CHILDREN'S PARTICIPATION IN DECISIONS REGARDING THEIR NURSING CARE: AN ETHNOGRAPHIC STUDY OF CHILDREN, PARENTS AND NURSES IN THE ONCOLOGY SETTING

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Declaration

This is to certify that the work contained within has been composed by me and is entirely my own work. No part of this thesis has been submitted for any other degree or professional qualification.

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Abstract

Background: The rights of children to freedom of expression and receiving information are underpinned by Articles 12 and 13 of the United Nations Convention on the Rights of the Child (UNCRC) (1989), which was ratified by the Malaysian government in 1995. There has been increasing shifts toward recognising the importance of children's rights with many initiatives to realise and uphold the rights of children in Malaysia. However, no previous studies of children's participation have been conducted in Malaysia. The aim of this study was to explore children's participation in decisions regarding their nursing care from the perspective of the children, their parents, and nurses in an oncological ward in Malaysia.

Methods: This was a focused ethnographic study. Participant observation was carried out with 61 participants (21 children, 21 parents, and 19 nurses) in the paediatric oncology-haematological ward, Malaysia. Semi-structured interviews were conducted with 21 participants (6 children, 7 parents, and 8 nurses). The existing documents pertinent to the research focus were examined to validate the participant observations and interview findings. Data were analysed using Roper and Shapira's (2000) focused ethnographic data analysis techniques.

Findings: There were different degrees of the participation of children in decisions among children diagnosed with leukaemia, including: being physically present, being informed, being consulted where children can express their wishes and opinions during the provision of nursing care, and being able to make their own decisions in relation to their nursing care. The degrees to which children participated in decisions fluctuated throughout the course of their hospitalization; moving from lesser degrees of participation (passive participant) to greater involvement (active participant) and vice-versa. The extent to which children participated in decisions were significantly influenced by the children's preferences for participation. The preferences of children also fluctuated over the course of their illness and treatment. There were several factors contributing to children's participation in decisions including; i) interpersonal relations in the child-parent-nurse interactions; ii) experiences of the child (veteran or novice); iii) attitude of nurses; iv) parental role; and v) the ward policy.

Conclusion: The children want to be involved and really appreciate participation in communication and decisions but their opportunities for participation are somewhat limited. This study calls for a flexible model to assess children’s preferences for participation and different forms of participation for children in relation to decision-making in paediatric oncology.

Keywords: Children, parents, nurses, decisions, participation, ethnography, Malaysia

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List of abbreviations

ALL	Acute Lymphoblastic Leukaemia
AML	Acute Myelogenous Leukaemia
ANC	Absolute Neutrophil Count
CML	Chronic Myelogenous Leukaemia
CN	Community Nurse
CNE	Continuing Nursing Education
CRC	Child Right Coalition
CVL	Central Venous Line
FBC	Full Blood Count
FCC	Family Centred Care
HN	Head Nurse
IFCC	Institutes of Family Centred Care
IT	Intra-thecal
IV	Intravenous
LP	Lumbar puncture
MOH	Ministry of Health
MREC	Medical Research Ethics Committee
MTX	Methotrexate

NIHR	National Institute of Health Research
NICU	Neonatal Intensive Care Unit
NMRR	National Medical Research Register
PICU	Paediatric Intensive Care Unit
RN	Registered Nurse
RT	Ryle’s tube
UNCRC	United Nation Convention of the Right of the Child

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Chapter 1: Introduction

1.1 Introduction

The rights of children to freedom of expression and receiving information are underpinned by Articles 12 and 13 of the United Nations Convention on the Rights of the Child (UNCRC) (1989), which was ratified by the Malaysian government in 1995. In relation to children's right to participation, the UNCRC specified that the best interests of the child must be the primary consideration and that the right of children to express themselves freely must be respected and promoted and their views should be given due weight in accordance with the age and maturity of the child (UNCRC, 1989). This reflects the recognition of the importance of children's participation in decisions made about them and respect for their views in decisions (Kilkelly & Donnelly, 2011). As part of the strategies to achieve these goals, many initiatives to realize and uphold the rights of children have been advanced by the Malaysian government. For instance, the introduction of the Child Act 2001, and withdrawing some of its initial reservations to the UNCRC. In 2010, the Malaysian government lifted reservations to Article 1 (defining the age of a child); Article 13 (regarding freedom of expression); and Article 15 (regarding freedom of assembly and participation). In consideration of these influential changes, it can be considered that views on childhood might change with an increased awareness of the child as an active subject in Malaysia (Child Rights Coalition Malaysia, 2007).

In relation to children in hospital there is a growing body of literature that emphasises the child's right to information and participation (Alderson et al., 2006; Coyne, 2006a; Franklin & Sloper, 2006; Kilkelly & Donnelly, 2011). It has been argued that it is essential to elicit the child's view to provide services that are responsive to their needs since they are the main focus of care whilst hospitalized (Coyne, 2006a). Nonetheless, there has been no research that has focused on children's participation in decisions specifically in relation to nursing care in Malaysia; although there is increasing shifts toward recognising the importance of children's rights. This indicates the need for research centred on understanding children's experiences of participation in decisions regarding their nursing care and within the Malaysian healthcare setting. This formed the basis of the research inquiry for this thesis.

