource and providing care during exacerbations of the disease (Wood and Bolyard, 2011). Interventions to improve outcomes of care in children may be more successful if the individual health literacy needs of parents or guardians are considered and addressed. Although patients with a chronic illness may be familiar with its symptoms and care practices, they will need to be educated in how to cope with it. Education can be a tool to encourage parents to enhance their ability for self-care. In addition, delivering education based on a clear approach is necessary to reduce the risk of low health literacy patients, so that the role of educator is important for a nurse (ibid.). The resources that a nurse possesses can help patients with lower health literacy levels to be more in control and to develop self-efficacy in managing the disease. The nurse's role can be complementary and they can undertake the mother's role if parents are unable to care for their child (Tedford and Price, 2011). They can also strengthen the bond between a parent and a child (Cockcroft, 2012) by recognising that the family is important (Robertson and Robertson, 1989).

This section has presented the key features of FCC and its role in the care of a child and the following section will examine the literature on the topic.

2.2 Literature search and review

The purpose of the literature search was to locate publications related to family-centred care and while this search was initially aimed at retrieving publications that only related to family-centred care of child patients, papers from other areas of care were later included. I initially used the terms “family centred” or “family centered” in several electronic databases, such as University MetaLib, CINHALL, Cochrane, MEDLINE (EBSCO), MEDLINE (Ovid), MEDLINE (PubMed), Wisely Library and ThaiLIS. I also conducted a manual search of literature published after 1987 as this was the year in which the family-centred care framework was launched.

The initial search identified a large number of publications: over 312,065 papers were associated with family-centred care and family-centred care in nursing. In order to narrow down the focus of the retrieval process, I developed inclusion/exclusion criteria (Table 2):

Table 2: Inclusion and Exclusion Criteria for a preliminary literature search

Inclusion criteria	Exclusion criteria	Rationale
Full text research articles, dissertations or theses	Books, reports, conference papers, abstracts as well as review articles.	Obtain primary research about family-centred care
Texts relating to children with a chronic illness	Texts relating to children in other settings, e.g. emergencies, maternal care, etc.	Chronic illness is the focus of this study
Studies published in English or Thai	Studies published in other languages	Establish the extent of research evidence in international and Thai literature; also no funds were available for translations of texts in other languages
Studies conducted in a health care unit	Studies conducted in social care or educational settings	This study is related to healthcare and not

		social care or education.
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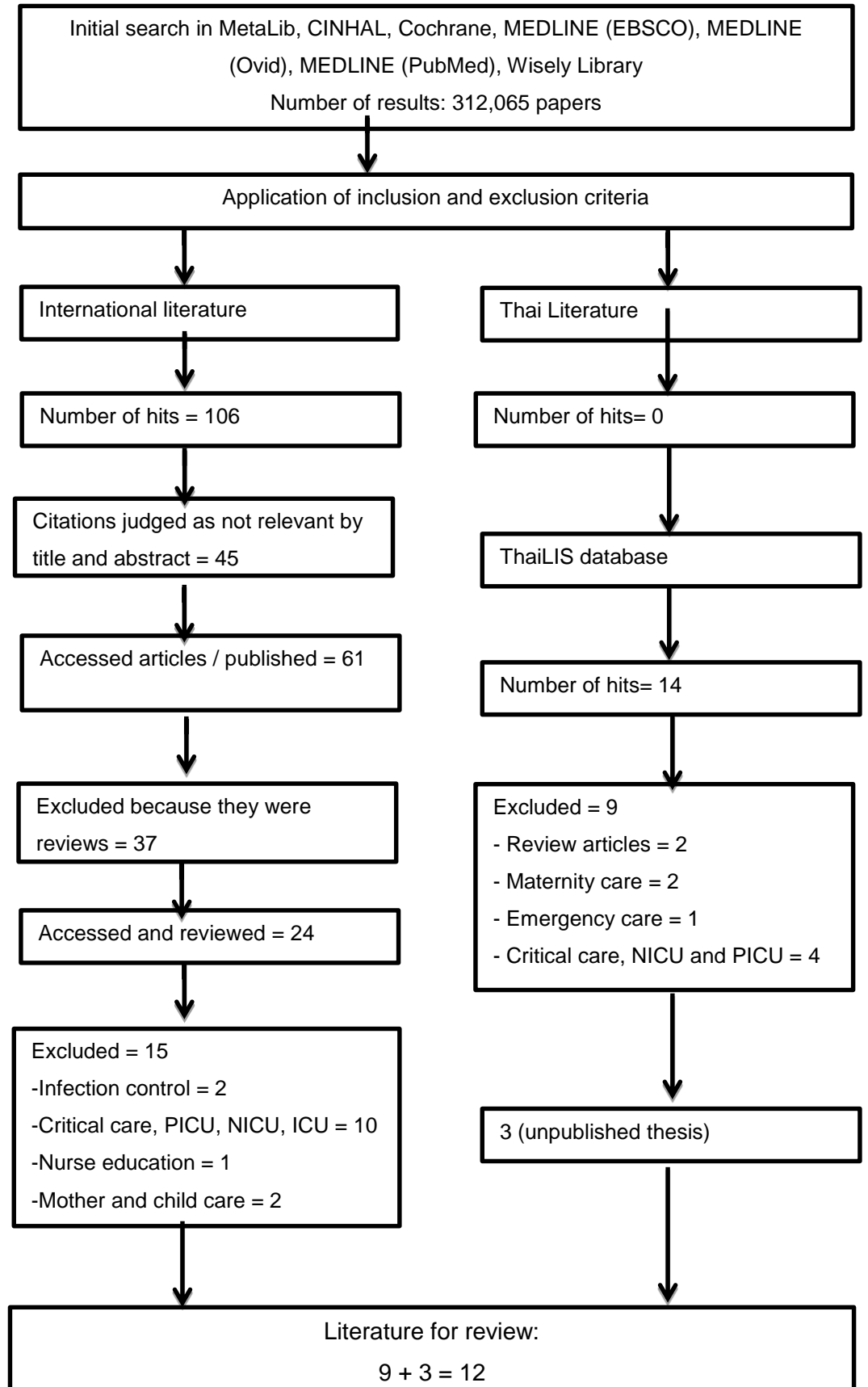
The use of the inclusion and exclusion criteria resulted in 106 articles and the next step was to narrow them further by applying the following criteria:

- (a) the research must be related to nursing practice in child care;
- (b) it must have been conducted in relation to chronic and/or long term illnesses;
- (c) studies have to be based in a hospital setting.

This resulted in 9 articles (Figure 3) which form a part of this literature review. In addition, Thai literature was reviewed so as to obtain perspectives from Thailand in order to compare them with the international literature. I found 3 theses that fulfilled the criteria and retrieved them. In order to form a comprehensive review, I read the 9 international publications and 3 Thai theses, analysed, and critiqued them in terms of their methodological and thematical strengths and weaknesses and grouped them into themes.

Table in appendix 14 shows an overview of the selected articles and theses, presenting their area of study, methods used to collect and analyse data, sampling, key findings, and their limitations.

Figure 3 Search strategies for family-centred care with children



2.2.1 Themes present in the reviewed literature

This literature review has brought together a diverse range of peer-reviewed articles with a great variation in approach, participants, aims and objectives. Nevertheless, there was a clear convergence across all articles. Despite their differences in approach and purpose, they all tended to capture a spirit of family-centred care, although from a variety of angles and using a multitude of methodologies (see Appendix 14).

Qualitative material was derived from interviews, free-answer questions of surveys and an action research project. The quantitative studies normally used validated and well established methods. They were the MPOCH-20 (Measure for Processes of Care, King et al., 2004) in the studies by Dix et al. (2009) and Moore et al. (2009), the FCCQ-R (Family-Centered Care Questionnaire-Reviewed, Bruce and Ritchie, 1997) in the publications by Coyne et al. (2011), Sagnatesawang (2008), Bruce et al. (2002) and the IPFCC (FCC Neonatal Intensive Care Unit Assessment Inventory) by Neal et al (2007). Self-designed, non-validated questionnaires were used by Dokkularb (2006) with 100 parents, by Hughes (2007) with 43 mothers and 28 nurses. These and most other surveys were predominantly descriptive in their analytical approach, with only Dix et al. (2009) and Moore et al. (2009) providing p-values for their results (all $p < 0.01$). No quantitative study provided a sample calculation. However, as the studies reported on local situations and issues without making any claims of generalisability, this does not represent a major deficiency.

Theme 1: Family-centred care is well understood and accepted

The most notable result of the studies was a good understanding and acceptance of family-centred care, including its principles and demands, by healthcare professionals and families. This was combined throughout all articles reviewed with a clear acceptance of these principles and with a positive attitude towards its practice.

These viewpoints were frequently expressed directly. For example, in Bruce et al. (2002, p.418) healthcare professionals asserted that all elements of family-centred care were 'necessary for FCC' (see also Attharos et al., 2003). Or by Hughes (2007), who found that parents ($n=100$) and nurses ($n=44$) agreed that parents should be permitted to carry out the majority of care for their child, but also care for

themselves in addition to the sick child. At times the language used was very assertive, placing parents as the 'experts, not supporters' concerning their child and as the constant in their child's life (Coyne et al., 2011, p.2566; MacKay and Gregory 2011). The most comprehensive description of family-centred care was outlined by in-depth interviews with eight children undertaken by Kennedy (2011). The children defined the components of 'their' care in terms that differ to those used by adults and that focus on themselves rather than the family:

- My best interests
- Virtues
- Talking and listening
- Being involved
- Knowing
- Making decisions
- Being connected

However, in terms of meaning, they do overlap remarkably with the established components of family-centred care.

In other publications the understanding of family-centred care was measured, either in addition to the free descriptions or on its own. This occurred with larger samples of participants (up to n=483 [Bruce et al., 2002]) and predominantly with healthcare professionals, especially nurses. The strength of the quantitative study was that it highlighted the fact that healthcare professionals are at times unable to carry over their high regard for family-centred care into practice, with both nurses and parents lamenting the problems they faced when they attempted to implement FCC fully (Hughes, 2007; Neal et al., 2007) and with family-health professional collaboration being the least important aspect of care practices (Bruce et al., 2002).

Theme 2: Challenges to its implementation

Despite this overwhelming approval, the family-centred approach to care did face great challenges that made its implementation difficult (Bruce et al., 2002; Hughes, 2007).

Overwhelmingly, the publications reported about the care of often very ill children, including those with cancer or acute trauma, with both acute and chronic health problems (Attharos et al., 2003; Sagnatesawang, 2008; Moore et al., 2009, MacKay and Gregory, 2011; Uhl et al., 2013, Dix et al., 2009). In these situations the severity and acuity of their diagnoses and/or illness provided severe challenges to the

implementation and practice of FCC. The challenge was two-fold. Firstly, some children needed technical care procedures, even during processes that are normally part of self-care administered by parents, making it necessary for nurses to become more involved or take over completely. Secondly, an increasing criticality of the child's condition augmented emotional demands on the parents. Their focus shifted to the child's survival and well-being and reduced their ability or willingness to play an active, even leading, role in decision-making. However, it was possible to implement aspects family-centred care in areas of complex care (for example oncology, see MacKay and Gregory, 2011) and Moore et al. (2009) highlighted that in these situations even incompletely implemented family-centred care significantly improved the perception of quality of life overall.

Recognising the need of children not to be separated from their parents, families of hospitalised children are meant to be allowed to stay together all day (Hughes, 2007). To support this aim appropriately the departmental environment with all the facilities it provides must be suitable not just for the children but also for their parents, for example by providing kitchen and rest facilities for parents (Coyne et al., 2011). However, nurses frequently highlighted shortcomings in this area, including unsuitable ward environments that were 'congested' or 'noisy' and lacked 'private spaces' (Neal et al., 2007; Uhl et al., 2013). Furthermore, nurses represent an important part of the care environment for the children and their parents. In one study (Hughes, 2007) parents lamented that they believed the nurses were too busy to attend to their children and they, therefore, felt unable to leave them in the nurses' sole care.

The provision of a suitable care environment and sufficient staffing levels is also linked to hospital policies, which have to be supportive to the implementation of family-centred care. However, they were not always reported to be sufficiently supportive, especially when developed without input from parents (Bruce et al., 2002). This can include comparatively minor measures that nevertheless have a great impact on families, such as actions to reduce the cost for families of staying with their child in hospital (i.e. parking charges or meals) (Hughes, 2007). For those children in a less critical state family-centred care normally takes place at home. However, healthcare delivery systems frequently do not take this into account and lack an acceptable ambulatory care provision, especially on evenings and weekends (Bruce et al., 2002).

Finally, the overall very strong picture of nurses supporting family-centred care was put into perspective by two Thai contributions (Attharos 2003; Sangnatesawang 2008). They considered nurses, and especially younger, less experienced nurses, who were not sufficiently aware what family-centred care actually is and how it is to be put into practice, to be obstacles to its implementation.

Theme 3: the parental role within family-centred care

Recognising the importance of the parents to the child as well as their need to fulfil their role as parents led to the premise in family-centred care that parents should be permitted to carry out most of the care. Here nurses only take over when the parents do not wish to do so or do not have enough skills. This was expressed clearly by the participants in Bruce et al.'s study (2002). However, from this simple statement arise a number of issues.

If the parents are to be involved completely and actively in the planning and delivery of family-centred care, and so fulfil a condition for delivering high quality care (Coyne et al., 2011), they need to be clear about what exactly their role is and what healthcare professionals expect of them (Bruce et al., 2002; Hughes, 2007; Kennedy, 2011; Uhl et al., 2013). The importance of knowing this was recognised by Attharos (2003) who devoted a whole cycle of his Action Research project to the promotion of mutual understanding of the model and the roles it attributes to parents. The child participants in Kennedy's study (2011) also recognised this and demanded that nurses and families get training to work as a team. However, the need to tailor the role of parents and the care they are to provide each time on an individual level represents a major difficulty in the delivery of family-centred care. It demands from healthcare professionals that, instead of dictating or controlling the working relationship with the family, they collaborate closely and work with great flexibility and adaptability to support and enable, even empower the families (MacKay and Gregory 2011; Dokkularb 2006; Coyne et al., 2011). Conversely, if there is a lack in nurse-parent collaboration (Bruce et al., 2002), the close nurse-patient-family relationship required for family-centred care (MacKay and Gregory, 2011) can become unachievable.

Theme 4: Information-sharing and collaboration

Information sharing was identified as a core aspect of working in partnership and of family-centred care. Parents can be expected to initially lack the knowledge needed to co-operate efficiently with healthcare professionals. If they can acquire the relevant knowledge and experience, they can influence their child's assessment and become truly involved in the negotiation and delivery of care (Coyne et al., 2011). To achieve all this, healthcare professionals require good verbal and non-verbal, and even written communication and teaching skills (Hughes, 2007; Sagnatesawang, 2008; Dix et al., 2009; Coyne et al., 2011; Uhl et al., 2013), and if they possess them information sharing is possible even if there is a lack of privacy (Neal et al., 2007). A less obvious but equally important pre-condition for successful information sharing is 'mutual learning', i.e. learning from each other. This is asserted by Attharos (2003), who outlines that rather than just provide information, nurses need to listen to and learn from the children and families in order to be able to provide care suitable for each individual patient. The parents in Attharos' Action Research study not only welcomed this approach, but reported an improved ability to fulfil their part in family-centred care. The need for an individually titrated information flow has been asserted by Dix et al. (2009) and Uhl et al. (2013), with the latter noting that although the family was allowed to be present and involved during doctors' ward rounds and nurses' handovers can be an efficient way of providing information to families, not all parents want this in-depth information and involvement.

Parent-professional collaboration as demanded by family-centred care surpasses sharing information and carrying out care. It includes the assessment of the child and most of all the setting of individualised goals and planning of care, according to the child's needs. Despite being recognised as an essential part of family-centred care, this remains the one aspect that is least consistently practiced (Bruce et al., 2002; Attharos et al., 2003). In an ideal world nurses as well as the families would be offered training to work as a team (Kennedy, 2011). In reality offering this kind of training remains unrealistic, bearing in mind the limited time frame (especially in the case of an acute illness) in which this training could take place. Moreover, parents of severely ill children in hospital frequently report feeling confused and anxious (Uhl et al., 2013).

Beyond caring for their child, the collaboration of parents with healthcare professionals and their involvement in the care can make the parents feel

empowered. It can also contribute to their own well-being (Sagnatesawang 2008; MacKay and Gregory 2011; Kennedy 2011; Uhl et al., 2013).

Theme 5: caring for the parents

Nurses are constantly reminded that parents in hospital frequently report feeling confused and anxious, especially if their children suffer from acute illnesses (Uhl et al., 2013). In the opinion of nurses, they therefore need 'looking after' as part of family-centred care (Hughes, 2007, p.2345). This does include considering the parents' physical needs by providing them with an appropriate environment as well as caring for their (individually varying) information needs (see above). What is appropriate does also vary according to the families' individual and ethnic culture. Lacking an understanding of their cultural background easily leads to misunderstandings and tensions between the families and healthcare professionals and the required respect and trust will not develop (Attharos et al., 2003; MacKay and Gregory, 2011; Kennedy, 2011).

Reducing the areas of concern for the parents also has to be considered. Allowing them to focus on their child as their core concern, helps parents to play their role in family-centred care. This can be achieved by implementing a family-friendly visiting policy that provides flexibility and allows parents to manage the outside parts of their families' lives (Hughes, 2007) or by providing financial support in the form of free car parking or allowing parents access to meals at a reduced price (Coyne et al., 2011). But even then the emotional burden remains heavy and so nurses asserted that providing psychological support for parents is an important component of family-centred care (Attharos, 2003; Coyne et al., 2011). All of these factors are especially difficult to achieve for single parents without family support (Sagnatesawang, 2008).

Theme 6: Barriers to FCC within and among healthcare professionals

Despite the widespread acceptance of the approach to care, healthcare professionals still have to overcome significant barriers in order to fully implement family-centred care. In order to enable and even enhance the delivery of family-centred care, ensuring the nurses' knowledge about this different approach to care is of great importance (Attharos, 2003; Sagnatesawang, 2008; MacKay and Gregory, 2011; Kennedy, 2011; Coyne et al., 2011). Relevant training for healthcare professionals needs to go beyond the delivery of facts and theory, and has to

enable nurses to be efficient team workers within the nursing team and beyond, encompassing all health and social care workers as well as the families (MacKay and Gregory, 2011; Coyne et al., 2011). It is also important that nurses are able to focus on patients and involve parents, rather than just follow treatment protocols (Attharos, 2003). This requires flexibility, the ability to change, the willingness to compromise and an openness for negotiation (MacKay and Gregory, 2011). Instead of dictating or controlling the working relationship with the family, close collaboration is needed in order to be able to tailor care (ibid.). Finally, using a family-centred approach for the delivery of care does require healthcare professionals to take time to 'talk and listen' (MacKay and Gregory, 2011; Kennedy, 2011) and so staffing levels must be sufficiently high (Coyne et al., 2011) as parents might otherwise feel that they have to stay with their child because the nurse is too 'busy' (Hughes, 2007).

2.3 Summary and limitations of the reviewed literature

Having reviewed the literature in the sections above, this section provides a summary of the key findings from the studies and then points out their limitations. MacKay and Gregory (2011), and Kennedy (2011) found similar perceptions of partnership between parents and health-care providers. Dokkularb (2006) and Moore et al. (2009) noted the eagerness of parents to participate in childcare. International studies found different factors that influenced FCC: hospital policy, setting, knowledge and attitude of the nurse, the child's stage of development, the stage of the illness, severity of the child's illness, and the family's coping mechanisms. Kennedy's study was one of few that focused on psychological support which is one of the elements of FCC (Shelton et al., 1987). Both healthcare professionals and parents had a positive view of FCC and felt that it could be of benefit to the care and wellbeing of children. Although some parents were already involved in the care of their child, they wished to increase their involvement. In addition, the use of FCC as an approach led to positive and strong relationships between healthcare professionals and parents and the concept of collaborative care was welcomed by both groups and the patients. However, both staff and parents expressed concerns and reservations regarding the implementation of FCC and its continued use. Some of these concerns were related to the lack of support from healthcare systems and hospital policies. Others

included the financial cost, the facilities for parents, and the health status of children, which if it deteriorates can form a barrier for collaboration.

The literature discussed here has a number of limitations and the first one relates to the FCC framework. According to the literature reviewed in the first section of this chapter, there are several frameworks for FCC and each has its own principles. However, it would appear that none of the studies reviewed examined the entirety of a framework as they excluded some principles. This means that there is limited literature on the use of the complete FCC framework.

Secondly, none of the studies that were reviewed took into consideration the contextual factors of the healthcare unit that can influence healthcare professionals and their practice. As was noted by Sangnatesawang (2008), FCC practice and perceptions of it depend on a number of factors, such as age, experiences, position, type of paediatric wards, etc. These contextual factors can be on a micro level, operating on the level of the institution, or on a macro level, operating on the societal level. A lack of acknowledgement of these contextual factors creates the impression that healthcare units function in a vacuum, without any external factors impinging on them.

Thirdly, although FCC has had a long international history, and studies of child care were conducted in the USA, Canada, and Europe, there have been no studies published on the use of FCC in Thailand. The three Thai texts reviewed in this chapter were theses, which were undertaken for educational purposes rather than to examine and / or improve practices. It should also be noted that these three theses have not been subjected to independent review as journal papers, which was the case with the other literature.

Fourthly, although the perception and practice of FCC has been examined, there are no clear and explicit guidelines on how FCC should be implemented. Neither Bruce et al. (2002), Neal et al. (2007), Kennedy (2011), nor Coyne et al. (2011) offer any suggestions on how FCC should be used. A lack of such guidelines means that the implementation of FCC can be haphazard and the models used might vary as organisations have to develop their own model by adjusting the original framework to suit their particular circumstances. It is interesting to note that the only study (Attharos, 2003) that examined the implementation of FCC was conducted in

Thailand and because it used an action research approach, the generalisability of this study is low.

Although the children who participated in the studies had a variety of diseases, none of them suffered from thalassaemia, which means that the appropriateness of the FCC framework for the care of children with thalassaemia has not been studied. Another limitation is that many researchers, e.g. Neal et al. (2007), Dokkularb (2006) and Sangnatesawang (2008), adopted the survey method as a research design using questionnaires that had closed questions, which, although they lead to a high level of reliability, do not allow participants to elaborate or expand on their responses. The responses obtained from questionnaires can also be contentious because participants might want to provide socially acceptable answers, i.e. answers they believe researchers would want to hear (Robson, 2002),

Regarding the sampling, many of the studies only recruited certain groups or individuals to participate and it is questionable how much the participants knew about FCC and systems of care. In addition, some studies, e.g. Neal et al. (2007), Hughes (2007), Attharos (2003), etc., only explored the perspectives of one group: nurses or family members but not both. The sample sizes and low response rates in some studies, e.g. Bruce et al. (2002), Hughes (2007), Neal (2007), also limit the quality of the studies.

Finally and interestingly, not all researchers acknowledged the limitations of their studies and this raises the question of whether they recognised the complexity of studying the use of FCC in the care of children.

Having reviewed the literature, it is evident that further research is needed. The retrieved papers were limited as the majority were conducted with the aim to research the quality of life, the level of participation and the effectiveness of this kind of care. The characteristics of family-centred care and the factors that influence it have not been studied. Family-centeredness in healthcare is a new approach in Thailand and studying the characteristics of FCC in Thailand and the factors that shape it adds to the body of literature, contributes to the expansion of knowledge in the field and can contribute to the improvement of the Thai healthcare system.

2.4 Justification for conducting this study

Thalassaemia is the most common genetic disease in Thailand and following the Health for All Policy healthcare services have changed in Thailand. In addition, care services have been modified to manage the lifelong effects of thalassaemia, taking the input of several healthcare professionals, including nurses working collaboratively in different units in the thalassaemia clinic, into account. These services are comprehensive and include screening, detecting, initial treatment as well as health education. The effectiveness of thalassaemia care is difficult to ascertain because a child suffering from the illness has anaemia that needs to be managed constantly. As a result, the life-style of a child and its family needs to be continually adapted.

Collaboration in child care is required as the family has a heavy responsibility for a child with thalassaemia. Given the evidence cited in this chapter, it is important to recognize the numerous barriers and limitations that nurses and other professionals experience when they provide children and their families with individualised care that focuses on their emotional needs as much as physical problems. Several of the studies examined in this literature review have revealed important insights into the value of family-centred care in relation to the care, period of hospitalisation, healthcare systems and mental well-being of children and family members. However,

- there are no studies in the application of family-centred care in thalassaemia care, neither internationally nor in Thailand;
- there has been no research into how children have been cared for in thalassaemia clinics in Thailand;
- the evidence from previous studies is limited due to the research design, as many researchers chose quantitative approaches to collect quantitative data;
- the literature review identified that there is currently very limited qualitative research of thalassaemia care;
- it also highlighted that there is only a limited amount of literature on the use of family-centred care in a hospital setting in Thailand.

For all these reasons, researching healthcare staff and parents' experiences of thalassaemia care in the hospital environment can help to illustrate the potential of

FCC and to offer suggestions for nurses for how to improve the care of ill children. Nurses play an important role in the care of sick children and the principles of family-centred care are well-established and practiced in different parts of the world. This study will explore the characteristics of family-centred care and the factors that influence family-centred approaches in a thalassaemia clinic in the Thai socio-cultural context. The purpose of this research is to provide qualitative findings that can help nurses and other healthcare professionals understand and apply family-centeredness for children diagnosed with thalassaemia and their families.

Therefore, the study aimed to answer one research question:

What are the characteristics of family-centred care in Thailand?

It also explored two secondary research objectives:

Does the Western concept of family-centred care occur in Thailand?

What factors influence the practice of family-centred care in Thailand?

Chapter 3

Research Methodology

This chapter focusses on the research methodology and methods used to explore and analyse the current state of nursing care for children with thalassaemia and the use of family-centred care in Northern Thailand. Taking into account the research questions presented in the previous chapter, this chapter will discuss why a qualitative research design and methodology were deemed appropriate to answer the questions. The case study approach, data collection methods, data analysis approach as well as the measures used to ensure trustworthiness will be explained, before the chapter concludes with a discussion of the underlying ethical principles and the procedures used.

3.1 Research design and methodology

A research design is a description of the process that connects the research question to the data collection methods, the findings and conclusions (Maxwell, 2005). According to Uys and Basson (1985), a research design can be interpreted in two ways as either the total strategy for a study or as the structural framework. The total strategy refers to decisions related to the identification of the research problem/question, methodology and data collection methods, while the structural framework refers to the blueprint of a study and guides the researcher in planning and implementing it. Optimal control is achieved through influencing factors (ibid.).

Patton (2002) suggests that a research methodology is a systematic approach to studying an issue. Patton offers the construction of research following the planning, structuring and the execution of research with an emphasis on the actual research process. This requires the researcher to consider one of three specific methodological models: a quantitative methodology, which is more prominent in the natural sciences, a qualitative methodology, which features strongly in human sciences, or a mixture of these two methods (Uys and Basson, 1985). These approaches can be categorised into positivist and naturalistic paradigms (Polit and Beck, 2003). The resulting alignment of quantitative research with

positivism and qualitative research with interpretivism has led to a great deal of debate over whether it is possible or desirable to mix methodologies within the same study (Creswell, 2003). Mixed methods research uses a combination of quantitative and qualitative methods, approaches and concepts in a single research study (Creswell, 2003; Polit and Beck, 2010). It employs strategies of inquiry that involve collecting data either simultaneously or sequentially to best understand research problems. This approach uses both quantitative and qualitative data collection methods followed by quantitative and qualitative methods of data analysis (Johnson and Onwuegbuzie, 2001). Thus, quantitative and qualitative analyses are combined to produce more comprehensive findings to inform theory and practice (ibid.).

3.1.1 Positivist/quantitative approaches

Positivism is a reflection of a broader cultural phenomenon and is referred to as modernism in the humanities (Polit and Beck, 2010). It emphasises the rational and the scientific (Polit and Beck, 2003), believing that natural phenomena occur on a regular basis and can be studied by examining a sample (Robson, 2002). This research approach is based on the notion that the real world has an objective reality (Robson, 2002) and knowledge is generated by testing theories and hypotheses deductively, explaining events with a 'cause and effect' model (Creswell, 1994). This means that phenomena can be measured quantitatively/numerically and empirical evidence can be gathered directly or indirectly, according to a pre-specified plan using formal instruments (Robson, 2002).

There are several types of quantitative studies. One of these is correlation research which is a systematic investigation of the relationship between or among two or more variables (Polit and Beck, 2010). Experimental research is undertaken to determine a cause-and-effect relationship. The researcher randomises a sample into two or more groups and then manipulates the variables (Burns and Grove, 1999). Quasi-experimental research, on the other hand, sets out to examine casual relationships or to determine the effect of one variable on another. It is undertaken when a researcher cannot control all the variables or the research environment, which can affect the results.

Quantitative researchers begin by identifying the population to which they wish to apply their generalized results (Lincoln and Guba, 1985). The researcher then sets out the variables that they wish to study. Robson (2002) describes the concept of a variable as the properties of things that can be measured and compared. There are two main types of variables in the quantitative analysis: the independent variable and the dependent variable. In the case of an independent variable the cause is known while in the case of the dependent variable the effect is known (Burns and Grove, 1999; Crooks and Davies, 1998).

In quantitative research, a hypothesis predicting the expected relationships between variables forms the basis of a research project (Creswell, 1994) and its results determine whether to reject or accept the hypothesis. Accepting a hypothesis is always temporary as new data might emerge leading to its rejection later on. The quantitative paradigm requires the researcher to remain detached and independent of the setting and participants to ensure a degree of control. This is assumed to lead to the collection of unbiased, reliable and valid data which can then be generalized and applied to a larger population (Polit and Beck, 2008). A quantitative researcher seeks to control and minimise bias and maximise validity by enumerating numerical data against measured values and analysing it statistically (ibid.).

The aims and research questions for this study were developed from the literature review (Chapter 2) and as noted above, the majority of the previous research focused on measuring the quality of FCC, the success in its implementation and effectiveness. A quantitative approach was the preferred methodology used to establish these outcomes, omitting the factors that may have influenced its success. Several of these studies used standardised tools e.g. MPOC, PedsQL 4.0, FCCQ, etc. to measure the quality of FCC (Bruce et al., 2002; Dix et al., 2009; Moore et al., 2009). Since the quantitative researcher focuses on seeking and establishing a correlation between two variables, many of the studies discussed in Chapter 2 used the implementation and effectiveness of FCC as variables. While this approach was effective in answering specific research questions, the questionnaires were rigid and produced limited results. Quantitative research designs and data collection tools do not allow the researcher the opportunity to explore or expand on potentially revealing data that could promote understanding.

Furthermore, quantitative tools were applied to different cultures without taking any contextual factors into account that the environment may have on the data and/or the quality of care. One reason why these factors were not taken into consideration is their complex nature and the difficulties in measuring and quantifying the contextual. Therefore, quantitative research was inappropriate to answer my research questions because my aims were to explore the nature of the complex healthcare system in Thailand. The quantitative paradigm would require me to look for cause and effect relations and to produce numerical data, which is impossible as numbers and statistics cannot explain the nature of family-centred care in which the experiences, values, and beliefs of family members and healthcare professionals influence their practice of childcare. In addition, quantitative research often overlooks the human subjective experience and discounts the importance of semantics (meaning) and emotion. The omission of these variables can lead to a concentration on quantifiable variables instead of people's voices.

3.1.2 Naturalistic/qualitative approaches

In contrast to the quantitative approach, the qualitative research design aims at facilitating an in-depth examination that seeks to understand a social phenomenon in the natural world (Parahoo, 2006). Qualitative research is a systematic and precise process to gain a comprehensive understanding of a phenomenon (Burns and Grove, 1999). Qualitative research is person-centred and its focus is on the way people make sense of their experiences and the world in which they live (Polit and Beck, 2003; Holloway and Wheeler, 2010). Qualitative research can provide reasons for particular types of behaviour through observation and interviews. It is normally situated in a natural environment and is therefore a naturalistic inquiry (Lincoln and Guba, 1985).

The qualitative approach emphasizes the emotional aspects of an individual's world and the meaning of culture. Consequently it does not focus on the use of statistical data but data that is based on insights into people, events and phenomena. Such a research approach is usually employed to explore problems or situations about which relatively little is known (Robson, 2002), and generally deals with descriptions of actions, behaviours and speech rather than numbers in order to interpret the phenomena (Pope and Mays, 2006)

Qualitative research empowers the participants, particularly minors, by allowing their voices to be heard (Armstrong et al., 2000). The importance of collecting the expressed views of children has been emphasised by the United Nations Convention on the Rights of the Child (Office of the United Nations High Commissioner for Human Rights, 1989). It includes sections arguing that the opinion of a child under the age of 14 should be taken into account when significant matters affecting it are decided. Therefore, it is vital to provide children and their parents with the opportunity to say what really matters to them about their health and quality of life. This can enable health-related agencies to optimise health care and the role nurses play in FCC (Uhl et al., 2013).

Qualitative research of healthcare professions usually investigates a problem in clinical practice or education for practice that cannot be answered by quantitative research (Holloway, 2005). The experiences of participants within healthcare systems are not always quantifiable or interpretable by numbers. In order to gain a better understanding of this phenomenon, notably in the healthcare system and its contextual environments, qualitative research methods are more suitable (Polit and Beck, 2010). Holloway (2005) emphasises that qualitative research is an important tool in understanding the emotions, perceptions and actions of people who are experiencing a health issue (Holloway, 2005). There are different aims of and methods in nursing research for solving clinical problems (Watson et al., 2008). I would like to take advantage of the flexibility of qualitative research to explore a host of factors that might be influencing a situation (Hancock and Algozzine, 2006), in this case family-centred care in Thailand. Pope and Mays (2006) assert that the naturalistic paradigm represents a major approach for conducting research in nursing. This paradigm is not a fixed entity but a construction of the individual research participants, in which reality depends on the specific context and numerous constructions of reality are possible (Polit and Beck, 2003). The strength of knowledge gained from qualitative research is maximised when the distance between the researcher and the participants is minimised (ibid.). In order to understand the complex world of human beings, the researcher acts as an instrument of understanding (Robson, 2002; Polit and Beck, 2003). The interpretations of the participants in the study are equally important for the understanding of the phenomenon of interest, and the findings from a naturalistic inquiry represent the result of an interaction between the researcher and the

participants (Robson, 2002). My aim was to gather detailed description of experiences, actions and thoughts about family-centred care so that my study adhered to the naturalistic paradigm. It focuses on gaining an in-depth understanding of the relations within a family than the services provided by health care professionals and considers the impact the practice of family-centred care has in Thailand.

A qualitative study also includes interactive, inductive, flexible and reflexive methods of data collection (Parahoo, 2006). In addition, qualitative research as a naturalistic and interpretative approach recognises the importance of the context in which events occur and have meaning (Ritchie and Lewis, 2003). The attention qualitative researchers pay to “the holistic setting and its impacts mean that greater attention can be given to nuance, setting, interdependencies, complexities, idiosyncrasies and context” (Patton, 1990, p.51). The thalassaemia clinic, where this study was conducted, is a complex public service in an under-resourced area. The participants in my study either work in the clinic or are patients and their families. The interactions between children, family members and healthcare professionals take place within an intricate healthcare process. Qualitative research allows me to convey this complex interplay within its natural context as it is naturally occurring.

This approach helps to clarify the confusion or ambiguity about the processes and results of healthcare practices and will contribute to an improvement of these practices (Shaw and Gould, 2002). It is very useful because it combines knowledge that is gained from a wide range of sources and it helps to describe and explain the social problems participants encounter. Family-centred care is not widely known in Thailand and my research aims at exploring existing knowledge and characteristics and to explain the factors that influence its use. Another strength of qualitative research is that the research questions of this study can focus on the experience of family-centred care.

Qualitative research also includes a flexibility in terms of instruments and methods (Creswell, 1994). Data collection can be modified as new information emerges to enable the production of in-depth and detailed accounts of participant’s behaviour and their views on it (Robson, 2002; Denzin and Lincoln, 2000). This means that interview questions can be adjusted to address social contexts, different linguistic abilities, awareness of personal identity, beliefs, social and economic structures

and health systems (Pope and Mays, 2006; Anderson, 2010). This flexibility with the triangulation of data and the close engagement of researchers with participants in field work is why qualitative research is well suited for the study of healthcare (Polit and Beck, 2003).

As a result of the limited literature on family-centred care about chronic illnesses in Thailand and South-East Asia, a qualitative design has been adopted for this study. This qualitative design has been consistent with the research questions and the objectives set out at the onset. The method allowed me to elicit in-depth information about the perceived meaning of family-centeredness, the provision of family-centred care and its benefit to the health of children with thalassaemia.

In summary, a quantitative method would have been unsuitable for my research because it follows a positivist paradigm that focuses on objective data (Creswell, 1994). It measures data numerically and analyses it statistically in order to examine cause and effect relationships with the aim to generate deductive knowledge (ibid.). This study does not attempt to measure whether family-centred care promoted or enhanced the quality of nursing care. Instead, it explores the principles of family-centred care in the context of the current state of nursing care for children suffering from thalassaemia in northern Thailand. The research object is a complex phenomenon that cannot be meaningfully reduced to numbers or variables to establish linear causal relationship as there may be difficulties in identifying all the causal variables and differentiating them from the effect. Consequently, a research strategy leaning towards a holistic approach that includes listening to participants, their values and life experiences is needed, meaning a qualitative rather than quantitative research (Boswell and Cannon, 2011).

Qualitative research designs can be divided into three main categories: “exploratory, descriptive and explanatory research” (Uys and Basson, 1985: p.38). Uys and Basson (1985) define exploratory studies as setting out to study a relatively unknown field with the main purpose of gaining new insights. These studies are sometimes understood as a preliminary investigation leading to a more structured study later on. Exploratory studies can determine priorities for further research by developing new hypotheses concerning an existing phenomenon (ibid.). Descriptive studies collect accurate data on the phenomenon to be studied, while the purpose of explanatory research is to reveal causality (Uys and Basson, 1995). There are a

variety of different types of qualitative research in addition to the ones just mentioned and they will be discussed in the next section.

3.2 Types of qualitative research

Within the category of qualitative/naturalistic research, there are several forms of research design, such as ethnography, grounded theory, phenomenology and the case study (Strauss and Corbin, 1998; Merriam, 2009; Robson, 2002). When selecting a particular qualitative research design, Strauss and Corbin (1998) suggest two key points: (a) the role of any qualitative research is to document the participants' own understandings of their social environment, and (b) the importance of flexibility, i.e. the need for researchers to be creative and tailor the approach to their own research settings and interests. Therefore the qualitative methods in this study were modified to suit the research questions.

According to Robson (2002), phenomenology focuses on the subjective experience of the individual being studied and the research question is a version of 'what is their experience like' in order to understand and describe what happens to them from their own point of view. Phenomenology also focuses on exploring how human beings make sense of their experience and transform it into consciousness both individually and as shared meaning (Patton, 2002). This approach requires data collection methods, such as in-depth interviews with people who have directly experienced the phenomenon of interest (Robson, 2002). Their lived experience remains with people while the impact of the environment fades. It could be argued that phenomenology is not suitable for this study as the clinic environment influences the participants' behaviour.

Merriam (2009) understands the second approach, ethnography, as focussing on human society and culture in unique or complex situations to uncover the cultural knowledge of participants. It allows the researcher to provide a description and interpretation of the culture and structure of social groups (Robson, 2002). A central feature of this approach is that people are studied for a long period of time in their natural environment. Robson (2002) notes that in this approach, researchers can sometimes be over-involved with the people being studied and might disturb or change the natural setting. This can compromise the quality of the research. The

research process is flexible as the boundary between the context and participant is difficult to identify which requires the researcher to be engrossed in fieldwork for a long period of time. Time and cost are some of the main difficulties of this approach. My study had limited funding and focused on a unit of healthcare, i.e. a place, over a brief period of time. As a result, an ethnographic study was impracticable as it would have required a long-term exposure to a setting or group of people.

The third approach, grounded theory, emphasises the development of a theory relating to a particular situation rather than testing it (Strauss and Corbin, 1998; Patton, 2002). Data is intermittently collected and analysed and the emergent theory is based on data obtained during the study, particularly from the actions, interactions and processes of the people involved. Grounded theory is a very complex and time-consuming method as it requires extensive fieldwork to generate data saturation. Its open-endedness and uncertain (but considerable) time span made this methodology unsuitable for my study.

The last approach is the case study, a well-established research strategy where the focus is on a case. The term can be interpreted widely and can include the study of an individual person, a group, a setting, or an organisation, but always includes the context (Robson, 2002).

3.3 The Case Study

Case studies are used to explore or describe a phenomenon in context using a variety of data sources (Yin, 2003; Fitzpatrick and Kazer, 2011). Yin asserts that a case study is appropriate

- 1) if the research aims to answer the “how ” and “why”,
- 2) to study the context of a phenomenon, especially if it cannot be separate from its context and
- 3) if a phenomenon cannot be manipulated by the researcher.

The case study approach allows an individual researcher or an organisation to explore a case in-depth and to expand understanding of a phenomenon about which little is known by examining, for example, why participants think or behave in certain ways (Yin, 2003; Stake, 1995). According to Nunhall (2011) the case study

can be used to either generate or test a theory. It can also be used when a problem has been identified and a solution needs to be found within the context of the current “real-life” situation (Fitzpatrick and Kazer, 2011; p.40). Case studies are often firmly located within the category of qualitative research, but Yin (2003) strongly opposes this position, pointing out that they can also be based on quantitative evidence.

The research process for a case study design is similar to the techniques used in other qualitative research designs (Rosenberg and Yates, 2007). It employs a variety of data sources to explore or describe a phenomenon in context. Thus, within a fixed period of time case studies employ multiple methods to collect data so as to gain an insight into actual behaviour and experiences in real situations as well as illuminate the research environment itself. As it has to adhere to the same quality assurance measures, this methodology has survived the positivist debate and is increasingly used in research of nursing (Fitzpatrick and Kazer, 2011). It has become a well-established and comprehensive research strategy used to examine phenomena within their context which are of interest in the field of nursing.

3.6 Types of case study

Merriam (1988) defines ‘a qualitative case study as an intensive, holistic description and analysis of a single instance, phenomenon, or social unit’ (p.21). It includes social norms, the roles people play within them, social institutions, the family and social hierarchies. This method is particularly suitable to study health care practices, in particular FCC, because it focuses on the process rather than the outcome.

Merriam (1998) suggests that there are three different types of case studies: *particularistic, descriptive and heuristic*. Particularistic case studies focus on a particular individual, group, event, programme or phenomenon. A descriptive case study can illustrate the complexities of a situation. In a heuristic case study the reasons for a problem or issue are explained. Yin (2003) offers an alternative view and considers case studies as either *exploratory, descriptive* or *explanatory* depending on their aims of knowledge development. *Exploratory* case studies set out to study a phenomenon that is of interest to the researcher (Yin, 2003). An

exploratory case study in the form of fieldwork and data collection may be undertaken prior to the formation of the research questions and hypotheses. It may result in unclear findings and this type of study can be used as a pilot study to determine the final projects (ibid.). The *descriptive* case study aims at describing a natural phenomenon that occurs within the research setting (Yin, 2003). The researcher begins with a descriptive theory to determine the depth and scope of the case under study and to describe the phenomenon by producing a story. Yin (2003) suggests that the *explanatory* case study is used to explain cause and effect relations in complex phenomena that are far beyond the scope of surveys and experimental methods.

A further typology is proposed by Stake (1995, p.3-4) who describes three types of case studies: “*intrinsic, instrumental and collective*”. An *intrinsic* case study consists of an individual study and its findings are only applicable to an individual person or event. It is suitable for a researcher who is interested in an in-depth analysis of a case and corresponds to Yin’s (2003, p.3) “single case study”. An *instrumental* case study has a wider scope than an intrinsic one and it combines several small cases in order to understand the influence their environment has on them. This typology is similar to Yin’s (2003, p.3) “embedded single case study”. A *collective* case study is a combination of an intrinsic and an instrumental case study. It is useful to generate more general findings. This type corresponds to Yin’s (2003) “multiple case study” and is valuable when the repetition of a study in different contexts is required to compare and contrast the results. This coordinating and aggregating of evidence means that the results be generalised because they are based on a number of individual cases (Stake, 1995).

A further method of distinguishing between the several types of case studies is determined by the level of analysis or unit of analysis (Stake, 1995). In a *single case analysis* only one unit of analysis in a single context is taken into consideration (Yin, 2003). An *embedded single case study* is more complex. The unit of analysis is divided into sub-units within the same context (ibid.). Case studies may contain multiple contexts and multiple cases. The differences between embedded single case studies and multiple case studies is the (number of) context(s). A single case study relates to one context even if it contains sub-units of cases. *Multiple case studies* refer to multiple cases and/or multiple settings, in which cases can be compared and contrasted with each other (Yin, 2003). The last type is the

embedded multiple case study (ibid.) which combines embedded single cases and multiple-case studies. Scholz and Olaf (2002) agree that embedded case studies involve more than one unit, or object, of analysis and are usually not limited to a qualitative analysis. The multiplicity of evidence is investigated at least partly in subunits which focus on different salient aspects of the case. Although this type of study is useful in providing an in-depth analysis, it can be time-consuming.

According to McDonough and McDonough (1997), a case study can be a descriptive case study, an interpretive case study or an evaluative case study. A descriptive qualitative case study presents a detailed account of the phenomenon studied. An interpretive qualitative case study uses detailed descriptions obtained from participants. The researcher interprets and attempts to formulate a theory about the phenomenon. An evaluative qualitative case study goes beyond the description and explanation of a studied phenomenon by attempting to evaluate and make judgements about it. Such a case study can be used to evaluate a procedure and judge its success.

Case studies are often used when the selected case might offer insights into a unique situation (Yin, 2003) and by using a case study approach, researchers are able to maintain the complexity of their object of interest, while highlighting specific details (Stake, 1995). I selected a case study methodology to answer my research questions because my research aim is to uncover the “how” and “what” of family-centred care in the specific context of a thalassaemia clinic. As explained above, the nature of family-centred care in Thailand needs to be explored in order to answer the question: “How is it conducted specifically in Thailand?” My case is “the thalassaemia clinic in the Lampang Hospital”. The hospital offers a public service, which means I cannot interfere with or manage the process of child care. This service is offered by healthcare staff and the children and family members play the role of a client. Thalassaemia care is complex and various factors influence the process. These factors include the facilities, policies and the social context, which will be taken into account in my research. Using a case study approach allowed me to study the phenomenon in its natural environment and I was, therefore, able to understand family-centredness as a phenomena pertaining to the process of care.

In summary, Yin (2003), Stake (2008) and Merriam (2009) agree that case studies are in-depth-studies of a case within its real situation and context. The case study in this research is an *embedded single case study* (Yin, 2003). It is divided into sub-

units in the same context and using an embedded single case study enabled me to explore the characteristics of family-centred care in the thalassaemia clinic in its natural environment in order to understand the nature of child care in a Thai context.

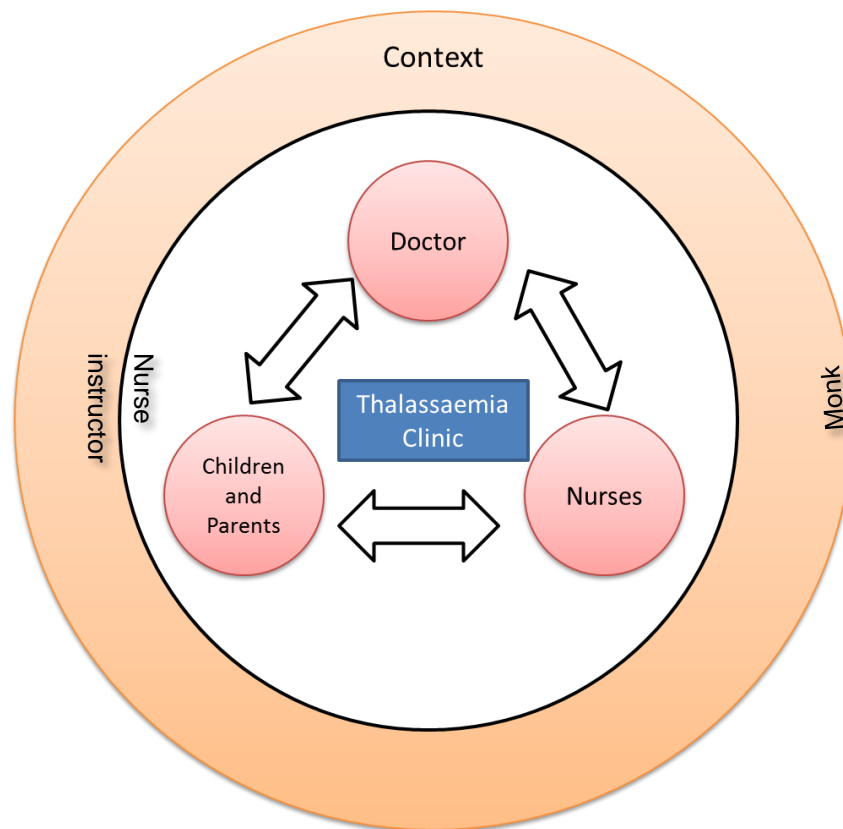
3.3.1 Case selection

The design of this case study is based on the work of Yin (2003) and Stake (1995). The topic is the nature of family-centred care for children with thalassaemia at Lampang Hospital in the north of Thailand, where a large number of patients are admitted to hospital every year. It adopts the embedded single case study approach as suggested by Yin and Stake in order to reflect the complexity within the context of the study.

The selection of a case is vital as this will determine the scope and the design of the study. A 'case' is a unit of analysis that can be viewed in-depth and from many angles (Yin, 2003; Thomas, 2011). Within the field of research, the word 'case' has been defined as a specific phenomenon related to a situation, place and event about which data is collected and/or analysed (Swanborn, 2010; Thomas, 2011). Selecting cases is a difficult process. Yin (1994) and Stake (1995) recommend that the selection offers the opportunity to maximize what can be learned, knowing that time is limited.

The number of cases in a case study can be large or small and depends on the scope of each case (Yin, 2003). A case study can be suitable to study one particular group, a community or other social unit with a small number of entities in depth (Polit and Beck, 2006). The number of cases can range between one and ten. Eisenhardt (1989) points out that it is difficult to generate theories if there are less than four cases, while Miles and Huberman (1994) warn that too many cases, especially more than 15, will produce too much data which the researcher may find difficult to analyse. I decided to examine a single case in-depth. The scope is limited to the thalassaemia clinic, meaning to one hospital in one specific geographic area. The following figure illustrates the case:

Figure 4: A Single Embedded Case Study Design



3.3.2 Sampling

The sampling procedure for this study was influenced by the methodological approach and the topic, rather than a need to establish generalisability (Higginbottom, 2004). I used purposive sampling which is based on information needs and which allows me to maximise the breadth and depth of gained information but does not facilitate generalisation (Lincoln and Guba, 1985).

The participants in this research were selected because they had all experienced the actual phenomenon that was being studied: The first group had direct contact with the disease, the second group provided healthcare services and the third group had an indirect experience of the disease and healthcare through their role, status and/or function. Third group can provide the social background that may affect health care behaviours. The participants were five families, consisting of the child and parents, four nurses, a doctor, a nurse instructor and a senior Buddhist monk who teaches Buddhism at the local university.

3.4 The context of study: General information of the setting in Lampang Hospital

I selected the thalassaemia clinic in the Lampang Hospital for this study, where over 1800 thalassaemia patients are admitted every year. The Lampang Hospital is situated in northern Thailand and was built under the National Economic and Social Development Plan No.4 during 1977 and 1981. The Ministry of Health established the hospital as a provincial hospital and classed it as a tertiary care unit. It works in partnership with the local Borommarajonani College of Nursing in professional and academic matters. It specialises in the treatment of children with chronic haematological illnesses and its Children's Department provides services to about 40 children who suffer from thalassaemia.

The hospital's vision and mission is to organise and provide holistic health services, particularly for patients with tertiary diseases that require a high level of resources. It also aims to be a high-quality medical institution which is reflected in the highly qualified health personnel. The other aims of the hospital are to promote knowledge development and research that can lead to health benefits and to create networks with other allied sectors (Lampang Hospital, 2010). Based on its aims, the hospital was a suitable case. The health care practices provided a significant amount of information about the healthcare system, approaches to treatment and nursing care for children with thalassaemia in northern Thailand.

3.5 The role of the researcher: The researcher as insider or outsider

Nurses must always remain concerned about balancing the dual roles of being a researcher and a health professional when undertaking research involving participant observation (Bonner and Tolhurst, 2002; Unluer, 2012). It is necessary to develop a relationship of trust with all participants and to 'fit in', so that the researcher's presence causes as little disruption as possible to normal activities. At the same time, distance is required to allow the researcher to make sense of the data.

In qualitative studies it is increasingly common for researchers to be part of the social group they intend to study. In this case I, the researcher, was already a native

or 'insider' (Kennedy, 1999; Pugh et al., 2000) before the study commenced. Having a greater understanding of the culture being studied as well as having an established professional relationship with the participants can promote both the telling and the judging of truth (Bonner and Tolhurst, 2002). Being an insider can also reduce numerous problems associated with research in the real world of clinical nursing practice because it facilitates gaining access, establishing a rapport with subjects, and dealing with ethical concerns.

Being an outsider, on the other hand, can increase opportunities for in-depth discussions and observations of daily action as the researcher is able to ask the manifest questions. Outsiders also have the advantage of not possessing prior knowledge of the staff and are thus able to view actions and behaviours with an open mind. Bonner and Tolhurst (2002) also suggest that being an outsider has the added benefit of avoiding the imposition of meaning on any verbal or non-verbal discourse due to not knowing the environment. It should be noted, however, that outsiders are visitors who are present for a limited period of time (Bartunek and Louis, 1996) and might gain a less deep understanding of certain aspects of the setting.

In this study and during the research project, I would consider my position as falling in both the 'insider' and 'outsider' categories (Bartunek and Louis, 1996), which was vital when collecting data. Insiders are researchers who already have an attachment to the field, whereas outsiders enter the setting on a temporary basis for the sole purpose of conducting research. Bonner and Tolhurst (2002) sum up three advantages of being an insider in the research domain: possession of a superior understanding of the group's culture; the ability to interact naturally with the group and its members; and a previously established, and therefore greater, relational intimacy with the group. As an insider I benefited from these advantages: I had already developed a rapport with the health care staff but was an outsider to the children and parents as I had had no previous contact with them.

It is also necessary to make my position in this research process explicit (Bonner and Tolhurst, 2002). The interpersonal relationship between researcher and participants such as doctors, nurses, children, parents, a nurse instructor and a monk must also be taken into consideration because it can affect the research

process and results. I was approaching the research field with multiple roles to gain comprehensive data.

My personal background was clarified to all participants as I needed to adopt a formal approach during fieldwork. The staff knew that I am a nursing instructor, who graduated with a bachelor's degree in nursing in 1993. I have been teaching paediatric nursing, both theory and practice, in a nursing college and I worked alongside other professional healthcare and clinical instructors. The study site is not only a healthcare but also a training unit for a number of healthcare professionals. In Thailand nurses and nursing instructors play different roles in the healthcare system – the nurse is the healthcare provider while nursing instructors act as educators. The boundary between the two is clearly defined and collaboration emerges when student nurses practice in the setting. The nursing instructor and healthcare professionals cooperate to train student nurses. This made negotiations easy as I could deal effectively with any practical issues that arose. My position of an insider meant that I engaged in the data collection knowing and understanding the routine of the clinic, policies, culture and jargon. However, I was mindful that the nurse educator is in a hierarchical position when compared to the nurses and I tried to manage this by being friendly but professional to the nurses. The position of nurse educator offered me an insider view of the education system which allowed me an understanding of the educational system and the process of nurse training in the clinic.

In addition, my status in the hospital changed when the healthcare staff realised that my current role was that of a researcher. From the outset of my research the nurses appeared to engage more with each other, and treated me, the researcher, as an outsider in the situation. I managed this by explaining my study and my new role to them. I tried to create trust by assuring them that any data from the data collection would be confidential and because of our pre-existing relationship, this trust developed more quickly than if I had been a complete stranger.

I also had concerns about my position towards the children and families as the nurse is recognised as a helper in Thai culture. Hence, patients and their families admire and respect the official role of the nurse. Social relationships play a major role in shaping behaviour, attitudes, feelings and thoughts and I was mindful that

this might influence behaviour and decision-making. I managed the situation by developing a rapport with the child and its parents.

Karnieli- Miller, Strier and Pessach (2009) warned the asymmetrical power relationship in quantitative research that the equality seems unrealistic in research. However my researcher's position has been described, I realised the interviewer-interviewee power relations are not perfect and equal. I also aware that interviews may reflect ascendancy in questions as same as I controlled time and process of interviews. In hierarchical structures, I play the role as a nurse instructor and co-worker. I realised that some power may influence and effect healthcare behaviour. The participants still have opportunities to terminate if they feel uncomfortable or want to reject the questions. It can be seen that the researcher and participants can exercise their power during the data collection (Kvale, 2006).

Three dilemmas relating to informant bias, reciprocity in interviews, and research ethics are examined from my insider researcher's perspective. I responded to the bias by planning to keep to the guidelines and approach as a researcher rather than as a colleague during the interviews and collecting documents. The multiple roles I had as a researcher influenced the data collection process as well as the professional relationship I had with the participants. The interviews in this research method do not make an erroneous tool regarding the asymmetrical power relationships (Smith, 2005).

3.6 Data collection procedures

3.6.1 Recruitment and Case Selection

Primary data could only be realistically collected at the thalassaemia clinic so that purposive sampling was necessary. In this sampling technique, also known as 'judgemental' technique, the researcher selects subjects or institutions on the basis of the information required (Pope and Mays, 2006). Tellis (1997) states that the selection of cases must maximize the capacity for learning within the period of time of the study. When selecting the hospital, my aim was to gain access to children and families, healthcare staff and nursing practice that would provide an

understanding of the nature of family-centred care of thalassaemia patients and their families. The thalassaemia clinics in four hospitals, Lampang, Chiang Mai, Lamphun and Mae Hongson were considered. Lampang Hospital was the most suitable because it is the central hospital within the region with the highest number of children. Additional factors influencing the decision were time constraints and the facilities within each of the thalassaemia clinics.

To identify the participants for the study, the following criteria were developed using the purposive sampling technique:

1. participating children must have been diagnosed with thalassaemia at least one year before the beginning of the study. They must live with their parents and must have attended the hospital at least three times;
2. participating nurses must have at least one year of experience in thalassaemia care;
3. the participating nurse instructor must have experience in thalassaemia care and teaching within the relevant area of the hospital;
4. participating doctors must have been in charge of the medical care of children with thalassaemia for at least six months;
5. the participating monk must understand the links between Buddhism, social norms and healthcare.

Although the sample was selected using the criteria above, I also devised the following exclusion criteria:

1. Parents who did not regularly attend the hospital and
2. Children who were critically ill at the time of the study were excluded.

3.6.1.1 Children and their families

Access to the participants was granted by the Director of Lampang Hospital and the medical director of the paediatric department. Both gave permission to conduct this research at the hospital and with patients under the hospital's care. Both were informed of the research project and a mode of operation was agreed.

Five families were identified from the hospital records as potential participants. They were contacted by telephone by me to introduce the aim and objectives of my

research. All families were interested in participating and received an information leaflet in the post (see Appendix 1). Care was taken to ensure that this letter was sent at least a week before their next appointment with the hospital. On the date of the appointment, I met the family at the hospital in a private room before it took place. This enabled me to introduce participants to the study in more detail and to provide answers to any questions. Following this, I asked the participating families and the children to give their consent (see Appendix 2).

3.6.1.2 Hospital staff

1 Doctor and 4 nurses in the paediatrics department who met the criteria were asked if they were willing to participate in the research. They were given information and sufficient time (at least 3 days) to consider the request and three nurses and one doctor agreed to participate in this research.

3.6.1.3 The nursing instructor

Because nursing instructors are not under the hospital's authority, I had to contact the head of the college of nursing in Lampang and ask for permission to include a nursing instructor in the research. The nursing instructor in case was given all relevant information and agreed to participate.

3.6.1.4 The monk

Monks are the most respected persons in the Thai society. They are not only the symbols of religious but their position is the centre of the society. The role of monks in Thailand is important. The monk leads religious rituals and ceremonies, and the people in the community always accompanied. The monk plays the role of leader in both times of crisis and times of happiness. The role of monk extends economic support. The monks can negotiate with the people in community and facilitate economic to support poor families. In the rural area, the monk plays a role of co-ordinator to link the need among people to develop community. Also, monks play role of consultant when people bring their problems. The monk and their 'wat', Buddhist temple, which Buddhism come together and experience a sense of peace

and kindness. The monk support by giving counsel and encouragement to the parent who come across problems.

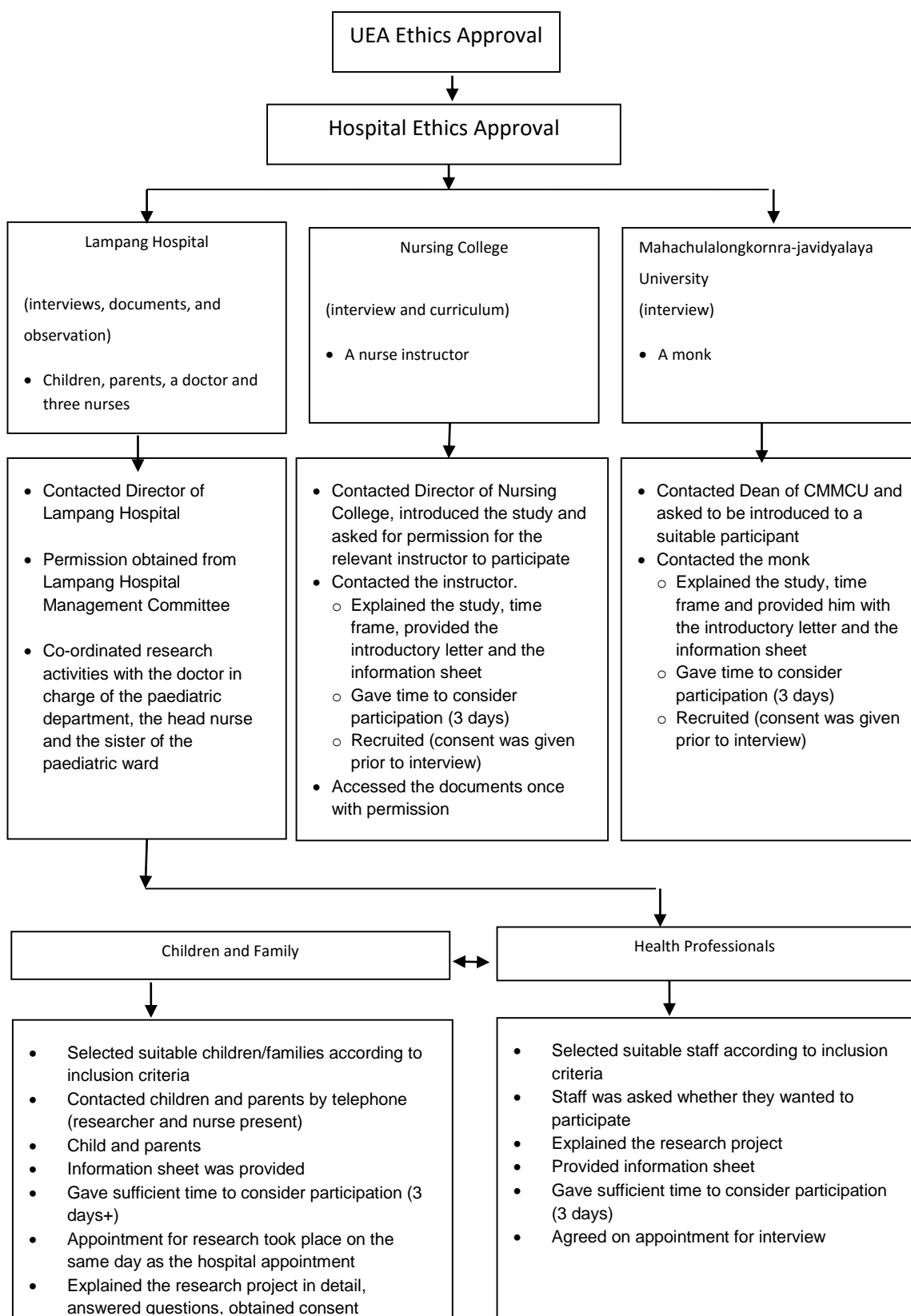
The legitimacy to grant permission to make formal contact with the person who is a member of the organisation is a common issue in Thai culture. The monk is considered the leader of morals and behaviour of Thai people. A monk has the potential to explain the impact of behaviour, culture, and belief that relate to their way of life. I contacted the Dean of Mahachulalongkornrajawittayalai University in the Chiang Mai Province to introduce my research. He then suggested a monk who had been teaching Buddhism at the university as a participant for the research. The monk was also given information sheet and sufficient time before agreeing to take part (see Appendix 10).

3.6.1.5 Documents

Yin (2009) suggests that a researcher can gain useful information from documents for research projects. The documents in form of the children's medical records and hospital policies were accessed after gaining permission from the director of the department and the head nurse. The nursing curriculum and teaching plan were accessed after obtaining permission from the head of the college of nursing.

A summary of the recruitment process can be found in Figure 5

Figure 5: The recruitment process



3.6.2 Methods of data collection

I designed a multi-method research strategy that supported the exploratory nature of the study. Three methods of data collection were used: observations, semi-structured interviews and document analysis. I had considered the appropriateness and accessibility of these methods for the setting (Yin, 2003) and that multiple documents of data such as patient records, archival records and physical artefacts (ibid.) were available.

I was seeking data about the nature of the doctor/nurse-child/parent interactions, actions and activities. This data included descriptions of communication, the provision of information to the families within the decision making process, and physical aspects such as the layout of the department. Verbal and non-verbal data was gathered from all participants and documents were reviewed in order to explore indications of family-centred care, in both the prescriptions and plans made as well as in the written communication between health professionals.

Since there is no “best method” to gather data (Robson 2002, p.385), I selected this approach which is commonly called triangulation (Robson, 2002). It allows for a multifaceted consideration of the phenomena being studied (Yin, 2003). I started with observations before moving to semi-structured interviews and concluded with an examination of documents.

3.6.3 Data collection 1: Observation

Robson (2002) defines observation as a method that can be used to collect data about actions, behaviours, and the setting through direct monitoring by an observer. Burns and Grove (1999) assert that observation leads to primary data that illustrates the setting as perceived by the observer. Stake (1995) suggest that direct observation can enable an in-depth understanding of actual phenomena.

There are various types of observations: participant/non-participant, overt/ covert, and structured/unstructured (Polit and Beck, 2003). Robson (2002) suggests that participant observation takes place when the observer participates in the event. This method is frequently used in anthropology although its flexibility makes it suitable for

many different types of research. On the other hand, a non-participant observer is not involved in any studied activities or phenomena (Polit and Beck, 2003). For the same reason this method is sometimes also called unobtrusive observation (Robson, 2002).

Covert and overt observation methods are subcategories of non-participant observation. During covert observations, participants do not know that they are being observed and are unaware that an observer is present. In contrast, participants are informed and are aware that observation is taking place during an overt observation. I share the opinion that participants have the right to decide if they want to be involved in this research. I, therefore, informed them that my observations were only conducted during the period of time that had been agreed on. Unstructured observation was discarded because of its loose focus on the theoretical framework. Structured observation offers consistency because the observer is looking for expected behaviours. These expectations were based on the theoretical framework and the use of a structure focused my observations so that I was able to concentrate on the behaviours described in the framework. Semi-structured interviews served to support observations and explore issues from the participants' perspectives. They allowed a detailed examination of events and emotion (Merriam, 1988).

During an observation data collection occurs in natural settings and the information is not disturbed as the data emerges from real situations without deliberating presence (Robson, 2002). Whichever type of observation method is chosen, it needs to be systematic, with regular record keeping to allow analysis and interpretation without distortion (Polit and Beck, 2003).

Observation is a flexible research method which enabled me to select the time and event I wanted to observe (Polit and Beck, 2003). In a structured observation the scope of the observation area is limited so that the observer is able to notice the presence or absence of target behaviours and their frequency can be recorded (Creswell, 1994).

3.6.3.1 Strengths and weaknesses of observation

During an observation the researcher uses his/her senses to collect visual and audible data (Robson, 2002). Observation can be a method to support other methods (ibid.) and I combined it with interviews and document analysis. Observations offer the researcher the ability to sample unexpected and expected events (McIlfatrick, 2008) which ensures that events that appear to be 'normal' as well as 'abnormal' to the participants can be observed (Robson, 2002).

Whilst observations allow researchers to obtain data hidden from other methods, it is not always straightforward (Robson, 2002) for several reasons. Firstly, instruments to document observational data need to be carefully designed to avoid producing unclear results. The observer might also not record the phenomenon properly, with data being lost through a lack of concentration (Polit and Beck, 2003). Thirdly, inexperienced researchers or insiders may neglect routine behaviours or distort data with their background knowledge (ibid.). Finally, the "Hawthorne effect", where behaviour changes because of the realisation of being observed, is common in observation (McIlfatrick, 2008, p.315).

3.6.3.2 Selected method of observation

Baring the aim of my research in mind, I decided to use non-participant observation as the most suitable method. Robson (2002) asserts that this is the most commonly used method in exploratory research when trying to understand the process, situation and interaction between people. It allowed me to observe every phenomenon that occurred (McIlfatrick, 2008). I appreciated that the observation was only useful if the activities or phenomena were recorded regularly and systematically. Guided by Polit and Beck (2003), I designed a structured observation schedule based on the principles of family-centred care. Instead of limiting recording to particular incidents (event sampling), however, I collected data in detail and focused on all behaviours, observing individual children and the family one at a time while remaining apart from them.

3.6.3.3 Preparation before observation

I developed categories of observation, observation guidelines and a time sampling (see Appendix 11) which were used during fieldwork (Polit and Beck, 2003). I observed parents and children, a doctor and nurses with a focus on

- how children with thalassaemia were cared for by health professionals;
- how closely the care resembled characteristics of family-centred care;
- what organisational structures were in place to enable, establish or provide family-centred care; and
- if any observable pre-requisites for family-centred care were lacking.

I engaged in fieldwork only after I had re-familiarised myself with the location, the process of health care services and had secured permission from healthcare staff. In addition, to avoid anxiety among the nurses I informed them of what I was doing. This included an explanation of the observation schedule, which also allowed me to minimise the Hawthorne effect, meaning minimise the influence my observation would have on the participants' behaviour (McIlfatrick, 2008). I informed them that I would follow the children from the outpatient department, where the child and parent[s] saw the doctor, to the child's room for the blood transfusion and through to discharge.

I recorded the actions, activities and behaviour of the children, parents, the nurse and the doctor during the length of their hospital visit. Frequent observational breaks were taken for note taking as the observation period of the child care unit in the hospital were long. I was careful to maintain an uninterrupted observation of the child as long as it remained in hospital, though.

3.6.3.4 Physical setting

The thalassaemia clinic is open on Tuesdays and Thursdays every week. Children and parents register at the front of the clinic when they arrive and the consultation takes place in a room behind the registration desk. I positioned myself near the registration desk as this enabled me to undertake observations offering me an in-depth understanding of the process (Robson, 2002). The dates of the observations and other data collection methods are described in the following tables 4 to 6.

Table 3: Schedule for data collection - Parent and child

	Family 1	Family 2	Family 3	Family 4	Family 5
Period Month/Year	1 Days 13/01/11	1 Days 20/01/11	1 Days 27/01/11	1 Days 03/02/11	1 Days 10/02/11

Table 4: Schedule for data collection - Nurse and Doctor

	Nurse 1 st	Nurse 2 nd	Nurse 3 rd	Nurse 4 th	A Doctor
Period Month/Year	2 Day 24/12/10 08/01/11	2 Day 27/12/10 14/01/11	2 Day 03/01/11 21/01/11	2 Day 10/01/11 28/01/11	2 Day 17/01/11 04/02/11

Table 5: Schedule for data collection - Nurse Instructor and Monk

	A Nurse instructor	A Monk
Period Month/Year	1 Days 16/02/2011	1 Days 23/02/2011

3.6.3.5 Observational Process

I ensured an open observation by creating a visible difference and appearance by not wearing a uniform and introducing myself to the participants. I realised that the most important aspect of this stage of my research was to observe the children. I engaged in conversations with them and found out if they had any nicknames so as to develop trust and gain their cooperation. I obtained consent from the parents and children before any data collection commenced and informed them again that I was not a member of staff and that I would not disrupt the process of care. Observation started after I had gained consent and I placed myself where I could see and hear the interactions of the doctor, nurse, parents and child during registration and the

initial consultation (Robson, 2002; McIlpatrick, 2008). The observation period from this point onwards lasted between 1-1½ hours per child.

The next observation stage took place in the blood transfusion room. This small room had 5 beds, but because of the number of children in the clinics, two children occupied one bed, so that there were 10 children in the room at any one time. I focused on the activities and behaviour of the child but experienced some difficulties due to the cramped conditions in the room. I tried to record data as soon as possible to maximise data accuracy (Polit and Hunger, 1999) and field notes and records were completed as soon as I finished observing. Participants were debriefed to ensure the accuracy of the collected data.

I followed five children and their parents throughout their day-long treatment visit to the department, from their arrival at the reception desk to the discharge after the completion of the transfusion. The care of the children occurred in several steps:

Step 1: Arrival (the reception), up to 1-1 ½ hours

All children and their families arrived at the clinic reception desk where the nurse and a nursing assistant were present. All documents and outpatient (OPD) cards had already been prepared and the registration process was completed within less than two minutes. Once registered, the parents weighed the child on nearby scales and recorded its weight on the OPD card. The family was then invited to see the nurse for an initial assessment and once this was completed, the children and their parents were sent to the haematology laboratory and blood bank to have blood taken for a full blood count and cross-matching.

Step 2: Blood sampling (the haematology laboratory), up to 30 minutes

The laboratory is situated about 50 yards from the outpatient's department on the same floor as the clinic. The families all knew where the laboratory was and did not require any explanation of how to get to it. Several technicians were available to collect the blood samples, but all children asked for one particular technician. The children knew this technician well and appeared to appreciate not only his skill, but also his friendly and relaxed manner. All parents were invited to stay with their children during this procedure and sat on a chair that had been prepared for them. Once the blood was taken, the technician reminded both the children and parents of how to get to the blood bank. There the parents reserved the blood for their

children. They were all familiar with the process and appeared relaxed. Before leaving, all families were informed that the results would be known in about an hour. It was noticeable that while the communication from the technician focused on and around the child, the parents' communication with the blood bank staff was technical, brief and professional.

Step 3: Seeing the doctor (the doctor's room), up to 10 minutes

When the blood sample had been taken and the transfusion had been ordered, the children and families waited in a waiting area. Once the results arrived they proceeded to see the doctor for the consultation. In the examination room the doctor reviewed the child's medical history and undertook physical examinations. In most cases this was an unhurried consultation and normally took a little over 10 minutes. However, two children needed more time because their health problems required specific examinations or treatments. Throughout the consultation the doctor took time to talk to the children and their parents, explaining the findings and general care each child would need at home. This included reminding the families of any symptoms they should look out for, the food it should avoid and the importance of avoiding accidents. The appointments ended with the doctor and families agreeing on the time and date of the next appointment. The nurse then told the parents to collect medication and/or blood transfusions that were needed.

Step 4: The treatment (the blood transfusion room), up to 4 hours

The blood transfusion service commenced at about 10am and the unit was situated in a single room with a waiting area in the wide corridor. One nurse and one nursing assistant looked after the families. The room contained 5 beds for the children and chairs for their parents. During the observations the beds were shared by more than one child although the parents and the children did not seem to mind this. The nurse was in regular contact with the blood bank, verifying the time when the blood was available for transfusion and asked the parents to sign the relevant consent forms, without giving any explanations. The parents gave their consent without hesitation as they knew the procedure and did not ask any questions. The nurses' explanations were infrequent and brief. They briefly reminded all the parents of symptoms they should be vigilant for in their children, for example fever, painful and itchiness. The parents of newly-diagnosed children, on the other hand, were given extensive attention. The nurse explained not just these medical points, but also all they needed to know about the physical facilities and the process of care.

The nurse commenced the transfusion as soon as the blood arrived, explaining that it would take about four hours to complete. While the transfusion progressed the nurse saw every child at least once every hour, checking vital signs and regulating the drip rate. While doing this, the nurse spoke with the child in a friendly and calm manner. Children and parents stayed together throughout most of the period of transfusion, but parents did take breaks, leaving their children in the care of the nurse. While with their parents, the children did not always remain on their beds. The hospital had provided benches and two big tables in the corridor outside the transfusion room, with the intention that parents could use these for their meals or for having a rest. However, the benches and tables were a popular place for the children as well as their parents to spend time while waiting for or during the transfusion. Almost all the care for the children was provided by their parents and this included helping the children to move and sit outside the room or to go to toilet. The nurse was, however, never far away, ensured that everything was safe and assisted when required.

The hospital did not provide any private area or rooms for the parents to use so that they ate and talked to each other in front of the transfusion room. The hospital provided meals for the children while some parents brought their own food from home and ate it with their children.

The parents keenly observed the blood flow at all times and told the nurse when blood bags were nearly empty. Once the transfusion was completed, the nurse removed the cannula and transfusion set, checked the child's vital signs and condition and once the parents had no more questions, the children were discharged.

Opportunistic observation: teaching sessions for parents

Throughout the treatment, health professionals provided parents with relevant information in order to enable them to care for their children at home. These informal sessions were often brief, serving as a reminder rather than a full health promotion activity. This was considered appropriate because the parents had previously taken part in group teaching sessions organised by the nurse.

During a visit to the haematology department, the opportunity arose to observe one of these teaching sessions for parents about how to perform the injections required for the iron-chelation therapy at home. The teaching began with the nurse explaining the importance of the injections, and the problems and health issues that were likely to arise if the therapy was not carried out. It was made clear that all parents were expected to administer the injections to the children, but also that those who felt unable to do so would be allowed to bring them to the hospital to have it done.

The nurse demonstrated the injection technique to the parents and used a slow step-by-step approach. The teaching content was simplified and the nurse used non-medical terminology in order to be understood by the parents and the child. She divided the session into two parts. In the first part she explained how to prepare the injection which was followed by questions and discussions. One parent, for example, asked the nurse to show her how to separate the needle from its protective cap. Once all questions had been answered, the second part of the teaching commenced. The nurse introduced the parents to the injection technique invited them to practice it while the others watched. They then commented on each other's practice and discussed how it could be done better. The nurse demonstrated and explained the process, but no written information was provided throughout the teaching.

The children were also able to participate and attend these teaching sessions, as they had to learn that they would receive injections from their parents. The nurse's focus did not exclusively remain with the parents, but included the children at appropriate moments, for example by asking them about side effects of elevated iron levels in the body.

3.6.4 Data collection 2: Interviews

An interview is a crucial source of information in a case study (Yin, 2009). Jackson, Delay, and Davidson (2008) state that interviews as a data collection method, whether in spoken or written form, can be conducted individually and with groups of people and are either face-to-face or over a distance. The usefulness of collected data depends on the ability of the interviewer and the method used in the interview. Jackson, Delay and Davidson, (2008) explain that interviews are structured if the

interviewer asks pre-determined questions without deviation and has complete control over the course of the interview. These fixed questions, however, can result in limited answers. In contrast, the interviewer has no prepared interview schedule in an unstructured interview and follows and reacts to the flow of the interviewee's speech, instead. While these interviews are considered to be more in-depth (Robson, 2002; Jackson et al., 2008), it can be argued that the researcher might not be able to take control and ensure that the interview covers all areas deemed necessary. Unstructured interviews were not considered appropriate for this research because FCC is not a recognised or well-known approach to nursing care in Thailand and consequently participants might have found it difficult to provide in-depth information.

The flexibility in semi-structured interviews allows the researcher to manage the limitations of unstructured and structured interviews. Semi-structured interviews unite the advantages of both interview approaches and an interview schedule provides either a list of questions or interview topics that ensure that no area of importance is omitted. These can help to reduce the discomfort of a structured interview and offer the opportunity to elicit deep ideas in a convincing manner (Robson, 2002). New topics that arise during the interview can be added and unnecessary points omitted (*ibid.*). I used a semi-structured approach to ensure that the interviewees could lead the interview in the direction they deemed important.

Interviews have advantages in terms of cost and time. They also allowed me to triangulate interview data with other methods as specific questions can fill the gap between observations and documentation. Following Burns and Grove (1999), I conducted interviews after the observations so that data related to the latter could be collected.

3.6.4.1 Selected method of interview

Face-to-face interviews were employed as this technique allowed me to explore the participants' views and opinions in detail. I was able to rephrase questions differently during the interview or change them to suit the participants' literacy levels and background. In addition, the participants were encouraged to participate in a two-way communication and were free to ask questions and to reveal any

information they wanted. The semi-structured interview uses an informal style, which is an acceptable approach because it reduces anxiety and discomfort participants might feel. As a result, the participants were able to discuss issues freely and reflect their interpretation of the health care system and nursing care.

3.6.4.2 Process of interview

First and foremost, I had to bear in mind that it was important to introduce myself to the interviewee as this helped me to build up a relationship of trust with them. To get the most out of the interview, it was important to ensure that its time and venue were appropriate, that it was audio-recorded and that the level of language used was appropriate for the interviewee.

Reviewing of interview schedule

This research was conducted in the clinic and in the Thai language. To ensure the appropriateness of the questions I consulted a language specialist to translate my questions from English to Thai. Despite this, some questions needed revising when I then used them with colleagues.

I interviewed the parents before the children and I interviewed younger children in the presence of their parents as I anticipated that their presence was a comfort to the child and would facilitate communication. Teenagers were given the option to be interviewed on their own (with a nursing instructor acting as a chaperone) or with their parents (one or both together as preferred by them). If both parents were interviewed together, the nurse caring for the child was informed that they would not be with the child for the duration of the interview. The health professionals and the monk were interviewed in an interview room at a time and place (i.e. hospital or university) convenient to them.

In this study, 5 parents, 4 children, 1 doctor, 3 nurses, 1 head nurse, 1 nurse instructor, and 1 monk were interviewed. Notable, one child is too young and not able to communicate therefore I decide to interviews parents. Before the date of the interview, I confirmed the date, time and the venue with all the participants in a telephone conversation. On the day of the interview I confirmed its length and the procedures during the interview. After consent to voice record the interview was

confirmed, it was conducted either in Thai or in the local dialect (Northern Thai Language) depending on the participants' preference.

The interviewees were informed that there was a private room available and they could choose to be interviewed in this room or another place. In order to create a comfortable atmosphere the initial questions were general and open, with the subsequent questions becoming more research specific.

Interviews with parents

Interviews with parents were conducted in a private room and I choose the time before their child was to be discharged. They were planned to last for approximately 45-60 minutes, which is seen as an appropriate length (Jackson et al., 2008). The opening and subsequent questions were planned so as to cover the main points. During the first interview I found that one parent did not respond directly to the question and so I adjusted it to obtain the information needed, as recommended by Merriam (1988). This incident was useful as it helped me to improve the quality of the interviews for the next four parents. I was more of a listener than a speaker and encouraged the participants to explain and expand their answers (see appendix 4).

Interviews with children

The same private room was also used for the interviews with the children and all of them chose to be interviewed with their parents present. They were often shy and easily distracted, and so did not always answer the questions that had been prepared. During the first interview their shyness combined with time limitations made it impossible to obtain all the information I wanted and I adjusted my approach for the next 3 children accordingly (see appendix 5).

Interviews with the health professionals (doctor and nurses) and the monk

For the interview with the doctor the questions were adjusted to suit the situation (Merriam, 1988) and to cover the desired research topics. When interviewing the nurses, I found that the first nurse responded well to the questions and therefore only some minor adjustments were needed (Merriam, 1988) for subsequent interviews. However, the nurses were worried about the content of the interview and felt that they were being examined (see appendix 6). Therefore, I had to clarify my position and the nature of the research. I interviewed the monk about the influence of Buddhism on the child, family and healthcare (see appendix 8). Nurse instructors was interview following the nurse Instructor (see appendix 7). At the end of the

interviews and before I concluded them, I gave all interviewees the opportunity to raise any issues and to correct any information they had given me.

3.6.5 Data collection 3: Documentation

In research terminology documents are any material that is constant and reusable (Yin, 2003). It can be text (Burn and Grove, 1999) and can include “letters, memoranda, agendas and other written report or events, administrative documents, formal studies, newspapers or articles” (Yin, 2003, p.86) as well as non-textual material, such as films, television programmes and still images, like “pictures, drawings and photographs” (Robson, 2002, p.349). Whether it is presented in a different format including internet material, publically available or not, it is a rich source of data (Burn and Grove, 1999). Document analysis is a technique used to gather and study documents for purpose of research. According to Yin (2003) documents are stable and repeatable and are an unobtrusive measure in the research (Robson, 2002). They offer the researcher a chance to corroborate or contrast information from other sources (Yin, 2003; Robson, 2002). Like other data collection methods, documents have their own bias and one of the main ones is the selection bias caused by difficulties in retrieving relevant documents, not knowing if documents are relevant or simply the lack of documents. Another issue is that documents have been developed for a certain purpose which might raise questions about their value, purpose and role in a research study (see appendix 9).

3.6.5.1 Selected documents

Taking into account the study’s aims I decided to use documentation as a supportive data collection method (Robson, 2002), fully aware of Merriam’s (1988) reservations. She warns that because documents contain information that has to be interpreted by the researcher, they should be used carefully. Nevertheless, documents offer an opportunity to draw on specific details of evidence to corroborate other sources which widened the opportunities I had to learn more about the nature of the setting (Yin, 2003), even though I had previously been familiar with it.

Documents relating to the care of the child and the education of nurses were reviewed in order to explore the presence of family-centred care (for example by involving the family in decision-making or considering their preferences) in both the prescriptions and plans made as well as in the written communication between health professionals. The following documents were reviewed:

- nurses' and doctor's notes relating to the child period of study,
- the information material and leaflets used,
- the curriculum document used for the education of nurses in the location.

A proforma in 3.8.1.2 was used to review the documents. It was based on core concepts of Family-Centred Care, as set out by Shelton et al. (1987), as a guide. I spent a total of 3 weeks reviewing 5 nurse's and 5 doctor's notes, 1 thalassaemia handbook for parents/children, 1 manual detailing the development of health indicators, 1 human development plan and finally, I reviewed the nursing curriculum and teaching plan for one week.

The doctor's and nurses' notes contained information on the child's health, while the thalassaemia handbook included details for the education and instructions for thalassaemia care for the family. The handbook contained details about the development of health indicators, healthcare policies and a guide on child development which offered advice to guide parents.

3.6.5.2 The process of collecting the documents

The head nurse, who functioned as a gate-keeper, gave me permission to access any relevant documents during my fieldwork. Although I already had permission to access the children's medical records and other documents, I asked her again before I accessed them. I implemented the strategy of selecting the "right document", "read them" and "think about them" (Thomas, 2011: p.164). I chose documents I considered relevant for my study and then spent time reading them and find aspects relating to the characteristics of family-centred care. I accessed confidential documents and patient folders on the days after the interviews (Wednesdays and Fridays). While I was permitted to take notes from the documents, I had to return the originals on the same day.

3.7 Transcription and translation procedures

Transcription

This section discusses the strategies employed to ensure the accurate transcription and translation of all data. Transcribing data, especially interviews, is a necessary part of qualitative studies (Lopez et al., 2008). Transcribing is the conversion process of spoken words into the written form which is sometimes difficult because speech usually includes incomplete phrases or sentences (Munday, 2001).

Repeated listening to audio-recordings helps to ensure that the meaning of statements of participants in the written transcripts is clear. I therefore listened repeatedly to the audio-recordings of particular statements in order to make sense of what the participants had said and, if necessary, added words to make the meaning explicit.

The observations and documents had been documented in Thai and were preliminarily recorded in note form during the course of the observations and at the end of the day. I carefully reviewed the information and stored it in a text editor file. The data from the interviews was recorded in “Kum Mung”, a dialect used in the North of Thailand, and was then transcribed. I was able to transcribe all the data myself due my familiarity with both Thai and Kum Mung as I have grown up speaking the language and its dialect. I began learning English as a foreign language when I was 11 years old.

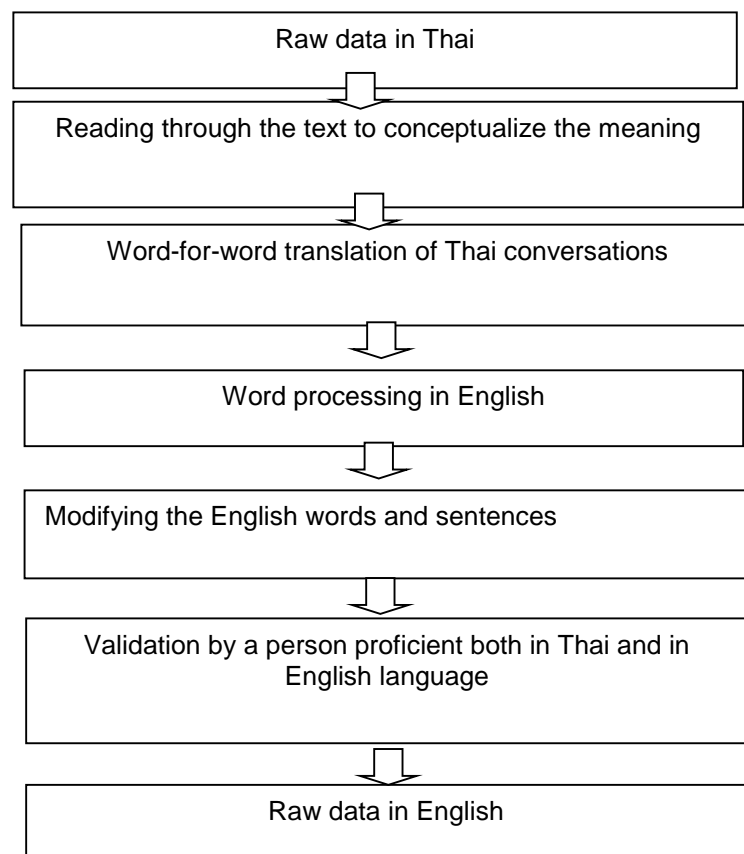
Translation

Twinn (1998) suggests that the researcher and the participants in cross-culture research should ideally be of the same native culture and use the same language. Whilst this was achieved during the data collection process, the results had to be translated because I was registered for my doctoral studies at an English university and was consequently writing my thesis in English. Translation is the process whereby the original written text (source text) is changed into another language (target text) (Munday, 2001).

This step should be undertaken by a professional expert translator, as the quality of the translation will have a direct impact on the quality of the research findings and the resulting reports. However, I was deterred by the cost of hiring such a translator. Moreover, I was concerned that professional translators may not understand the

field-specific jargon (Squires, 2008). Healthcare terminology and words used in paediatric care are specific and complex and as a result potentially confusing to an outsider or a novice translator. Thus, I felt that because of my language and professional skills as well as my deep understanding of the embedded culture I was the most appropriate person to translate the data. Having only one translator can help to ensure the consistency of a translation (Twinn, 1998). However, decisions made during the translation process have a direct impact on the trustworthiness of research and require a balance between language proficiency and cultural knowledge (Denzin and Lincoln, 2000). Consequently, I had to make a number of translation-related choices which will be discussed in the next section.

Figure 6: The process of translation in this study



3.7.1 Managing the complex process of translating data

There were a number of issues related to the translation from Thai and/or “Kum Mung” to English which will be discussed in this section. The interpretation of

spoken language is as important as that of the written language and Lopez et al. (2008) assert that verbatim transcripts and translations are necessary because they capture the richness of the participant's narrations. However, not every word in the data could be translated directly in terms of its meaning in this study. Thai proverbs, for example, had to be translated into English before their true meaning could be revealed:

Thai	เอาใจเขามาใส่ใจเรา (“Aou Jai Kao ma sai jai rao”)
Literal translation	“put yourself into the person’s shoes”
Meaning	“be considerate”.

Secondly, Thai sentences often omit subjects, objects and conjunctions. For example, a parent said “ไม่ได้ทำอะไร” or Mai-dai-tum-ar-rai which, when translated literally says “Do not do anything”. The subject and object were omitted and it is difficult to identify who is taking action in this statement. Thirdly, some words cannot be translated from their original dialect and language as there is no equivalent word in English. In these instances, the original words were kept and not translated. Fourthly, Thai verbs are not inflected whereas English verbs are. They do not indicate the tense in the sentence so that I had to be careful during the transcription and translation. For example, the literal translation of “พยาบาลบอกว่าลูกต้องรักษานาน และต่อเนื่อง แม่ต้องช่วยดูแล” is “nurse say comment child have to treatment long time and continue mother have to help look after”. The meaning of the sentence is “the nurse said that the child needs treatments for a long time and the mother should help her child”. In addition, Thai nouns are not differentiated by singular or plural. “เขา” or “Kao”, for instance, means him/her, while “เด็ก” or “Dek” means child or children. On a similar note, some pronouns, such as “Mor”, can mean doctor or other health care staff, in which case I had to clarify with the participants who they were referring to.

The misplacing of the word order can also lead to difficulties in capturing the meaning of an utterance. I managed this ambiguity by re-listening to the original recordings and by taking the grammar and the context into consideration.

While translating, I often added subjects or appropriate words to make the sentences understandable to the English speaking reader. “ไปกลับก็สองร้อยแล้วละ”, for instance, literally translates into “go-return is 200”. It really means “I spent 200 Baht for a return ticket”. This information is still incomplete and inaccurate as the

participant also implied that the tickets were expensive which was expressed by saying it in a high pitched voice. While it was not explicitly said so, the implied emotions and the meaning was clear to me: “The transportation fares are expensive. A round trip ticket costs two hundred Baht.” It can also avoid misleading interpretations of the words participants use and the information they give.

I might misunderstand some of the interviewee’s words and the resulting translation can cause significant confusion and further deviation from the original interviews. For example, one participant said their child is “อะไรก็ได้” – “feel it is ok”. What this participant was trying to say was that she felt disappointed because she was not able to control the situation at the hospital and did not know how to deal with it. The word-for-word translation of this may result in an inaccurate meaning. For this reason, I had to modify several sentences and the sentences below exemplify the process.

Northern Thai language: “ข้างเบิ้ลเตอะ แล้วแต่เบิ้ลจะยะอย่างไร เหมามาหาเบิ้ลแล้ว อื้อเบิ้ลช่วยเฮา”

Thai Official Language: “ไม่ต้องคิดว่าพยาบาลจะทำอะไร แล้วแต่เขาพยาบาลจะตัดสินใจ เหมามาขอความช่วยเหลือ ให้เขาช่วยเรา”

Before modification: I do not think what nurse does. Let nurse decides. We are asking for help give them help us.

After modification: I do not mind what care the nurse provides. I let the nurse make the decisions. I am asking for help and I give her permission.

The final issue is that the basic components of a Thai sentence are a subject, a verb, and an object with some modifications. But the language contains nuances and subtleties and adding a particle at the beginning or the end of a sentence or using a grammatical marker can influence its meaning. Sentences can include auxiliary units and in Thai orthography punctuation at the end of a sentence is not used. This makes sentences difficult to define as there is no sign to mark their end (Aroonmanakun, 2002).

Thai person may state the following question, for instance: “เธอ อยู่ ที่ ประเทศอังกฤษ มา นาน เท่าไหร่ แล้ว”. This when translated literally says “You live at England come how long already?” and is in modified English “How long have you been living in England?”. The response to this question is “ฉัน อาศัย อยู่ ประเทศอังกฤษ มา แล้ว 5 ปี” translates into “I live

be England come already five years” and means “I have been living in England for five years”.

3.7.2 Verification of the translation

As stated above, I had to make a number of translation-related decisions to report the data collected in one language and present the findings in another. I was aware that a translation should reflect the original text as accurately as possible, while at the same time sound naturally in the target language, and that it should be presented in an understandable manner covering all dimensions of meaning (Birbili, 2000; Larkin et al., 2007; Lopez et al., 2008). Birbili (2000) discusses the need for dealing with translation dilemmas, such as parallel meanings of words, by consulting other people. I decided to engage external translators in the translation process. Once I had completed the translations, an English-language academic from the Chiang Mai University and a nurse instructor who had studied for her PhD in the United States reviewed all documents to ensure the accuracy of the content translated. Working with these individuals strengthened the rigor of the translations and consequently the data. The process of translation and verification is described in the following table and figure:

Table 6: An example of a translation check in an interview transcript

Raw data in Thai
<p>Q: คุณแม่ได้ดูแลน้องอย่างไรบ้างครับ ในช่วงเวลาที่น้องให้เลือด</p> <p>A: ฉันดูระยะว่าเลือดลงเร็วหรือช้า ดูหยดเลือด ถ้าเร็วก็บอกพยาบาล หรือ ถ้าช้าก็บอกพยาบาล ก็ต้องดูนะค่ะ เพราะเขาต้องดูแลหลายคนอาจจะดูแลไม่ทั่วถึง พยาบาลอาจมองไม่เห็นปัญหา เพราะบางทีพยาบาลก็จะมาถามว่าเป็นยังไง เลือดช้าไหมพี่ เราก็บอกเขาที่เราดูมา</p>
Raw data: word-for-word translation into English
<p>Q: How do you help your child while she has blood transfusion?</p> <p>A: I look at blood drop too fast or too slow look at blood drop. If too fast I tell nurse or too slow I tell nurse. We have to look because nurse look after many patients. She may not see the small problems because nurses sometimes ask how blood slow sister I tell her I look for</p>
Raw data in English after modification
<p>Q: How do you help your child while she has a blood transfusion?</p> <p>A: I take care of the blood flow by looking at the drip rate of the blood. If I find it too fast or too slow I tell the nurse. I do this because she takes care of many patients. She may not notice this problem. The nurses sometimes ask me how the flow rate is and I tell them my observations.</p>
Raw data in English after translation check
<p>Q: How do you help your child while she has blood transfusion?</p> <p>A: I observe the blood flow in that I observe drip rate of the blood. If I find that the flow rate is too fast or too slow I tell the nurse. I take on that role because the nurse looks after many patients and may overlook this small problem. The nurses sometimes ask me how the flow rate is and I tell them my observations.</p>

3.8 Analytic procedures

The purpose of a qualitative study is to produce results which is achieved through the cumulative activities of analysis, interpretation and presentation of findings (Patton, 2002). Qualitative data analysis involves the examination, categorisation, tabulation, and the combination of the evidence to produce findings (Yin, 2009). This process includes familiarising oneself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming them, and producing the report (Braun and Clarke, 2006).

Although, there are many approaches to qualitative data analysis, there are some elements that are common to most of them. Thematic analysis and qualitative content analysis, for example, share a common approach (Braun and Clarke, 2006; Polit and Beck, 2008). Thematic analysis as a generic qualitative analytical approach is not limited to a specific qualitative methodology which enables researchers to condense extensive and rich qualitative data to codes, and then identify, analyse and report patterns within that data (Braun and Clarke, 2006). It is a widely accepted analytical method in healthcare, because it allows the researcher to integrate data derived from different collection methods (Boyatzis, 1988) and to analyse it inductively and deductively (Braun and Clarke, 2006). Using a thematic analysis, the researcher can search for recurrent and important themes to describe the phenomenon (*ibid.*). Its flexibility makes thematic analysis especially suitable for this study. However, this type of analysis is an independent qualitative descriptive approach and has been described as “a method for identifying, analysing and reporting patterns (themes) within data” (Braun and Clarke, 2006: p.79). A qualitative descriptive method also teaches researchers core skills which can be applied to other forms of qualitative analysis. Vaismoradi, Turunen and Bondas (2013) warn that the thematic analysis method has received little attention and many researchers do not fully explain what they are actually doing when carrying out a thematic analysis.

The type of analytical approach adopted by any study depends on the research objectives and questions (Crabtree and Miller, 1999; Denzin and Lincoln, 2000). I maintained the rigor of thematic analysis by following a set step-by-step process of analysis. The data collection process provided me with qualitative data that was in-depth, described situations and people, their interactions and observed behaviours.

It described events that its participants experienced as well as their attitudes, thoughts and beliefs. The data was derived from observations and included as many direct quotes from people who have used the services of the thalassaemia clinic as possible (Patton, 2002).

Boyatzis (1998) asserts that thematic analysis can identify theory-driven codes, which are derived from the researcher's or other existing theories, inductive codes, which are derived bottom-up from the data or prior-research driven codes. Deductive analysis seeks to answer questions about the prior framework used in the inductive analysis to reach the interpretive understanding. Inductive analysis seeks the "What", "How" and "Why" of a phenomenon and leads to a hypothesis. (Boyatzis, 1998; Braun and Clarke, 2006). This study has adopted a hybrid method of inductive and deductive thematic analysis. Fereday (2006) recommends this hybrid method of analysis because it incorporates both the theory-driven deductive approach and the data-driven inductive approach.

I attempted to represent a view of the actual phenomena via a systematic process of deductive and inductive analysis, identifying topics in the texts that are progressively integrated into themes. Therefore, my approach consists of two stages, which are described in the following sections.

3.8.1 Deductive analysis

In order to recognise and describe the family-centredness of the care provided to the children in this study, any elements of that care that represent the facets of an established model of Family-Centred Care (Shelton et al., 1987) had to be identified and noted. This required the initial part of analysis to be deductive, which is less common in social sciences but is increasingly used to bridge the gap between inductive qualitative research and other qualitative approaches (Pope et al., 2000; Pope and Mays, 2006).

3.8.1.1 Familiarisation and preparing data

The first analytical step was familiarisation with the raw data to develop an idea of the current situation and themes by listening to tapes, transcribing, reading

transcripts and studying notes (Pope et al., 2000; Braun and Clarke, 2006). At this stage, the data set was divided into two categories. The first was data relating to parents, children, nurses, and doctors and the second was data from the nurse instructor and a monk, i.e. people who influenced the healthcare principles and social context. This second set of contextual data was required to increase my understanding of the first set of data. The case comprised three types of data: observation, interview and documentation, which were cross-referenced to achieve triangulation (Figure 7).

Figure 7: Data sets of case and context

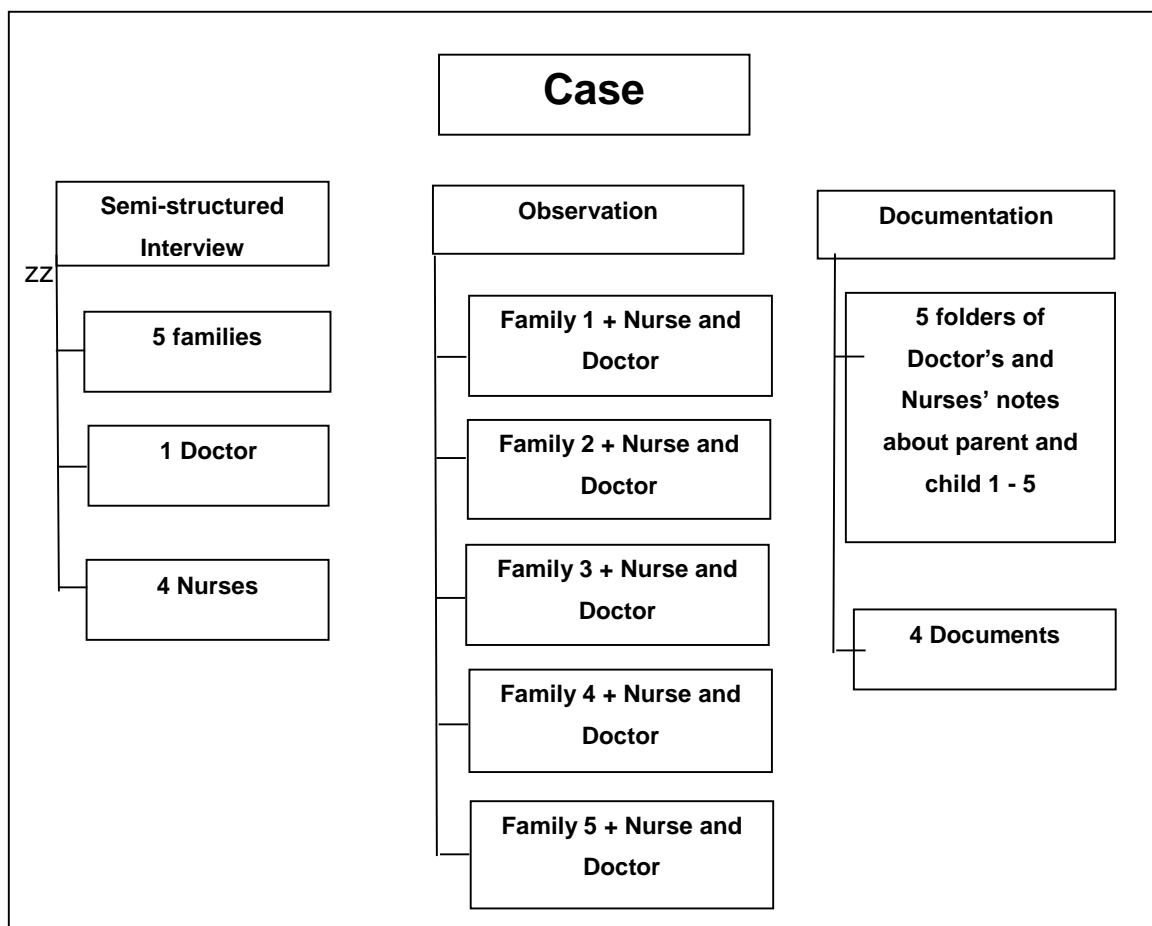
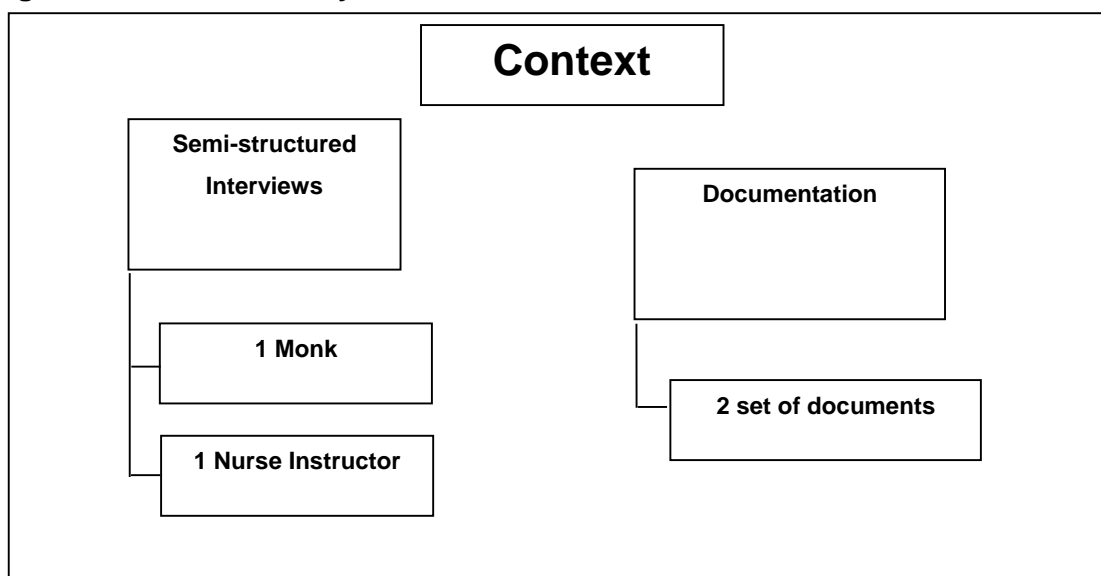


Figure 8: Context of study



This familiarising with and preparing of the data stage also involved my field notes on the data collection process. I read the observation field notes and my research diary until I was very familiar with both. The observational data reflected my view of the actual events and behaviour witnessed (Ritchie and Spencer, 1994).

3.8.1.2 Identifying a thematic framework

I commenced the process of deductive analysis by identifying distinct and defining elements of family-centred care based on an existing recognised model (Shelton et al., 1987). These identified elements were:

1. Recognition that the **family is the constant** in the child's life while the service systems and personnel within those systems fluctuate
2. **Facilitation of parent/professional collaboration** at all levels of healthcare
3. **Recognition of families strengths and individuality** and **respect** for different coping strategies
4. **Sharing of unbiased and complete information** with parents about their child's care on an ongoing basis in an appropriate and supportive manner
5. Encouragement and facilitation of **parent-to-child support**

6. Understanding for and **incorporation of the developmental and emotional needs** of infants, children and adolescents and their families into the healthcare delivery systems
7. Implementation of appropriate policies and programmes that are comprehensive and provide **emotional and financial support to meet families' needs**
8. Assurance that the design of healthcare **delivery systems is flexible, accessible and responsive to family needs**

The data was examined for any information that represented actions or omissions, statements or observations of any of these eight elements. However, the family-centred care framework used had originated in an English-speaking Western country, and aspects of this can be expected to vary in its outward expression due to cultural differences. I, therefore, avoided using the definitions too narrowly, but, as with the translation process, considered their broader meaning.

3.8.1.3 Indexing

All data from the data collection was used throughout the analytical process, classified and placed in corresponding elements as outlined below.

Indexing is the third analytical step, after the transcribing and translating and it requires the identification of portions or sections of the data that correspond with a particular theme. I applied the thematic framework to all the data in textual form by annotating the transcripts with numerical codes from the index, supported by short text descriptors to elaborate the index heading (Ritchie and Spencer, 1994). An example for this method can be found in the following table.

Table 7: Indexing

Theme framework	Initial Index
The family is the constant	-1A The nurses and the doctor are familiar with the child and its family. -The doctor invites the parents to stay with the child during the examination.
Facilitation of parent/professional collaboration	4C Involvement in care: "Could you please hold your child's hand then I will take its blood."

In the initial stages of this indexing, I was uncertain which index was relevant for the original framework and so I read the principles of coding again. I struggled with the meaning of the interview results and decided to read the entire raw data several times to ensure that the indexing was accurate. In addition, I discussed this step with my supervisors.

The original framework was used to describe and better understand the nature of FCC in the thalassaemia clinic and among health professionals, the challenges and barriers they experienced, how the hospital supported or failed to support nurses in their endeavours, and the skills that the nurses used to incorporate FCC into their practice.

3.8.1.4 Charting

The next step was charting the appropriate part of the thematic framework to which the participants' utterances relate. Unlike simple cut and paste methods that are used to group verbatim texts, the charts contained summaries of the participants' views and experiences. The charting process, thus, involved a considerable amount of abstraction and synthesis and it was important to maintain an open mind and not force the data to fit the pre-selected themes. However, since the research was designed around these themes, it is most likely that they guided the deductive analysis in some way. Ritchie and Spencer (1994) stress that the thematic framework is only tentative and that there are further chances of refining it at subsequent stages of analysis. The important point to remember here was that

although the pieces of data were extracted from their context, the data remained clearly identifiable as to which case it came from. For clarity, cases were always kept in the same order in each chart (Ritchie and Spencer, 1994).

Table 8: Charting

Theme framework	Initial Index
1. Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate	1.1 Assurance nurse understand the parents is important 1.2 Support by providing self-care 1.3 Invitation to participate in child care
2. Facilitation of parent/professional collaboration at all levels of health care	2.1 greeting with warm personality 2.2 providing education 2.3 with/during routine procedures

3.8.1.5 Mapping and interpretation

Finally, mapping and interpretation was undertaken and the charts were used to define concepts, map the range and nature of phenomena, create typologies and find associations between themes with a view to provide explanations for the findings (Ritchie and Spencer, 1994). This involved the analysis of the key characteristics as laid out in the charts so as to ensure that interpretations by the researcher echo the real attitudes, beliefs, and values of the participants. It was at this point that I had to be aware of the objectives of qualitative analysis, which are: "defining concepts, mapping range and nature of phenomena, creating typologies, finding associations, providing explanations, and developing strategies" (Pope et al., 2000: p.6). The process of mapping and interpretation was influenced by the original research objectives as well as by the thematic framework based on Shelton et al.'s eight elements of family-centred care.

3.8.2 Inductive analysis

The deductive analysis described above searched for pre-defined aspects of family-centred care within the data. As this analytical approach cannot be expected to explore the data completely, I had to conduct an inductive thematic analysis as well.

The three data sets, observations, interviews and documents, were reviewed again one by one. As I had personally undertaken the transcription and translation of the data as well as completing the process of deductive analysis, I had become very familiar with the whole data set which enabled me to remember the raw data. The aim of the inductive analysis was to gain a new understanding and potential meaning of the data (Mile and Huberman, 1994). Therefore, I started looking for words, phrases, sentences and paragraphs again, searching for issues other than those already known that might emerge in the data. These codes were categorised and united into new themes independent from the earlier frameworks and the process is described below.

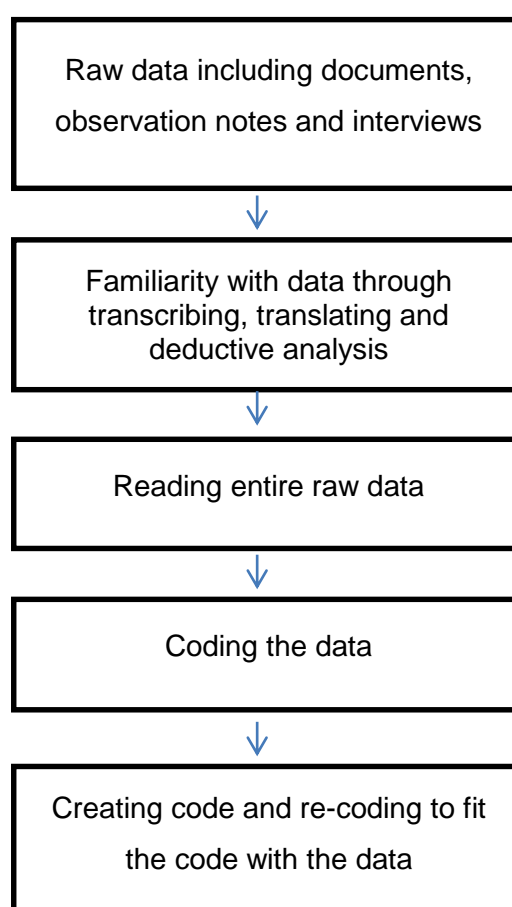
3.8.2.1 Coding data

Initially, I looked through the data and began by looking at the interview data, the observational field notes, followed by the notes of the documents and my diary records. I highlighted words, phrases, sentences, and paragraphs that indicated a theme which allowed me to code each new theme. I then undertook the same process for the data collected about each of the family followed by the data from the 4 nurses and a doctor. This process required either the use of the codes from the first dataset or the generation of new codes. I then applied the same process to the dataset from the nurse instructor and the monk.

Code segments were written in the right hand margin of each data sheet, which had been analysed by using a highlighter pen to increase visibility and to indicate potential themes. The highlighting of the actual spoken words and complete sentences of participants ensured that I avoided the potential loss of meaning.

Table 9: Code Segments

Data extract	First phase of code	Second phase of code
We have to hurry because the children and the parents come from other districts. Some of them come to the hospital by public transport and have to go home before the timetable close. (IN3-4)	-Response to parent need, -Perform speedy services	Providing effective care

Figure 9: Coding diagram

I proceeded to the next step when all datasets from the interviews, documents and observations had been coded. A long list of codes had been derived from the three sets of data and I started to consider the differences and similarities between the codes across the three data sets. These codes were then combined and I decided to display the data in tabular form in order to confirm their potential meaning and to

establish the code across three datasets. In addition, I reviewed codes and then divided them into categories. Codes were then grouped by taking their potential meaning into account (see appendix 13).

3.8.2.2 Grouping and classifying themes and sub-themes

Aronson (1994) offers a 4 step approach to develop a theme: "collecting data", "identify data that relate to a classified pattern", "combine and catalogue related patterns into sub-themes" and "build a valid argument for choosing the themes" (Aronson, 1994: p.1). Boyatzis (1998) and Braun and Clarke (2006) agree that a theme represents an identifiable pattern across a data-set, while Buetow (2010) defines it as a set of codes that recur generally and are linked to each other in a pattern.

At this stage, sub-themes were developed within the case analysis. I considered the factors that influenced family-centred care and combined related patterns into themes. Themes emerged from data formed a picture of the participants' experiences. I then reviewed all the data relating to each code and categorised it. The codes from three data sets were used to generate sub-themes and themes.

3.8.2.3 Reporting

I checked the selected themes for accuracy and selected quotations from the data that best reflected my findings and illustrated the nature of thalassaemia care for children at Lampang Hospital. Where results were found that differed from the original family-centred care framework, I demonstrated any adaptation needed to adjust the Western framework to the Thai context.

3.9 Ensuring quality and trustworthiness of the research study

The trustworthiness of qualitative research is often questioned by positivists because the concepts of validity and reliability cannot be addressed in the same way in naturalistic work as in quantitative studies, although there is some debate about this. For example, validity is a frequently used concept in quantitative

research but is equally applicable to qualitative research although the procedures used to demonstrate it may differ (Porter, 2007). Sandelowski (1993) rejects the use of the concept of reliability for qualitative research and suggests that trustworthiness is more suitable. The rigour of qualitative research is established by demonstrating trustworthiness in terms of credibility, transferability, dependability, and confirmability. Rigor is essential and without it research is worthless, fictional and loses its utility (Lincoln and Guba, 1985).

3.9.1 Credibility

Lincoln and Guba (1985) assert that credibility is established through the use of multiple techniques, such as triangulation, member checking and peer-debriefing. I personally collected all the data for this study and conducted the analysis. Marshall and Rossman (2011) stress that rich data can be gathered by an experienced researcher with good communication skills by using gentle probing for elaboration. Although I am not an experienced researcher, I am an experienced nurse with more than 10 years clinical practice which included getting patient histories. This has provided me with good interpersonal and communication skills.

I collected and triangulated the data from the interviews with the observational and documentation data. This not only supplemented the interview data, but also provided multiple views on actual phenomena.

The observation periods at the child care unit in the hospital were prolonged. I attended the department several times for prolonged periods of time in order to familiarise myself with the way that the department functioned and operated. I also became less of a stranger and potential threat to the nurses. During the observation days, continuous observation over the whole day was possible, and this investment in time enabled me to obtain a more in-depth insight into the families' and health workers' experience, which in turn helped my judgement on the relevance and focus of the observations (Lincoln and Guba, 1985; Spradley, 1980).

Within the analytical process my supervisors acted as peer-debriefers (Lincoln and Guba 1985; Creswell and Miller, 2000). They discussed the research findings with me at regular intervals, exposing me to 'searching questions' and helped me 'test'

any emerging findings and insights. This technique was applied to the data collecting process and analysis as well as to my position to the data and its analysis. For time reasons, it was not possible for me to present my data or my findings to the participants so as to gain respondent validation. I have, however, presented the findings to other audiences, e.g. the nurses in the hospital at Lampang, etc.

3.9.2 Transferability

Transferability means that findings from one research setting can be applied to another setting (Lincoln and Guba, 1985; Shenton, 2004). Yin (2003) suggests that transferability is achieved by being transparent and explicitly describing the study's methodology, setting and participants in vivid detail. Stake (1995: p.85) uses the term "naturalistic generalisation" to indicate transferability specifically for case studies.

I have provided extensive descriptions of the design, setting, sampling, data collection, analysis, and findings. The study was conducted in Thailand, which has its own unique culture and religious traditions described in Chapter 1, and the context was explained clearly to allow the reader to decide whether the findings are transferable to their own setting (Lincoln and Guba, 1985).

3.9.3 Dependability and confirmability

Merriam (1988) states that dependability and confirmability are accomplished by the use of audit trail, triangulation, and reflexivity. Dependability refers to the stability of data over time and under different conditions (*ibid.*). Therefore, it is important to state the principle and criteria used to select participants and detail the participants' main characteristics so that the transferability of the result into other contexts can be assessed.

The principle of confirmability is the qualitative investigator's comparable concern for objectivity (Patton, 2002). The researcher has to ensure that the findings are based on the experiences and ideas of the participants, rather than on the characteristics and preferences of the researcher. Miles and Huberman (1994)

consider the extent to which the researcher admits his or her predispositions a key criterion for confirmability. The role of triangulation in promoting such confirmability is emphasised and serves in this context to reduce the impact of the researcher's perspectives (Denzin and Lincoln, 1994).

The recruiting process was defined as well as the process of collecting data and in addition to ensuring dependability and confirmability, it will provide an audit of the research process (Lincoln and Guba, 1985). Audit trail offers the reader trace detailed methodological description and enables the reader to determine how far the data and constructs emerging from it may be accepted.

In qualitative research, reflexivity is a common method. The researcher reflects on how their actions, values and perceptions impact upon the research setting (Cutcliffe and McKenna, 2002). This self-examination exposes assumptions and biases that might affect the data collection and analysis (Gerrish and Lacey, 2010).

To ensure dependability, I reported the research study in detail, allowing an auditor to repeat this research if necessary to achieve the similar results (Shenton, 2004). I have described the research process explicitly, including an explanation of the design (an embedded single case study) used and the rationale behind it in order to allow readers to judge its appropriateness (Marshall and Rossman, 2011).

3.10 Ethical issues

Lindsay (2007) asserts that all research in health and social care must follow certain ethical principles in order to guarantee its standards of practice and conduct. The Research Ethics Framework developed by the Economic and Social Research Council includes the following criteria: concern for the welfare and rights of participants, respect for participants, the provision of knowledge/information and the protection of the researcher in order to guarantee that the research is valid and ethical (Patton, 2002).

When undertaking research that involves human beings, a researcher is required to consider a number of specific issues and concerns related to research ethics. These consist of:

- 1) informing participants in detail about their involvement in the research,
- 2) avoiding any physical or emotional harm to a participant,
- 3) allowing free choice to participate in the study, and
- 4) ensuring privacy, confidentiality, and anonymity

(Polit and Beck, 2006; Munhall, 2007; Pope and Mays, 2006).

I addressed each of these individual issues in the ethic research proposal applications that were submitted and subsequently approved by the Faculty of Health Research Ethics Committee at the University of East Anglia and the Management Committee of Lampang Hospital in Thailand.

1) Informing a participant in detail about their involvement in the research

All participants received comprehensive information, both in verbal and written form, about the research before they were asked to. All potential participants were given the information leaflet and consent form three days before they were asked to give consent and were given the opportunity to ask questions.

Other children and parents who were attending the clinic during the data collection period were informed of the research project, were made aware of my role as a researcher and the purpose of my presence through a notice placed in a prominent place in the clinic.

2) Avoiding any physical or emotional harm to a participant

It was not anticipated that participating in this research would cause any distress to the participants. However, during interviews, I looked out for any signs of distress as the interviews and observations could potentially induce stress. Had this occurred, the interview would have been discontinued immediately.

Participants knew that they could stop the interview at any time and, at the end of the interview, were given time to speak about their feelings to ensure that they were not left distressed after talking about sensitive topics.

The parents were aware that any information that was of concern to the child's well-being would be reported to the child's doctors or the relevant authorities. If any unsafe nursing practices were observed, they would be

reported, according to the risk report protocol of the hospital, but this was not required as no unsafe practice occurred.

The children and their parents were in the clinic for 7-8 hours and during this time, children were interviewed with their parents present so that no chaperone was required.

The same measures were taken to ensure that no physical or emotional harm was inflicted on the nurses, the doctor, the monk and the instructor who participated in the study. As a result, none of these participants showed any signs of distress during the data collection procedures.

3) Allowing free choice to participate in the study

Once they had given their consent, all participants retained the right to withdraw from the study at any time, without having to give a reason and without any repercussions to the parents, their children, their treatment or professional standing. The same principles were applied to the monk and nurse instructor who participated in the study. Parents gave formal consent for themselves as well as their children. Children only took part in the study if they also assented to participate (see appendix 3).

4) Ensuring privacy, confidentiality, and anonymity

Confidentiality was ensured through the use of pseudonyms for all participants. Where children and parents featured in the field notes or thalassaemia clinic processes, all identities were anonymised using abbreviations. All healthcare notes were reviewed following the permission from the director of nursing on the day on the hospital premises and returned immediately. During this review, the doctor's and nurses' notes were not seen by anyone else.

3.11 Conclusion

This chapter has given a detailed outline of the methodology, methods and analysis used in this study and explored the issues of trustworthiness and ethics related to it. The out-patients department in Lampang hospital in the Lampang province was

selected as the case study of this research project. The participants included children, parents, nurses, a doctor, a nurse instructor and a monk. Semi-structured interviews, observation and documentations were the methods of data collection. All data sets were analysed inductively and deductively using thematic analysis and the results are presented in the next chapter.

Chapter 4

Results

This chapter presents the findings of the data collected in observations, interviews, and document analysis in the Lampang province of Thailand. The data was initially analysed deductively using the 8 criteria of family-centred care and these results will be presented in the first section of this chapter. The deductive analysis was complemented by an inductive thematic analysis and the themes and sub-themes developed from the three data sets are presented in the second section of this chapter to complete the picture of family-centred care for children with thalassaemia.

The results in this chapter include verbatim quotes from interviews and notes from the observations and the document analysis. The quotes are labelled with the following identifications:

O - Observation, I - Interview, DOC - Document,
F - Family, N - Nurse, D – Doctor, T - Nurse instructor, and M -
Monk.

They are followed with two numbers: the first identifies the family, nurse, etc., and the second indicates where this quote or observation can be found in the transcript. Therefore, (IN3-1), for example, relates to 'interview with Nurse 3' and the quote can be found on Page 1 of the relevant transcript.

A profile of the participants and documents analysed in this study is presented in the following tables

Table 10: profiles of families and children

Family	Mother or father interviewed	Age of child	Number of years since thalassaemia was diagnosed	Number of years the child has been attending hospital	Does the child receive injections at home?	Does the child receive healthcare services between hospital visits?	Length of observation for data collection / length of interview
1	Mother	12 Years	12 Years	12 Years	Yes	Yes	7¼ hours / 1 hour
2	Father	10 Years	10 Years	10 Years	Yes	Yes	7½ hours / 1 hour
3	Mother	10 Years	10 Years	10 Years	Yes	Yes	7¼ hours / 50 minutes
4	Mother	10 Years	10 Years	10 Years	Yes	Yes	7½ hours / 56 minutes
5	Father	10 months	8 months	6 Months	No	Yes	7½ hours / 48 minutes

Table 11: additional information about parents and children

	Education		Occupation	Extended Family	Distance between home and hospital (km)
	Child	Parent			
Family 1	6 th year	High School	Farmer	Grandparents (live in the same village)	56
Family 2	4 th year	College	Vendor	Grandparents (live in the same house)	29
Family 3	4 th year	Bachelor's degree	Owner of local business (grocery shop)	Grandparents (live in the same house)	109
Family 4	4 th year	College	Farmer	Grandparents (live in the same house)	5
Family 5	-	Bachelor's degree	Owner of local business (wood store)	Grandparents (live in the same village)	114

Table 12: Profile of healthcare staff, nurse instructor and monk

	Position in the clinic	Professional qualification	Work experience in thalassaemia clinic (years)
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Nurse 1	Registered nurse	Bachelor of Nursing Science	17
Nurse 2	Registered nurse	Bachelor of Nursing Science	26
Nurse 3	Registered nurse	Bachelor of Nursing Science	11
Nurse 4	Head nurse	Bachelor of Nursing Science	31
Doctor	Haematologist / head of clinic	Doctor of Medicine	2
Nurse Instructor	External co-worker	Master Degree	-
Monk	-	Master Degree	-

Table 13: Reviewed documents

Number	Nature of document	Title of document
5	Medical records	Nurse's and doctor's notes
1	Handbook	Thalassemia handbook for parents / children
1	Manual / planning	Human development plan (includes statement of policy)
1	Nursing curriculum / teaching plan	Nursing curriculum

4.1 Deductive thematic analysis

4.1.1 Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate

The first principle of family-centred care asserts that the family is permanently present providing constant support for the child whether at home or at the hospital. The data demonstrated that throughout the process of care at the hospital, the parents were never separated from their children: *'I am a mother, I sympathise with my son. I have to support him because I want him to be safe' (IF4-6)* and *'The parent always stays with the child and supports the child by telling the child to follow the nurse's orders (OF1-2)*. Their presence was also acknowledged by the staff: *'I invite them to stay with the child when I am doing nursing procedure' (NI1-3)*.

The parents also remained with the child throughout all the medical procedures: *'I spend time here [near child's bed] when he has blood transfusions' (FI2-4)*. In the

laboratory nurses asked the parents to help with the collection of a blood sample by assisting them by touching and talking to their children, for example.

The doctor and all the nurses agreed that parents are important for the child and they allowed them to remain with it during medical procedures:

'They are fathers or mothers. They should know about thalassaemia care to help their child' (DI1-1).

'Parent is the first priority. The most important people in the child care when the child is ill and has the treatment. A child is dependent and needs support' (IN2-5).

Not all parents realised how important they were for their children and felt that their contribution to their children's welfare was comparatively minor: *'I just support him. I sit beside him and talk to him to reduce his stress' (IF2-7)*. The children in families 1, 2, 3 and 4 appreciated the presence of their parents as it comforted them, reduced stress and discomfort while they were at the hospital: *'I want my mother coming and sitting with me. I am happy to see my mother and staying with me when I have blood transfusions' (IF3-1-Child)*.

During one interview the fact emerged that this close inclusion of parents had been a comparatively recent development. One parent reported that when they first came to the hospital, she was separated from her child during the medical treatment because the nurses believed that it would be better for the mother:

'First the nurses did not allow me to stay with her. ... They explained to me that they do not want me to be upset when I saw my daughter crying' (IF1-3).

However, over time the nurses realised how important parents are for their children and recognised that their presence made their children feel more comfortable: *'We know that the child needs the parents; therefore the parents have to stay with the children' (IN4-5)*.

The doctor, nurses and parents agree that children need consistency from the family and invited parents to stay with the child throughout the process of care:

'The child's health will be good, if the parent become a part of care. The parents need to care for their child correctly and continuously, whether in the hospital or at home' (ID1-10).

'Parent is the first priority person, the most important people in child care... for their child... and when the child became ill and during treatments' (IN2-9).

The doctor and the nurses see parents as the consistent caregiver and their potential for caring for their child was recognised when the nurse trusted them to continue the care at home: *'The child's health will be good, if the parent become a part of care' (ID1-1)*. The extended family also provides a form of constancy to the child when grandparents look after it together with or in the absence of the parents: *'My father-in-law comes with me and helps me look after him' (IF5-3)*. The nurses also considered the grandparent as key figures in childcare in some families.

In conclusion, the data demonstrates that parents were invited and allowed to care for the child throughout the process of care. The nurses and the doctor realised that they are important and that the children valued their parents' presence.

4.1.2 Facilitation of parent-professional collaboration at all levels of healthcare

Collaboration between healthcare professionals and the parents was apparent on many occasions throughout the process of care. The first occurred early on in the visit to the hospital, when a blood sample was needed to determine the child's need for a blood transfusion and other potential treatments. The nurse involved the parents in the assessment: *'We get the basic illness history by asking the parents about the previous blood transfusions' (IN3-1)*. Throughout the process of blood sampling the conversation was friendly, clear but brief and neither the parents nor the children asked anything. Nevertheless, all parents and children co-operated willingly and the former appeared comfortable to help the healthcare staff.

Significant collaboration with healthcare staff was considered necessary to improve self-care. The doctor believed that parents could look after the child but that they needed support when the child showed serious symptoms: *'They prefer to know their child's symptoms. If the child has anaemia, they expect to have blood transfusions. I think... participation depend on the parents' (ID1-9)*. More experienced parents knew their child's symptoms and were able to judge its condition.

In another part of the treatment parents assisted their children with walking to the toilet while the transfusions were in progress. As these movements interfered with the intended rate of the transfusion, the parents adjusted the roller clamp to maintain the normal rate. This happened with the consent of the nurses, who had taught the parents how to regulate the drip rate because they expected them to know how to look after their children during blood transfusions and to be involved in the care:

'I asked the mother to observe their condition during blood transfusion process because the child may have occlusion in line or loose' (IN1-8).

'Could you please keep your eyes on the blood bag? Please let me know immediately, when it has obstruction' (OF4-8).

When the parents noticed that the blood bag was nearly empty, they called for the nurse and *'while they were waiting for the nurse, they move the blood bag higher than normal to let the blood flow'* (OF1-16). The parents felt confident about their collaboration: *'I take care of the blood flow in that I observe drip rate of the blood. If I find blood drip is too fast or too slow, I alert the nurse'* (IF3-6).

The level of collaboration depended greatly on the parents' educational level and position in the family, which was most obvious in the case of family 5. The father negotiated the care his child should receive with the healthcare staff about and his actions can be explained with the fact that he had a bachelor's degree. He also negotiated the cost of treatment and was happy to spend extra money on different equipment:

'They provided the standard equipment. I have notified them of my plan that my son will have bone marrow transplantation. I delight to pay extra cost' (IF5-5).

Co-operation between the parents and all healthcare professionals occurred throughout the observation periods. However, this co-operation consisted mainly on the parents assisting with the provision of healthcare under the guidance of the healthcare professionals. In the interviews the parents were highly motivated to care for their child:

'I told them: if they are not confident in child care, please ask help from the hospital' (IN2-6).

'I can remember the advice because the doctor taught me to take the role of a doctor; however I am not a doctor. I have to observe critical signs' (IF4-2).

The activities and behaviours of the children and their parents can be understood as a type of extended self-care, which is exercised by following the advice from healthcare professionals and consequentially in collaboration with them. In addition, the parents expected to regularly come to the hospital where their children would receive medical treatment: *'The best thing I can do for my son is to take him to the hospital regarding appointment' (IF5-1)*. This included taking over basic healthcare activities: *'On registration the parents took their child's weight, height and temperature. In the blood transfusion process, the parent observed blood drip' (OF1-1)*. Their activities also included monitoring the child for *'fever after the blood transfusion' (IF2-6)*. One parent viewed this contribution to the child's care as being relatively minor:

'I have not helped them. I just feed my daughter and sit beside the bed to support her. The nurses care for my daughter by themselves' (IF1-5).

Parents were given a choice about the nature of their collaboration and the healthcare professionals recognised the importance of the parents' involvement: *'The nurse's duty is cooperation' (IN3-8); 'the child's health will be good, if the parent become a part of care' (ID1-8); 'the parents help a lot because they look after the child all the time. This includes giving the injections at home. The parents have to know about the timing and preparation of the medication' (IN3-2); 'the doctor wants me to care for my son at home. The nurse taught me injection procedure. It is not difficult procedure but it is difficult to deal with my son' (IF4-4)*. The nurses also invited all family members including the grandparents to participate in the care: *'Whether the parents are fathers, mothers or grandparents, I ask them every time because they are the closest care givers' (IN3-2)* and *'...all relatives are welcome to participate because they can care for the child' (IN1-11)*. The nurses' efforts were appreciated by the parents:

'I think they are working to full capacity. They are busy. I understand that their job is hard as the children are moody and naughty' (IF3-7).

Finally, the health professionals made great efforts to promote and enhance collaboration between themselves and the families but remained aware of their limitations. They tried to reduce these limitation by working together with a network consisting of local hospitals:

'I give the parents suggestion to meet the doctor at local hospital or this hospital. It depends on the parents to make decision' (IN3-11).

In summary, the collaboration between parent and healthcare staff occurs on several levels although it is most dominant on the level of medical care.

Experienced parents and new parents showed different levels of co-operation as the former knew more about care and the routine in the hospital. Parents realised they had to undertake the care of their child at home, for example by giving it injections. However, it is interesting to note that the level of collaboration is negotiated in some instances and that parents' involvement thus depends on the family's educational background or income. In addition, it is the nurse who initiates collaboration by educating the parents.

4.1.3 Sharing of unbiased and complete information with parents about their child's care on an ongoing basis and in an appropriate and supportive manner

Information sharing is recognised as an important aspect of the healthcare of children: *'The advice was appropriate. They showed me the current services step by step. It was clear and I did not get confused' (IF5-3)*. It is significant that the parents regarded the doctor as the main source of information and that the doctor was content to provide it: *'I am willing to spend more time when they need to talk with me and ask any questions' (ID1-5)*. This information was adapted to the unique circumstances of each individual family:

'It is difficult to decide who can involve in thalassaemia care. The parents who can afford extra cost and keen to learn more to improve their skill for child quality of life. They will ask me or consult me about making decision to choose medication such as oral medication [iron chelation] and bone marrow transplantation' (ID1-7).

However, the doctor suggested that she was not always the main source of knowledge as information is easily available on the internet: *'... I prefer to advise the parent to take benefit from the internet (ID1-10)'*. The parent of family 5 had a high level of computer literacy and, therefore, preferred to use the internet rather than wait for a doctor or nurse: *'I think that people in Thailand have different levels of literacy, I have got bachelor degree and therefore I can find other thalassaemia resources, for example on the internet' (IF5-6)*.

These self-learning approaches were effective for some families and the parents of family 5 had a good understanding of thalassaemia care. This led to greater co-operation with the doctor and the nurses and was reflected in the parents' confidence. For parents 4 and five this changed their role from a passive to an active participant:

'I will explain my son signs and symptoms. After that I will ask which treatment for my son' (IF5-6).

Information about the child's condition was shared with the patient and the parents after the blood sampling was completed. This prompt sharing of information had a positive effect on the children as they could soon receive the blood transfusion or be transferred to other departments. Nurse 4 emphasised the importance of collecting and sharing information: *'update information. We collect information from the child's parents. The parents can give us good information' (IN4-1)*. This process included that information was tailored to the level of previous knowledge or the individual child's specific needs and that it was phrased in non-technical language. Using simple words did not mean that the information transmitted was trivialised, which can be seen in the following example of a nurse communicating some of the results of the blood test to the family:

'Your child's haematocrit is about 25% that means your child have anaemia and is going to have blood transfusion today' (OF4-1).

The healthcare professional explained results to the parents who knew that this was useful information, not because they understood what it meant but because they understood the consequences of this information. It is important to note that most of the information flow went only in one direction: from the healthcare professional to

the child and its family. Even when the nurse communicated with them about the child's physical condition, the one-way information flow persisted:

'The nurse asks the child about the medicines that have been taken at home. "How many tablets of medicines do you have at home? Do you take them regularly?" "Yes, I take them every day"' (OF1-4).

The focus of the conversations remained on medical information. Any examination results, for example, were shared immediately with the families:

'A physical examination was observed being done unhurriedly, resulting in a relaxed and co-operative patient and the doctor informed the child and family of the findings immediately after completing his examination. The doctor spoke to the child and looked at the parent, while she did the physical examination. 'Let me see your eyelids, and your hands.' Then the doctor checked the child's eyes by looking at the eye lids and touching the child's hands. While he did the physical examination the doctor used simple word such as 'You are pale and need blood and then you are going to have a blood transfusion as usual' (OF1-5).

General information about the child's medical condition and treatment was also shared. This usually took place in form of health education provided by the doctor and nurse, ensuring that the parents cared for their child effectively. Each parent asked the doctor whether the child needed a blood transfusion and in each case this necessity was instantly confirmed:

'I ask a mother about anaemia. If a mother said her child has anaemia, I will verify it by looking at child's eye lids and lips and blood result after that I give the child blood transfusions' (ID5-13).

Healthcare professionals had to keep a balance between providing specific information to a child during the process of care and looking after a large number of children in the hospital. Despite the large number of patients, none of the consultations were rushed and the doctor had time for a conversation and allowed parents to raise questions or concerns. The exchanges observed did not always represent the two-way information sharing intended in the concept of family-centred care as a sharing of information did not consistently take place. While parents and healthcare professionals focused on medical issues in all the interactions, the communication also took the needs of the children and parents into account.

The healthcare professionals were also aware of the need for families to know about the condition and the care. They *'expect the parents to know in general about thalassaemia not only when to attend for a blood transfusion'* (ID1-1):

'I expect the parents to know the basic knowledge about self-care' (ID1-1).

'We expect the child to have proper care because that should lead to the child happy and better health' (IN2-7).

'We will teach children and parents about observation symptoms and medications to reassure they can care for the child properly' (IN2-2).

Therefore, the most prominent information sharing with the parents took the form of health education: *'The dominant aspect of this blood clinic is about telling, talking information'* (ID1-7), and *'giving information is the first priority and an important procedure to do at the same time, every time'* (IN2-6). The information focused on iron and iron-levels, nutrition and the detection of infections and anaemia.

The health education occurred predominantly verbally: *'The doctor and the nurses give me advice about nutrition, medicine. They always give verbal advice'* (IF3-4). Only some written information was used: *'I advise them about books, brochures, and internet websites to read. The parents have to learn from those sources rather than only waiting for the education from the doctor'* (ID1-4).

The nurses usually spend as much time with the patients and their families as necessary:

'I spend various amounts of time with the individual children, it depends on their problems. For example, a child who has a first blood transfusion needs more time, so I support them more, including counselling' (IN1-8).

But this advice had to be shortened at times to include only the most important issues and problems:

'The nurse at the clinic gave me advice that if I find fever, I have to bring my daughter to the hospital immediately' (IF3-1).

Communication with healthcare professionals was not always easy for the families as they perceived their own status as below that of the nurses. As a result, a lot of parents were reluctant to ask questions:

'I have no idea how to talk with the nurses' (IF1-3) and 'No, I did not talk with them. I am afraid to start a conversation because they may be in a bad mood when I ask' (IF2-9).

To counteract these problems, the nurses would *'ask open questions. We will give them an opportunity to share their experiences about the problems they encounter at home'* (IN3-4). They also used a language the families could understand: *'If they have problems to understand technical term, I will tell them or ask them using lay words'* (IN3-4). This adjustment was very important as advice given by doctors was not always understood by parents: *'I speak to them two or three times about self-care but they still do not understand. They do not understand because sometimes they are not able make sense of my words'* (ID1-2).

In order for the communication to work, nurses needed to develop a relationship of trust with the families and children:

'The development of relationship is the first step of working and treatment. Without it the parents may not be willing to open their mind and to answer the truth' (IN2-4).

This technique included the use of a family prefix, such as 'น้อง', or *'I will use the child's nickname such as น้อง so-and-so'* (IN3-2). The prefix 'น้อง' literally means sister and using it as a form of address means that the nurses treat the children and parents like close family members.

In summary, information sharing relates only to medical care and the healthcare staff provided information about the child's condition and the medical treatment needed. The gap in communication was reduced by addressing children and their parents as family members, although this address was mostly verbal. Conversations also aided sharing information but for some families this process was very one-sided as they merely listened to the nurses and followed their instructions. The effectiveness of information sharing dependent on the relationship between parents and healthcare professionals, as well as on the parents' educational background.

4.1.4 Implementation of appropriate policies and programmes that are comprehensive and provide emotional and financial support to meet the families' needs

For all participants in this study the healthcare provided was free and a number of policies, procedures and circumstances ensured that the emotional well-being of the children and their families was maintained:

- children were never separated from their parents which reduced stress levels and feelings of loneliness and thus improved their general emotional wellbeing (criterion 1);
- nurses and the doctor provided the families with all available information and results at the earliest possible point in time (criterion 3);
- Neither the nurses nor the doctor rushed the process of taking blood samples or the provision of care and spent time with the child. Parents were relaxed as the child did not show any fear of the nurse (criterion 6).

The extreme north of Thailand is comparatively poor and many families have to carefully budget their finances to be able to cope with the associated costs of attending the hospital, even though the Thai government subsidises medical care: *'I do not pay much money for him [i.e. his treatment]. It is a free service' (IF2-4)*. Nevertheless, parents have to pay for their own transportation and food on the day of the visit. There is an additional subsidy for the children from poor families and this also covers the cost of some equipment: *'The doctor subsidises injection machine for me because I have not enough money but my child really needs it' (IF1-5)*.

Nurses work with the social support department of the hospital to obtain additional financial support for families. They assess the family and if a need is identified, the nurses authorise it. Occasionally, families have to deal with unexpected costs. A family who was registered at another hospital, for example, had recently moved to the North and brought their child to Lampang Hospital. However, they did not have the necessary documents which meant that they would have to pay a substantial fee. When the nurses became aware of this, they informed the doctor who decided to offer free treatment:

'I had a problem about transferring from another hospital to this hospital because I forgot the proper form. I then had to pay by my

own, but I do not have enough money. So the nurse helped me by sending me to see the doctor and making another appointment for a blood transfusion for free' (IF3-2).

In order to reduce travel costs, the parents were given the option to take their children to the local community hospital: *'The nurses suggested me to bring my daughter to the local hospital because it is saves cost' (IF1-3); 'We solve this problem by advising them to visit their local hospital. I will make an appointment at the local hospital for them, if they prefer' (IN1-13).*

The hospital did not completely solve the financial issues of the families but by co-operating with the hospital's social support department and other community organisations, the nurses could often help them, especially *'when they were orphaned children growing up with their grandparents' (IN1-17)* or children living in remote villages (IN4-3). *'Some parents coming from the rural areas might have difficulties. If it is an economic problem, we refer them to the social support department' (IN2-8).* They could also make individual arrangements for some patients: *'If the parents are not able to return to their home, we provide them with a place to sleep without any formal request and free of charge. The child also has free dinner' (IN3-6).*

The healthcare system allows every child to have access to free essential services as part of thalassaemia care. The nurses and the doctor played the role of a supporter when children need additional medical treatment: *'If the parents have economic problems, I will send a form to the social support department' (IN1-18).* Thus, nurses and the doctor help families with potential financial issues:

'If the parents have financial problems, the social support department or Local Administration Organization Office (LAOO) helps them. I write a recommending letter to the LAOO, asking for their corporation' (ID1-7).

The doctor also explained that the hospital provided mental health services for children who required this additional treatment:

'There is a psychiatric department to help the child. The child I mentioned before has two or three problems. The psychiatric department offer mental healthcare' (ID1-4).

In conclusion, the Lampang hospital provided comprehensive care that meet the child's needs. It provided facilities to ensure that the child was never separated from its parents and that its emotional needs were met. The hospital worked in partnership with the Local Administration Organization Office and the local hospitals to ensure that a co-ordinated approach to care could be offered.

4.1.5 Recognition of family strengths and individuality and respect for different methods of coping.

The thalassaemia service at the hospital catered for a large number of children with limited resources and meant that care processes were standardised. This presented major obstacles for the provision of individualised care which would require that a family's particular circumstances are taken into account.

However, where possible variations were made to accommodate individual needs. The teaching sessions for parents and children, for example, were individualised by addressing specific issues relevant for the child and families of newly diagnosed children or families who encountered any difficulties were given additional support: *'It is the personal teaching for thalassaemia children. If a child has high iron-levels and need iron-chelation treatment, they have to be taught individually'* (IN2-7). Nevertheless, the general content that was taught was standardised and based on the handbook.

Throughout all the observations, all healthcare professionals used lay language when speaking to and especially when teaching parents. By avoiding overly technical terms, they ensured that the child and its parents understood what was said. In addition, nurses talked to the parents in their local dialect if the parents preferred it, even though they understood the national language:

'The local language is easy to understand. The parents [and the children] know the local language and they are able to understand my advice' (IN3-4).

The nurses believed that grandparents often lacked knowledge and were consequently unable to care for children on their own: *'Fathers and mothers have better perception than grandparents, but grandparents may well able to care partly for a child'* (IN2-1).

The setting of the study in the Northern provinces of Thailand was also significant as people in rural Northern Thailand have a reputation of being reserved when dealing with authority. My study confirms this assumption. Parents would only ask a nurse who they were already familiar with: *'No, I do not ask them. The nurses have changed. I just asked the nurses at the reception, who I know her'* (IF1-5). They also did not ask nurses who they thought were 'busy' as this might be perceived as a lack of consideration: *'People in the north, if they are asked, would not tell what they think. Northern people are quiet and a bit fearful. The old people are too shy to talk'* (IF5-6).

Local culture and religious beliefs also played a role. For example, parents did not seek psychological support from health professionals. Although they experienced stress from the children's illness, they never asked for help from anyone as they believed they could cope with it on their own:

'I have never consulted the hospital about stress at all, no one' (IF2-8).

'I am aware and stressed about my daughter's illness. I can cope by myself' (IF3-5).

'I don't want mental support I think I have no problems. There is Buddhist image in front of the clinic. I pray for my son and me to be strong. ...Or...I go to a temple and make merit. I ask for a blessing that helps my son to be healthy' (IF5-4).

Parents preferred to manage their stress by going to a temple to make merit and/or accept the illness as the result of karma:

'I prefer to pray every Buddhist Holy day. Everybody has to think, to pray and to accept things as they come. I do it because I belief that it is my old karma. It is my belief, whether it is real or not. I often make merit and I hope this will result in a miracle to help to my son' (IF5-4).

These cultural and religious views were known to and accepted by the nurses: *'I allow the parents to put a small coin on the bed because they believe that they might lie on a bed in which another person died. Their child may become ill [with another illness] by lying down on the bed of a dead person'* (IN3-8).

In conclusion, the healthcare system did not focus on the individuality of the children and their families because of the large number of patients and limited resources. The healthcare professionals understood and accepted the nature of a family's spiritual beliefs and tried to incorporate them into the care. However, their actions did not have to focus on religious and spiritual needs as religion was part of the families own coping strategies.

4.1.6 Understanding and incorporating the developmental needs of infants, children and their families into healthcare delivery systems

Criterion 6 of the FCC framework requires health professionals to take children's developmental stage into account when caring for them and their families. Aspects of this requirement were observed in the criteria described above, such as avoiding the separation of a child and its parents during the hospital treatment. Moreover, a child-centred mode of communication served to create an atmosphere of trust: *'They [nurses] talk and play with my child. They always participate with polite conversations and gently approach to my child'* (F11-5). Another child was observed asking the following question: *'The child came to the blood transfusion room and asked the nurse: "Is my blood ready?"'* (OF1-10). Addressing a nurse or an authority figure as such would not be considered normal for a Thai child, but this child felt comfortable enough to set conventions aside. These incidences involved mainly young children and older children were also treated according to their age. In Thai law the age of consent is 21 years and, although the concept of assent does not exist, the nurse gave the child the opportunity to be involved in decisions about the treatment:

'I allow them to decide that part of nursing care [which arm to use for the blood transfusion] because the child may want to do activities and feel comfortable during the blood transfusion. ... If I put the cannula in that dominant hand, they may not able to do any activities during the blood transfusion so I listen to them (IN3-6).

This example demonstrated that the nurse understood the child's educational background and developmental stage. The healthcare in this department was delivered by a small number of professionals for a large number of children and cost and efficiency considerations appeared to be the prominent factors influencing the design of the department's operational mode. However, avoiding separation from

the parents throughout the treatment, communicating in an age-appropriate manner and offering patients choices did cater to the developmental needs of the children:

'If child can communicate, I will tell them directly because they can learn and understand. If the child is young and dependent, I will talk them via the parents' (IN2-9).

These measures had the desired effect of increasing participation and resulted in a relationship of trust between the children and the health professionals.

The nursing care given to the children was very similar across all age groups. However, the initial care procedures relied very much on the involvement of the parents: *'The care for the children should be involve care givers' (IN2-3).* The nurses' expectations of the child increased with its age and adjustments were made to the delivery of care:

'I would play with them during nursing round. If the child is old and needs privacy because the age changes from a child to teenager. I will ask them in different ways' (IN3-3).

The communication was another aspect of care that was adjusted according to the patient's age. The parents mentioned that the nurses used their children's nick name and that the children appreciated this:

'They call her by her nick name. It makes them familiar' (IF1-6).

'I meet the nurse and she remembers my child and I'm so happy the nurse remembers my child' (IF2-9).

'They speak politely and pay attention to my son. They gently approach and tell my son the process of care. I think my son understands' (IF4-7).

According to societal norms in Thailand, children are expected to be quiet and remain disciplined when they are in a hospital. This, however, was not always the case because the children and nurses were very familiar with each other, using terms that would be used in an extended family, such as "Pe" (sister or brother), "Lung" (uncle) and "Pa" (aunt). This style of communication had the desired effect of generating trust: *'If they call me "aunt" it means that they respect, trust and desire collaboration' (IN2-5).*

Many health professionals also had 'normal' conversations with children about their school and popular television programmes and offered them toys that were suitable for their particular age and developmental stage:

'They give books to my child and toys to younger children' (IF2-8).

'They play with my child more than the older children and attract my child with colourful toys' (IF5-8).

The nurse instructor was concerned that more should be done to promote the children's development as the activities in the hospital were limited. She felt that more than biomedical care was needed:

'They may need to learn to live with normal children and do activities as same as other children but just some activities need to be careful. The education is important because certification is important to get jobs. They need to learn at least at primary school to get paid job' (IT1-1).

All children stated that they preferred to live and eat at home and play with friends but they knew that they were restricted in some activities. Parents often limited their child's activities because they were worried about its health. Nurses, on the other hand, focused more on enhancing a child's development. It was often a challenge for both sides to find a balance and ensure a child's wellbeing.

In summary, this results in this section of my research results indicates that healthcare staff at the Lampang hospital provided care that was appropriate for the child's age. They adapted verbal support, conversations and care actions. In addition to meeting the children's developmental needs, these adapted style of interaction enabled the healthcare practitioners to deliver effective care and to form and sustain a therapeutic relationship. All the nurses agreed that a child's age needed to be taken into account when they offered it recreational activities while it was waiting for its medication or during blood transfusions.

4.1.7 Encouragement and facilitation of parent-to-parent support

No formal encouragement or facilitation of parent-to-parent support was noted throughout the observations, although there were some examples of informal parents to parent support. The hospital had provided benches and tables for parents, thus putting them in close proximity of each other. The parents seemed familiar with each other and their conversations frequently turned to thalassaemia-related issues. The parents who knew each other well shared their experiences. They did not talk about the care provided in the hospital, but rather about their experiences of handling the care of their children at home: *'They discuss how to prevent accidents. For example one parent does not allow the child to ride on a bicycle'* (OF4-1).

Nutrition was a major topic of conversation between parents. One parent was observed trying to convince the other parents that preparing food at home was safer and cheaper than buying food from vendors in the hospital because it allowed them to protect their child from eating food with a high iron content. This was useful advice for parents of a newly diagnosed child:

'The experienced parent talks about the child wanting to eat chocolate and liver, while the new parent told that he will not prepare these foods in the house' (OF5-11).

Getting help from relatives with raising the children was also discussed. As already explained in the above section (criterion 2), grandparents were often involved in the day-to-day care of Thai children because the parents were temporarily absent. This did occasionally lead to tensions. The parents from the fifth family, for example, were concerned that the grandparents cooked food with a high iron content for the ill child because they did not understand the necessity of avoiding this. Another informal kind of parent-to-parent support emerged when parents shared responsibilities with each other in the blood transfusion room. Typically, one parent asked another to look after a child while they took a break:

'A parent goes outside to have a meal at the canteen. The child stays with the other parent while the nurse is out of the room. The parent asks the other parent to look for the child. "I want to go to have lunch. Could you please look after my child for a while?" The other parent is willing to look after the child. "You can go then I will care for her" (OF1-13).

Throughout the observation period, the hospital did not provide any formal opportunities for parents to meet: *'We do not set a group activity or group teaching as our only service is treatment' (IN1-12)*. However, the healthcare professionals were aware of parent-to-parent interactions: *'Parents from the same village then they become a network' (IN2-8)*. This was considered an important development because *'some new parents may happy among other parents. They can talk about children have the similar health condition' (IN3-5)*. The nurses welcomed it as it helped parents to *'learn from other parents' (IN4-4)*.

In conclusion, the hospital system did not include parent-to-parent support in the process of thalassaemia care. However, experienced parents shared and discussed essential knowledge and information. The nurses acknowledged this peer support but did not take further actions to coordinate these activities. Thus, informal peer support existed and it functioned without the help of healthcare professionals.

4.1.8 Assurance that the design of healthcare delivery systems is flexible, accessible and responsive to a family's needs

Flexibility is required in three main areas: responding to the needs of the family, ensuring that all children who need a blood transfusion receive it and ensuring that parents and families are content with the service offered by the hospital.

As the hospital was short-staffed, there were only some opportunities to offer flexible care. One of the adjustments the hospital offered was a modification of the normal service to suit the needs of some children: firstly, the hospital allowed parents who were unable to come to the hospital during the week to bring their children on the weekend to receive a blood transfusion. This, however, was reserved for exceptional cases because of the staff shortage.

Secondly, the hospital allowed older children to come after school to give a blood sample. This had the additional advantage that the child would only need to spend a short period of time at the hospital on the day of the blood transfusion as the cross matching of the blood had already been done: *'It makes the child happier to have short waiting list in the morning.*

They can come to have blood test after school and they will come to see me next day' (ID1-10).

A major issue for the hospital was the large number of patients and to reduce congestion at the clinics while still providing comprehensive care, plans were in place to extend the service by keeping the clinic open in the evening with a nurse on duty: *'The child can come in the evening to have blood test and then they come again in the next morning to see the doctor' (IN1-14).*

While the care for thalassemia children was mainly centralised, it was also provided in local community hospitals. One parent, for example, who had received the standard lesson was still unsure about how to inject the medicine by themselves. The nurse at the central hospital contacted the nurses at the local hospital to ask them for assistance: *'She [nurse] reassure me the child will has medication and then she will contact the nurse at local healthcare unit. They will help me when I cannot do injection process' (IF1-3).* This seemed to give this parent the confidence to undertake the injections at home.

Despite the high number of patients and the limited resources, healthcare professionals had some flexibility to shape the services according to the families' needs. This flexibility, however, was limited due to the varying nature of government funding for individual therapeutic interventions. In the Lampang hospital, for instance, families and children were offered treatment on days that suited them:

'If they have a complication, they can have blood transfusion on the weekend or at any time' (IN3-7).

'For me, I will negotiate with the nurse and give her the date that is convenient. There are not many thalassaemia children on Thursday so I prefer to attend on that date' (IF4-5).

Furthermore, the hospital provided an efficient transfusion process that enabled parents and children to return home as soon as the post-transfusion observations were completed. This was very appreciated by the families as many had to travel far to return home.

The large numbers of patients treated at the children's department by only a few healthcare professionals represented an organisational challenge, but remaining flexible was still considered important for the children's well-being:

'We have a particular management system for the blood transfusion room. I made an agreement with the health staff. The health staff work 8 to 4 but they may last finish at 8pm' (IN4-8).

'They just need a blood transfusion, and then they return home. We manage the place to separate them from the others and to reduce the number of patients on the main ward and make them more comfortable' (IN3-5).

Equally important was the nurses' understanding that important events in the child's life might also require flexibility: *'If, because of their [school] examinations, the children are not able to attend on a Tuesday or Thursday, we allow them to make an appointment on another day to attend the hospital for the blood transfusion' (IN3-7).* The hospital also offered extended services to children who might have difficulties to keep regular appointments:

'The parents can negotiate to receive the blood out of office hours or on Saturdays and Sundays if that is more suitable for them' (IN1-14).

The hospital also provided educational support for the children while they were at the hospital. Two teachers were available and the learning centre was open from 8am to 4pm. The parents liked this service even though not all of them used it:

'My daughter sometimes plays computer games with the teacher' (IF1-6).

'It may release the child's stress. I am satisfied even though I never spent time there' (IF3-4).

In summary, the data reflects the hospital's attempt to provide efficient and flexible services which take the children's development into account and adjust to their schedules. These services included educational support in form of basic medical information for the parents and a learning centre for the children. Both parents and healthcare professionals felt that all services were effective.

4.1.9 Summary

The matrix below shows how the families, the nurses and the doctor perceive the eight criteria of family-centred care.

Table 14: Perception of family-centred care

Participants	Criterion 1	Criterion 2	Criterion 3	Criterion 4	Criterion 5	Criterion 6	Criterion 7	Criterion 8
Family 1	P	Y	Y	Y	Y	Y	Y	Y
Family 2	P	Y	Y	Y	N	Y	N	P
Family 3	Y	Y	Y	Y	Y	N	Y	P
Family 4	Y	Y	Y	N	N	Y	Y	Y
Family 5	Y	Y	Y	N	Y	Y	Y	Y
Nurse 1	Y	Y	Y	Y	Y	Y	P	Y
Nurse 2	Y	Y	Y	Y	Y	Y	P	P
Nurse 3	Y	Y	Y	Y	Y	Y	P	Y
Nurse 4	Y	P	P	Y	P	P	P	Y
Doctor	Y	Y	Y	Y	Y	Y	N	Y

Key: Y (the criteria existed); P (the criterion only partially existed); N (the criterion did not exist)

Criterion 1: Most families acknowledged that they were allowed to stay with the child throughout the process of care and were invited to participate in it. Two parents accepted that involvement in childcare was necessary but they chose how they wanted to be involved. All the nurses acknowledged that parents were important and ensured that they were present during the process of care and were prepared to continue this care at home.

Criterion 2: All parents agreed that co-operation in the process of care occurred at all times in the thalassaemia clinic. Almost all nurses used a range of strategies to train parents so that they could participate in the transfusion process which had the added benefit of encouraging them to participate in the decision making and to communicate with the nurses. The only exception among the nurses was the head nurse (nurse 4) who did not directly collaborate or participate in the care. The doctor thought that collaboration took place at every appointment. However, many parents found collaboration with the doctor difficult because of their different educational and economic status.

Criterion 3: All participants agreed that information was shared between healthcare professionals and parents and that this occurred during consultations, physical examinations, the blood transfusion process and discharge. Almost all the nurses and the doctor delivered information related to blood results as well as the essential aspects of thalassaemia care. All parents accepted that information sharing without bias was important and valued it. Nevertheless, the consistency of this process varied due to time and staff shortage.

Criterion 4: Almost all participants felt that relevant policies were in place to support the treatment and to provide comprehensive care that was appropriate to the child's needs. However, the hospital found it difficult to meet all the needs due to the large number of patients. All nurses were polite and friendly to the children and the parents which was appreciated by the latter. Some parents felt that the hospital collaborated effectively with other organisations to provide additional services for the child and its family.

Criterion 5: Almost all the nurses knew a family's background and used this knowledge to communicate appropriately with parents as individuals. All the nurses aimed to promote a family's ability to care for the ill child while respecting their individual coping strategies. For some parents religious beliefs and rituals offered a lot of comfort and helped them cope with the situation.

Criterion 6: Almost all the families felt that the nurses interacted appropriately with them and their children by taking their age and needs into account and by using non-technical terms to communicate with them. The nurses knew that children's needs can vary and adjusted their nursing actions accordingly. Almost all participants felt that relevant and acceptable activities were available for the children.

Criterion 7: All the parents had access to peer support and found these informal useful for sharing knowledge. All the nurses recognised peer support as an important factor but did not participate or facilitate it due to limited resources.

Criterion 8: All the parents felt that the hospital provided flexible and effective healthcare. The nurses were aware of hospital policies but accepted that, although the healthcare system was rigid, some flexibility was possible. This included the

option to postpone appointments, have blood tests done in advance and the opportunity to access local healthcare services.

In summary, family-centred care existed in the research setting although the level of its implementation varied in individual cases. In addition, there were differences between the views of the parents and those of the healthcare professionals. Even though all the criteria of FCC were present, it appeared that the healthcare staff remained the leading figures in the care process.

4.2 Inductive analysis

The data from the observations, interviews and documents was initially analysed by using the 8 criteria of FCC. The analysis showed that all the elements of FCC were present, albeit in varying degrees. The data demonstrated how healthcare professionals communicated and interacted with the children and their families and that the families were very familiar with the staff and the procedures in hospital. However, the deductive analysis missed a point essential for the understanding of how care was delivered in the setting. It did not take the factors that influenced the nature of FCC into account. In this part of the analysis I will return to the data using an inductive frame.

The themes and subthemes developed from the data demonstrate an understanding of the healthcare services that relate to FCC in the thalassaemia clinic. They are presented in this section together with quotations from the datasets which illustrate the experiences and perspectives of healthcare professional and parents with FCC in order to obtain a full picture of FCC for children who suffer from thalassaemia (Appendix 12).

4.2.1 Theme 1: Family

This theme explores the family factors that influenced FCC in the thalassaemia clinic in Lampang hospital and it consists of three subthemes: 1) low self-efficacy, 2) changes to the role of the family and 3) different levels of involvement in care.

4.2.1.1 Subtheme 1: Low self-efficacy

Parents' low self-efficacy in thalassaemia care consisted of three aspects: dependent on professionals, limited knowledge and reluctance to ask. The parents often played a passive role in the care of their child as they lacked confidence. They felt that their role was limited to bringing their child to the hospital where the doctor and nurses would take care of it: *'I think that if the doctor treats my daughter, she will be better'* (IF1-3). The parents believed in the healthcare professionals and listened to the advice of the doctor and nurses: *'I have no idea but I must bring my child to the hospital as soon as possible. I just listen and do follow their advice'* (IF2-1) and *'I look after my child according to the doctor and nurses advice'* (IF4-1).

The parents' limited knowledge of thalassaemia was a factor that influenced their behaviour. The main issues parents were familiar with were nutrition and anaemia. Most parents were aware of the need to avoid food with a high iron content and adjusted their eating and cooking behaviours:

'The doctor does not allow my child to eat high iron food... I cook for everyone with the same food therefore everyone have to eat the same menu. I do not want suffer her if we eat our favourite food [food that has high iron content]' (IF1-1).

The parents were aware of their limited knowledge of other aspects of thalassaemia, although they understood that it was important to have this knowledge: *'It is dangerous if they [parents] do not understand about the disease and keep quiet. I think, quiet refer to parents have poor knowledge'* (IF5-7).

Nurses also found that parents had a limited knowledge of thalassaemia care and were concerned about the impact this might have on their ability to deliver care by themselves:

'They do not have enough knowledge, therefore they cannot observe their child's illness' (F4-3). *'I think that the parent does not pay attention on self-care. If they provide good self-care, their child may live as a normal child'* (IN3-6).

The nurses tried to change this so that parents could play a more active role in the process of care.

Parents were reluctant to ask questions or seek more information from the nurses as they did not want to add to the nurse's workload: *'They are busy. I do not bother her. It can be seen that there are many patients in the room. I do not want to interrupt her'* (IF1-3). They preferred not to disturb the nurse: *'I do not want to disturb her. I also feel compassion for her tiredness'* (IF3-6). In addition they worried about *'Krang jai'* (be afraid of offending). The parents concerned their interruption may increase nurse's workload and they are unhappy.

The parents confidently responded to the child's needs and informed the nurse when the blood bag was almost empty: *'I take care of the blood flow in that I observe drip rate of the blood. If I find that the flow rate is too fast or too slow I alert the nurse. I take on that role because the nurse might overlook this small problem'* (IF3-6). This is result of nurses' attempts to conduct parent's involvement were observed during the blood transfusion process at the clinic and seemed to be successful.

As this section has shown, the parents' low self-efficacy limited their potential to care. They depended on healthcare professionals and had a strong belief in the doctor's and the nurses' advice. Their limited knowledge also influenced their ability to participate in the care process and most parents were reluctant to ask nurses for information for a variety of reasons. Nurses worked with parents to increase their knowledge and self-efficacy which enabled parents to engage in some aspects of care.

4.2.1.2 Subtheme 2: Changes to the role of the family

This subtheme relates to the constantly changing role of the family in response to a child's illness and the required therapy. The roles taken on by the parents are managing the child's care and protecting it from additional health-risks. Adopting these roles had an impact on the family as a whole.

Managing child care involved numerous activities: the first was medication management which was a significant activity as the child needed mineral supplements to increase the volume of red blood cells. Parents followed the

healthcare professionals' instructions to ensure that their child took the correct medication at the right time: *'parents told to manage medication regularly'* (OF2-2). They were constantly reminded of it: *'The nurses always told me after blood transfusion process, such as don't forget give my child medications'* (IF1-5).

The parent's role at home was to ensure the safe and effective handling of medicines which often needed the co-operation of other members of the family: *'My husband helps me looking after her. [The child has injections during daytime]. My husband gives my daughter the injections and then I spend time on other work'* (IF1-1).

Medication management consisted of two steps: administering the medicines and monitoring the child for side-effects after the procedure. The parents learnt about the procedure and were aware of the possible complications: *'My child had pain at the injection site. There also was swelling, but I am not sure. I do nothing and it healed by itself. I used to inject him into 3 or 4 areas. If he feel pain, I will change inject site to other part of the body'* (IF2-3).

The parents were also aware of the risks caused by the low red blood cell count and the resulting weakness in the child's bones. They restricted the child's activities in order to reduce the risk of injury at home. For example, parents restricted activities that might lead to bleeding wounds such as riding a bicycle and playing football. Some parents did not allow their child to play with other children in the neighbourhood: *'My daughter is not allowed to play with her friends outside the house, for running and riding a bicycle'* (IF1-5).

The parents always looked after the children and helped them live an ordinary life if possible. The child's development was altered due to a lack of information and the uncertainty of thalassaemia symptoms. The parents in family 4 were concerned about their child's activities and ensured that they were present to help and to prevent accidents:

'I will help him with his hands and legs [i.e. by doing things for him]. It means I will take him to wherever, if he wants to go. I don't want him falling down or have accident cause of bleeding' (IF4-6).

The parents monitored the child when they were at home and looked out for any symptoms. Their main focus was on nutrition: *'The main problem is children have high iron levels in their body, so it is easy to control the high blood iron levels by controlling their food'* (IF5-5).

This section described the parents' role in thalassaemia care and how they managed the care, by, for example, administering medicines and protecting the child from potential complications.

42.1.3 Subtheme 3: Different levels of involvement in care

This subtheme reflects on some of parents' attempts to be involved in the care of their child. The parents' involvement in the process of care usually began with a change in their role when they started to administer medication and took actions to protect their child. However, the kind of participation varied in individual families. Well-educated parents were able to participate in a more authoritative way: *'If he has anaemia I have to bring him to the hospital immediately, I will tell the doctor that my son needs blood transfusions'* (IF4-5).

This is in contrast to less educated families with a lower income who showed a lower level of participation in the care and who did not ask questions: *'No, I did not talk with them. I do not know what to talk about'* (IF2-2). For other parents, the participation led to a form of negotiation with the staff: *'I will negotiate with the nurse and give her the date that is convenient for me, if I am not able to attend the set appointment. However, the date can be changed, my son's condition is important'* (IF4-5).

Despite these variations, participation was important for all parents as it sometimes helped them to be better informed: *'I want the nurses to talk to the parents and educate them about food for thalassemia. They are able to give proper advice'* (IF5-13). In other cases, participation led to cheaper or better treatments: *'Nurse did not suggest special blood equipment because it is expensive. I have to pay for it by my own but I am happy to pay for it but I insisted to do it'* (IF5-1). Participation also allowed parents to be more involved in the decision making process as they were more confident if they

had been provided with sufficient information: *'I informed them about my plan that my son will have bone marrow transplantation. I asked them about proper equipment. The doctor advised me to use only the special blood transfusion set, not the standard one'* (IF5-9).

This section demonstrated the various levels of parental involvement in the care of their child and that it depended on their educational level and income. However, all parents valued participation as they and their child benefited from it.

The discussion of these subthemes has illustrated the impact the child's illness has on the family and how the parents' role changed when they participated in the care of their child. Their involvement was limited by their limited knowledge which also led to a greater reliance on the healthcare staff for information and advice. The nurse was seen as the leading figure in healthcare and used different techniques to increase the parents' ability and competence in processes of care. In addition, the education and income influence parent's behaviour to design the degree of involvement. Parents with high education and high income more involved in the decision making process.

4.2.2 Theme 2: Hospital

This theme refers to the activities and influence of the hospital when it provides care for children with thalassaemia. It consists of four subthemes: 1) promoting self-care, 2) providing education, 3) providing efficient services, and 4) coordinating care.

4.2.2.1 Subtheme 1: Promoting self-care

This subtheme describes the services provided by the nurse to children and parents when they attended the clinic. Promoting self-care can be a way to increase self-efficacy and the nurses achieved this by providing families with specific information on a range of topics, such as healthy living, recognising critical symptoms of thalassaemia, etc. The nurses were concerned about the parents' ability to provide care even though some of them had already been caring for their child at home. The nurses felt that it was their duty to improve the parents' ability to carry out basic

medical procedures for their child: *'I try to build their [parents] confidence by giving them opportunities to practice at the hospital' (IN3-1)* and *'Some parents give inject medicines for their children. I provide those with knowledge of enable self-care. Some children and parents bought a big bottle of disinfectant solution [used for preparing the skin before injection] and they need to know about medication's expiration date' (IN3-1).*

The nurses organised an event at the thalassaemia clinic for parents, their children and other family members to promote their involvement in the process of care. The focus of this event was on the assessment of a child's illness so that families could learn to recognise the critical signs: *'I teach them to care for their child. For example, when the child has fever the parents have to take the child to the hospital. This self-care includes parents being able to assess the anaemia by anaemic classification and the blood transfusion side effects such as fever' (IN1-14).*

The nurse had learnt about the experiences of other parents used her knowledge in her teaching: *'I learn from experience, such as learning from one child for the others. For example, I find a child with poor self-care practice that often suffers from complications. I use this poor practice as a case study to teach other children' (IN2-3).*

The nurse encouraged children to look after themselves and explained to parents how they can help them to do this: *'We [nurses] also consider self-care and give information to the children and their families. We will focus on giving advice about nutrition and self-care. Then, the parent can look after their child and the child have a good health' (IN4-1).*

The parents could perform basic procedures but when the child was at the hospital, the nurses were in charge. The nurses respected the parents' decisions but allowed them to perform basic actions:

'I agree with the parent that they can care for their child at the hospital but I have to be ensure that the children are safe. I cannot let the parent do everything on their own. For example, the parent can reduce child's temperature with water because it is easy' (IN2-3).

Throughout the observations it was obvious that the children and the parents were happy to participate in the care and to co-operate with the professionals who cared for them in a supportive environment (OF1-2).

The paediatric department in the Lampang hospital aimed at improving the nurses' abilities and knowledge in thalassaemia care so that they were confident to teach parents: *'The paediatric department has been established for a long time and we cared for the children continuously. We promote our health staff capacity in terms of knowledge, nursing care and advice'* (IN4-3). However, the service offered by the hospital was limited and the head nurse reported that there was a shortage of staff: *'There is only one haematologist, one nurse at registration and one nurse at blood transfusion room. We find this limitation for so long and we hope it can be solved shortly'* (IN4-6). Nevertheless, the human resources plan did not appear to address these workforce issues (Doc-Human development plan). The access to training was also limited: *'There are many innovations in thalassaemia care, ... but the nurses from the paediatric ward were not invited to attend this seminar'* (IN4-3).

One effect of the staff shortage was that nurses were required to undertake other activities. I noted in my observations that the nurse at the registration desk had other roles, such as co-ordinating care, supporting and teaching families, and maintaining records (OF1-3). Nurse 1 described her multiple roles as follows: *'The doctor will have started planning for the children but it is my duty follow interpretation of blood results. If I see that the child has high blood iron-levels we will start talking with the children. For example, I taught 2 children and 2 parents about iron-chelation but the doctor did not'* (IN1-3).

One reason for their multiple roles was that families preferred to talk to nurses rather than to the doctor: *'They [children/parents] do not dare to tell the doctor but they can talk to nurses about every issue'* (IN1-18). Parents also realised that the nurses were short-staffed: *'She was busy at that moment because there are many patients waiting for the doctor, therefore there isn't enough time to do anything'* (IF3-6).

Thus, nurses promoted self-care because it improved the quality of a child's life. Several barriers, however, prevented the nurses from carrying out their role effectively and the main one was staff shortage.

4.2.2.2 Subtheme 3: Providing education

This subtheme describes the various ways in which healthcare staff provided education in the thalassaemia clinic. Because parents had a low level of self-efficacy, the nurses attempted to improve their competence through education programmes aiming at reducing the gaps in knowledge. Most parents learnt from the nurses when they were attending the clinic.

The teaching methods used by the nurses took the parents' needs, potential and ability into consideration. For example, Nurse 1 used a step-by-step approach to demonstrate the injection technique:

'I instruct them step by step and demonstrate injection procedure. I also give them brochures that remind them at home. I spend around 2 hours each time to teach them. ... The session does take long. Parents can ask and learn from other parents during the session' (IN1-15).

The sessions took place with either a group of parents or with individual ones. Parents appeared to enjoy the group teaching because they saw that others had similar difficulties. They were less nervous when learning with others and helped each other until all could do the task equally well. Nurse 1 and 2 also reported that group learning was more effective:

'Initial setup of injection training was held in small group. A group of parents can share experience and support uneven learning skills. They were taught in a small group and then they dare to share with other people. This session focuses on the application of practical manner in culturally congruent practice. The injection training session will be held in the afternoon at the reception' (IN2-4).

'I invited parents, mother, father and family members, to learn about injection methods. Some of them come to learn together. I gave them advices and expected helping within family and confident to do self-care' (IN1-3).

It is interesting to note that although the nurses undertook the teaching of parents in groups, they did not consider this activity as a form of peer support for parents. As was noted in the deductive analysis, the nurses did not think that peer support took place or that they facilitated such activities. Nevertheless, the inductive analysis

demonstrates that peer support did occur although it was not identified or labelled as such.

The nurse use repeated the teaching to ensure that parents were competent at their tasks and during the observations it became clear that all nurses considered this the teaching of parents as part of the care routine. *'The care givers should practice the right care, so we always focus on repeatedly teaching about health care, finding and solving problems for children'* (IN2-4).

The nurse used the local dialect during the teaching: *'The local language is easy to understand. The parents [and the children] know the local language and they can understand my advice'* (IN3-3).

The education programme was not limited to parents as the nurse provided instructions and demonstrations to members of the extended family: *'Fathers and mothers have better perception than grandparents, but grandparents can care for a child. I will teach grandparents to solve some problems'* (IN2-1). The nurse also taught the children about self-care and they were then asked to pass on their knowledge to other family members: *'I gave the child instruction and told the child to read for the grandparent and family members when they practice injection procedures'* (IN1-5). Teaching the children was also important as it showed that the nurses wanted them to participate in their own care.

The education provided was in general appreciated by the parents: *'The nurse is very good today. She is a good saying [explain everything to me]'* (IF5-7).

The content of teaching aimed at reducing the gap in knowledge. The handbook contained guidelines for thalassaemia care, such as general information about thalassaemia, nutrition, symptoms and critical signs (Doc2-Handbook), and was used as a source for the content of the lessons. In the sessions the nurses addressed a range of topics:

'The nurse gave me two books. ... I learn about its severity and alternative treatments to cure my child. I read them and then I asked the doctor about bone marrow transplantation. I heard that a child at Siriraj Hospital was cured by bone marrow transplantation' (IF5-2).

The teaching also addresses some complex issues related to side-effects of treatments:

'This self-care includes parents being able to evaluate anaemia by anaemic classification and the blood transfusion side effects such as fever. In addition parents have to know if a child is crying because of being uncomfortable or weak' (IF1-14).

The doctor knew that there was a shortage of staff and time, which prevented that education to be carried out effectively. Consequently, she advised the family to obtain information from other sources: *'The doctor is not able to spend the much time with teaching because there are many patients waiting for treatment....I advise them to read books, brochures, and internet websites' (ID1-1).*

The families in this study, however, preferred to be taught verbally by the doctor and the nurses rather than seeking out information for themselves: *'I beliefs that personal teaching is better than brochures. The doctors and nurses are concerned about patients' healthy.... We are parents who dare to ask more and show that we are concerned about our child's health' (IF5-8).*

The children were supposed to continue with the schooling during their stay at the hospital and this took place in the education room. However, these sessions were more directed at child development rather than improving knowledge and the teacher used games, recreational activities and a computer game. As a result, the children were happy to spend some time playing.

This section has shown the methods used in teaching families and the content of the education. The nurses took on the role of educator and informed the parents and the children. The educational programme in the clinic occurred either in form of individual or group teaching and a range of topics were addressed.

4.2.2.3 Subtheme 2: Providing efficient services

This subtheme refers to the hospital's attempt to provide efficient services. The parents stated that the service in the clinic was far superior to services provided in the local hospital, although attending the latter was more convenient:

'The nurses suggested me to bring my daughter to the local hospital because it saves cost and my daughter does not need to wake up early to visit here' (IF1-3).

I prefer this hospital because it is convenient even though it is far away from my house. Importantly, my daughter is familiar with the doctor and the nurses in this hospital. (IF3-3)

The head nurse stated that the staff tried to be provide efficiency service which was appreciated by parents and children:

'The healthcare services have to finish in one day therefore we have to hurry otherwise our patients will not go the house on time. I always find the way to operate blood clinic faster. I co-operate with other departments to reduce unnecessary procedures such as accounts department and blood bank. The accounts department provides short cut services because those children deserve free services' (IN4-5).

The paediatric department modified the opening hours of the blood transfusion room. The healthcare professionals chose to start their working day at 7am without additional payment while the nurses in the blood transfusion room started at 10am: *'I come to work at 10 am to 6 pm. It is different working time compare to normal ward' (IN2-5).* One nurse cared for approximately 40 children receiving transfusions. The views of the child and its parents were taken into account as the staff felt that the family's satisfaction was a key aim. At the same time, they were always seeking ways to improve the service. The head nurse reported that they conducted surveys to measure satisfaction:

'We evaluate patient satisfaction about the hospital services every 6 months. We found that the problems focus on the place of service' (IN4-6)

Overcrowding was an issue: *'High number of children come to the hospital therefore the child have to share beds. There is the limited number of beds, because there are only 6 beds in the room. Secondly, there are many children attending the blood clinic at the same time. Therefore, two or more children may lie on one bed, it is overcrowded' (IN2-8).*

In response to feedback from parents, the hospital ensured flexible access to the hospital facilities for the children and their families. The hospital modified the shift patterns of staff by including additional shifts and expand the working day of the clinic. It also sought ways of reducing the congestion

in the clinic: *'The parents can negotiate to receive the blood out of office hours [after 4.00 pm] or on Saturdays and Sundays if that is suitable for them'* (IN1-14). The child could also attend the clinic early in the morning or in the evening to do the cross matching in advance:

'I took the child to the hospital in the evening and have blood test. I come again in the morning and then I just go to check blood result. I just wait only the doctor to order prescriptions. If my child needs blood transfusions, I have short cut service to blood transfusion room' (IF4-3). Occasionally, and in order to avoid disrupting the child's school day *'I used to ask the nurse to come on weekend because my child had examinations. The hospital allowed my child have medical on weekend. It is not normal services because they told me there is limit staff on weekend'* (IF2-3).

The staff tried to move some children to the main paediatric ward but this measure was unsuccessful: *'They say that it is uncomfortable and they have difficulties breathing. But for newly diagnosed children it is not suitable to stay with general [ward] children'* (IN2-8).

As was mentioned in the deductive analysis, the clinic had a learning centre where books and toys were available for the children to learn, play and read during their stay at the thalassaemia clinic: *'There is a learning centre for hospitalized child at the hospital. If the child wants to move to the learning centre, they can go there. Then, I go to the learning centre to record vital sign for every hour'* (IN3-4).

This section described the ways in which the staff in the thalassaemia clinic managed the available resources to increase the quality of services and the satisfaction of patients and their parents. The comprehensive and flexible service offered helped to overcome some of the limitations in space and the consequences of staff shortage.

4.2.2.4 Subtheme 4: Coordinating care

This subtheme describes the hospital's role in the coordination of a collaboration with other organisations in the process of care for a child. The staff in the hospital were often concerned about the economic situation of parents as the cost of transportation from their home town to the clinic was usually high: *'It depends upon*

how I travel to the hospital. I spent around five hundred Baht if drive myself in a private car. On the other hand, for public transportation, I spend around 200 Baht' (IF3-7). Hospital staff liaised with local organisations to subsidise the transportation costs and other expenses that might be incurred:

'If parents live in the area of our social support department or the local hospital, I will contact the local health staff who is working in this area to visit them at home and send the information to the Local Administration Organization Office (LAOO). There are many children that get financial support from LAOO. The doctor will sign for the necessary application form for LAOO' (IN1-18).

In addition, the type of equipment used for the injections also influenced the costs. The doctor provided a small number of injection machines for children which were used by most parents. However, if parents found this injection technique too difficult, there was more complex but also more expensive equipment available: *'An injection machine costs 12,000 Baht but the machine that the doctor offers is cheaper than the retail price. The doctor support at the price 500 Baht'* (IN1-16).

To reduce some of the costs, nurses referred the child to local medical care units, which consisted of a primary healthcare unit (sub-district) and the local hospital (district). This co-operate ensured that full healthcare was provided: *'I ask the parents whether they encountered any problems. If I find that the medicine had been taken irregularly, I will take further step to help. ... I also co-operate with the local hospital because the local hospital can provides medicine and support the families'* (IN1-2). This section demonstrated the various ways in which the hospital co-operated with other services to ensure continuous and comprehensive care and to help with some of the financial difficulties that parents were experiencing.

This theme about the effect of hospital services on the care process has shown how the Lampang hospital promoted self-care by providing education to the parents and thus increasing their potential to participate in childcare. The hospital operated its thalassaemia clinic in a way that ensured the quality of services and adopted a flexible approach to care to meet the needs of the parents and their children.

4.2.3 Theme 3: Thai culture

This theme significantly influenced the thalassaemia care of children in the Lampang hospital and it consists of five subthemes: 1) Buddhism, 2) trust in hierarchy, 3) friendly approaches, 4) extended family and 5) alternative mental coping.

4.2.3.1 Subtheme 1: Buddhism

Belief in a Buddhist society is based on several principles: illness is karma, which is seen as an action with a reaction and making merit.

There is no consensus that Buddhism influences physical well-being but an effect on moral well-being is proofed. All the parents believed that illness was caused by karma: *'I belief my child ill because it is my old karma. It is my belief, whether it is real or not' (IF5-4)* and *'I talk with my husband and we agree that it depends on karma' (IF3-6)*.

My observations showed that a statue of Buddha was placed in a prominent location in the hospital grounds and was accessible for all patients, families and staff to make merit. The monk explained making merit in Buddhism:

'If we summarise, it means that in Buddhism when people get ill they make merit to reduce their suffering. It can be said that it is a symbolic ceremony or that it looks like symbolic rituals reflected the ways to coping, making peaceful and happiness' (IM-3).

Common rituals related to Buddhist beliefs were mentioned in the interviews and observed. According to karma, making merit was necessary when parents needed mental support:

'I think my son will be healthy. I believe doing good things will result in receiving good things. As a result of making merit, everyone in my family will be happy' (IF5-4).

The parents seemed to accept their fate and experienced parents did not think that they could change their child's illness. They accepted that they had to live with an ill child but though that it should receive regular medical treatment for their illness. The

parent care for their child so they might practice, think and speak of good and positive things to ensure their child's mental well-being.

The Monk and parents agreed that Buddhism influenced their behaviour:

'They have to live with their ill child then their Karma will be redeemed' (IM-2).

'I think it is our Karma to have illness like this, I accept I have to look after him until he dies' (IF3-7).

'Dhamma can adapt continuously for use in work. Even foreigners use the word "adaptation" and that is a corner stone in the world. Every organisation can use Dhamma to adapt it into its care procedures and this means adapting their mind, attitude and others for the current context and environment' (IM-12).

'I calm down after reading Dhamma. It is really helpful. I will put my burden down and clear my mind. I think positively that my daughter has thalassaemia, but she could have had another disease. I believe that her appearance has not changed. Other people complement my daughter that she looks like a normal child. I talk with my husband and we agree that it depends upon karma' (IF3-6).

Parents explained that were doing good deeds, for example by paying attention to their child and convincing it to be optimistic, while also supervising their nutrition and medication. The concept of action and reaction was mentioned frequently by all parents and they explained that moderation and temperance in daily life and spiritual beliefs also helped to reduce suffering:

'I made merit to my parents who are old and who used to look after me. It will help me at least decreasing my bad karma. I have to make merit to my father and mother and then merit may return to me by curing my son' (IF5-7).

'Actually, suffering and soulless are not just beliefs because they can be touched and seen. It is about the understanding of life that is nature. Impermanence, suffering and soulless are the normal rule that we have to learn and understand' (IM-9).

This section revealed the impact Buddhist religion has on parents and children and that it was greatly beneficial for the mental health of the parents.

4.2.3.2 Subtheme 2: Trust in hierarchy

This subtheme explores the impact of people's trust in hierarchy, which is an important aspect of the Thai social system. The data showed that parents and children trusted the healthcare professionals and organisations to provide efficient healthcare.

In thalassaemia care children and parents trusted tertiary hospital services. Parents trusted the doctor to care for their child: *'I will bring my daughter to see the doctor because the doctor told me that my daughter's illness needs proper treatment and this doctor can make my child better'* (IF1-3). This implicit trust meant that parents did not question staff: *'I have never asked them. I think it is ashamed of myself and I think the nurse is professionals'* (IF2-8).

In return for this trust, the hospital accepted the parents' decisions to bring their children to the Lampang hospital and provided a good service, despite overcrowding and congestion in the clinic:

'We accept their decision because we are not able to force them away to other hospitals. We are aware about our patient's rights' (IN1-13).

'The child can go to the local hospital if they want but we cannot push them back to the local hospital because they had arrived here and spend a lot of transportation fee' (IN4-5).

The parents knew that health professionals had a duty to provide care to the children and parents. The nurses' uniform and the doctor's white coat were also seen as symbols of authority and efficiency, generating trust: *'The nurse is going to help my child. She works fast and swiftly with good practice. My child will be ok after blood transfusion'* (IF3-5).

The healthcare professionals took on a leadership role which was seen to be the norm and accepted by the child and parents. All the parents stated that they followed the doctor's instructions:

'When I met the doctor, she told me that I have to accept my son's illness. I have to look after him and prevent him from eating inappropriate food and promote proper food. He may easily have an accident because of his weak bones. He is not allowed to play with other friends because of the illness, such as weak bones and active bleeding so I do everything the doctor tells me' (IF4-1).

'I respect them that they can care for my child and they are doctors and nurses' (IF1-7).

This section described the relationship between the healthcare staff and the patients and their families which was built on trust.

4.2.3.3 Subtheme 3: Friendly approaches

This subtheme explains the nature of communication in Thailand. Whenever any healthcare professional communicated with the children or their parents, the communication was always friendly. In addition, nurses addressed the child using the appropriate pronoun and gender to make it feel comfortable. Nurses smiled at the children and spent time talking to them rather than merely focusing on the medical procedures. Even though these conversations were brief, they helped the children to relax and prepared them for the procedures:

The health staff talked with the child gently. "Come to sit here, little girl, let me see your hand." As she searches for a vein she continues "Did you eat something in the morning?" (OF3-1).

The friendliness increased when the nurse called a child by its nickname rather than its formal name. Thai nicknames are normally only used by parents, close relatives or friends. When the nurse used them, it made the children feel that they were in a safe environment, surrounded by people they could trust.

In addition, the nurses talked in a calm and unhurried manner about general topics to enable the child to relax. This also facilitated co-operation throughout the care process:

The smiling nurse started a conversation with the child about the journey to the hospital. "How did you come to the hospital?" (OF1-11).

"What channel are you watching on the television?" the nurse asked. ... The child is happy to speak with the nurse, telling her how she felt throughout the time the blood transfusion took (OF3-8).

The friendly communication style was also used during painful procedures, mainly during cannulation, when the nurse talked to the children in a calming and re-

assuring tone. In one case, I observed the nurse talking to the child while inserting the needle into its vein (OF1-13). Parents also commented on the friendliness of the nurses: *'They are polite and working fast' (IF1-8). 'They answered politely and gave more details about causes and reasons' (IF2-11).*

This section provided evidence for the positive effect of a friendly style of communication used by nurses in the Lampang hospital. It resulted in a reduction of stress for the parents and an increase in parental co-operation. The friendly nature of the communication was observed in all the interactions between healthcare professionals, children and their families.

4.2.3.4 Subtheme 4: Extended family

The healthcare professionals also knew the members of the child's extended family. One of the nurse, for example, noticed that a child's grandmother stopped coming to the hospital and inquired what had happened. Similarly, the doctor was aware of a couple's divorce and shaped her advice accordingly.

As most of the parents in the study had to work during the day, it was common for other family members, especially grandparents, to care for the children during the day and to accompany them to hospital. They were recognised by the nurses and the doctor as carers and were considered as important to the child as the parents so that they received the same support and information:

'The parents explain that the grandparent helps them to care for the child, with feeding and observing symptoms. They mention that the nurse also taught the grandparents when they came to hospital with the child' (OF1-11).

Nurse 2 agreed that grandparents provided good care for the child by looking after its nutrition and general hygiene: *'I think that grandparent cook for the child and care for the child hygiene. For my opinion, the grandparent loves the child more than father and mother' (IN2-3).*

The dynamics within a family could also affect a child's well-being. In all the families interviewed for this study the grandparents helped the parents to look after the children. The parents reported that support within the family was necessary, cost

effective and less time consuming as grandparents either lived in the same house or close-by:

'My father-in-law comes with me and helps me look after him. I can go outside to work and collect money for bone marrow transplantations' (IF5-6).

'They support me to look after my daughter when my daughter has injection. They pay attention to avoid obstruction of the injection on day time every day' (IF1-2).

For one mother the support from her extended family included everyday activities: *'I have not much time to look after my child but my parents always help him and cook for him'* (IF4-3). As mentioned in section 4B.2.1, the involvement of the extended family was recognised by the nurses, who included them in the teaching sessions to promote self-care.

This subtheme explained the dynamics within a family and that the extended family offered important support with the medical care as well as in activities of daily life.

4.2.3.5 Subtheme 5: Alternative mental coping

This subtheme describes alternative psychological care and support that is not delivered by nurses or doctors but consists of Buddhism, making merit and positive thinking.

The parents' methods of coping are mainly individual coping strategies, rather than relying on support from the healthcare system. They are based on Buddhist religion:

'I accepted that whatever will be, will be. I taught her Dhamma, to accept that she was born with the disease. She will come to the temple and stay for seven or nine days and 'make merit'. It make her peaceful' (IF3-17).

The parents also practiced Buddhist rituals that were *'...really helpful. I calm down after reading Dhamma. I will put my burden down and clean my chaotic thinking. I think positively that my daughter with thalassaemia, otherwise she may have had more threatening disease. I talk with my husband and we agree that it depends upon our karma'* (IF3-17).

The monk also linked the illness to Karma and suggested that their acceptance of this fact would help them cope:

'Every people cannot avoid Karma therefore people have to redeem Karma in one way or others. They should accept and live with it until they are clean' (IM1-1).

One mother did not expect that the practice of Dhamma would cure anaemia but was aware of its impact on the mental well-being of her child: *'Her illness needs medicines and treatments but her mind needs someone to look after as well. For me I think that if she thinks positively and is happy, she will be fine' (IF3-18).*

The parents in family 5 strongly believed in positive thinking, which is the foundation of Buddhist belief, and accepted their fate. They performed good deeds at every holy occasion to reduce stress:

'I am still thinking about the illness. I prefer to pray every day. All people are upset about the illness, but this must not continue too long. Everybody has to think about current situations, to pray and to accept things as they may come. I and my wife usually go to a temple. ... I am always looking for chances to make merit for my son and "Tan Kun Kaw" to people who passed away. I do it because I belief that it is my old karma. It is my belief, whether it is real or not. I think I do "Tan Kun Kaw" to ask for forgiveness and to support our ancestors in previous life. I often make merit to parents and I hope this will result in a miracle to help to my son' (IF5-8).

This subtheme revealed that alternative coping mechanisms were integrated in the life of the families. The parents and the children perform spiritual and religious practices to relax and find a peace of mind. Stress and anxiety were reduced by positive thinking and acceptance of the situation.

This theme has explored aspects of Thai society and religious beliefs that influenced the care of children. The general trust in hierarchy and prominent religious beliefs had an impact on how children and parents interacted with healthcare professionals and on the state of their mental health. Healthcare professionals tried to counteract hierarchal structures by adopting a friendly approach to their interactions with children and parents.

4.3 Conclusion

This chapter has examined the data and has establishes that FCC shapes the nature of care for children with thalassaemia in the study setting, even though the term is not explicitly mentioned. All the elements of the western model of FCC exist in the Lampang hospital. The examined data has also revealed the three extraneous factors, the family, the hospital and Thai culture that shape the nature of this care.

Chapter 5

Discussion

The principle aim of this chapter is to discuss the study findings, as reported in Chapter 4 in relation to the three research questions in the context of current literature and will conclude with a discussion of the characteristics of family-centred care as practiced in the study setting.

5.1 The characteristics of family-centred care in Thailand

It is interesting that none of the participants mentioned the term 'FCC' and the assumption can be made that FCC is not practiced. However, this is not the case as the data has shown that most of the elements of FCC as described by Shelton et al. (1987) are present. The discussion will commence by examining several themes in relation to how FCC is practiced in the study setting and will conclude with a model that depicts the nature of FCC as practiced in the thalassaemia clinic.

5.1.1 Family

This section discusses the complexities of the impact of chronic illnesses such as thalassaemia on the role and function of parents in the context of healthcare services in Thailand. Chronic illness causes difficulties and disturbances to the child's normal lifestyle, activities and routine, which can also be caused by the treatment (Miller, 1992). This study found that the disease (thalassaemia) and the treatment had an impact not only on the child but also on the family in terms of the role of the family, different levels of involvement and self-efficacy.

5.1.2 The impact of a child's illness on the family

The illness had an impact on the families' emotional states, daily activities, family relationships, involvement medical care, support given to family members, work, economic situation, and planning (Golics et al., 2013a; Golics et al., 2013b).

Self-efficacy has been reduced following complex medical care. Low self-efficacy appears when medical care is complex and parents cannot carry out all processes by themselves. The parents are aware of the fact that their care may not be as efficient as that provided by nurses which can result in a lower quality of life for the child. The parents realise that caring for a child with thalassaemia requires specific knowledge. While they can provide daily care, manage oral medication, and prevent complications and risks, they are not confident when asked about details. The paradox in child care appears when very self-sufficient parents accept that the nurses are in charge of the thalassaemia clinic. Self-efficacy appears lower in families from a low-education background but higher in well-educated families.

The impact of chronic illness also means that parents are dependent on support from the hospital to practice palliative care at home to enable the child to live a normal life (Bouso et al., 2012). The hospital is a primary source for treatment and knowledge for parents. For example, parents have to change their cooking and eating habits. The parents have to control the quality of food because the thalassaemia child needs food that is low in iron. It needs food that helps the body to effectively produce red blood cells and keep the iron levels in the cells low. This impacts the other family members because they also have to eat different food and prevent the child from eating unwanted food. They adapt their life style to the child's condition to maintain its health.

When parents are reluctant to manage care at home properly it creates conflicts between nurses and parents. Some families cooperated to manage their child's care, seeking resources to help them solve their difficulties but they did not talk to the nurses about the child's care management in detail. Instead, they only talked about general information.

The families' experienced different levels of stress and anxiety depending on the age of the child, its condition and length of treatment programmes. The severity of the impact on families of patients is often unrecognised and underestimated. Kelo, Martikainen and Eriksson (2013) found that it is not easy to transfer complex care to

caregivers because they are not as competent as healthcare professionals. The impact of chronic diseases correlated with daily activities (Lim and Zebrack, 2004). Pedrón-Giner, Calderón, Martínez-Costa, Borraz Gracia and Gómez-López (2014) studied the impact of neurological diseases on primary care givers. This study found that the parents hid their feelings but were seeking emotional support through spiritual and religious coping strategies. Parents with young children worried about their child's future and treatment more than experienced parents but this did not mean that experienced parents were not aware of the child's illness and further effects.

The impact of illness influenced how parents balance their work and childcare. The illness impacted not only on the parents' work but also on the family members who co-operated in child care when the parents were absent for work. Low-income families experienced the financial impact even though thalassaemia care for children is a free service. The burden consists of the costs for transportation, daily expenses and loss of income, because parents from a low-education background did not earn anything on the days they were absent. Parents in high-income families selected expensive and advanced treatments and even searched for part-time jobs to earn more money. The parents increased their efforts to get the best treatment for their child either by spending more time or money on it.

The chronically ill child needs its parents, so their role becomes that of a care giver. The role change depends on the parents' competence and they stretch it far beyond basic care to medical care (Årestedt et al., 2014). The role of care giver includes that family members have to co-operate and share information (Kelo et al., 2013). This finding shows that the parents fulfilled their role in child care depending on their ability. The need to co-operate in childcare was a cause for stress in low-education and low-income families. Some parents felt uncomfortable to talk about the details of childcare to the nurse because they were not confident about their palliative care at home.

The environment had an impact on a family's competence. The family management styles changed over time when the child symptoms changed. Parents were confident and believed that they could practice childcare and control in their house. The parents might not be able to care for the child doing every procedure (Vichinsky et al., 2014). The fathers mostly took care of medical injections while the mothers provided basic care for child. Some parents could not practice injection and needed

support from the local hospital. The parent could decide that they did not want to do the injections at home. Another option was to include the extended family and friends in the care.

Even though it was difficult, the knowledge that the child would not recover enabled family members to face the challenges that lay ahead in the course of the illness. In their attempt to adapt to this new situation, parents considered their goals to be: protect the child, express their love for the child on a daily basis, keep hoping, uphold usual family routines, and manage symptoms.

5.2 The family as a concept

The smallest unit of the social structure is the family and this section will discuss the concept of the family by examining its definition, function and roles. Families have the greatest potential for raising healthy individuals and can also allow their members to grow (Denny and Earle, 2005). Many people view the family as consisting of the classic image of a mother, father and children. That is actually the definition of the smallest unit of social structure, the nuclear family, which consists of parents and one or more children (Giddens and Sutton, 2013).

The concept of the family was identified by Murdock (1949) and is seen as a social group that is characterized by common residence, economic cooperation, and reproduction. Murdock sees the family in its most common form as a small group consisting of father, mother, one or more children, and serving as the foundation of a social structure. Parsons (1955) gives a definition of a family based on the idea of kinship and limited to the family's function.

The definition of the family offered by Murdock (1949) as all those individuals living under one roof could be seen as too narrow for several reasons. Firstly, the family may be described by its shared physical appearance and the relationship of its members. Secondly, it does not describe the nature of the relationship between the members of the family or how healthy these relationships are. Thirdly, there are types of families that differ from the traditional family structure as described by Murdock which are present in many societies today and the discussion will now examine the different forms of a family. In Thai families the grandparents also offer

support even if they are not living under the same roof. This can be explained by the strong family ties in Thailand. The family members are the most important resource to look after the ill child.

5.2.1 Types of family

A family can be formed through genetics, adoption, marriage, or from a desire for mutual support. Families reproduce culture and spirituality and create communities and nations (Giddens and Sutton, 2013). The traditional and classical family structure is the nuclear family that performs four essential functions (Murdock, 1949): the sexual, reproductive, educational and economic function. The sexual function refers to the sexual gratification of the parents of the family. The reproductive function means that the family produces a new generation for society. Thus, the family creates consumers as well as workers and fulfils an economic function. The family is also an educational institution that teaches the new generation the norms and values of society. According to Murdock, this is the socialisation of children. The economic function plays also an important role in the family.

Parsons (1955), on the other hand, argues that the nuclear family has two purposes: primary socialisation and stabilisation of the adult personality. A nuclear family consists of a mother, father, and their biological or adopted descendants, a structure that is also known as the traditional family. Parsons (1955) defines three types of nuclear families depending on the employment status of the parents. In the first type, it is the man's duty to work outside the home while the woman works as housewife inside the home caring for the children. The women's work is unpaid. In the second type of nuclear family, the woman works outside the home and the man cares for the children. In the third kind of married nuclear family, both the wife and the husband work outside the home and are income providers. This type of family structure reflects the modern Thai family in which men and women are equal. Men and women work for paid jobs, either in their own business or if they are the employees of the company. Families with single mothers usually get support from their family members.

The occupation of parents impacts on the pattern of care for the child. Family structures have altered in recent years with an increase in the number of single parent families (Giddens and Sutton, 2013). In this type of family, there is only one parent in the household raising the children. This difference from the 'classical' family has attracted a number of negative stereotypes and prejudices. This study has shown that the single mother received a lot of help and support from their extended families.

An extended family encompasses two or more adults from different generations of a family sharing a household (Parson, 1955). Extended families can be found in different communities and countries and they consist of other family members than the parents and children. An extended family can live together for many reasons, which include financial, logistic or pragmatic reasons. It should be noted that in some instances extended families may not always live in the same house but are in very close proximity and usually in the same community. It should also be noted that extended families do not only consist of grandparents but also siblings. Brothers and sisters might be living in the same household and this could also be considered an extended family.

5.2.2 Functions of the family

Murdock (1949) states that the family has the potential to socialise the next generation by teaching them societal norms and values. A family provides for the essential needs of its members by offering a safe place to live and food to eat. Parson (1955) argues that a family's function is largely dependent on the kind and type of society in which the family lives and this will be explored in a subsequent section of this chapter. Another view of the functions of the family in the context of FCC can be gleaned by examining the principles of FCC (Shelton et al., 1987) and comparing them with Maslow's model of the hierarchy of needs (Maslow, 1943). This model has five motivational needs, often depicted as a pyramid, and each need must be met before the next one in the pyramid can be considered. I will only discuss the first two basic needs here because they are the ones primarily met by the families in this research. The basic or most essential need is physical needs. The next one is to be safe and comfortable and this is closely linked to the data from this study, where the presence of parents at all times was seen as being central to

ensure that children felt safe when receiving care. This need was also seen when parents discouraged their child from certain activities e.g. riding a bicycle as it was considered to be dangerous. Maslow (1943) states that the higher needs can only be met after the need for the physiological needs have been met. According to Maslow's theory, children remain close to their parents or family members for reasons of personal safety and as this study showed the hospital supported this relationship between the child and the family.

It is necessary to acknowledge that the role of the family and its members has changed in many developing and developed countries. Family roles are increasingly changing from traditional family patterns and there is a diversity of family structures. The reasons for this are numerous and they include demographic changes, changes in the economic structure of countries and the changing nature of employment.

5.2.3 The Thai family structure

The family is seen as the cornerstone of Thai society and Thai family life is often more closely knit than in Western cultures (Mulder, 2000). The Thai family is hierarchical with the parents at the top (ibid.). The children are taught to honour their parents and the rules within the family are similar to those in Buddhist religion although they are less prescriptive. The father is recognised as the head of the family, and children are supposed to obey their parents (Embree, 2009). Parents are expected to provide for their children in several ways: providing food, clothing, and shelter, teaching them the difference between right and wrong, encouraging acceptable behaviour, providing or facilitating education, assisting them in matrimonial arrangements, and transferring property and wealth to children. In contrast, a child's duties toward their parents include taking care of their parents when they are old, help them with their work, keep the good name of the family, be obedient and trustworthy, use their property in a wise manner and remember their parents after their death (Embree, 2009).

Changes in the Thai attitude to the family are slowly taking place. Government programmes that create new jobs, improve housing, or restrict drug trafficking are helping to support family life. However, with the existence of such programmes the

family is no longer seen as solely responsible for overcoming social problems. Instead, this has become a joint responsibility for families and the government.

5.2.4 The nature of Thai society and its impact on health and wellness

During the last decade, local organisations have been established following the decentralization of power and authority from the government. It introduced Tambons, meaning sub-districts, as a form of local administration (Department of Local Administration, 1999). The members in community can elect each other to form a new organization called Tambon Administrative Organizations or TAOs. It is an independent organization with its own budget and administrative personnel. This local organisations are the partners of the hospital but TAOs need a recommendation from the hospital to subsidise the family budget for transportation and life expense.

Thailand is a democratic society but it still has a strong social and economic hierarchy (Hanks, 1962). In the family, parents are the putative head and children are supposed to obey their parents but there is no strong commitment of duty and obligation which was characteristic of family life in the past (Embree, 2009). Embree (2009) states that the Thai way of life can be described as a cabaret life, where people smile whether they are happy or not. In the same way, Thai people are ready to laugh at themselves and their way of life and the trait of pleasure-loving can mean that it is not always possible or easy to understand Thais due to a misinterpretation of their laughter and smile (ibid.).

From the study, it is interesting to note that the structure, role and function of family life was reflected in the roles of nurse and parents when they were in the healthcare system. Low income families relied on the healthcare system and parents always treated doctors and nurses with great respect. This social behaviour may lead to a passive role for parents as they believe that they have to obey and follow the advice and instruction of a doctor and a nurse, because they are in a higher position, and this relationship is similar to that of a parent and child. For this reasons, parents addressed both the nurse and the doctor with “Kun-mor”, meaning doctor. In addition to showing respect, this relationship also often resulted in a lack of involvement of parents in healthcare. Although they had the potential to become

more involved, this did not always occur due to the class and social status of the parents.

Most Thai are Buddhists, a religion that requires them to respect monks and their superiors in social and educational terms. As was seen in the data, one consequence of these factors was that little discussion took place between parents and the healthcare staff. The relationship between them was usually on the healthcare professional's terms as the parents considered it the duty of the professional to provide care and they expected the nurse to provide the medical care and provide them with information.

The relationships between Thai people in Thai culture can be explained from a Buddhist perspective. Their positions in society are metaphorically related to others in six different directions of Dhamma. The directions point to relationships with different levels of respect and responsibilities. The above, below, front, back, right and left are referred to as different categories surrounding people (Bhikkhu, undated). The directions mean: the above are Buddhist monks and religious people; the below are servants and subordinates; the front are parents; the back are children, wife and husband; the right are teachers and the left are relatives and friends. They reflect the hierarchy in Thai society which is hidden under the cover of religious belief.

In Buddhist belief, these directions mandate a reciprocal duty of individuals to others. The parents matter to the children because they give life to them and raise them. Therefore, parents are regarded as the authority figures in the home and the creators of children's lives who children must respect (Phra Thamkittiwong, 1998). Thai children are taught from a young age at home and at school about parental devotion and filial reverence. The role of each family member is to do good deeds for the children who are in the back. It includes the moral in Thai culture that a stronger family member will not neglect the weaker members of the family. In this research, grandparents who lived in a different house were willing to come and help their child.

The findings reveal that Thai society is a hierarchical society. The position people occupy depends on their age, sex, wealth, power and education (Burnard and Gill, 2008). Government officials assume superior roles (Phu Yai) over villagers who are

Phu Noi or the inferiors (Knutson, 2004). The doctor and the nurses represented the government's official status based on the superior-inferior hierarchy. As a result, villagers have to respect and listen to officials who, in turn, must show their benevolence to the villagers (Mulder, 2000). The villagers demonstrate their respect by body gestures or using appropriate words. A popular gesture of respect is wai (Vongvipanond, 1994). Villagers cannot sit high above of the officials and so on. The parents' reactions to the conversation revealed social hierarchies. The parents from a low economical background kept quiet and accepted the suggestion of healthcare professionals. All children and parents made the gesture of respect. This finding exposes the hidden hierarchy in Thai culture and explains the issue that parents considered the hierarchy more important than their duty of childcare.

5.2.5 Family responses to illness

The families' responses to the chronic illness patient necessitate a number of changes within the family, which vary between families. A diagnosis of thalassaemia will have both immediate and long-term consequences for the family.

The child with thalassaemia needs care from the parents and the hospital. The parents' role in thalassaemia care is biomedical care and some of the parents extended it to spiritual care. The child's happiness and medical treatment do not always go together so that parents also take on the role of the people who compromise with others on behalf of the child (Zhang et al., 2014). They teach the child to accept the illness and live with it.

Parents' self-efficacy in childcare refers to the potential of being in control in the provision of care as described by Bandura (1995). This social cognitive theory defines people's beliefs about their ability to demonstrate designated levels of performance and it can influence people's behaviour. There are four essential elements of this theory: the mastery of experiences, vicarious experiences, social persuasion, and the improvement of somatic and emotional states (ibid.). Mastery of experiences occurs when people experience success. People familiar with success tend to have high self-efficacy while the experience of failure results in the opposite. The second essential element, vicarious experiences, refers to people persevering in their efforts to succeed. People desire to develop their competence by seeking

patterns that reflect their abilities. The third element, social persuasion, refers to the ability to persuade people of their potential to succeed in any given activities, resulting in an increased effort which leads to success. The fourth, improvement of somatic and emotional states, refers to the people's perception of their abilities. The psychological and emotional state affects the performance of self-efficacy, with a positive emotional state enhancing self-efficacy. All of these relate to the parents' self-efficacy in caring for children with chronic health conditions. Family members of a child with a chronic illness often find it stressful or difficult to deal with it. Chronic illnesses can impact on the quality of life, by causing changes of roles and functions within the family (Cooper, 1999) as well as by creating feelings of powerlessness (Hummel, 2009).

Chronic illnesses make it necessary to acknowledge the changes in the roles of the family and its members (Shum et al., 2014). Self-management relies on patient- (in this case often parent-) education and must also include processes that allow for parents to be actively involved. The resulting responsibility for families and successful self-management strategies of chronic diseases depend on specific knowledge of self-management and the availability of trusted sources for information. However, it can be undermined by insufficient care from doctors, a lack of information and barriers to access health information (Shum et al., 2014).

According to Whitney et al. (2006), joint decision making may not always occur because all decisions lie in the physician's hands. This decision-making process corresponds with reports from parents who said they were not always actively involved in the decisions about treatment, despite their preference for collaborative decision-making. In situations where the best treatment option is unknown, patients and parents should be more actively involved in the decision-making process.

5.2.6 The family as a coping resource in illness

Lazarus and Folkman (1984) suggest that people cope differently when stressors such as the illness of their child overwhelm their resources, like time, energy and skills. Parents in this study had to cope not only with the diagnosis of Thalassaemia but also with their child's long-term treatment, including blood transfusions and iron chelation therapy. Sometimes surgery was required when the child had severe

anaemia and an enlarged liver. Parents have many duties when caring for a child with a chronic illness and these include maintaining daily life, adapting to a new lifestyle, learning and practicing the skill of self-care and dealing with changes in role (Miller, 1992). In addition, the impact of the disease requires their child to be absent from school and causes a delayed physical, psychological, educational and social development (Vila et al., 2003). The family often has to cope with periods of crises and critical symptoms and complications that can cause parents to be stressed and frustration. The family can manage this by keeping a balance between the child's care and living their daily lives.

In chronic diseases, the complex nature of tasks and the resources required influence parents' method of coping. The injection procedure and observing of possible complications may cause caregivers anxiety about any possible errors (Donelan et al., 2002) that may occur during the injection, especially if parents are administering it. Additional resources help caregivers to achieve a balance in these tasks and so become less stressed (Lazarus and Folkman, 1984).

Donelan et al. (2002) demonstrated that seeking informal instruction or receiving assistance from family members and friends as well as the healthcare services and nursing care can help caregivers to balance their needs (Donelan et al., 2002). The findings from this study demonstrate that families had two approaches to coping. Firstly, families continued to focus on the children's physical illness and ensured that the medical treatment continued and that the anaemia was treated. This result is similar to the work of Zhang et al. (2014) who found that parents demonstrated a firm commitment to the treatment by carrying on the treatment for the child. The parents in this study received verbal instructions about how to undertake the physical care for their child which they managed at home although they experienced some difficulties in undertaking the complex aspects. Secondly, the parents realised that the nurses were busy and consequently avoided asking for more help or assistance from them.

Lazarus and Folkman (1984) defined the concepts of stress, appraisal and coping. Firstly, they stated stress is experienced when there is an imbalance in the relationship between the person and their environment that they appraise as significant to them when they have limited resources for coping. Cognitive appraisal refers to how a person considers the events that they might find stressful. Cognitive appraisal can be divided into primary and secondary appraisal (Lazarus and

Folkman, 1984). Primary appraisal occurs when the person identifies the potential stressor (threat or harmless) and secondary appraisal occurs when they decide that they can cope with it. Their child's anaemia was appraised as important and, therefore, the parents could make a primary appraisal of threat and then a secondary appraisal that they were unable to cope with this. This appraisal increased their stress levels. Most parents recognised thalassaemia as harmful but perceived it as a challenge rather than a threat and did not get overwhelmed by stress, they coped by recognising their responsibilities to look after their child.

Coping can also be explained as a process of changing the cognitive perception and behaviour to manage personal demands. Lazarus and Folkman (1984) identified 2 coping methods: Problem-focused coping and emotion-focused coping. Problem-focused coping occurs when a problem can be resolved. An example is when parents were seeking specific information about medication when they attended the clinic. The parent could control the situation by negotiating with the nurse. When the nurse and the parent negotiated, the problem was resolved, showing that problem solving was the most effective coping method in this situation. The use of emotional-focused coping is effective when the situation cannot be resolved and the person has to learn to live with it. For example, all parents had to learn to accept the diagnosis of thalassaemia for their child.

Festinger (1954) offers a social comparison theory according to which people evaluate and appraise their situation by comparing themselves to other people. They compare themselves with similar (lateral comparison), superior (upward comparison) and inferior (downward comparison) people (O'Brien and DeLongis, 1996; Maddux, 2011). Festinger's work has been applied to healthcare situations to explain human behaviour when confronted with serious illness. In this scenario making upward comparisons is detrimental to psychological health because the person is comparing themselves to someone who is in good health. Making a downward comparison is better for the psychological health as the person compares themselves with someone who is worse off than themselves.

This research found that some families used more than one coping method. The parents and children coped by using downwards comparisons with people who had more serious illnesses and disabilities. This indicated a good adjustment to the illness.

5.3 Organisational culture and its impact on healthcare

A major factor in the thalassaemia services offered to children in the study was the hospital and this section will examine it as an organisation with its own culture.

There are two types of organisations, formal and informal ones, and both are designed to achieve specific objectives (Bond and Bond, 1994). They can consist of personal or impersonal groups and can be diverse, ranging from business corporations to religious groups. Formal organisations are created by superior-subordinate relations and form the dominant kind of organisation throughout the world (Giddens and Sutton, 2013).

A formal organisation is created intentionally by a process based on rationality and efficiency (Bond and Bond, 1994). It operates according to rules, regulations and procedures, which are usually written down (Giddens and Sutton, 2013). In a formal organisational structure individuals are assigned a specific job and they interact with a fixed authority or decision-making power. The thalassaemia clinic is a formal organisation within the Lampang hospital. In contrast, in an informal organisational structure people create social groups and networks (Bond and Bond, 1994). An informal organisational structure is usually created without planning and the main purpose of such a structure is psychological satisfaction. Informal structures rely on formal structures because people working in different job positions interact with each other and form informal structures. So, without a formal structure, there is no job position and without these job positions people will not form informal structures (Bond and Bond, 1994).

The setting of this study was clearly a formal organisation. The clinic worked systematically, co-ordinating the activities of various departments with the process of care. Numerous trained healthcare professionals worked in specific tasks. There was no duplication or overlapping of work, although the nurses took on multiple roles in the system. In addition, the hospital as an organisation worked with other organisations to provide comprehensive care. Its policies were regulated, making the care process less flexible (apart from some modifications on a micro level). These policies played a strong role in defining the structure of the care provided by the hospital and its employees' duties.

My findings show that the hospital cooperated with local organisations to support the families. During the last decade, local organisations have been established following the decentralization of power and authority by the government (Department of Local Administration, 1999). The hospital supported the families with food, while the Tambon Administrative Organisations (TAOs) offered support for transportation fees and other expenses. My findings also showed that the doctor and the nurses adapted their behaviour to deal with social and economic issues the families were facing.

My study has shown that the thalassaemia clinic offers continuity, consistency and convenience. Continuity consists of informational continuity, relational continuity and management continuity. Informational continuity refers to sharing information between healthcare providers and families. Relational continuity refers to the familiarity between healthcare providers and families, which leads to trust. Management continuity can be carried out despite the limitation of resources, such as staff shortage and limited space. Consistency refers to the standardisation of the process of treatment, the consistency of the healthcare team, and the availability of information. Convenience refers to the fast track treatment of children offered by the thalassaemia clinic. The children received a service without interruption by other patients. However, the thalassaemia clinic offered these services only on Tuesdays and Thursdays and did not have specific procedures in place to manage patients' needs outside the normal operational thalassaemia clinic hours. During these periods, thalassaemia children had to follow the hospital's normal procedures like other patients.

5.3.1 Bureaucracy

Weber (2012) was deeply interested in the nature of power and authority within organisations and saw them as forms of social structure. For him bureaucracy could lead to the highest degree of efficiency and was the most rational known means of exercising authority over human beings. Weber (ibid.) described the distinctive characteristics that relate to the nature of power and authority in political, administrative, and economic domains. According to him, bureaucratic coordination of activities is the distinctive mark of the modern era and it needs to be organised

according to rational principles. Bureaucratic organisations have been instrumental in shaping modern policy, economy and technology. Their effectiveness depends on long-term planning on a large-scale and is necessary for both the modern state and economy.

The structure of an organisation is a form of bureaucracy with a hierarchical order and its operations are shaped by impersonal rules. People within organisations are governed by a methodical allocation of areas of responsibility and specific duties according to their training and competence. Bureaucratic types of organisations are considered superior to all other forms of administration because duties and assignments are authorised according to specialised qualifications rather than informal criteria (Diefenbach and Sillince, 2011). The people within organisations are ranked in an hierarchal order and bureaucratic systems follow rigid rules (Morone, 1993). The line organisation of the Lampang hospital put the nurse under the line of duties.

Giddens (1981) named three categories of power: traditional, charismatic and rational-legal authority. Traditional authorities are established through cultural patterns which are based on the common rules in a society. This is reflected in Thai culture when Thais show respect to their elders as they are the highest and most powerful people in the family. Charismatic authority is created if a leader with a special trait creates feelings of subordination in other people. An example would be the King in Thailand who is revered by the people. The rational-legal authority replaces the traditional authority as a source for the rules and regulations that shape political life and society. In my study the doctor and the nurses, for instance, exercised their powers through their medical and legal authority in the context of the hospital.

The healthcare professional has to comply with government and hospital policies and is relatively powerless, but has power over the patients and families by controlling the access to treatment and medication and monitoring patients (Morone, 1993). An example for how healthcare professionals were able to exercise their power was when they provided free services. They could also reduce unnecessary processes of care to create a fast-track for children in the thalassaemia clinic. However, because of the highly bureaucratic nature of the hospital, there were

some areas which the healthcare professionals could not influence, such as the days when the thalassaemia clinic operated.

Too much power over patients and families can be harmful and McQueen (2000) suggests that sometimes healthcare professionals use their knowledge and duty to exercise control over other people. The findings of this study demonstrate that the healthcare professionals controlled communication during interviews and when they provided advice. The parents accepted their status as professionals and their ability to help them with their child's illness. The families' powerlessness was reflected in their passive behaviour. However, healthcare professionals can use their authority to achieve positive results. They can, for example, create a friendly atmosphere to increase participation. This practice is recommended by McQueen (2000) to reduce the gap in power to ensure the provision of effective care and building relationships of trust. Similar practices include respecting patients, maintaining confidentiality, making patients feel valued and showing professional credibility (ibid.). Casey (1995) suggests that healthcare professionals can decrease the effect of their power by allowing (or even inviting) parents to undertake the basic care which can have a positive impact on family-centred care.

In this study the healthcare professionals used their authority on a small scale to adapt restrictive policies to meet the needs of children and their families. The nurses, for instance, allowed some children to attend the clinic after school or allowed relatives to take the place of parents who were unable to stay with their child. Thus, the healthcare professionals enhanced flexibility despite the hospital's rigid bureaucracy. By respecting a family's coping mechanisms, some healthcare professionals did at times change their role from being a leader to being a supporter, which empowered their patients. Nevertheless, within the wider organisation of a large hospital, the healthcare professionals recognised that they were relatively powerless and had to work within the set policies of the system.

5.3.2 Respect for social hierarchy

In the Thai context, status influences the role and the position of everybody in the hospital, and Thais show respect and agree with a person from a higher hierarchical level. This directly affects both the child and family members and the healthcare

professionals, who have a duty towards the institution. These relationships are clearly recognisable within Thai society and norms. Accordingly, the children and their families respected seniority and closely followed the advice and instructions of healthcare professionals because they are in a higher position than the child and family in healthcare organisations.

Giddens (1981) states that this domination is due to individual characteristics, like the level of education and occupation. On occasion, the hierarchical order within the hospital can be altered because of the status of the parents. For example the family with a better educational background was able to be more active and outspoken. They were also able to explain their needs to the nurses and make suggestions. Similarly, families with a better financial status could influence their child's treatment by being able to afford private treatment. However regardless of the individual family's situation within society and their ability to afford advanced treatment beyond free services, all parents in this research respected the nurses and the doctor as the key decision makers in the healthcare services.

There are two classical sociologists, Marx and Weber, who are very important in the discussion of class. Weber (2012) considers class to be important, especially for life chances and the distribution of power in society and in social relationships. Marx defined class by the ownership of property into the following three classes of society: the bourgeoisie, landowners, and the proletariat. Political organizations and power are the instruments of class struggle, and predominant ideas are its reflection (Giddens and Sutton, 2013). Marxist theory has helped me to understand class, its impact on families and healthcare. Class is a concept does not exist anymore in Thailand but Thai society is very hierarchical. This study found differences between the families, depending on their place in the social hierarchy. Parents from high-income families often reacted strongly and impatiently and asked if they needed anything for their child. Parents from low-income families, on the other hand, considered the treatment a gift and did not want to bother the health professionals.

Hierarchical systems take the form of a pyramid, ranking people according to their wealth and power and hierarchical societies function from the top-down, with those at the top in a protected and coveted position (Giddens and Sutton, 2013). In a hierarchical society occupants of the top positions are honoured and are more important than others. They also have more wealth and personal freedom. Social

class is one of the most important concepts that sociologists discuss and yet its definition is often illusive (ibid.).

Thai people respect hierarchical relationships in which one person is superior to the other (Embree, 2009). Parents are superior to their children, teachers to their students, and managers to their subordinates. The healthcare system represents an organisation and as far as patients are concerned healthcare staff who are providing medical services are at the top of the hierarchy. However, the staff themselves see hospital directors, and by implication their guidelines, as superior to themselves. It was a challenge for the nurse to empower families to become active partners in childcare and it required courage on the nurses' part.

The nurses asked the parents about their care practices at home because they wanted to ensure that children received proper care. However, the parents often thought that the nurses were controlling them. This behaviour can be explained by the social hierarchy that exists in Thai culture (Choowattanapakorn, 1999). The parents preferred to maintain a good relationship with the nurses to ensure the quality of childcare. Most Thais believe that they will receive good healthcare services if they rely on the hierarchically managed healthcare system. In addition, they have confidence in nurses who use their extensive knowledge to provide care (Chunuan et al., 2007).

In Thailand young people always show respect to older people. In general, the more senior one is, the more respect one receives. Occasional errors by superiors are readily ignored because of their age, seniority and experience. In nursing practice, this culture of respect influences how nurses approach patients from different backgrounds and the interpersonal relationships they initiate vary. For example, the name used by the nurses to address family members was related to their status and they showed their respect to older parents by calling them 'Kun Por' or 'Kun Mae', meaning 'father' and 'mother'.

Status can be displayed in a number of ways including clothing, general appearance, age, job, education, family name, and social connections (Howard, 2008). To parents, nurses enjoy a high authority in the healthcare unit and their uniform is a sign for power. It can have a negative effect on the collaboration. The findings of this study showed how the parents respected and expected the nurse to

provide healthcare for their child. They readily agreed to allow healthcare staff to make decisions because for them the hospital assigned authority and decision-making powers to the healthcare professionals.

It is important that nurses modify the individual nursing process to meet the child's physical and mental needs and the family's preference and beliefs. Although respect for individuality is not always recognised in Thailand, this study showed that nurses within the healthcare system made considerable efforts that demonstrated their respect for the needs of their patients and their families Chunuan et al. (2007). Respecting the patients' dignity was expressed in the way in which the nurses listened to the child and the family' members and their perspectives on healthcare and nursing practices. They also shared information and encouraged the families' participation if not always collaboration in care.

5.3.3 Hospital system

Hospitals are under government organisation and provide free medical care for the disadvantaged (Lyndsay, 1976). The Thai public hospital is a not-for-profit organisation and consequently, its effectiveness cannot be measured by looking at its financial efficiency, i.e. profit and loss. However, the hospital's efficiency and effectiveness can be evaluated by quality assurance mechanisms (ibid.). The World Health Organization (WHO) (2010) suggests implementing organisation structures and assurance mechanisms to manage the quality of healthcare services. The government started a hospital accreditation programme which aimed at improving and standardising health care. The thalassaemia clinic is a specialised clinic that provides high quality and effective services and general access. The services offered at the Lampang hospital are restricted by government policies that ensure that the hospital authorities follow the tertiary hospital system features. The policy prioritises physical healthcare approaches and makes it difficult to modify care. Therefore, the performance of healthcare professional is influenced by the organisational structure and the care management system of the hospital.

The healthcare services in China, which are managed by the government, best illustrate the nature of healthcare in Asia. Li et al. (2012) interviewed residents in Shanghai to evaluate the effectiveness of the local healthcare system. They found

that the effectiveness of the service was related to the health insurance system, access to essential medicine, basic clinical services and public health services (Li et al., 2012). The results showed that the clinical care services and the public/prevention services were well-received by the residents who expressed satisfaction with the effectiveness of the services. As in China, the Thai National Health Insurance is crucial for the provision of healthcare, including thalassaemia services, which Thai people can access for free. However, the level of service is not the same throughout the country despite the guidelines of thalassaemia care in Thailand (Thalassaemia Foundation of Thailand, 21976005) which outline the treatment and health education for children with thalassaemia and their parents. The directive also calls for all care-providers to operate in the same manner. Despite these differences, parents play a key role by ensuring that the child attends the hospital and it could be argued that this continued attendance implies satisfaction with the services provided and its impact on the child's welfare (Adams, 1996).

The clinic provided a day clinic with a reliable and consistent service. Denison and Mishra (1995) recommend consistency to ensure the effectiveness of an organisation. The effectiveness of a hospital consists of two traits: flexibility, which encompasses involvement and adaptability, and the combination of consistency and the mission of an organisation (*ibid.*; cf. also Davisa et al., 2013). My study revealed that the mission of the hospital was to provide the best and most satisfactory tertiary care, even though their services were limited by hospital and government policies. The health-care professionals attempted to work within the limitations of the policies and the situation in order to achieve the children's and parents' well-being.

Giddens and Sutton (2013) argue that an effective organisation should consider the social culture of the individuals within the organisation as they are part of it. This study shows that the Lampang hospital had a very positive image which resulted in a high demand. This study found that the hospital cared for a large number of patients on the days of the thalassaemia clinic. There were also delays in service. The doctor and nurses in the central hospital identified certain factors, such as the lack of time, staff and space, particularly in the blood transfusion rooms, that hindered thalassaemia care. Pink et al. (2003) found that the same limitations lead to lower ratings and lower satisfaction scores for hospitals.

A paradox of consistency existed because the clinic was only open on two days a week. As a result, parents were unsure if their child received the same treatments as in the thalassaemia clinic when they came on another day. Fortunately, the hospital offered evening and weekend services. The result reveals a deficiency in the flexibility of the hospital system that should be improved to assure that children and parents have access to a thalassaemia specialist at any time.

The Lampang hospital is a tertiary hospital that provides specific care including thalassaemia care. It has highly trained and specialised doctors, such as a haematologist, and trained nurses. In addition, the standard of healthcare services and health management are higher than in local and community hospitals. The efficiency and effectiveness of the hospital correlate with the expertise of health care staff and the hospital's facilities. The parents and the children expected the hospital to provide comprehensive healthcare services. Ludwig et al. (2010) tested the efficiency of hospitals. They found that the efficiency of care was related to the relationship between the hospital and patients and internal organisations. This study asserts that the cooperation between departments in the hospital was essential to reduce complicated processes and create shortcuts to services to increase the efficiency and effectiveness of thalassaemia services.

This research found that nurses only filled in standard forms that did not include comments about their own behaviour. These formal records could not be changed. The effectiveness of a hospital can be measured by its documentation because it is the evidence for nursing practices (Devkaran, 2014). The quality of services and their outcome could be traced by the documentation but it was only medical-focused and not FCC-focused. Therefore, the inflexible forms meant that there was no formal documentation to prove that FCC existed. Integrating questions into the form about the provision of FCC would help the hospital to monitor the quality of treatment.

Gibson et al. (2000) state that organisational effectiveness is the performance of a set of relevant organisational achievements, which include production, efficiency, satisfaction, and development. Thalassaemia services were efficient and patients were satisfied. Even though the guidelines focused on short-term symptom relief and medical treatments, the nurses provided the relevant information to support these in long-term care. This process, however, was informal and it patients and

their parents would benefit of a formally organised support. They were aware that family members were important for the provision of child care (Higman and Shaw, 2008). The nurses also used their limited power and managed their limited resources within the organisation to provide a comfortable space for thalassaemia care and maximise parental knowledge and their involvement in the care.

The nurses also controlled the healthcare process and managed uninterrupted medical services. This research suggests that they should use their abilities to facilitate peer-to-peer support. Peer support can help parents to understand and exchange their knowledge about thalassaemia care. The nurses could co-operate with the parents to conduct formal peer-to-peer support in the thalassaemia clinic, which could help the hospital to promote self-care.

5.3.4 Trust and respect

Trust is necessary in a healthcare system as the patient traditionally has to trust the healthcare professional (Rowe and Calnan, 2006). The hospital has policies in place to maintain standards of healthcare but these standards also depend on the level of trust, as mistrust and/or loss of trust can cause patients to become uncooperative and refuse treatment (Hupcey and Miller, 2006). It is important to note that relationships of trust are delicate and healthcare professionals need to be careful and watch out for signs of a loss of trust (*ibid.*).

Harrison, Innes, and Zwanenberg (2003) state that the facilities of a hospital and the appearance of its staff can create trust. In addition, knowledge, skills and the competence of healthcare professionals is expected to be high to generate trust (Calnan and Sanford, 2004). Gilson (2003) and Brink-Muinen and Rijken (2006) identify three kinds of trust: trust in present healthcare, trust in future healthcare and trust in existing medical interventions.

First, trust in present healthcare develops if ill people experience effective treatment (Hupcey and Miller, 2006). Trust in a healthcare setting consists of establishing respect, involvement, and collaboration and the experienced patient expects to play an active part in the decision-making process about their treatment. In turn, a nurse trusts a parent to care for the child and to manage medication and self-care.

Second, trust in future healthcare is created if the hospital can successfully deal with the challenges caused by a rising demand for healthcare (ibid.). Changes of the service provided by healthcare professionals influence the physical, emotional and technical resources of patients. In the healthcare unit, healthcare professionals interact with patients and are in constant contact with people using verbal and non-verbal communication to learn about a patient's condition. Healthcare services dealing with chronic illnesses can be adjusted to suit the needs of the children and their families.

Thirdly, trust in existing medical interventions is created by their success (Hupcey and Miller, 2006). The findings of this study revealed that all children could access healthcare on a high standard, for example efficient blood transfusion techniques. The hospital provided an equal and similar service for every child, thus consistency of care was present. The healthcare professionals responded to physical and spiritual needs. They carefully performed nursing practices with the aim to reduce stress and fear for children. The parents' needs were also taken into account. Healthcare professionals took the time to talk to the parents if they needed more information on childcare so that the process of care helped families to trust them more.

The parents and children in my study trusted the hospital as an organisation. Rowe and Calnan (2006) asserted that trust in healthcare services is associated with trust in institutions and in healthcare professionals. As my findings show, the level of trust between healthcare professionals and the parents influenced the latter's ability to provide self-care. Healthcare professionals who trusted parents taught them more. Parents and patients trusted the healthcare providers because of their professional knowledge and their status. In addition, the welfare system guaranteed government support to ensure the quality of the treatment. For Rowe and Calnan (2006) trust is associated with the philosophies and the functioning of organizations. Mutual trust and mutual goals mean that the healthcare professionals and the patients can work together to achieve the patients' well-being (Nooteboom and Six, 2003). Trust can increase the degree of interdependence that develops between healthcare professionals and family members (Rousseau et al., 1998).

The findings of this research show that people voluntarily trusted each other. All three forms of trust, in present and future healthcare as well as in existing medical

interventions, was present in the study setting (Gilson, 2003; Brink-Muinen and Rijken, 2006). According to Nooteboom and Six (2003), trust is a crucial concept when risks are involved and when uncertainty in the future emerges. In Pfeil's (1997) study of the perception of duty of healthcare staff he found that nurses thought that it was their and not the parents', duty and responsibility to care for the patients. In my research setting inconsistencies arose when a nurse, for example, acted as a leader but attempted to encourage the parents to take more responsibility and be active in the care of their child. In this case, parents were the leaders at home but were overshadowed by the practical medical care in the hospital.

A study of public trust in healthcare in the United Kingdom showed that trust was different than in this study. The study found that patients distrusted all areas of healthcare. In a developed country the patient has high expectations and the highest levels of distrust were found in relation to how the healthcare service was run and financed. Patients were particularly concerned about waiting times and the implications of cost cutting (Calnan and Sanford, 2004).

In this study, patients and parents trusted the highly skilled healthcare professionals. Also the behaviour of the healthcare staff influenced the development of trust and familiarity. In addition, trust was developed and maintained during efficient healthcare processes, which complied with the standards of the healthcare system. Healthcare staff were ready to provide required services, and patients were encouraged to express their needs and concerns. The nurses demonstrated their duty of care and provided an integrative service, while being aware of the limitations of this service due to insufficient resources and the large number of patients.

The nurses also challenged the combination nursing of cultural in nursing care to provide educational programme for the children and parents. In Thailand, healthcare professionals are considered to be very important because people believe that they help them to become healthy again. In rural areas, in particular, people strongly respect healthcare providers, who are part of the community and involved in various activities, including rituals and religious ceremonies.

5.3.5 Promoting self-care

This section discusses the hospital services that aimed at promoting self-care. Self-care is defined by the actions individuals take to care for themselves, the lifestyle choices they make to adapt to their chronic condition and to prevent further illness or accidents (Kennedy et al., 2007). Self-care is a key concept, allowing the individual to optimise their health and depend on themselves and not on healthcare providers (Miller, 1992).

I will discuss two models of personal care: Orem's theory of self-care and the middle range of self-care. Orem's theory of self-care offers the framework to understand and interpret experiences using the concepts of self-care, self-care deficit, and nursing agency (Orem et al., 2001). It recognises that individuals need to receive physical and emotional care. Thus, self-care according to Orem consists of activities and practices people perform to maintain their life, health and well-being. These actions are based on their knowledge and abilities (ibid.). Self-care deficit occurs when the need for self-care is higher than the actual abilities (ibid.). The limitation of patient abilities means that they need support from healthcare professionals. The nurse plays the role of nursing agency and facilitates self-care. According to Orem's theory, parents can provide self-care for the child on the same level as the nurse.

Orem's theory of self-care contains three basic systems of nursing care (Orem et al., 2001): First, the wholly compensatory system, which is suitable for patients who are unable to care for themselves. The nurse needs to provide complete nursing care to fulfil their needs. The wholly compensatory system has less potential to be adapted to thalassaemia care because the young child is not able to care for itself. Parents can perform self-care on behalf of the child. This type of self-care is a partly compensatory system which is suitable for parents with different levels of competence in childcare. The partly compensatory system needs the collaboration of healthcare professionals with patients to achieve the goal of self-care (ibid.). This study illustrates that the parents, together with other family members, practiced self-care for the child. Thalassaemia is a dynamic illness with fluctuating symptoms which is why the wholly compensatory system would not work. Instead, the nurses and the families worked together to perform complex self-care activities for the children.

Parents and patients shared the care and medical procedures with the healthcare professionals and worked well together under the nurses' instructions. In this study, some parents needed help repeatedly with complex medical procedures. If the injection site had to be changed, for example, the parents had to be shown again how to do it. Thus, the partly compensatory system was suitable for parents who only needed support when they had difficulties with self-care. The self-care system used depended on the competence of the parents and Orem's theory suggests that a supportive education system can overcome these limitations. The nurses used resources and educational tools to teach the thalassaemia child to perform self-care. Families who were not very well educated also needed partial self-care and educational self-care support. As the findings show, the parents learned and performed childcare with the assistance of the nurses. Interestingly, the parents could perform self-care but needed the healthcare professionals to make decisions.

Orem's theory offers the concept of self-care but the guideline to perform self-care in this thalassaemia clinic was a combination with the middle range of self-care. The middle range of self-care is suitable for both healthy and ill states of a chronic disease (Riegel et al., 2012). The chronic illness alters between illness and stability so that a continuity of care is necessary. When an individual with a chronic illness is stable, he or she is often able to maintain self-care at home and reduce the need for support from the hospital and healthcare professionals. The middle range theory of self-care consists of self-care maintenance, self-care monitoring and self-care management.

Self-care maintenance allows people who perform self-care to maintain physical health and emotional stability (Riegel et al., 2012). Cené, Haymore, Dolan-Soto, Lin, Pignone, DeWalt, Wu, Jones, and Corbie-Smith (2013) conducted research to evaluate perceived self-care maintenance by measuring emotional/informational support. The benefits from self-care maintenance reflect the usefulness of the behaviour (Cené, et al., 2013). This informed self-care needs to be maintained on a daily basis and consists of both medical and non-medical care. The study found that maintenance adherence is an essential component of self-care and associated with the best outcomes. The patients can spend more time at home living a normal life and are not so dependent on hospital care.

To extend Orem's theory, self-care maintenance allows parents to combine their practice of care with their own lifestyle to maintain their physical and emotional well-being (Riegel et al., 2012). There is limited research to support a combination of Orem's theory and the middle range theory. This study extends the knowledge of self-care by looking at the potential of children and the role of the family to practice self-care for the child.

Self-care monitoring is a process of routine checking of changes of a body and symptoms and it is a part of the self-care process (Riegel et al., 2012). If a change is occurring because of the chronic illness it results in physical sensations and bodily changes (ibid.). In this study, parents and children with thalassaemia were encouraged to perform routine severe anaemia and symptom assessments. The parents and the children then planned further actions or decided to get support from healthcare professionals. The result of this study implied that self-care could be monitored by the parents and the child who knew about its needs. This study confirms that self-care monitoring is complex and needs nurse-led intervention to care for the child.

Daily monitoring is a basic part of self-care according to Todd and Mullan's (2014) study. They studied self-monitoring in young adults who suffer from sleep disturbances. The research offers an understanding of self-monitoring as referring to simple everyday behaviours. The result illustrates the significance of the three sleep hygiene behaviours: avoiding hunger and thirst, avoiding anxiety and activity before going to bed, and making the bedroom and sleep environment restful. These self-monitoring behaviours provide a simple intervention that can improve the quality of life (ibid.). This study implies that thalassaemia children and their parents can practice simple monitoring, such as monitoring body weight, height, food and weakness. It suggests that parents and children knew their situation and planned child care. Once the child's symptoms were severe, for instance, parents had only one choice, namely getting treatment at the hospital. The state of health fell into a self-deficit so that they needed a nurse (Orem et al., 2001).

Self-care management is an important part of self-care that responds to individuals and their families (Ryan and Sawin, 2009). The management involves an evaluation of changes caused by the illness, treatment, or the environment that can result in physical and emotional signs and symptoms. Petrie and Weinman (2006) and

Bayliss et al. (2003) suggest that patients living with a chronic condition should manage symptoms, treatment, and the physical and psychosocial consequences. This study extends Petrie and Weinman's statement by concluding that education is part of self-management. In this study the nurses offered education to promote self-care. Davies' study illustrated the same effect that nurses provided education to improve self-management for patients with long-term conditions (Davies et al., 2010). Self-management can be used together with education to increase the effectiveness of self-care (Lillyman and Farquharson, 2013; Walker et al., 2014). In Chronic Obstructive Disease (COPD) rehabilitation programmes, self-management with education was a tool to improve patients' functional status and quality of life (Kaptein et al., 2014). People with COPD reported positive outcomes after they used a self-care approach to control their symptoms (ibid.). This practice resulted in delayed or less critical symptoms and patients needed less hospital visits. Riegel et al. (2012) state that practical self-care is difficult when the patient is unable to care for themselves or self-deficit is taking place. Therefore, the family members, parents in particular, are essential caregivers in the care of thalassaemia children.

In this study, the central hospital was expected to provide the care for the child. Hospitals need to encourage healthcare providers and patients to work together to improve the care by increasing the patient's self-management (Frist, 2005). The Lampang hospital provided the parents with efficient training in child care, such as teaching them how to do injections or manage their child's health at home. Such an activity needs a lot of cooperation between parents or family members and healthcare professionals to maintain care in daily life. According to this study, the parents were motivated to take on more responsibility by performing self-injections, identifying side effects and cooperating with the hospital and/or the community healthcare unit as well as monitor the child's daily activities. Thus, the parents became the main caregivers. However, the nurses verified the results of this self-management and acted as supervisors to ensure the child's safety.

5.3.6 Health Education

The educational health model helps family members and patients to maintain and improve their health, reduce the progression of a disease, and manage the chronic illness (World Health Organisation, 2012). The consistency of education has an

impact on the child's health and the parents' competence. The nurse agrees to increase the parents' potential to do so by constantly providing them with health education. The LEARN model enables the nurse to adapt how they teach nursing skills to the parents. (Berlin and Fowkes, 1983). Healthcare providers should consider the LEARN model of learning to practice FCC, which consists of listen, explain, acknowledge, recommend and negotiate (ibid.). This model offers a communication framework that can help healthcare providers to overcome cultural barriers and succeed in delivering education.

Nurses can choose to adapt the LEARN model to improve their skills of providing FCC (Smith and Coleman, 2009). First, listening allows them to understand the families' perception of the children's illness. It encourages children and parents to discuss the reasons for and results of the illness. It helps them to develop an understanding of the illness progression, prognosis and resources that the patient considers to be appropriate. Understanding a patient's conceptualizations and preferences constitutes the first step. Second, explanation requires an essential interaction between healthcare staff and the patient and their families and helps the former to understand their cultural beliefs. Third, acknowledging the children's feedback and understanding their problems improve the quality of healthcare. These skills are useful in family-centred care (ibid.).

In this study education processes were offered on a personal and group level. Personal education relates to immediate education and implies an inconsistency in the education process in healthcare. In addition, an education plan can serve as a compass for healthcare. The nurses in this study recorded physical care but rarely the educational processes. This is not an optimal approach to education because there is minimal evidence of the provided education. Therefore, the educational programme needs to be managed better. This is necessary so that other nurses and healthcare professionals can track the progress and evaluate the effectiveness of education.

Education improves the parent's competence in childcare. The study of Rosenstock et al. (1994) explained the advantages of group learning by watching other people, meaning observational learning. This educational method is a combination of formal education and peer support that teaches a credible, effective method for long-term care (ibid.). The aims of education in health promotion are to prevent illnesses and

protect health (Downie et al., 1997). They state that the value of education is the biggest part of health promotion, and the method of education depends on the context of the healthcare system (ibid.). Since it is questionable if children can provide proper self-care, parents are important to facilitate it. This study found that the complexity of medical care meant that parents needed more instructions. The hospital could not offer an education session unless the injection was required. The injection training would take place when the parents needed more support with the complex procedure. The study found that the educational process provided information together with physical treatments. Technically specific knowledge of thalassaemia was also required. Most parents underestimated their knowledge and did not demonstrate it during the hospital stay of their child because of their respect for the nurses.

Tones, Robinson and Tilford (2013) offer a preventive education model that persuades the patients to take responsibility on a primary, secondary and tertiary level of prevention. Primary prevention means adopting behaviour believed to reduce the risk of a disease. Secondary prevention is the next step: and refers to learning self-care and seeking appropriate treatments. Part of this prevention is that patients comply with medical treatments to minimise the severity of a disease. Tertiary prevention aims at preventing deterioration, relapse and complications of a disease. In addition, it promotes rehabilitation. Preventive care is part of the education process (Ouyang and Hu, 2014). The preventive model was practiced in the research setting even though the nurses were not aware of the theory. However, the preventions were adapted to suit the Thai context. In this context other factors, such as the economic and educational background of the family and the current hospital setting, were taken into account and combined with the prevention model.

5.3.7 Nurse as a health educator and a resource

According to Henderson (2003), the nurse regularly provides the necessary knowledge to encourage the parents to co-operate within the hospital and parents accept the nurses' suggestions and recommendations about child care. The nurses treated the parents and the child with respect. The nurses had to ensure that individual needs were taken into account and that they show respect for the diversity of patient values and perspectives to understand the uniqueness of

children. They demonstrated educational processes through teaching, educating, instructing, advising, demonstrating and facilitating care for the patients and the children. A child's and a family's knowledge, beliefs, values, and cultural backgrounds are integrated into the practice and implementation and evaluation of healthcare. Planning is a concern because it can facilitate co-operation with the parents and ensure that they are involved in every level of care.

In addition, appropriate information is provided in a timely, thorough and accurate manner so that children and families are able to participate and be involved in care and decision-making. The finding correlates with Picton (1995) according to who the nurses teach parents to improve their ability to care for the child at home to increase opportunities to practice basic care.

Due to the limitations of staff in the hospital, nurses provided nursing care and performed multiple roles. In the health-care setting, patients listened to doctors and nurses and never questioned the advice they were given. They were also hesitant to ask doctors questions if they did not understand a particular plan of treatment. Nurses played the role of an intermediary when parents needed to communicate with the doctor and they informed the doctor about the parents' needs.

5.4 The FCC approach and Buddhist belief

Religious activities often constitute a significant part of an individual's identity and influence coping mechanisms as well as inform decisions about medical treatments. According to Marx (1976), religions contribute to the suppression of the people by persuading them to accept their status in society as God-given. He continues that in order to develop their potential to learn and to gain confidence, and thereby to change their situation and status in society, people have to be liberated from the suppression of religion. The difficulty for this change to occur is asserted by Barnes (2000), who notes that power structures in a society will only change if the economic and educational situation of the people changes.

Thai society is influenced deeply by religion. The healthcare professionals, patients and their families in this study were all Buddhists. Rather than go along with Marx' assertions, a social scientist looking at a Buddhist society would be more likely to

agree with Anthony Giddens' views of religion as an enabling structure in society and not as a constraint (Mestrovic, 1998). Thai Buddhists could be expected to argue that their religion can improve a society and even create a better one. This would be achieved by the focus of Buddhism on the improvement of the individual. By 'Making Merit' (doing good deeds) and following the Buddha (i.e. His teachings) Buddhists believe that adhering to the principles of Buddhism will improve their mental well-being, achieve individual happiness and potentially personal enlightenment (Lopez 2005). Beyond benefitting the individual, they believe that it will also influence their lives on a societal level by improving the lives of the sum of individuals.

In this study religious beliefs and practices were seen as being effective in helping people to cope. These results therefore challenge Marxist thinking. The parents in this study taught their child to pray and practice meditation in accordance with Buddhist beliefs, hoping this would make their child happy because they would be doing a 'good deed'. They also adhered to Buddhist practices, such as donating food and praying, which encouraged specific behaviour and created beneficial emotional states. The families felt that meditation as a form of religious practice enabled them and their children to achieve control of their minds, which made them in turn more confident and created greater awareness. They also thought that it increased the children's mental and emotional control and so helped them to remain calm and relaxed, remain positive and be patient. The parents were convinced that their children were more cheerful, happy, kind and generous if they made merit and radiated loving-kindness towards all beings (Metta chanting).

Similar results have been reported in other studies. Khieosopha (2004) found that making merit and practicing Metta chanting increased kindness and compassion. A multitude of authors (Wall 2005; Rosaen and Benn, 2006; Bogels et al., 2008; Lau and Hue, 2011) report that practicing Buddhism can be beneficial because it enhances self-awareness, self-control and confidence. Importantly for this study, Lechtenberg (2012) reported that young children used meditation to maintain and improve familial relationships: one child meditated when it was angry with family members, whilst another practiced meditation together with her parents at home.

Underlying Buddhist belief is the knowledge that change is an inherent part of life. Thalassaemia is an unpredictable, life-changing illness. According to Buddhist

belief, people have to face four unavoidable things in their life time, namely living, growing old, getting sick and dying. However unavoidable, getting sick and dying is still frightening, and in order to cope with this anxiety and loss of control people practice social rituals to reduce their anxiety over unpredictable outcomes. Most prominent of all, however, is the Buddhist core belief that life is a transition and inevitably ends in loss. In Buddhist terms, the appropriate way of dealing with this transition is to recognise the fluidity of life and to let go of possessions of any type, including the people we love (Lopez, 2005).

In this study parents also went regularly to the temple, where they sought advice from monks and performed religious rituals. They rarely, if ever, used the formal psychological support mechanisms offered by the hospital for the children and their families. Indeed, these were not considered necessary by the families in this study. These results are in accordance with previous studies by Rosaen and Benn (2006), Lau and Hue (2011), Lechtenberg (2012) and especially with Rennie's (2008) suggestion that the principles of Buddhism, including meditation, can be employed as a mind tool. They can help people to focus on the present moment, calm their minds and thus improve their mental well-being and help them to cope with their lives. These results are congruent with a number of studies, including Barnes et al. (2003), Singh et al. (2007) and especially Powell et al. (2003), who showed that attendance at a religious service at least once a week improved people's mental state.

The support religion provides when coping with life crises holds true not just for Buddhism. This study also corroborates findings in the US (Koenig, 2004), according to which patients in general medicine, cardiology, and neurology services reported that their religious beliefs and practices are powerful sources of comfort, hope, and meaning, particularly for patients coping with chronic illnesses.

Durkheim views religion as a source of solidarity with the power to unite people into a moral community (James, 1986). Furthermore, Koenig (2004) describes that healthcare professionals recognise the positive impact religion has on emotional wellbeing. The nurses and healthcare professionals looking after the children and their families in this study shared the same religious beliefs with their patients. Being Buddhists themselves, they were able to recognise that children's and parents' behaviour is influenced by the Buddhist principle of *Sraddha*. Originating from

Sanskrit and often translated as "faith", it can also mean trust, confidence or fidelity. It expresses people's beliefs in the practice of religion. This understanding and respect for their patients' beliefs and practices made them culturally competent (Durkheim, 1994). While prioritising physical care within a system where resources are scarce, they understood that children and parents used religious rituals to cope with the situation. Even though the healthcare professionals in this study were unable to modify the overall healthcare system to support this form of coping, they provided nursing care according to Buddhist principles. The changes they introduced were small to the point of appearing trivial, but nevertheless important. Families were allowed to eat together and so maintain some aspects of normality in their family lives. They were provided with financial support to cope with the (transport) costs of visiting their children, a small improvised temple area was available for prayer, whenever needed the nurses spoke to the families in local dialects or languages rather than official Thai and they used traditional terms of endearment when talking to the children.

The nurses were convinced that they were simply doing their duty but the observations showed that they acted in accordance with Buddhist belief when they approached the children and their families. They also demonstrated that doing these 'good deeds' helped the nurses to form positive relationships with the children's families. The importance of individual religious beliefs for healthcare practitioners was outlined by Curlin et al. (2006) who reported that 55% of physicians in the United States said their religious beliefs influenced their practice of medicine. The present findings point to a similar result.

Burnard and Naiyapatana (2004) in an interview study exploring Thai culture and communication within nursing found 'Thainess' rather than being Buddhist to be the most prominent theme. The participants defined 'Thainess' as including modesty and simplicity as well as an ever-smiling politeness and showing respect that avoids confrontation at nearly any cost. But it also included 'language, culture, being proud, being Buddhist' (ibid.: p.758). The religious aspects of this definition, i.e. Buddhism, was deeply entrenched into other issues of great importance, such as making merit or the attribution of severe illness to khamma. However, the high importance of social status and the emphasis on respect towards one's betters was attributed to culture, rather than religion.

The inclusion of Buddhism into the definition of Thainess does, however, raise the question whether within what Klausner (1993) termed the Thai social and cultural labyrinth it is actually possible to always distinguish clearly between culture and religion in this context. This is supported by the social changes taking place in Thai society.

While social hierarchies still exist, changes in education and economic situation influence the system of power and control. In Thailand today the government-run hospital system is very powerful and it radiates a lot of its power onto the healthcare professionals it employs. Within the hospital the nurses, being in a position of power, provided care according to the standards of the hospital. This was never put into question, neither was their role of guiding the parents, who were encouraged to provide basic dependent care (McLaughlin and Taylor, 2003) for their chronically ill children, as well as undertake some aspects of medical care at home. During this research it could be observed that parents with a university education and comparatively wealthy families were able to take a greater part in the care for their child and even negotiate treatments. They were far more assertive towards healthcare professionals, asked more and more specific questions, but in the end complied with the nurses' directions. This made it clear that in terms of status, they were still noticeably 'inferior' compared to the healthcare professionals. This demonstrated that the advanced financial and educational status of the parents had not resulted in an essential change in power as predicted by Barnes (2000). For the poor families the division was even clearer. They could not even attempt to cross these social norms. They felt unable to ask questions, negotiate with the nurses or stated that they did not want to disturb the nurses during their practice by asking questions. Similarly, most children in this study were unable to receive (because their parents were unable to afford) advanced treatments with less side-effects. Instead, the poorer families unquestioningly accepted standard treatments and used their personal coping strategies to overcome the disadvantages caused by side effects.

To this day Thai society remains very hierarchical and change is often limited to the personal lives of individuals. However, there are clear signals that change does happen. The most important recent change is that the education system in Thailand has become more inclusive. Schools are free for all and people can borrow money from the government to finance their children's higher education. This study found

that parents with a good education and from a better economic background had the potential to influence the care for their child. They also had access to information about chronic illnesses and new treatments from various sources, such as the internet or books.

The nurses provided some aspects of family-centred care but the less educated families with a correspondingly lower economic background were unable to benefit from this approach. The nurses gave parents the opportunity to ask questions, for example, but these parents were unable to make use of this offer.

Free access to education and financial stability are necessary for changes in society (Lynch and Baker, 2005). Better educated people can use their knowledge to make decisions about medical treatments. While this result confirms, at least at micro level, Marx's assumption that education facilitates societal change, Barnes' (2000) assertion that power structures in a society will only change if the economic and educational situation of the people changes still holds true at the higher level.

This study has shown the Buddhist principle of accepting one's fate helps both children and parents to cope with uncertainty and life crises. Yet, if interpreted negatively it also comes close to Marx' idea of religion as a societal narcotic. According to the teaching of the Buddha, a good human being is kind to others and accepts the status quo and one's position in the social hierarchy. Young people maintain good relationships by not contradicting and agreeing with people who are their seniors, thus showing their respect for them. This is based on the assumption that older people or people with a higher social status are more knowledgeable and can provide guidance for young people. It is considered a sin if a young person resists an opinion or argues with someone who is their senior, and they will accumulate bad karma. This belief is deeply imbedded in Thai people and was reflected in the interactions observed in the hospital. Parents and children take on the role of younger people, while nurses and the doctor are treated as their superiors. Religion organises people in a hierarchical structure and thus maintains social hierarchies. As a result of this hierarchy, nurses can expect a smooth and productive collaboration with parents and other healthcare professionals who possess widely varying intellectual, ideological and spiritual needs.

In conclusion, Marx' materialist conception of society and rejection of religion on social grounds should be balanced with Emile Durkheim's views (James, 1986). His

warning that society becomes ever more complex due to increased population density and growth, combined with his view on religion being able to help form a moral community at a time when rapid change can lead to a breakdown of norms, values, and understandings may be over a hundred years old, but it rings very true in 21st century Thailand.

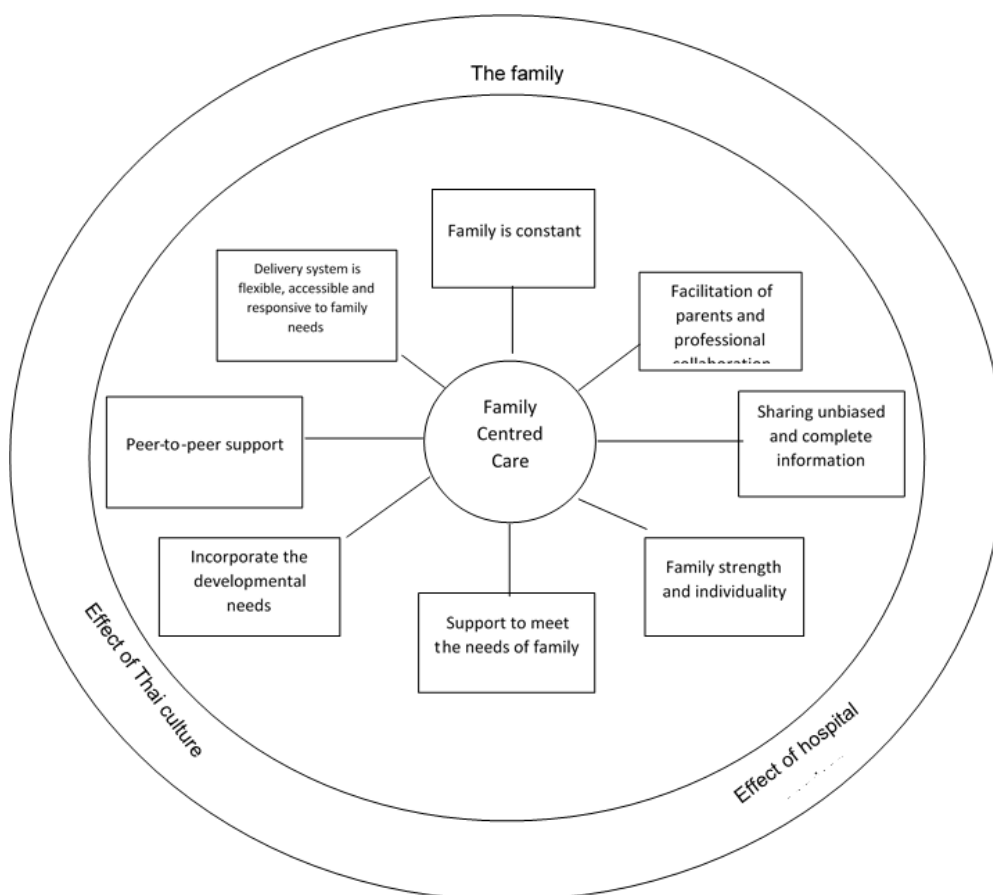
5.5 Framework for the family-centred care provided in a thalassaemia clinic in Thailand

This research was conducted to explore the nature of family-centred care in a thalassaemia clinic in a hospital in Thailand, analysing triangulated data from nurses, a doctor, parents, children, a nursing instructor and a monk. This data was gathered in interviews, through observations and from documents.

This study provides an understanding of the nature of family-centred care in thalassaemia care in order to move towards a more integrated model of FCC. The knowledge from previous literature will be extended to present a model of family-centred care that describes its nature, character, and the factors that influence it. The findings illustrate the practices and processes of care and the impact of the healthcare system and Thai culture.

The framework consists of two key components: characteristics that describe the practice of care which aim at improving the child's well-being and factors that influences these characteristics. The framework is presented in Figure10:

Figure 10: Nature of FCC in thalassaemia care in Thailand



5.5.1 The first component: Characteristics of family-centred care in Thailand

Even though the hospital had no formal policy to deliver care based on the principles of FCC, the core elements were in place. Each element illustrates the different level of family involvement.

Family is constant

This characteristic demonstrated that parents were important to the child and the healthcare professionals acknowledged that parents had to play a key role in care processes. They encouraged the parents' presence, which varied according to the families' abilities and their willingness to participate in the care. The healthcare professionals understood the children's and parents' needs and provided a supportive environment to enable the parents to stay with their child.

Facilitation of parents and professional collaboration

Collaboration between the family and healthcare professionals took place in varying degrees which created a comfortable and safe environment for the child. Healthcare professionals encouraged parents to be partners in care and to manage the care of the child at home.

Sharing unbiased and complete information

Information sharing and the provision of training for parents by healthcare professionals occurred quite frequently. The aim was to promote more active participation and to teach the parents how to undertake self-care at home. In addition, it contributed to the development of self-confidence, awareness and a positive approach to healthcare.

Family strength and individuality

The families' background and prior knowledge were taken into consideration by healthcare professionals and, where possible, taken into account. The main obstacle to ensuring that this was uniformly implemented was the large number of children attending the hospital which led to standardised rather than individualised care. One area where individuality was acknowledged was the fact that healthcare professionals accepted the families' own methods of coping with the child's illness.

Support to meet the needs of family

The healthcare professionals provided educational and psychological support to the family and child. They also helped parents who were burdened with financial issues. The environment within the clinic was in general supportive which was visible in the way healthcare professionals interacted with the children and their families.

Incorporate the developmental needs

A holistic approach to care was in place and healthcare professionals tried to ensure that the psychological and social aspects were incorporated in the physical care. They had some difficulties in meeting the psychological needs because of the large number of children attending the clinic and the limited resources. Healthcare professionals also tried to provide age-appropriate care and resources for the educational needs of the children.

Peer-to-peer support

Peer-to-peer support occurred on an informal basis between parents when their children attended the same clinic or if they lived within the same community. Parents shared information and experience with each other and the main area that was frequently discussed were strategies to manage a child's nutritional needs. Experienced parents were happy to pass on their knowledge to parents of newly-diagnosed children. Healthcare professionals did not facilitate peer-to-peer support actively, although they were aware and supportive of it occurring informally. The main reason that healthcare professionals did not facilitate this support was due to their need to concentrate on the physical aspects of care.

Delivery system is flexible, accessible and responsive to family needs

The healthcare system tried to adjust its mode of operation to meet the families' needs in a number of ways. It engaged the support of departments within the hospital as well as hospitals that were situated near a family's home to ensure that parents received comprehensive care. The main reasons that flexibility and responsiveness of the healthcare system were not more common were the large number of patients who attended the hospital and a lack of sufficient resources to meet the different needs of families.

5.5.2 The second component; the factor of family centeredness

The second component consisted of three factors: the characteristics of the family, the characteristics of the hospital and culture and in this instance, Thai culture. Parents from a middle-class background had the potential to change their role in child care. Interestingly, the nurses were aware that family members are important to provide child care.

The family

Thai family structure influences the family's involvement in healthcare processes. The Thai nuclear family offers support to every family member, even if they are not living in the same house. In addition, family members co-operate with healthcare professionals when the parents are unable to carry out medical care due to their employment. The level of education of the parents and the severity of the child's illness affected the level of participation. The family members' involvement led to a

better quality of life because they offered additional support. The families' background affected the interaction of parents and healthcare professionals. Parents with a high level of education tended to demand better service as they were confident to express their needs. They also understood the health education better and practiced childcare properly. They could do research about thalassaemia care and adapted their self-care. This meant that these parents were more confident in their negotiations and communication with healthcare professionals. Some demands of the parents for thalassaemia care meant that nurses had to modify the healthcare services. In contrast, low-education and low-income families were not confident to participate as much in childcare.

The families of chronically ill children are economically burdened and their way of life changes. Changing the pattern of life and increasing income become crucial. The economic burden consists of costs for the transport to and expenses during the child's stay at the clinic. In addition, the family needs to manage medical care and time to bring the child to the hospital. Parents try to protect the child from complications and unwanted symptoms. Daily activities are disturbed by medical treatments. The roles in a family change when a child is diagnosed with a chronic illness to provide continuous care. The elders in a family are the main support for parents with the demands of daily care as well as the managing of medication.

The parents responded to their child's illness and complex medical care by extending their roles. They demonstrated this by managing the daily care and medication to prevent complications and other risks. Therefore, they learned to observe their child's symptoms. The limited knowledge was a barrier for self-care. Parents believed that they did not know as much about thalassaemia care as a nurse or a doctor. Their ability to extend their knowledge both in the hospital and through other sources, such as the library or the internet, was limited. The parents managed their child's activities to try to avoid accidents and risky activities that might cause bleeding and fractures. This protective behaviour reduced the children's quality of life and limited their development. Their daily activities were adjusted to their conditions.

Effect of hospital services

Hospital management with limited resources for thalassaemia care is difficult but flexibility in practice ensured that the children were able to access standard

treatments. The hospital, therefore, provided efficient services. It promoted self-care to increase the parents' abilities to care for their children. The nurses expected that offering parents to care for the child taught them effective self-care. Because of the complexity of services and limited facilities in a hospital, nurses had to adapt their practice and use suitable approaches to deal with the parents and the child. The time and space limitations, the high amount of patients and an awareness of the parents' abilities influenced the potential of family-centred care. To achieve successful care, the hospital offered services on the weekend and in the evening to reduce congestion in the clinic. It also reduced unnecessary processes to save time and to make the children feel more comfortable. Children attended the clinic regularly for check-ups and blood transfusions. The frequency of their attendance depended on their condition.

The nurse and the doctor represented the hospital system. However, while they provided services under the hospital's policy and regulation, they also realised that the parents were important for the child's health. The nurses provided thalassaemia care using friendliness, which is an important value in Thai culture. They also reduced the gap by using terms to create family relationships with patients. The parents' demands depended on their educational background and financial status. The nurses sometimes had to change their role to be supporters rather than supervisors.

The parents showed different levels of involvement in healthcare. They could negotiate the date of an appointment and gave the nurses necessary information. In addition, they checked anaemia and observed symptoms when they were at the hospital. Some parents participated actively by asking the nurse questions and negotiated to make the child more comfortable. However, the parents had only limited power in the complex relationship with the healthcare professionals. This unequal relationship could be eliminated by the promotion of self-efficacy, appropriate roles and involvement.

The nurses attempted to increase the parents' self-care capacity by providing health education. The methods of education varied depending on time and occasion. The nurses mostly provided education during the procedures or nursing practices. Formal sessions took place when a complex procedure, such as injections, was needed. The importance of continuity of care was the reason why the nurses

provided parents with knowledge about nutrition and instructions for injections. The nurses also provided education about complications and side-effects of blood transfusions during every visit. In addition, health education sessions were conducted with individuals and groups, which indicated peer support among the parents. Thus, the education process was mainly informal and took place during the normal treatment. Complex care was an issue when the parents struggled to manage the child's symptoms and activities. Further training in this kind of care was provided to parents individually.

The nurses and the doctor mainly supported the parents and the children with financial difficulties by connecting them with local organisations. In addition, the nurses increased the comfort of the children by asking local hospitals to help the parents if they could not perform complex self-care or difficult procedures. Moreover, the hospital co-operated with a local organisation to support a poor family enabling them to visit the hospital.

Effect of Thai culture

Hierarchical society

In the Thai context, status influences the role and the position of people in the hospital. Thai people show respect and agree with a person from a higher hierarchical level. Social hierarchy is a factor that influences thalassaemia care.

Respect directly affects both the family members and healthcare staff, meaning the nurses' duties and the parents' status as clients of the hospital. Doctrine and obeying seniority are part of Thai culture. The nurses made an effort to overcome the hierarchical structures, by communicating with the children in a friendly and calm manner. They used 'wai', the traditional Thai greeting, to show their respect. The communication also included lay language that was appropriate for young people. It was common for nurses to insert the word 'sister' and 'daughter' or 'brother' and 'son' into their conversation to create an informal setting.

The social hierarchy is reflected in the fact that low-income families, who felt they had to rely on the government, thought they were unable to say anything or complain. Parents in middle-class families showed more potential and a higher self-efficacy than low-income families. In contrast, the latter group depended on healthcare professionals and practiced healthcare following the nurses' and the

doctor's advice and showed less participation. Results from this study indicated that parents considered the status quo as relatively fair and legitimate in all conditions. Low-income parents were particularly likely to support the status quo if they were treated benevolently by hospital staff.

Religion, spirituality and Buddhism

It is important to discuss the role of religious practices that might affect healthcare in Thailand. Nurses need to be aware of the stronghold of Buddhism when they provide family-centred care. The parents were concerned about karma and thought that bad karma caused the illness and that they, therefore, had to accept it.

In Thailand, mental health support is an essential part of Buddhist practice and principles and is thus an alternative coping mechanism. Positive thinking about the illness can reduce suffering. The effect of action and reaction also promises that if parents practice childcare well the child will get better. The power of a clean mind is supposed to help parents to be peaceful and calm. The families had their own ways of coping and the nurses had to discuss these to analyse their practices and their ability for childcare.

Buddhism teaches karma as a way to understand life. It also includes the idea of the middle way that can be not too rigid and not too loose in practice, which can be beneficial for an ill child's development by providing it with the proper activities and the right food. The parents might practice temperance to be able to cope with their child's illness. The parents sought emotional support by adapting Buddhist belief and the practice of making merit to suit their lifestyle. The Buddhist monk was a spiritual counsellor and helped them to suffer less because his advice and their faith helped them to accept their child's illness.

In conclusion, this framework contributes to the existing literature by modifying the strengths of FCC frameworks to suit the particular research context. The strength of this framework is that it acknowledges the process of care in a context previous definitions do not refer to. The second strength of this framework is that it demonstrates the cooperation between the hospital and local organisations, which offer additional and remote support. This aspect of FCC has not been taken into account in previous frameworks. The third strength is that it takes the families' background and how it influences their ability to provide independent self-care into

account. The fourth strength is that this framework shows the reduction of barriers in childcare by the hospital with the aim to improve the children's well-being. Finally, the framework recognises the importance of the child's and the parents' individuality in the provision of thalassemia care. A limitation of this framework is that it refers to a specific research setting. Nevertheless, the results and conclusions about family-centred care are applicable to similar hospital settings in Thailand.

Chapter 6

Strengths and Limitations of the Study

As stated in the literature review, research about the implementation of family-centred care in hospitals and its relationship with the well-being of children needs to be expanded. This study explored the characteristics of family-centred care and the factors that influenced a family-centred approach in a thalassaemia clinic in a Thai socio-cultural context. The purpose of this research was to provide qualitative data that can help nurses and healthcare professionals understand and apply family-centeredness in the care of children suffering from thalassaemia and their families.

Therefore, the study aimed to answer one research question:

What are the characteristics of family-centred care in Thailand?

and to consider two research objectives:

Does the Western concept of family-centred care occur in Thailand?

What factors influence the practice of family-centred care in Thailand?

The study identified that the provision of family-centred care (FCC) in a Thalassaemia clinic in Thailand is, as expected, strongly influenced by the Thai Health Care System but also by other national, local and hospital policies. These policies aim at maintaining or enhancing children's well-being and self-care. The hospital provided compulsory medical care to children in order to treat them and maintain their well-being and family-centeredness as an additional service.

The data has shown that the western concept of family-centred care exists in the thalassaemia clinic of the Lampang hospital, which is representative for the care of chronic illnesses in paediatric care in the Thai health care system. Aspects of FCC were present in nursing practices as an approach to dealing with the family of a chronically ill child but the staff showed different degrees of awareness of these processes and there were also differences in its implementation.

The basic aspects of family-centred care in Thailand are similar to other parts of the world but the specific characteristics of family involvement, collaboration and advocacy are different. Thai families were very involved in the planning and

implementation of home based childcare but their involvement was weak while the child was in hospital. In hospital, parents became dependent and less aware of their potential to deliver care and treatment. Parents of critically ill children had an increased awareness, which is in contrast with the original assumption of FCC that parental advocacy is consistent independently from the care environment.

Healthcare professionals and families shared the same perspectives on family-centred care regarding the child's physical needs. Most FCC characteristics in Thailand were present but in different forms consistent with the Thai context. The strength of the family was a common factor as it gave the child confidence and a feeling of safety. Parents offer the best support for their children and all the nurses and the doctor recognised their importance for the management of their child's care. The nurses and the doctor perceived family-centred care as part of their interventions. Most healthcare professionals and family members supported family-centred care and wished to continue practising it. However, the co-operation between nurses and parents needed to be improved to increase the parents' abilities to care independently for their child. Moreover, the nurses considered that parents could work together with them but would not be able to do complex care processes by themselves.

The nurses asked the parents for the patient history and if necessary, the parents gathered additional information from their children. In general, the parents communicated with the nurses but there were some obstacles for parents with a low education level. According to the results of this study, informal peer support provided by parents to each other could help fill this gap in communication. This peer support was not explicitly promoted or facilitated by the hospital because the nurses often had enough time to explain things. The rigidity of the hospital's policies limited peer support for parents because it prevented the nurses from organising parent groups, so that peer support mainly took place during training sessions.

Some parents also thought they benefited from family-centred care. They explained how it helped them improve their everyday activities with their children and their general psychological well-being. However, some children and family members found that it was difficult to be involved in the care process because of time constraints, over-crowding in the hospital and their own perceived lack of competence. In general, they had to balance their duty and confidence with safety

considerations of nursing practices. They also thought that the inclusion of Buddhism, particularly the acceptance of their fate, making merit and meditation, should be taught to improve psychological well-being.

Families, nurses and the doctor had generally similar ideas about their co-operation with each other and the potential role of FCC for the children's well-being. However, there were differences between parents from different backgrounds. Middle-class parents were not just better educated but also more affluent which allowed them more options for their child's treatment and to manage their own stress and personal problems. They also had a better understanding of the benefits of medical treatment and knew how it could help improve their child's well-being and quality of life.

Individual characteristics of the families, healthcare professionals and organisations have an impact on FCC. The practice of family-centredness can be adjusted if the nurses understand the social and religious factors affecting the family. They can also change their roles to fit the FCC approach. The study resulted in a FCC framework that describes the processes and characteristics of family-centred care. It also highlights the factors influencing the nature of FCC in the Lampang hospital, and contains nursing practices that provided family-centred care in terms of support, empowerment, learning and participation with the children and their families, and illustrates the potential of the approach.

This study has shown the potential specific structures, processes and systems in the care for thalassaemia patients have to enhance the well-being of children with a long-term condition. The recommendations aim at helping healthcare providers and policymakers to understand and value this model of care.

6.1 Contribution to knowledge

This study adds to the existing theories by employing a complex approach, combining a deductive with an inductive approach to analyse a qualitative study that was tailored to the specific needs of the research questions. It aimed specifically at exploring the provision of nursing care for children with thalassaemia in a hospital in northern Thailand in order to offer recommendations to develop family-centredness

in this area of nursing care. The results will allow healthcare providers to understand the importance of family-centeredness for children with thalassaemia and their families.

There is currently little understanding of FCC in Thailand and the literature on the subject is limited. This study contributes to filling gaps in knowledge and to furthering the successful implementation of FCC in Thailand by exploring possible barriers and success-promoting factors.

It is anticipated that the results from this study will be used to create processes and services based on the views of the participants and their perspectives on family-centredness. Consequently, the findings can contribute to the development of guidelines suitable for the Thai context and of more effective healthcare that will improve the quality of life of patients.

This research project was complex and consisted of the exploration of an approach to nursing in a cultural setting in which it had not been used consciously, unlike in the countries in which FCC was first developed. Consulting children, their families and healthcare professionals required different data collection methods and the use of techniques to build trust.

A qualitative single-case study approach was employed to explore and understand the complex phenomenon of thalassaemia care in a real life setting. This methodology addressed the limitations in the literature because it allowed me to explore the application of family-centred care in paediatric care in a Thai context.

6.2 Strengths and limitations of the study

The study has the following strengths:

- This is the first study that explores the nature of family-centred care and its contribution to the well-being of children with thalassaemia in Thailand.
- As mentioned above, there was no written evidence in the hospital's policies that family-centred care was undertaken. However, my observations revealed that FCC was practiced in the research setting.

- A qualitative single-case study approach was employed to explore and understand a complex phenomenon in a real life setting and the use of this methodology addressed limitations in previous studies.
- This study employed multiple methods of data collection from a range of participants: observations of and semi-structured interviews with children and families, nurses and a doctor, and further interviews with a nurse educator and a Buddhist monk. The use of multiple methods of data collection enabled me to investigate the phenomenon from multiple perspectives to identify key research findings.
- The sample size for this study was suitable as it included 4 nurses and 5 families and a large volume of data was collected.
- Data saturation was achieved in respect of both the family and healthcare professional's data thus resulting in reliable findings.
- Case selection enabled the researcher to gain an in-depth understanding of the phenomenon and increased the transferability of the study findings.

This study has provided reliable and valuable information and contributes to a better understanding of the provision of family-centred care, education and its role in promoting the well-being of children with thalassaemia in the Lampang province in Thailand. However, it also has some limitations:

- The data collection was only undertaken over a period of four months. A longer period for data collection may have been helpful, although all necessary data was collected within the planned time frame.
- Some children might not have had the opportunity to participate in this study because of their medical treatment. The researcher planned to recruit participants during hospital visits. However, it was not possible to gain full participation so that families and their children were approached during the blood transfusion. Due to the crowded environment, it was also impossible to attend all medical treatments so that not all children who might have been interested were able to volunteer.
- Due to the time limits, I did not give the families detailed feedback but only a summary after observations took place.
- Limited setting: specific hospital in specific region in Thailand.

- The people in the research setting knew me.

6.3 Reflexivity

The thesis concludes with an examination of my feelings and thoughts on the research process in order to illustrate the personal development that took place.

6.3.1 Literature search

A number of family-centred studies have been designed to address the practical implementation of the western model of FCC in developed countries. I decided that it was essential to examine the implementation of FCC and to explore its relevance and effectiveness in paediatric care in a hospital in Thailand.

The inspiration for this topic came from my professional experience of caring for children with thalassaemia. This experience, together with my over 16 years of experience working as a nursing instructor, helped me to appreciate the needs of children with a chronic illness. Thalassaemia is a psycho-social as well as a physical burden for the children and their families. The healthcare system in Thailand focuses on three areas: prevention, treatment and recovery. For children with thalassaemia each area takes place in a different setting: prevention during the antenatal period happens while the parents are living in their community; treatment and recovery occur in the paediatric department of a hospital.

I already knew from my previous experience that the paediatric department is the key area because most of the care takes place in it. In addition, thalassaemia care is complex and since the diagnosis is made early in a child's life, parents and guardians are crucial for the young patients' health and wellbeing. Young children are dependent so that parents make decisions about treatment. Many parents choose to participate in the process of their child's care. Thalassaemia care combines hospital and home care which requires co-operation between healthcare professionals and parents. I have healthy children and I cannot imagine what it is like to have a child with a chronic debilitating illness. As an experienced nurse it has always been important to me to provide the best care possible. Nevertheless, I

recognised that the hierarchical practice of healthcare professionals in Thailand could be a potential problem when the child is discharged. If parents were given more responsibility in the treatment in hospital, they would feel more confident about the care at home, which would benefit their child. So family-centred care in Thailand was a very important approach to care that I wanted to explore further.

Thai society is complex and international healthcare models cannot be implemented into the healthcare system without modification. Thai society places a high value on respect for older people and authorities and life is governed by the principles of Buddhism. These factors can influence people's confidence in themselves and in the healthcare system positively and negatively.

6.3.2 Reflection on the selection of the case study

Before I started working on this study, I had gained experience in the care for children in a complex hospital environment. It was clear to me that a case study approach was suitable to study a complex site where it was difficult to separate the context from the subject of study. I was certain that this approach had the potential to explore the nature of thalassaemia care in Thailand in a setting in which real-life situations and in-depth analysis were necessary to fully research the phenomenon. A case study also needs rigour to ensure that it meets the required academic standards for a PhD thesis and I approached the case using a triangulation of multiple sources and methods, including member checking.

I found that healthcare services cannot stop because of the research process. I also recognised the ethical principle that people have the right to refuse to participate in my research. I informed patients about my research by putting up information signs on the wall and on tables in the waiting area.

I had improved my research skills in my fieldwork. I developed structures and guidelines together with a set of tentative research questions and observational guidelines before I began my fieldwork. I undertook fieldwork for 4 months and this period of immersion enabled me to refine my data collection techniques. Using case study research, allowed me an in-depth study with a borderless context. In addition,

the variety of methods and participants led to reliable and generalizable data. I found that human behaviour was affected by personal and social factors.

6.3.3 Research methodology

This study used the appropriate methodology to research the reality of family-centred care in Thailand. A case study design provides an in depth examination of a particular area without interfering with the nature of the setting. This approach allowed me to narrow down the setting to the place where the child received medical care. Using this approach, I selected a small unit to identify the nature of family-centred care in a hospital in northern Thailand and examined the care practices of experienced healthcare professionals and a doctor. The design of this study and its aims are original.

The chosen method allowed me to identify characteristics of family-centred care in Thailand. The data collected from the research participants provided the basis for a range of meaningful discussions about the phenomenon.

6.3.4 The challenge of the research process

At the beginning of the process I felt an increase in self-esteem and confidence in myself when I talked to the participants. For the first time in my post graduate student experience I had to take a step back, reflect on and think about my experiences and those of the participants.

My previous experience of interviewing patients was different from research interviews, because the latter were with people who were experiencing current complex issues. This forced me to remain flexible during the interviews and the observations, prompting me to think about my role and status. In a clinical interview I was searching for an explanation of symptoms, which differed greatly from my research interviews in which my main aim was to reduce discomfort. I conducted the interviews with parents who had come to the hospital for the health care services and the children's wellbeing was a big concern. The parents knew that their answers might affect the healthcare services provided and I had to reassure them that the data would be kept secure and that I would not share their answer with the

hospital. The rapport and trust between the participants and myself was very important.

Thailand is a Buddhist country and is known as 'the land of smiles' in which the people revere their king who is loved for his care of the poor. Respecting people and help them reduce their suffering is an important value in Thai culture. Thai people perceive doctors as powerful helpers. As a result, parents answered carefully when I asked them the questions related to healthcare professionals. I always explained my own status and they were aware of my former position as a nursing instructor to promote trust.

The data collection methods revealed that the participants' opinions about the illness depended on their beliefs and experiences. My research also documented the behaviour of parents and healthcare professionals towards each other. The observation was difficult when many patients came to the clinic and I had to concentrate on the details of the process of care. These were complex and my previous experience allowed me to identify the practices that are part of family-centred care.

Finally, I was concerned about my status in the healthcare unit. I was familiar with the healthcare staff and the system. In order to ensure that I conducted my research according to the proper procedures and negotiated my status as a researcher with the staff. Even though I explained the purpose of my research to committees, the head nurse and the doctor, I was concerned that the healthcare staff might be demonstrating their best behaviour rather than their usual practice. In order to limit the Hawthorne effect, I treated them as healthcare professionals rather than participants. All in all, I think that I achieved a relationship of trust with all the participants and motivated them to be involved in my research.

Chapter 7

Recommendations for practice and future research

The results of this study suggest that nurses and a doctor, who work in a hospital in a province in Thailand, perceive family-centred care as beneficial for the well-being of children with thalassaemia. In addition, most participants had positive opinions about the provision of family-centred care and supported its continued provision for children with thalassaemia. Based on these findings, I propose the following recommendations:

- In order to use family-centred care effectively, healthcare providers should have access to appropriate training to ensure that they are qualified to perform nursing care that includes increasing families' competences to self-care.
- Healthcare providers should be given appropriate information to enable them to understand potential benefits of FCC.
- The training should also be used to increase the confidence of nursing students and their knowledge of the efficacy of family-centred practices.
- This study revealed that family-centred care was not part of the formal hospital policy or thalassaemia care programmes in Thailand. The findings suggest that an inclusion of family-centred care in these programmes would improve the well-being of children with thalassaemia.
- The educational resources for the training of healthcare professionals need to be modified: nurses need to be provided with a form and training to keep written records, which would enable them to identify when FCC takes place.
- The data also suggests that, in addition to the doctor and nurses, other family members and Buddhist religion offer support that contributes to the psychological well-being of the parents and children. Thus, the extended family and Buddhist monks are part of the social structure that should be made use of to support family-centred care.
- FCC should be added to the nursing curriculum. Its characteristics and the effectiveness of its implementation should be taught to a new generation of nurses.

- This study concluded with a discussion of a framework for family-centred care and future research is needed to establish the applicability and transferability of this model to other thalassaemia clinics in other parts of Thailand.
- The findings from this study could inform the Ministries of Public Health and Nurse Education and other health-related agencies in Thailand about the value and usefulness of family-centred care in hospital settings, particularly its influence on the well-being of children with thalassaemia. The data could convince these organisations to consider officially using FCC to promote well-being and self-care.
- The study has illustrated the crucial role hospital policies play in providing family-centred care for thalassaemia patients. Therefore, they would benefit greatly if healthcare policies would include FCC to ensure that it is provided in each step of the care process.

7.1 Action plan to improve nursing care and ensure family-centredness

The action plan to improve nursing care follows the findings of this study:

1. Integrate family-centredness into the nursing (and medical) curriculum. This can have a positive influence on the competence of student nurses.
 - 1.1. Set priorities and develop a teaching plan to establish patient- and family-centred care on an undergraduate and postgraduate level of education in nursing degrees.
 - 1.2. Develop orientation and education programmes for student nurses about family-centred practices, which should include the collaboration with patients and their families.
2. Develop resources for family-centredness by creating learning programmes for all healthcare professionals, patients, families, and staff from other areas of the hospital. Written records will ensure that evidence of family-centred practices can be gathered and evaluated.

3. Findings from this research of FCC will be published in a peer-reviewed journal.
4. Promote the collaboration of patients and their families with nurses and the doctor for an optimal quality of care. This should include the education of patients, their families and staff and a plan for the process of care to ensure the parents' involvement.
5. Promote peer support among parents to empower them in childcare as well as help them create a support network, as networking allows parents to participate without interference from a hierarchical system.
6. Empower parents from low socio-economic backgrounds to increase their involvement in the care process. Information sharing, consistently providing education and the use of a friendliness approach will enable these parents to increase their self-efficacy.

7.2 Future research

This single case study is the first to illustrate that family-centred care can be effective in promoting the well-being of children with thalassaemia in a Thai healthcare setting. Further research is now needed to build on these initial findings in order to provide greater understanding of family-centred care and its implementation in Thailand. For example, this study considered family-centred care only in a hospital. The child, however, is cared for mostly at home, and therefore this exploration must be widened to the child's home environment. Similarly, this study has acknowledged the significant role that Thai culture and the religious beliefs held by its people have on nursing practice.

The data also suggests that other family members and the Buddhist religion they follow also offer support that contributes to the psychological well-being of both the parents and their children. Thai society was, and still is, deeply influenced by tradition and the Buddhist religion. These traditions and the social influence of religion on society are, however, changing. As part of these changes aspects of family-centred care could be observed throughout this study. This achievement is, however, not yet fully embedded in the healthcare system or the minds of the

families and professionals. For that reason it is in need of firm consolidation through the educational promotion of family-centred care principles. Taking all of this into account, it becomes obvious that any future research efforts to develop this approach to healthcare further must focus on two principal approaches.

Quantitative approaches to research will be useful to determine what happens and what is being done, but it must fail to explore why events occur, or what the motivations and inhibitions of the individuals involved actually are. Therefore, future research must consult the children, their families and the healthcare workers involved. They need to be invited to express their needs (as they perceive them), their preferences and their concerns. This makes using a qualitative research methodology compulsory. Furthermore, the existing need to embed the awareness and appreciation of family-centred care deeper into the healthcare system, and to assist healthcare practitioners practice it, demands a combination of educational and research strategies. This may be best achieved using an Action Research approach, as only this combines the discipline inherent in research with the groundedness and flexibility of applied service improvement. Action research would also allow participants, i.e. the families and professionals concerned, to be actively involved. This strategy that can be expected to enhance the probability of family-centred care to be embraced more completely and consistently by professionals and families, who will 'own' this new style of providing healthcare for children.

This study has observed and described aspects of family-centred care in the healthcare provision for Thai children suffering from thalassaemia. It is limited to one area of care in one part of Thailand, but its conclusions can be expected to reverberate across Thailand. The study has arrived at a considerable number of recommendations concerning the practice of family-centred care and also urges that further research into its practice should be undertaken using primarily qualitative methodologies.

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Appendices

Appendix 1: Information sheet for parents

My name is Choosak Yuennan, I am a student at the University of East Anglia in England, where I study for a doctoral degree.

My studies focus on the care children with thalassaemia receive from their nurses and doctors in Lampang province. More precisely I want to find out how this care can be improved from your, the parents', point of view.

Why am I doing this research?

Thalassaemia is a chronic blood disease that affects children and families. It is a major health challenge to the people of northern Thailand. This study will explore the provision of nursing care for the families of children with thalassaemia in Lampang province with a view of improving the nursing care children with thalassaemia receive.

Why have I been invited to take part?

You have been invited to join our study because you are the parent of a child with thalassaemia. Your experiences will provide useful information that may lead to service improvement.

Do I have to take part?

No. It is important for you to know that you are free not to take part in the study. Choosing not to participate in this study will not affect your child's treatment in any way. If you agree to participate, you have the right not to answer any questions that you do not want to discuss, and you can choose to stop participating in this study at any time, even after you start to answer the questions and during observation process. This will not adversely affect you or your child in any way.

What will happen to me if I take part?

If you agree to be in this study, I would like to be with you and your child on the day of your appointment and observe what happens throughout your child's visit to hospital for thalassaemia treatment. From time to time I will write down what I observe to make sure I can remember what I have seen during your visit.

After you have seen the doctor and before the transfusion takes place I would like to interview you and your child. During the interview I would like to learn about your experiences of your child's treatment. With your permission, I would like to audio-record the interview.

After you visit the hospital I would also like to see what your doctors and nurses have written about your child's care. Therefore, I would like you to allow me to have access to your child's medical and nursing notes for the period of the study and then all data will be destroyed after 5 years.

What are the possible risk and discomforts for me if I take part in the research?

Talking about your child's illness could possibly make you feel uncomfortable. If you do feel uncomfortable or find the discussion hard to deal with, you can take a break and continue later, or you can choose to stop the interview. If you [or your child] need emotional support, I can give you the contact telephone number of the counselling centre in the hospital.

Is there anything else to be worried about if I take part?

All records of this study will be kept confidential. Only I will know your personal details and what you said, but I will not disclose this at any time. When the results of this study are published, I will not include any information that will make it possible to identify you.

For your child's safety, any information that causes concern for your child's wellbeing that may be found in this research will be reported according to the risk report protocol of the hospital to your child's doctors or the relevant authorities.

What are the possible benefits of taking part?

There will be no benefits to you or your child in direct return for participation in the study. However, your participation will help me explore the provision of nursing care for the families of children with thalassaemia in northern Thailand with a view of making recommendations to develop the family-centredness of this area of nursing care.

Contact details

If you have any questions about this research now or later, please contact:

Choosak Yuennan Office in Thailand: 053121121

(Researcher) E-mail address: fccuea@googlemail.com

Address: 312 M 4 Tumbon Yangnerng

Sarapee, Chiang Mai

50140, Thailand

Appendix 2 : Consent form [Parents]**Please initial box**

1	I confirm that I have read and understand the information sheet for study. I have had the opportunity to consider the information, ask a questions and have had these answered satisfactorily.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time even during the interview or observation without giving any reason and with no detrimental effect on my child's treatment.	
3	I am aware of the procedures involved in this study, including any inconvenience.	
4	I agree to Mr Choosak having only access to my child's medical and nursing notes for the period of the study.	
5	I agree to take part in this study.	
6	I agree to the voice recording of the interview[s].	
7	I agree to anonymous quotations from the interview[s] being used in publications.	

.....

Participant's Name

Date

Signature

.....

Researcher's Name

Date

Signature

Appendix 3: Assent form for the child or young person

Please circle your answer to all these questions:

Has someone explained the project to you? Yes/No

Do you understand what this project is about? Yes/No

Have you asked all the questions you want? Yes/No

Have you asked all the questions you want? Yes/No

Are you happy what I will access to your medical record
and nursing notes? Yes/No

Do you understand that it is OK to stop taking part at any time? Yes/No

Are you happy to take part? Yes/No

If any answers are “no” or you don’t want to take part, don’t sign your name below!

If you do want to take part, please write your name and today’s date

Your name.....Date.....

Your parent or guardian must write their name here too if they are happy for you to do the project.

Sign.....Date.....

The person who explained this project to you needs to sign too:

.....

Researcher’s Name

Date

Signature

Appendix 4: Interview Schedule for Parent[s]

Opening Questions	Potential supplementary Questions
Please tell me how the doctors and nurses care for your child in hospital.	<ul style="list-style-type: none">• Do they listen to what you have to say?• How does the hospital provide services for your children?
How have doctors and nurses participate with you?	<ul style="list-style-type: none">• How do they approach you when you care for your child?• Do they invited you to care for your child?
How often do you participate in child care?	<ul style="list-style-type: none">• How does health staff support you to have self-care?• How do they react to your requests?
Please tell me how (and what) you learnt about child care from health staff.	<ul style="list-style-type: none">• What has the staff told you about thalassaemia?• How often do you get information from the hospital?
Please tell me about your contact with other families of children with thalassaemia.	<ul style="list-style-type: none">• How do you know other parents of children?• How often have you talked with these other parents?
Please tell me about how the health staff takes account of your child's age when giving care.	<ul style="list-style-type: none">• How does your child play at the hospital?
Please tell me about the ways in which the hospital gives you support when your child is admitted.	<ul style="list-style-type: none">• How do you think about the hospital system?• What is the potential of the hospital to provide
How does the hospital's staff respond if you need to make changes to your child's care, such as changing an appointment?	<ul style="list-style-type: none">• How does the hospital adjust the services for your child?

Appendix 5: Interview Schedule for Children

Opening Questions	Supplementary Questions
Please tell me about the doctors and nurses care for you in hospital.	<ul style="list-style-type: none"> • What is the nurses and a doctor do for you at the hospital • How is the nurse practice
How do nurses care for you?	<ul style="list-style-type: none"> • Where is your parent when you have a blood transfusion? • What does the nurse do for you when you are at the blood clinic?
How do the hospital staff help you?	<ul style="list-style-type: none"> • How do the doctors and nurses help you feel more comfortable?
(How) Do doctors and nurses tell you about what they are doing for you?	<ul style="list-style-type: none"> • Do they ask you for your opinion? • Do they ask how you want things while you have blood transfusion?
Please tell me how it is when you stay at the hospital.	<ul style="list-style-type: none"> • How does the hospital set up the service for you? • How do you feel when you see the doctor?
Please tell me how you feel when you are at hospital.	<ul style="list-style-type: none"> • What do you get from doctors and nurses when you fell upset?

Appendix 6: Interview Schedule for nurses and the doctor

Opening Questions	Potential supplementary Questions
Please tell me about how you care for children with thalassaemia in hospital.	<ul style="list-style-type: none"> • What type of information do you ask for when you talk with the children or their parents? • How do you exchange relevant information about a child's illness with your colleagues and families? • Do you think it to be important and/or advantageous to learn about the child's or parents' preferences concerning treatment and care?
Please tell me about the process of caring for children with thalassaemia?	<ul style="list-style-type: none"> • How do you approach a child and a family when they are admitted to hospital?
What can you tell me about the provision of health education for thalassaemia children and parents?	<ul style="list-style-type: none"> • What is the purpose of giving healthcare-related information to them? • How detailed does this information need to be?
Please tell me about communication with children and families.	<ul style="list-style-type: none"> • How do you give the illness- or treatment-related information to them? • How do you promote childcare children and parents? • What do you see as the main problems in promote self-care and what do you do about it?
Please tell me about the services that the hospital provides to thalassaemia patients?	<ul style="list-style-type: none"> • How do services help the child? What activities that you allow the parent to participation in thalassaemia care?

Opening Questions	Potential supplementary Questions
<p>Please tell me what is the main purpose of chronic child care?</p>	<ul style="list-style-type: none"> • How do you provide information to children and parents? • How do you vary the provision of care for the wide range of ages of children? • Do you think that children with chronic health issues, such as thalassaemia, and their families have different, specific needs (when compared with more acute problems)?

Appendix 7: Interview Schedule for the Nurse Instructor

Opening Questions	Potential supplementary Questions
Is family-centred care part of the nursing curriculum? Please explain/give details	<ul style="list-style-type: none">• How are student nurses taught to give nursing care to a child and its family?• What do your student nurses learn about team work?• Are (Can) the families of ill children be part of the team? Please explain.
Please tell me about curriculum of nursing education and how it is considered in your teaching.	<ul style="list-style-type: none">• Why is curriculum important for child care?
Please tell me about how you teach students about the child care.	<ul style="list-style-type: none">• What is the role of the children and their families in the nursing process?
How do you consider the care of chronically ill children in your teaching?	<ul style="list-style-type: none">• How do you transfer the core concept of nursing care in the curriculum to student practice?• Please tell me about the training concerning chronic illness your students receive.
Is flexibility needed in practice to adjust the care given to the needs of the child and family? Please explain.	<ul style="list-style-type: none">• Please tell me about how you teach your students this useful.

Appendix 8: Semi-structured Interview Schedule (Buddhist monk)

Opening Questions	Supplementary Questions
Please tell me how Buddhism is important in the provision of health care?	<ul style="list-style-type: none"> • How can Buddhism affect people when they are ill?
How does Buddhism relate Thai belief?	<ul style="list-style-type: none"> • How does karma relate to illness? • How do (in Buddhism) the deeds of the parents relate to the life and health of their children?
Please tell me why, according to Buddhist teaching, people should give good care to others?	<ul style="list-style-type: none"> • How does this translate to the care that parents give their children? • How can Buddhist teaching influence the health professionals' approach to caring?
Please tell me about the importance of telling the truth in Buddhism?	<ul style="list-style-type: none"> • How can/does Buddhism help health care providers improve their services?
Does Buddhism tell us to help each other? Please explain.	<ul style="list-style-type: none"> • How does this relate to parents and families of ill children supporting each other?
Please tell me about what ill people expect when they come to see a monk and why?	<ul style="list-style-type: none"> • Why do you think mental health in child care is important? • How might Buddhism reduce mental health problems?
Please tell me about how Buddhism helps people to cope.	<ul style="list-style-type: none"> • How can Buddhism support a child and a family when they struggle with illness?
Please tell me about karma in the wider Thai context and how it relates to receiving healthcare (as	

Opening Questions	Supplementary Questions
a patient) or to giving it (as a health professional).	

Appendix 9: Document record guideline

Type of document	Criteria for collected data from documents
1. Medical Records	<ol style="list-style-type: none">1. Contents show activities of nursing care that relate characteristic of family-centred care.2. Contents show process of medical care that relate to the characteristic of family-centred care.3. Contents show frequency of attendant.4. Contents show planning of next medical care and/or education teaching.5. Content show result of treatments.
2. Thalassaemia Handbook	<ol style="list-style-type: none">1. Contents show guideline and advices of thalassaemia care that relate to FCC.2. Process of using handbook
3. Nursing Curriculum and teaching plan	<ol style="list-style-type: none">1. Content s show family is involve in health care2. Content s shows current recommendation to care family.
4. Policy and Human development plan	<ol style="list-style-type: none">1. Contents show policy2. Contents show plan of development human resources in child care

Appendix 10: Information sheet for a Buddhist

This is a student research project conducted under the supervision of Dr Bruce Lindsay and Dr Michael Pfeil from the University of East Anglia, United Kingdom. This project has been approved by the Faculty of Health Ethics Committee, University of East Anglia and the Lampang Hospital Management Committee.

What is the aim of this research?

This study will explore the provision of nursing care to the families of children with thalassaemia in northern Thailand with a view of making recommendations to develop the family-centredness of this area of nursing care.

Why have I been invited to take part?

You have been invited to participate in our study because as a monk your learning and understanding of the influence of karma and Buddhism on the personal, spiritual and public life of Thai people can help us to understand better how they influence the provision of healthcare.

Do I have to take part?

No. You can choose not to take part in the study. Choosing not to participate in this study will not adversely affect you in any way. If you agree to participate you have the right not to answer any question that you do not want to discuss and you can stop a discussion at any time. You may freely withdraw from the study at any stage of the process. .

What will happen to me I take part?

If you agree to be in this study, we will conduct a semi-structured interview with you. The interview will last for about 45 minutes. With your permission, we would also like to audio-record the interview.

What are the possible risk and discomforts and might I have some if I take part in the research?

We do not believe that this interview will consider any topics that you might find difficult to talk about. We therefore believe that there is no risk or discomfort for you involved in this study.

Is there anything else to be worried about if I take part?

Your name and identity will not be disclosed at any time. When the results of this study are published, I will not include any information that will make it possible to identify you.

Research records will be kept in a locked file; I will be the only researcher to have access to the records. The transcription of the interview will be anonymised before it will be examined by members of the research team, and I will erase any recorded data after five years.

What are the possible benefits of taking part?

There will be no direct benefit to you by taking part in this study, but your participation will help to explore the provision of nursing care for the families of children with thalassaemia in northern Thailand with a view of making recommendations to develop the family-centredness of this area of nursing care.

Contact details

If you have any question about this research now or later, please contact:

Mr Choosak Yuennan Office in Thailand: (0)53121121

(Researcher) E-mail address: fccuea@googlemail.com

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Sarapee, Chiang Mai

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Thailand

Appendix 11: Observational guidelines

The use of FCC	Dimension of
<ul style="list-style-type: none"> • How do doctors and nurses provide services for children and parents? • How do parents and health professionals work together in the child's care? • How do health professionals use the family's strength while giving care? • How does a health professional deliver information? • How does a health professional teach a parent and a child? • How do a child and a parent communication with others; extent, application, time, place • How do health professionals, child and parent participate together? • How do health professionals encourage parents to be a part of the team for child care? • How does staff provide opportunities for emotional or financial support? • How do health professionals give advice to parents when discussing equipment or services? 	Operation of the clinic
	<ul style="list-style-type: none"> - Reception - Blood test - Education - Blood transfusions - Discharge - Ward environment - Evaluation of nursing care for child.
	Activity
	<ul style="list-style-type: none"> - Inviting - Physical Assessment - Nursing Round; - Nursing care; activity, time, - Teaching health education - Blood transfusion process; activity, participation. - Nurse's action and parent's action - History taking process, nurse; child and parent emotion. - Health education process and answering questions - time, sequence of services
	Relationship, Cooperation, Behaviour

Appendix 12: Transcript Nurse 3

How do you care for thalassaemia children?
Mostly, I give them advice when they attended an appointment. I always remind them about nutrition, hygiene care and anaemia. If a child has iron chelation injections, I will teach them about the complications of injections and oral medicine taking. For the child has been taking vitamin C and folic acid I make a point of telling them to avoid buying medicine [without prescription order] by themselves. For example, vitamin C is not a prescription medicine but the child just needs specific dosage therefore they may buy high dosage of vitamin C by mistake. Some children take inject medicines at home. I provide them with knowledge of enable self-care. Some children and parents bought a big bottle of medical disinfectant (used for preparing the skin before injection) and they may to need to be reminded about its expiration date. The solution may expire before it is empty.
How do you provide education for injection?
I always try to develop their confidence by giving them opportunities to practice at the hospital. If they [the child and/or parent] use an injection machine, I will train them to use it until they [child and/or parent] are able to use the machine confidently. They [child and/or parent] are taught how to prepare the medicine, clean the skin before the insertion of the cannula because the child needs to inject subcutaneously by themselves.
How long do you teach the child and the parent?
If a child is mature and confident, they will be taught only one time.
When the child has problems while taking the injection medicine at home what do you do or what advice do you give them?
I always give them to notice abnormal symptoms, such as the swollen skin because the cannula is injected too deep or too superficial. Skin that has not been well prepared and is contaminated is a cause of infection. If the child has persistent problems [at home], I advise them to contact an OPD nurse. The parents can to call the nurse directly. Some parent may choose to get help from their nearest primary health centre.
How do you contact the local health services when the child need support?
The nurse at OPD contacts to the health staff at the primary health care services unit. They cooperate to solve the problems about subcutaneous injection. They may just give the child advice. For example, some parents are not able to prepare medication for injection because the parent who always injects is away from home. If the child [and the parent] is not able to do the injection at that time, the health staff will do the injection at the primary care service unit.
What topics do you talk with a child at the blood transfusion room?
We will talk to them to collect the illness history, by asking the parents about the previous blood transfusions and look at the medical records. I will record any complications of blood transfusions. I often ask the child and the parent whether they had any side effects of a blood transfusion. If older children are can to explain to me about the [possible] complications by themselves, then that shows the children remember the important or critical symptoms. I will pay attention to the parents who look after younger children. They have to

remember the child's blood group and any blood complications [and medical history]. I have to ask them before starting the blood transfusion because that is a medical protocol.
How do you share the information?
I will ask the parents about the child if it is young. I always meet the parents and known them well. I verify the information from the parents with previous illness recorded in the OPD card. The OPD card shows the blood group and any necessary information. The information will be verified by the computer [database]. The parents are fathers, mothers or grandparents, I am going to ask them every time because they are the closest care givers.
How do the grandparents care for the child? (i.e. different from the parents, or better than the parents)
Grandparent do care better for a child [than the father and mother]. The grandparents spend more time to look after and prepare food for the child. The father or the mother do not spoil the child [i.e. tend to control the child]
How do you manage any information concerning a child to other health staff?
I put it on with the medical record, such as blood group and side effects suffered from a blood transfusion. The child's problems will be recorded. If I find that the child's symptoms have changing rapidly since the previous attendance, I will review symptoms with the parents. A wrist band indicates the blood group by colours. I will use when the child have blood transfusion. Even though the wrist band shows the blood group, I have to ask the child and the parents to verify the child's blood group.
How much do you think the parents help you to care for a child either at the hospital or at home?
The parents help a lot because they look after the child all the time at home such as doing the injections at home. The parents have to know about the timing and preparation of the medication. They learn to care for the child promptly. The parents bring a child to the hospital [for attendance] and stay with the child while the child has a blood transfusion. They also help me by doing tepid sponging [in febrile children]. They do (all of this) well.
How do you know about caring for a thalassaemia child at home?
I ask them questions when they come to the hospital, such as how they take medicine at home. Mostly, they parents I know very well, therefore I start developing relationship by asking about their life in general. Then they tell me about what happened [to the child and parents] at home. I take that opportunity to repeat [education] to them about caring for their child at home. And, [I] ask them about how they manage the medicine for a child at home. And, [I] ask them any symptoms and complications, etc.
How do you participate with the child when you meet them?
I prefer to call the child's real name to verify the name. If I am familiar with the child I will call the child's nick name such as brother but I also verify the real name before giving them a blood transfusion.
Why do you call the child by it's nick name?
I would like to develop to relationship between the child and me. This enables me to undertake nursing practice more easily and they will relax. If the child fears mw, I [will] care for the child as we are the same family.
How do you care for a child and a parent when they feel uncomfortable?

I treat them very similar to a closely related person by calling them by their name but I put a prefix before the parent's name such as 'mother'. I also call them by their child's name because just the parent's name may not enough to link them to the right child. Family relationship is common and I show friendly relationship as same as family members. I talk to them as usual. I ask them and sometimes they ask me. Some parents and children prefer to speak local language. Most of them are happy to speak local language. I speak the local language if they talk to me in local language.
Why do you use the local language?
The local language is easy to understand. The parents [and the children] know the local language and they are able to understand my advice better.
How do you approach to the child when they are not happy to have treatments?
If the child is young, I have to develop a relationship by talking with the mother then ask the mother to talk to the child. I sometime give the child a toy or turn the television on to distract their attention while I insert the cannula. If the child attends the hospital often, I have nothing to do [for developing relationship again] so.
How do you interviews the children and the families?
I ask same questions but using a different technique. If the child is young, I would play with them. If the child is old and needs privacy because the age change from a child to teenager I will ask them in different ways. I can ask them directly.
How do you use the information from the children and parents?
If the child is admitted, I ask them everything, focusing focus on the blood group and side effects. I verify the medical history and ask whether the child may need antihistamine before a blood transfusion. The children and the parents have to remember any blood allergies. If the doctor forgot to ask, the child and the parent have to remind them because they have a risk to have this complication. I have to check their history again.
When you care for thalassaemia children, what kind of foundation of nursing care do you use?
The patience is the foundation of child care. The nurse needs to be patient when caring for the child. Children that are new will cry the first time [they are here]. Then the nurse has to spend time talking with the child, no rush. It takes a long time [to do the nursing care] but I have to tell the parent to wait and to be patient. I also tell them that next time the process will not take as long. I show them the other children that are having a blood transfusion as an example. I have to be patient and give them information. Some children will be calm watching television. Overall, I feel comfortable with [thalassaemia] child care.
Can you give me an example nursing approaches of the children?
If a school child is admitted to hospital and is in a bad behaviour because parents over protect the child. I will use different approaches throughout the wide range of ages. If the younger children are crying, I use psychological techniques for the young child more than for the school child. For example, I will give them a toy to distract the child. If the older children have privacy, we allow them a plenty of space. I have to allow them to co-operate with the nursing care. They can decide themselves which activities [they want to do] during their blood transfusion such as reading or playing at studying room.. I have to spend more time to insert the cannula.
How do you care for a child with over-protective parents?

If the children are old enough they will be patient, but the younger ones will cry. We have to set up activities for them, not only give nursing care. I will separate them into different corners [of the room]. We have to observe the child during a blood transfusion closely, and we hope the hospital will facilitate play corner near the blood transfusion room.
What activities can the children do during a blood transfusion?
There is a learning centre for hospitalized child at the hospital. If the child is able to move to the learning centre, they can go there. Then I go to the learning centre to record vital sign for every hour. Other children may do other activities such as reading at the corner provided. I consider the proper activities that are suitable for the children's ability. The teacher always gives the children painting activities. There is also a television in the blood transfusion room [for the children].
What do you communication with the hill tribe people?
The hill tribe people understand the Thai language. They are also literate. I have no problem to communicate with them and no need for a translator. If they have problems to understand Thai, I will tell them or ask them using easy words. There are many people at their village able to read Thai, so I suggest them to ask their neighbours to read brochure to them. The written advice is not difficult to understand for lay people.
Do you evaluate the child's emotion during a blood transfusion?
Yes, I do. I always look out for any symptoms in the child. When I record the vital signs I also ask them about any abnormal symptoms. Some children do not want to have a blood transfusion but almost all of them watch television in the room. They have fun, I do not often meet bored children.
Why do you approach the child to motivate self-care?
Almost all of the [thalassaemia] children have adapted well. Some get bore if they have to wait [for the blood] for a long time. I explain the reasons to them and the essentials of treatment and self-care. It is important to motivate them to know about self-care.
How much the parents cooperate with treatments?
The parents help me a lot because they live with the child. They must know that their child has to be treated continuously. The parent's knowledge is an important part of the child's care. The care the parents give depends on their education and awareness.
Do you evaluate your nursing care to confirm that it meets the child's needs?
We [the hospital] have a satisfaction form to evaluate their satisfaction and used to frequently carry out surveys to learn about the patient satisfaction levels. The survey includes the blood transfusions, facilities, timings and an open question to allow the parents to write down their comments. Now, we survey 2 times a year.
Why have you moved the blood transfusion unit to this place?
The blood transfusion unit was moved because previously thalassaemia children were admitted with other patients and some children were fearful because they saw all the other critical ill patients. The thalassaemia children know that they their illness is not critical. They just have a blood transfusion, then they return home. We manage the place to separate them from the others and to reduce the number of patients on the main ward.
When was the learning centre established?

It has been established around 2-3 years ago.
Who teaches the children?
There are the teachers from the special school teaching the children. The teachers teach the children and parents. Some children prefer to spend time at the learning centre while others prefer to watch television in the room. Some parents prefer to read a book at the book corner. We provide books for parents and children.
Why the thalassaemia care is not set in the main ward?
The blood transfusion room is small. We have to arrange the space to service high numbers of the children and parents. The high demand of services. The parent and the child want fast services especially with the young thalassaemia children. If the nurse's station is on the main ward, the abnormal symptoms are difficult to notice.
How do the parents react when they stay so close to the nurse?
If the parents who familiar with the nurse, they ask the nurse about daily life. The parents talk to the nurse to entertain themselves [reduce boredom]. Some new parents may feel happier among parents [of children] with the same condition. Others may feel uncomfortable but they may become familiar with the nurse because they see the others talk to the nurse.
How do parents participate the nurse?
Some parents call her sister, doctor and nurse. They call her doctor to show their high respect.
How do you feel that they call you sister?
There is nothing because they use this word in general to call the older people. If they think I am younger than them, they should call me sister but they prefer to call me doctor.
What principles underlie your care for of the children?
I care for them as my relatives. If it seems that we are close relatives then I have to give them very good care. Typically, I provide equal services to everybody.
What does a child who familiar with you react to the treatment?
They tend to cooperate with me because [they think] I am a trustworthy. They do not fear the blood transfusion procedure. This is a good aspect of being familiar [with the procedure]. If the child notices any abnormal symptoms, they tell me immediately. A new child will fear the nurses then they do not tell me anything.
How do you develop familiarity with a new child?
I talk to their parents ask them about their lives in general, then I would tell the child a funny story. I also ask the parents to help me to care for their child. If the parents stay close to the child, they seem not to fear [the nurse]. If the child has the first blood transfusion, they need time to become familiar with the cannula. The children who frequently attend appointments are familiar with the nurse.
Have you met the parents who fear the nurse?
I have not met too many fearful parents. Almost all of them are known to us. If they are new, they will become familiar soon. If they have frequent appointment, they will dare to ask the questions. Some parents attend the hospital 2 or 3 times a month, but do still not become familiar. It depends upon the parents' personality.

What do they ask you about their child's illness?
They ask me whether there are any abnormal symptoms at this attendance, the child's state of health and any anaemia. They always ask the same questions, some parents even ask about proper food; "can my child eat this food".
Do you provide nursing care for children who believe in different religions?
Yes, I do. Almost Thai is Buddhist. We invite a monk to visit the hospital every Wednesday and Friday, therefore the Buddhists at the hospital are able to make merit. On Buddhism Day, we do the same activities.
We provide only food to other religions, such as Muslim [ie. Halal] food, therefore the hospital provides extensive meal for them.
What benefit does inviting a monk to visit the hospital bring to the treatment of the children?
Making merit supports [the patient's] mental health because the child and the parents need encouragement. If they have a strong mind, they will co-operate by paying attention to care for their illness. If they have no hope they will neglect everything.
How do you care for the mental health of thalassaemia children and their parents?
They are anxious at the time of the blood transfusions. They are concerned about late blood transfusions. This service is our responsibility, therefore I explain the process of blood requisition to them. I also follow-up the requisition to the reducing waiting time. There is a standard of time frame for the blood transfusion process. Some parents live in villages that far away from the hospital. They want to have rapid blood transfusions because they woke up early but they will get home late after the blood transfusion. Some of them leave for their home before their child has had the blood transfusion. I notice their awareness of the blood transfusion timings. It takes around 3 to 4 hours to have a blood transfusion. If the parents are not able to return to their home, the hospital provides them with a place to sleep over without any formal request and free of charge. The child also has one dinner for free.
How do the nurses assess the expectations of the parents about their child's future?
I think that the parent does not pay attention on self-care. If they provide good self-care, their child may live as a normal child. For example, in a family with many thalassaemia children, once the older child has grown up without serious illness, the other children may be able to grow up in the same way. I will point out this sample that the child's future relates to [successful] self-care. If the child has improper care, it affects the child's future.
Why do you allow the child choose the area to place the cannula?
I allow them to decide that part of nursing care because the child may want to do activities and feel comfortable during the blood transfusion. For example, the children want to read a book or paint. They want to use their dominant hand to do so. If I put the cannula in that dominant hand, they may not be able to do any activities during the blood transfusion. It also helps the child to develop trust in me.
Have you had any child or the parents asking for a bed at the main ward?
Yes I have found some older children asking for such a bed. It is our policy to provide the services that are comfortable to the patients. If the patient does not like a crowded area because of many children attending an appointment at the same time, they are allowed to stay at the main ward.
What is the ratio of nurse to thalassaemia children?

It is around 20 to 40 children per nurse on the day. Blood transfusion is the longest services in the thalassaemia clinic.
How do the nurses work at the blood transfusion room?
Every nurse in paediatrics ward has to work at the blood transfusion room at least once a month. The children will return to the blood transfusion room every 2 or 3 weeks.
Do you recognise the individual needs of the child and parents?
Some parents want only blood from their relatives because they only have confident in their relative's blood. I suggest and explain to them about the blood shortage. If the child needs the blood immediately and they are not able to find the blood, the hospital has blood that is safe for their child. The blood has been tested and passed the standard.
What do you provide nursing care after the blood transfusion?
I tell them about abnormal symptoms to watch out for at home. The, if the child has abnormal symptoms, the parents know how to care for their child. For example, how to deal with fever within 24 hours of a blood transfusion.
Do any children attend the hospital on another day [when the blood clinic is closed]?
Yes they do. Because of their [school] examinations The children are not able to attend on Tuesday and Thursday. They are allowed to make an appointment for the next week and attend the hospital for the blood transfusion then. If the children have severe anemia they are able come on any work day. If they have a complication, they are able to attend on the weekend or at any time. They have to be aware of the importance of self-care.
How do you cooperate between the OPD and the blood transfusion room?
We do, if the child needs special help for the blood transfusion. For example, if the child needs the blood on another day [not the blood clinic day], the OPD nurse will call to the main ward asking for a blood transfusion for the child even on Saturday. If the child has a problem and needs help we are able to cooperate.
Why do you put the refrigerator into the blood transfusion room?
The nurse has to care for many children; therefore she has to stay at the blood transfusion room all the time. It makes her job easier. Otherwise the nurse would have to keep the blood in the refrigerator on the main ward because blood needs to be cool at a stable temperature and that would mean she has to leaves the blood transfusion room for a while.
How do you provide nursing care following patients' belief at the hospital?
I allow the parents to put a small coin on the bed because they believe that they might lie on a bed in which another person died. Their child may become ill [with another illness] by lying down on the bed of a dead person. I see them wai at the Buddhist Statue
I see the paediatric ward starts a party for the National Children's Day, why did you set the party at the ward?
The patients of this ward are children. The children need to play and have fun, especially on the National Children's Day. We have the party there, so the children can play and be happy.
What are you doing for the children when they want to play with other children?

We will allow the children who are not critically ill to play with a small water gun at the hospital but we will take their illness into consideration. In addition we will set out an area for them to play at the front of the ward to prevent any disturbance to the critically ill children.
What care can you give to the family?
If the parent has economic problems, that mean they have no money to bring their child to the hospital, I will send them to the social support department. They help with [costs due to] continuous treatment. The nurse's duty is cooperation.

Appendix 13: Table of code interviews, observations and documents

Theme	Sub-theme	Code- level 2	Code level 1
Impact of illness to families	Low self-efficacy	Dependent on professionals	-follow doctor's and nurse's orders/advice
			-wait for information
			-follow instruction/advice without ask
			-listen more than talk
			-let nurse talk
		Limited knowledge	-does not know about illness
			-has little knowledge compare to nurse
		Reluctance to ask	-never ask or comment
			-do not bother
	-do not want to disturb nurse		
	Changes to the role of the family	Parents manage the child's care	-protecting the child
			-symptoms change
			-injections at home
			-nutrition control
			-limited child activities
			-do not play with friend
Protecting child's health		-monitoring symptoms	

			-monitoring of critical signs
			-managing symptoms
			-critical symptoms reminders to self
			-asking for more support
			-knowledge is important
	Different levels of involvement in care	Involvement in care varies Decision making in care varies	-change appointment dates
			-giving information to professionals
			-checking anaemia
			-asking questions
			-negotiating
			- limited decision making when in hospital

Effect of hospital services	Promoting self-care	Promoting child well-being	-training
			-support for medication management
			-reduce hospital attendance
			-aware about self-care in thalassaemia
			- basic care for the child
		Limited facilities and health staff support	-nurse keeps records
			- only one nurse at registration
			-adjustment of nursing shift
	Providing education	Education Methods	-one haematologist at hospital and only one nurse in transfusion room.
			-small number of beds in hospital
			-small room
			-multiple tasks for the nurse
			-brief teaching sessions
			-verbal rather than written, guidelines, book
			-repeating teaching at every visit
			Communication
	Providing efficient services	Essential content of disease	-individual Teaching
			-group teaching
			-routine advice
			-nutrition
			-injection instruction
			Complications
			-complex child care
		Extend services offered	-services on Saturday
			-evening services
			-co-operate with Local Authority Organisations

			- offer the transport for return home
	Reassure parents of service availability		-allow the parent stay with the child
			-regularly assesses symptoms
			-suggest services at local hospital
			-regular visit by head nurse
			-prompt interpretation of symptoms
			-maintaining standards of care
	Reduce effect of limited facilities		-flexible management of space in the ward
			-listen to parents and children
			-high number of children in the clinic
			-provide activities; books and toys
			-provide child play area
			-staff meeting about workflow
	Coordinating role of hospital	Cooperation between organisation	-economic support by local authority office.
			-injection support
			-co-operation with local health services
			-co-ordinator
Buddhism	Concerned about possible beliefs about karma		-illness is karma
			-acceptance in destiny
			-understand about life
			-no one can escape death
	Moderation and temperance		-Buddhist middle path
			-lifestyle and acceptance life issue
			-effect depend on my actions
			-concerned with value of life
			-good things and do good

Effect of Thai culture	Trust in hierarchy	Power of clean mind	-positive thinking
			-calm down
			-peaceful
			-let it be as it be
	Extended family	Support within family members	-grandparent's authority
			-remind family members about diet- no liver, etc
	Friendliness approaches	Trust and respect in meritocracy	-support from grandparent
			-listen to the grandparent and people in high social position
			-listen and follow
			-uniform
	Alternative mental coping		-nurse's role
			-nurse's and doctor's position
		Positive responsive	-'wai'
			-willing to talk
			-give detail
	Seeking and accepting help	Use appropriate language	-use nickname
			-always smile
			- polite
	Follow advice of the monk	Positive thinking	-Acceptance
			-belief of good karma
			-Tan Kun Kao/ donation for ancestors
	Making merit/ donation for monk		-Making merit/ donation for monk
			Follow advice of the monk

Appendix 14: Summary of studies on the use of family-centred care of children with a chronic / long-term illness.

The greatest advantage of quantitative research, its generalisability, is insubstantial as the participants' interpretation of the subject area as well as the questions asked will be viewed through their spectacles of their particular cultural background. Do not allow the participants to express themselves freely without the limitations and uncertainties imposed by yes/no replies

- 1 Bruce, B., Letourneau, N., Ritchie, J., Larocque, S., Dennis, C., & Elliott, M. R. (2002). A Multisite Study of Health Professionals' Perceptions and Practices of Family-Centered Care. *Journal of Family Nursing*, 8 (4), 408-429.

Design and Participants	Aims	Data Collection methods	Key Findings
A survey using a wide range of health and social care professionals (n=483) all based in tertiary care hospitals, including many nurses (n=223).	To determine the differences in health professionals' perceptions and practices of FCC and examine factors that influence these perceptions and practices.	Family-centred Care Questionnaire (FCCQ-R)	<p>All health professionals had a good understanding of FCC and perceived that all of Shelton et al's FCC elements were necessary aspects of true FCC. Practices were also linked to these perceptions, although not consistently enough. The extend of this inconsistency varied according to site, with parent-professional collaboration (most significantly when establishing the individual child's needs) being a universally agreed but the least practiced aspect.</p> <p>According to the professionals the practice of FCC was also limited by the context, including</p> <ol style="list-style-type: none"> 1. The design of the healthcare delivery system, for example a lack of ambulatory care including evenings and weekends. 2. Healthcare policies that did not support family-centred care and had been developed without input from parents.
Strengths <ul style="list-style-type: none"> • Provides a clear explanation of the research background, aims, data collection process and discussion as well as the study's strengths and limitations. • Uses a recognised standard questionnaire that fits exactly with the research goals and objectives (FCCQ_R based on the FCC framework by ACCH (Shelton et al., 1987), Bruce 1993) to measure FCC-related perceptions and practices. • The sample includes a wide variety of appropriate professionals with nurses (223 of 483) dominating but not overpowering the sample. • The response rates (45%, 36%, 34%) were within normally expected limits. • The statistical methods comparing the sub scales were descriptive only (mean and SD), with the overall comparatively low SDs (0.39-0.8) and significant pointing to good consistency within the replies. T-test scores helped compare the averages of the different parts of the sample, i.e. perception and practice. An ANOVA was used to compare the averages between parts of the sample relating to length of experience, professional groups, age and position [i.e. more than 2). All results were statistically significant ($p < 0.5$ to < 0.001). 			

Limitations

- The study used comparatively old data (collected seven years prior to publication).
- The number of participants appears appropriate, however, there is no justification or sample size calculation.
- This study was limited to three Canadian tertiary settings, limiting is generalisation by excluding community healthcare.
- All participants were health professionals, missing out on contributions by parents.

2. Attharos, T. (2003). Development of a Family-Centered Care Model for Children with Cancer in a Pediatric Cancer Unit. PhD Thesis: Mahidol University: Thailand.

Design and Participants	Aims	Data Collection methods	Key Findings
<p>Action Research conducted at a cancer unit in Bangkok, Thailand.</p> <p>41 children diagnosed with cancer, 45 parents or primary care givers and 26 nurses</p>	<p>To develop a family-centred care model for children with cancer and their families</p> <p>To train the participating nurses to understand their role within FCC, enabling them to implement FCC.</p>	<p>Interviews, group discussions, field notes, observations, documentation (nurses' notes and care records of children with cancer)</p> <p>Multiple collecting data method and points showed triangulation of method and more specifically (as this was Action Research) prolonged exposure. The latter visualising the development of issues and individual steps over time.</p> <p>In particular the study made use reflective practice to advocate nurses to understand and practice the knowledge in during and after providing care. This included daily case-study</p>	<p>Three cycles are involved in this study.</p> <p>Cycle I promoted mutual understanding of the model. The reflections of this cycle demonstrated improved knowledge and understanding among nurses and increased awareness of family importance. The family and the nurses agreed that care practices needed to be improved.</p> <p>Cycle II established individualised practice by applying the model. Results of cycle two were improved knowledge, understanding and practice of family-centred care among nursing staff.</p> <p>Cycle III supported a nursing team practicing and improving the model by helping them to achieve deeper understanding through reflective practice.</p> <p>The final model allowed the provision of holistic and family-centred care in a cancer care setting. Its leading themes were</p> <ol style="list-style-type: none"> 1. A caring and empathetic relationship, 2. Mutual learning, 3. Partnership, and 4. Enhancing strength. <p>The nurses accepted and welcomed the model and in their practice adhered to it (including the holistic approach to care and the family involvement), because they felt that it provided the best care from healthcare professionals and their families with beneficial outcomes for both children and parents. Their perspective of caring for children with cancer changed from following treatment protocols to focusing on the patients but not</p>

		<p>discussions, relating the cases to FCC.</p> <p>Finally, the researcher, nurses, children, and the family met every morning to set up goals and action plans for the day.</p>	<p>involving their families, little participation between families and nurses, and having some family-centred care practices.</p> <p>As a result of FCC the children achieved better overall outcomes (including of their medical treatment),</p> <p>The families (most caregivers were mothers) welcomed it and reported an improved ability to care for their children (including maintaining their role a parents)</p> <p>And the nurses had a better perception of importance of their professional role. Helping them understand the families' internal rules and 'traditions' assisted them in appreciating the importance of FCC.</p> <p>Existing and potential barriers to the implementation of FCC became obvious. They were:</p> <ul style="list-style-type: none"> • The severity of the underlying disease (i.e. cancer) • Nurses with limited knowledge of FCC (due to staff turnover) or the children's condition and their needs
<p>Strengths</p> <ul style="list-style-type: none"> • Provides a clear explanation of research background, its aims, data collection and discussion as well as strengths and limitations • The qualitative approach was included to evaluate the programme and participant's experience • A gradual progression using triangulated data was employed throughout. • A trustworthy study used the triangulation was used by the investigator. Three modes of data collection were interview, observation, and focus group. The uses of different sources were organized by interviewing parents, children with cancer, and nurses. The researcher described the process of data collection clearly. 			

Limitations

- The thesis does not provide the time frame of the study. It does not state exactly when it was conducted and how long it lasted.
- Despite its child (family-) centredness the thesis
 - does not consider the impact on the children's emotions in any depth.
 - does not show any awareness of the right of the child.
- Data from the documentation did not appear in the thesis.

3. Dokkularb, P. (2006). Need of The family-Centered Care Among Families of Pediatric Patients at Rachaburi Hospital. Masters disserttion: Burapha University. Thailand.

Design and Participants	Aims	Data Collection methods	Key Findings
A survey involving the caregivers of 100 children (infants = 50; toddlers = 50) with acute and chronic illnesses at Rachaburi Hospital, Thailand.	- to study the need for family-centred care practice among families of paediatric in-patients at Rachaburi Hospital	<p>Questionnaire (self-designed, not validated, rating questions with a five-point scale)</p> <p>demographic questions (age, relationship, education, occupation and income)</p> <p>Questions relating to:</p> <ul style="list-style-type: none"> • Respecting the family (5 questions), • Collaboration (8 questions), • Information (13 questions) • Family support (7 questions) <p>Taken together the questions were meant to measure the parents' need for family-centred care.</p>	<ol style="list-style-type: none"> 1. The need for FCC did not differ regarding the child's age overall ($t= 1.180$, $p= 0.241$) and across all areas: <ul style="list-style-type: none"> - respect for to family and age ($t= 1.757$, $p=0.8$), - collaboration and age ($t= 0.953$, $p= 3.43$), - information sharing and age ($t= 0.975$, $p= 0.332$), - family support and age ($t= 0.816$, $p= 0.416$), 2. The need for FCC regarding type of illness did not differ either, whether this was overall ($t= 0.427$, $p= 0.67$) or across the different areas: <ul style="list-style-type: none"> - respect to family and illness ($t= 1.182$, $p=0.63$), - collaboration and illness ($t= 0.953$, $p= 3.43$), - information sharing and illness ($t= 0.013$, $p= 0.990$), - family support and illness ($t= 0.457$, $p= 0.649$) 3. Parents scored their needs of FCC aspects out of five; <ul style="list-style-type: none"> - Information sharing ($m= 4.16$, $SD=0.60$) - Respect of family ($m=4.08$ $SD=0.81$) - Collaboration ($m=4.08$ $SD=0.81$) - Family support ($m=3.98$, $SD=0.71$) 4. Top of the list for each individual group of questions were: <ul style="list-style-type: none"> - for respecting the family: the health professional practices politely ($m= 4.2$, $SD=0.71$) - for collaboration: teaching and demonstrating ($m= 4.31$, $SD=0.7$) - for information sharing: focus of treatment and symptoms ($m=4.4$, $SD= 0.71$)

			- for family support: caring with close attention to childcare (m=4.46, SD=0.64)
Strengths: <ul style="list-style-type: none"> • The dissertation provides a clear explanation of the research background, its aims, data collection and discussion. • Sample size was appropriate, covering 18% of the population in between January-February 2006. • The sample characteristics was clearly defined (demographic data was collected, a timeframe was given). • All participants were volunteers. • Content validity (i.e. the extent to which the self-designed questionnaire represented all facets of FCC) was assessed by three experts in nursing. The experts were 3 nurse instructors, 2 paediatrics nurses and 1 family nurse. • The scale reliability of the self-designed questionnaire was high (Cronbach's alpha 0.86). • The statistical tests, independent T-test, used were limited but appropriate. The statistic is appropriated to answer the research questions. 			
Limitations: <ul style="list-style-type: none"> • It is difficult to conclude whether the context that the nurses worked in (i.e. oncology care) made a difference to their activities. • The families' views of their needs and experiences of their care were not really explored, using closed questions this would have been very difficult to do in any depth. • The children's illness was identified as 'acute' or 'chronic', but there is not clear evidence how each of group was selected. • There is distinction of parents' needs in terms of parent occupation, education and income. 			

4. Hughes, M. (2007). Parents' and nurses' attitudes to family-centred care: an Irish. Journal of Clinical Nursing, 2341-2348.			
Design / participants	Aims	Data Collection	Key Findings
<p>Descriptive (quantitative) survey</p> <p>'Simple random sampling' of 43/100 mothers (43%) and 28/44 nurses (65%) in one Children's Unit at an Irish Hospital.</p>	<p>To examine the attitudes of parents and nurses to the model of care delivery on an in-patient children's unit in a regional general hospital</p>	<p>Two questionnaires (self-designed, piloted but not validated)</p>	<ul style="list-style-type: none"> - A positive attitude to FCC was largely but not completely carried over into practice. - 90% of nurses stated that parents should be permitted to carry out most care for their child with nurses only taking over when the parents did not have the necessary skills. - All mothers felt that they were included in the care of their child - Mothers often (56%) did not know what was expected of them. - Information provision for parents varied: Verbal information giving was good (90% of mothers, 82% of nurses) while written information often did not meet parents' needs (mothers 3.6%, nurses 52.7%). - 1 in 3 parents felt a need to stay with their children because the nurses were busy. - Most mothers (79%) and nurses (60%) felt that nurses needed to attend to the children. - All nurses agreed that it was important for parents to be present with their child in hospital. - The visiting policy was family friendly (93% for both groups) - Nurses and mothers agreed that the cost for parents to stay with a child in hospital were high. - All nurses agreed that parents should be cared for in addition to their sick child.
<p>Strengths</p> <ul style="list-style-type: none"> - The paper provides a clear explanation of research background, aims, data collection and discussion as well as strengths and limitations. - This study illustrated clear literature review related to FCC characteristics and its effectiveness on health of children supported by several published articles. - Sample selection appears un-biased (all nurses working at the unit and a 'significant percentage' of parents staying overnight over a three month period). There is no claim of full representativeness or generalisability. - The analysis is not developed beyond simple percentages, however, the paper does also not make any overstated, unrealistic claims. 			
<p>Limitations</p> <ul style="list-style-type: none"> - The study focus is on Casey's Partnership Model of Children's Nursing, which is closely related to, but not fully identical to FCC. 			

- A self-designed questionnaire, not validated. Validity and reliability of the questionnaires remain unclear. No sample calculation.
- No sample calculation, no statistical power beyond describing replies in percentages.
- The use of closed questions in the questionnaires did not allow the participants to express their experiences in detail.
- Claims that the data is to be analysed on a Likert scale (methods section), but results are Yes/No/Don't know, giving the overall number and percentage of the replies (for ex 55.8%, n=24).

5. Neal, A., Frost, M., Kuhn, J., Green, A., Gance-Cleveland, B., Kersten, R. (2007). Family-Centered Care Within an Infant-Toddler Unit. *Pediatric Nursing*, 33 6), 481-486.

Design and Participants	Aims	Data Collection methods	Key Findings
<p>Descriptive survey</p> <p>A convenience sample of 38 parents of children hospitalised for at least 24 hours and 75 (i.e. all) staff (wide range of health and social care professionals) from one 35-bed Infant/Toddler Unit at a hospital in Little Rock, Arkansas.</p> <p>Many patients care for at the study unit had chronic, complex care needs.</p>	<p>To examine:</p> <ul style="list-style-type: none"> - how families and staff perceive the FCC delivered. - how family and staff perceptions compare. 	<p>Questionnaire used: adapted versions of the Family Centered Care Neonatal Intensive Care assessment inventory (staff and parent versions)</p>	<p>Staff and Family responses differed significantly across the major areas ($p=0.00005$) with parents giving more positive responses.</p> <p>Deficiencies in the care environment highlighted by most staff (60%) as not meeting the needs of families. This criticism included unit congestion (staff 80%, families 55%). Most of the parents (65%), on the other hand, felt it to be satisfactory, hinting at a reduced importance of the environment to the practice of FCC.</p> <p>Dissatisfaction with the overall care delivery according to FCC principles was low (staff 11%%, families 22%) with the parents concerns focusing on continuity of care and pain relief.</p> <p>Dissatisfaction with their welcome to the unit was low among parents (11%), although 31% of nurses thought this to be the case.</p> <p>Staff-family communication was judged to be positive by 81% of parents and 52% of nurses, despite an expressed lack of private spaces for staff and families to speak.</p>
<p>Strengths</p> <ul style="list-style-type: none"> - The paper provides a clear explanation of the study background, aims, data collection and discussion as well as strengths and limitations. - Good sampling given the limitations of the study. 			

- The statistical tests used were limited but appropriate, using the Chi-square test made establishing the significance differences in staff and family replies clear.

Weaknesses

- Despite carefully selecting a sample no demographic data was collected.
- The adapted questionnaire was not fully validated.
- This is a small, local survey, it could not (and did not pretend to) produce generalisable results.

6. Sangnatesawang, N. (2008). Perception and Practice of Family-Centered Care in Health Care Professionals. Masters Thesis: Mahidol University: Thailand.			
Design and Participants	Aims	Data Collection methods	Key Findings
<p>A survey of 198 health professionals (head nurses, nurses, nurse assistants, nurse instructors) in a general paediatric setting.</p> <p>This research was conducted in the hospital in Bangkok.</p>	<p>1) To examine perceptions and practice of family-centred care by health professionals</p> <p>2) To investigate the relationship between certain factors (age, position, experience and health care unit) and perceptions of family-centred care</p>	<p>A standardised Family-Centred Care Questionnaire (FCCQ)</p> <p>Questionnaire</p> <ul style="list-style-type: none"> was validated (Cronbach's alpha = 0.91) asked 45 questions with a 4-step rating scale. <p>It consisted of 40 questions on 9 aspects of FCC to measure health professional's perception and practice of FCC:</p> <ul style="list-style-type: none"> constant of the parents 3 items, collaboration of parents & health professionals 6 items, family strength 5 items, information sharing 5 items, Family or peer-support 4 items, 	<ul style="list-style-type: none"> All healthcare professionals had a positive perception of family-centred care but used it only moderately. (Alpha Cronbrach Values for perception =0.94 and for practice =0.91). There was a positive relationship between parents' attitude to and satisfaction with FCC and its practice. All results were comparatively moderate (Avg.= 3.18, SD= 0.32) Acknowledgement of family-strengths scored highest (m=3.22, SD=0.42) Parent-nurse collaboration scored lowest (Avg.=3.02, SD 0.41) Peer support in perception score was high at score was (m= 3.12, SD=0.39) Age, experience and position of nurse significantly correlated with the perception of FCC ($p < 0.05$). Most nurses (71.7%) learned about FCC while at seminars and training events. Nurse instructors and head nurses had more opportunities to learn about FCC than staff nurses. They also had a better understanding of FCC than staff nurses (ANOVA; $F_{2, 196} = 13.597$, $p = .000$). Which healthcare unit the nurses practiced in had not effect on their perception of FCC.

		<ul style="list-style-type: none"> • provide health care regarding child's developments 5 items, • policy of economy support 4 items, • flexibility application and practice 7 items • supporting health professionals' needs 6 items. 	
Strengths <ul style="list-style-type: none"> - Provides a clear explanation of the research process, aims and data collection methods - Questionnaire was clearly focused and was analysed with appropriate statistical methods; Pearson correlation and Eta were used to measure correlation of the factors such age, experience, position and health care unit and perception FCC. ANOVA is used to measure the variant of positions regarding perception of FCC. - Clear validity of the Thai version of the FCCQ-R was ensured by translation and back translation. - The scale reliability of the internal consistency of standardised questionnaire was high (Cronbach's alpha 0.91). - The sample size was acceptable at 198 participants 			
Limitations <ul style="list-style-type: none"> -There is no indication of ethical approval being granted. - This is a comparatively small, local survey, it could not (and did not pretend to) produce generalisable results. 			

7. Dix, D. B., Klassen, A. F., Papsdorf, M., Klaassen, R. J., Pritchard, S., & Sung, L. (2009). Factors Affecting the Delivery of Family-Centered Care in Pediatric Oncology. *Pediatric Blood & Cancer*, 53(6), 1079-1085

Design and participants	Aims	Data Collection methods	Key Findings
<p>A cross-sectional study involving five Canadian children's hospitals.</p> <p>412 parents of children with cancer recruited over a 2-year period (80.3% response rate)</p>	<p>Examines factors related to parental perception of the family-centredness of paediatric oncology services.</p>	<p>A carefully selected battery of validated questionnaires, relevant for this paper is the Measure of Process of Care (MPOC-20) questionnaire, the first subscale of which considers aspects of FCC, the second does focus on meeting information needs.</p> <p>This paper represents a subset of a larger study designed to evaluate the burden of care for parents of children who are treated for cancer.</p>	<p>The majority of parents in all five centres rated FCC highly.</p> <p>A small but important minority of parents reported low scores.</p> <ul style="list-style-type: none"> • Worse parental psychosocial health scores ($p < 0.01$) • Parental perception of the child's prognosis ($p < 0.01$) • Prognosis ($p < 0.01$) • Single parents with less family support ($p = 0.03$) <p>Indicating that the experience of this aspects is linked to less pronounced experience of FCC.</p> <p>Recognising the reasons for low scoring and identifying families dissatisfied with the care provided is highlighted as important to optimise the provision of FCC.</p> <p>In one hospital the parents rated the provision of information lower than in all others (no p-value supplied). This point is used to highlight the importance of good information giving as part of FCC,</p>
<p>Strengths</p> <ul style="list-style-type: none"> - Uses a standardised, validated questionnaire completed by a large sample. - Provides a clear explanation of research background, aims, recruitment and sampling, data collection and discussion as well as strengths and limitations. - The characteristic of children, parents, illness and household factors were reported. - The study does all that is possible within a quantitative approach to produce generalisable data. However, the nature of the setting and the focus of the study make any reliable generalisation impossible. 			
<p>Limitations</p>			

- The study was able to detect greater dissatisfaction with the care provided, but due to the limited nature of a) the quantitative approach, and b) the questionnaire design, could not explain why this was the case. Instead the authors had to revert to speculation to explain potential reasons for their results.
- Due to the aims and design of the overall study healthcare staff did not participate, their views were not represented.
- The use of closed questions in the questionnaires did not allow patients to express their experiences in any detail.

8. Moore, M. H., Mah, K. K., & Trute, B. (2009). Family-centred care and health-related quality of life of patients in paediatric neurosciences. *Child:care, health and development*, 35(4), 454-461.

Design and participants	Aims	Data Collection methods	Key Findings
A survey of 187 families (response rate 45%) consisting of a caregiver and a child aged 8-18 years and a long-term patient at the Neurosciences Clinic of the Alberta Children's Hospital.	To explore the relationship between and quality of life in a sample of neurology patients at a large acute children's hospital.	A carefully selected battery of validated questionnaires, relevant for measuring the FCC related aspects were: - the Measure of Process of Care (MPOC-20) questionnaire, the first subscale of which considers aspects of FCC, the second does focus on meeting information needs. - the Pediatric Quality of Life Inventory (PedsQL) to measure the children's quality of life.	- MPOC-20 scores (m= 24.8) suggest that FCC practices were experienced to 'a fairly great extend'. - The severity of the children's illness was a greater predictor of the child's QoL than FCC satisfaction (t= 6.00 vs 3.73, P<0.001). - Nevertheless, FCC predicted 7% of the variance in physical and 13% of the variance in psychosocial QoL. - When FCC was controlled for illness severity, it remained a significant predictor of physical, psychosocial and total HRQL scores. - Uptake of FCC into the care provision can significantly increase the children's perceived QoL.

Strengths

- A sufficiently large sample size (although no sample size calculation is provided).
- An appropriate sampling and recruitment strategy.
- Research background, aims, recruitment and sampling, and data collection are described well.
- The characteristic of children, parents, illness and household factors were reported.
- Multiple instruments were used: Health-related quality of life (HRQL), The Functional Independence Measure (FIM) and Measure of Processes of Care (MPOC-20).
- Results were controlled for severity of illness.
- A link between FCC and children's HRQL has been established, independent of the severity of the neurological illness.
- The study results should be applicable to similar care settings.

Limitations

- Due to the aims and design of the overall study healthcare staff did not participate, their views were not represented.
- The use of closed questions in the questionnaires did not allow patients to express their experiences in any detail.

9. MacKay, L. J., & Gregory, D. (2011). Exploring family-centered care among pediatric oncology nurses. *Journal of Pediatric Oncology Nursing*, 28(1), 43-52.

Design and participants	Aims	Data Collection methods	Key Findings
<p>A naturalistic enquiry employing a generic qualitative approach with aspects of Grounded Theory..</p> <p>20 nurses and nurse practitioners</p>	<p>To explore FCC among paediatric oncology nurses at a Canadian Children's Hospital.</p> <ul style="list-style-type: none"> - How far they practice within that framework. - Highlight barriers and challenges and how skills help overcome these. - How the hospital supports and encourages FCC. 	<p>Semi-structured ('person-centred') interviews, achieving saturation after the 14th interview. Thematic analysis of the interview data.</p>	<p>All nurses asserted that FCC includes the whole family, recognising that the child should always be surrounded by family.</p> <p>To establish (and enhance) FCC requires specific skills</p> <ul style="list-style-type: none"> = close collaboration with the patient-family, as FCC is a collaborative effort. Parents were seen as experts, not supporters = respecting the families' culture, values, and beliefs, this requires close engagement and active listening skills = being able to teamwork with colleagues, including beyond nursing. Being able to rely on other professionals and to be able to consult them = a close nurse-patient-family relationship to enhance the ability to tailor care according to the patient's and individual family's needs. = being flexible, able to change, willing to compromise, and open to negotiation, not dictating or controlling. = an ability to educate the family, this ultimately enables the family to participate in care decisions and the care itself, equipping them to ask questions. <p>Barriers towards providing FCC</p> <p>These were often the opposites to the above, i.e.</p> <ul style="list-style-type: none"> = not understanding the families culture = contradictions and tensions between nurses and families = difficult working relationships

			<p>But also:</p> <ul style="list-style-type: none"> = lack of time and increasing acuity of patients = restraints in budgets and resources increase stress in nurses and decrease their ability to provide FCC, = lack of education about FCC for all health workers <p>Overall the hospital did support FCC by including it into its mission statement, and by its architecture and layout (n=16), although four nurses noted that this support was not carried out as fully as possible.</p> <p>The study demonstrated that the nurses clearly felt that the provision of FCC is possible even in an area of care that is complex and complicated, such as oncology care.</p>
<p>Strengths</p> <ul style="list-style-type: none"> - Clear explanation of research process, study aims, data collection and analysis - Sample size is small, but acceptable. - The paper does provide a clear explanation of research background and its aims. - Due to the qualitative approach, where participants can express themselves clearly, the study results can be applied (transferred) with greater confidence. 			
<p>Limitations</p> <ul style="list-style-type: none"> - The study is limited to nurses omitted the viewpoints of the families. - The methodology could have been outlined in much greater clarity. 			

10. Kennedy, A. P. (2011). Systematic ethnography of school-age children with bleeding disorders and other chronic illnesses: exploring children's perceptions of partnership roles in family-centred care of their chronic illness. *Child: care, health and development* , 863-869.

Design and participants	Aims	Data collection methods	Key Findings
<p>Systematic Ethnography</p> <p>8 school children aged between 7 and 11 years with a chronic illness living in Western Canada.</p>	<p>To examine how school children understand their role in family-centred care.</p>	<p>Phase I: unstructured interviews (n=8)</p> <p>Phase II: comparing children's views with institutional and legal documents</p> <p>Phase III: validation interviews (n=4)</p>	<p>Phase I: 7 domains of how children understood their role in FCC:</p> <ul style="list-style-type: none"> - recognising and upholding their best interests (supported by parents), - Having four virtues: respect, trust, trustworthiness, doing our best. - All involved need time to talk and listen, - Clarity of (their) role(s) allowing them to be involved, - having relevant knowledge is needed to influence, - making decisions, alone or as a team, while being aware of consequences - getting training to work as a team. <p>Phase II: the domains were all present in the UN Rights of the Child and local legislation, but less so in policy documents.</p> <p>Phase III: confirmed the domains and generated key strategies to support children's role as FCC partners by using</p> <ul style="list-style-type: none"> - a 'treasure map' illustrated the domains in a user(child)-friendly way, this is to used as a teaching tool. - all-ages interactive workshops for children and adults to learn about FCC - transforming the treasure map into a computer game to teach children how to make decisions.
<p>Strengths</p> <ul style="list-style-type: none"> - The study aims are described in detail, the (purposive) sampling method is appropriate to achieve the study aims. - The sample is small but sufficient - The interview process was tailored to the abilities and needs of the children and is well explained for the reader. - The data analysis is outlined sufficiently well. 			

- The study design and focus is rare as it gives the children a clear voice.

Limitations

- This descriptions of the study results, especially the domains, could be more detailed.
- There is very little information n concerning the documents, laws and policies used in phase 2.

11. Coyne, I., O'Neill, C., Murphy, M., Costello, T., & O'Shea, R. (2011). What does family-centred care mean to nurses and how do they think it could be enhanced in practice. *Journal of Advanced Nursing*, 67(12), 2561-2573.

Design and Participants	Aims	Data Collection methods	Key Findings
Survey of 250 nurses (a response rate of 33%) in seven children's units in Ireland (three children's hospitals, a children's ward in a general hospital and three children's units across Ireland).	To report nurses' perceptions and practices of family-centred care.	The data used for this study came from 2 open-ended questions contained within a survey	<p>The nurses have a good understanding of FCC, making the family the centre point of their care. Two core themes were identified.</p> <ol style="list-style-type: none"> 1 Components of FCC <ul style="list-style-type: none"> - Family involvement (information-sharing, decision-making, family as the constant for the child) - Working in partnership (encourage and empower to participate, ...) - Negotiated care (incl. teaching, re-assuring, relationship building, ...) - Delivering high quality care (only possible with family involvement) - Multidisciplinary approach (vital for FCC) 2 Enhancing FCC (to overcome difficulties to put FCC into practice) <ul style="list-style-type: none"> - better facilities for families (social areas for families, resting facilities) - better facilities for inpatients (especially separate from adult patients) - psychosocial and financial support (important but both are lacking) - staffing levels (to increase), managerial support (appreciation of FCC) - Better communication (esp to ensure appropriate negotiation of care) - Education and training (for staff, to understand FCC fully)

Strengths:

- Very large sample size for qualitative data, although this is offset by the small amount of data per participant.
- The process of the applied analytical method (content analysis) is explained well and the core themes have been peer-debriefed.
- The complete set of codes, categories and core themes is included in the article.
- The research background, aims, data collection and analysis are explained well, there is a coherent in-depth discussion and any study limitations are highlighted.
- A lack of organizational and managerial support to appropriately implement FCC is highlighted.

Limitations:

- The study focused exclusively on nurses.
- The nature of the data collection (i.e. written answers of open-ended questions within a survey) provided only very limited space/time for the participants to express their views, the data is therefore by necessity limited.
- Content analysis is by its nature a more limited analytic tool. However, given the limited data it was nevertheless appropriate to use it for this study.
- The other parts of the survey also focussed on FCC, but that data or those results are not included.

12. Uhl, Tammy, Fisher, K., Docherty, S. L., & Brandon, D. H. (2013). Insights into Patient and Family-Centered Care through the Hospital Experiences of Parents. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 42, 121-131.

Design and Participants	Aims	Data Collection methods	Key Findings
<p>Two-phase mixed-method study carried out at the Children's Hospital, Boston.</p> <p>Participants: Phase 1: nine parents Phase 2: 134 parents (of children aged 1 to 13 years)</p>	<p>To understand the parents' care experience during the hospitalization of their children.</p> <p>To identify strategies that could improve the provision of family-centred care.</p>	<p>Phase I Three Focus groups with 3 parents each</p> <p>Phase II In-patient hospital experience survey, using a hospital-specific but validated questionnaire based on FCC characteristics.</p> <p>Questionnaire return rate 10.4%</p>	<p>Focus groups resulted in three themes:</p> <p>Apprehending the reality = the initial shock of their children's admission to hospital, with high levels of anxiety, disbelief, ... = parents lack knowledge to co-operate with health professionals = Parents perceive collaboration to be essential but struggled to regain control</p> <p>Engaging adversity = How parents experienced their role during hospitalisation, often dominated by confusion and uncertainty</p> <ul style="list-style-type: none"> - Parents feel they need to relinquish their role as main care-giver - Parents begin to define or re-define their role - The importance of getting information (difficulty or ease of getting it) <p>= Empowerment</p> <ul style="list-style-type: none"> - How nurses helped to prepare parents - Becoming experienced meant increasing influence in decision-making and created a feeling of being empowered <p>= Communication</p> <ul style="list-style-type: none"> - having a primary nurse throughout - when parental input is encouraged/desired <p>Advancing forward (transitioning from hospital back home)</p> <ul style="list-style-type: none"> - again a challenging time of stress - understanding the effects of hospitalisation helps to succeed

			<ul style="list-style-type: none"> - Support needs to continue post discharge to assist parents in coping (These were chronically ill children requiring continued care) <p>Survey results:</p> <p>Exploration of parental experiences of FCC initiatives at the Boston Children's Hospital.</p> <ul style="list-style-type: none"> - Parental participation in ward rounds: <ul style="list-style-type: none"> = principally welcomed = most but not all parents wish to participate - Parental presence during nursing hand-overs <ul style="list-style-type: none"> = appreciated by all parents = seen as a good way to get 'updates' concerning their child = some parents felt nurses should be left alone, so they can speak more freely. <p>Inpatient experience</p> <ul style="list-style-type: none"> = Quality of the care was excellent and the care could be trusted = Nurses were seen as not always sufficiently helpful and courteous = There was greater confidence in the doctors' knowledge than that of nurses = Pain-relief was efficient = Medication-related communication and experiences were positive = The hospital environment was criticised, especially in terms of noise, cleanliness and quality of meals = Discharge and discharge planning were seen as helpful and a positive experience
<p>Strengths</p> <ul style="list-style-type: none"> - The paper provided a clear explanation of research background, aims, data collection and analysis, discussion and limitations. - The focus groups were limited in size and number but generated more and deeper data than usual for this method. - The smaller focus group appear to have enabled a better flow of conversations and allowed the participants to express their ideas in depth. - Less than ideal outcomes are presented openly. - The methodology and method are described well 			

Limitations

- The focus of this study is on one hospital only.
- The survey was more an evaluation of services than a study on FCC, nevertheless important relevant aspects can be extrapolated.