This chapter first introduces the research problem based on my own personal reflections. Next, it outlines the context of the study. The aim of the study is then presented in conjunction with the research questions. The structure of this thesis is detailed at the end of the chapter. The terms 'child' and 'children' are used in this thesis to refer to children and young people under the age of 18, as defined in Article 1 of the UNCRC.

1.2 Personal reflections on the research problem

Initially, the motivation for conducting this study was based on my own experience of working within clinical practice in Malaysia (previously as a paediatric nurse and recently as a nurse educator). This experience led me to observe that there was a gap between the recommendations by the UNCRC regarding children's rights to expression and what was happening in clinical practice. For instance, I observed that the involvement of children in discussion and decisions regarding their care was limited; the healthcare professionals, including nurses, frequently discussed the child's care with the parents instead of the child. This occurs despite the recommendations by the UNCRC for children to express their views regarding matters affecting them, and the availability of a patient and family rights policy in the majority of hospitals in Malaysia that encourages the involvement of patients (including child patients) and families in the patient's care and decisions. It was because of these irregularities that I began to question whether the participation of children in their own care and decisions affecting them is being emphasised at any level within the Malaysian healthcare system. Undeniably, this gap became obvious to me because I have been reading research about children's participation in decisions since the year 2012 while working on my proposal for this thesis.

The impetus of this study is derived from two main considerations. First, in order to understand children's participation in decisions in a healthcare setting in Malaysia, it is important to explore the extent to which children participate in decisions. Second, paediatric care entails at least a triad, involving the medical team, patient and parents (DeCivita & Dobkin, 2004), thus, what is happening in the triadic interactions during the provision of nursing care must be understood in order to encourage and support children's participation in decisions with regards to their nursing care. Therefore, this study employed a focused ethnographic approach, using participant observation together with individual interviews so that the participation of children in decisions can be better understood.

1.3 Context of the study

When designing this study, the literature related to children's participation in the nursing context and other disciplines of children's participation was examined. Compared to the research on children's participation in other disciplines, such as in end-of-life (e.g. Hinds et al., 2001; 2005), clinical research decisions (e.g.; Snethen et al., 2006; Varma et al., 2008), in law and policy reform (e.g. Littlechild, 2000; Tisdall & Davis, 2004), in schools (e.g. Lundy, 2007; Smith, 2007), and in family law proceedings (e.g. Raitt, 2007; Taylor, Tapp and Henaghan, 2007; Fitzgerald, 2009), limited studies in the nursing literature have been specifically engaged in this topic. Findings from previous nursing research in other countries provided insight into the influential issues regarding the participation of children in decisions.

Qualitative studies that have been conducted to understand children's participation in decisions concerning their care in healthcare have contributed to some level of evidence in the literature. Research found that the involvement of children in consultation is often limited (Coyne, 2006a; Young et al., 2006; Coyne & Gallagher, 2011). This may be a result of children's own choice, but it may also be caused by adults' protectiveness or incomplete knowledge of children's ability to understand information and to be an active participant in decisions regarding their care (Young et al., 2006; Lambert et al., 2008; 2011). Some children have reported being dissatisfied with their non-participant status that can hinder their ability to understand their illness and to have their expression considered (Odigwe, 2004; Coyne, 2006a; Young et al., 2003; 2006; Coyne & Gallagher, 2011). Remarkably, little is known about the preferences of children in participating in decisions with regards to their nursing care. Moreover, most of the research in the past has obtained data from parents or professionals on children's lives and has thus been on or about children, rather than with children. This has had a doubly silencing effect, and as a result the perspectives of children are not considered, which is now changing. Increasingly, researchers are recognising the importance of directly recording children's own perspectives (Coyne, 2006a; Coyne et al., 2006; Moore & Kirk, 2010). Despite these studies, there is little research on children's participation in decisions regarding their care by observing what happens in the triad interaction during the nursing care provision, and this may minimise the understanding of the whole picture of children's participation in decisions with regards to their nursing care.

Leukaemia is one of the most common types of childhood cancer in Malaysia (Lim, 2002). As such it has been described as a life-threatening and traumatic event, one that causes considerable emotional and physical distress for children and their families (Ow, 2003). Increasingly, however, children diagnosed with childhood cancer, including leukaemia, are surviving due to medical advances and better treatment protocols (Lim, 2002). Nonetheless, the lengthy and aggressive treatments including chemotherapy, surgery, bone marrow transplant, along with numerous medical examinations and procedures, cause both children and parents multiple issues that require decisions throughout the children's courses of treatment (Lim, 2002; Woodgate & Degner, 2002). As previously mentioned, the recommendation by the UNCRC requires that all children should be supported and encouraged to participate in decisions affecting them (UNCRC, 1989). This thesis considers the participation of children diagnosed with leukaemia in decisions with regards to their nursing care by exploring the children's, their parents' and nurses' perspectives in an oncological setting in Malaysia. When embarking on this research it was recognised that each individual child could experience different levels of participation, and that their parent and nurses may have their own perceptions and different ways of supporting or hindering children's participation. Therefore, taking the perspectives of the child, the parent and nurse as a participant, the context of children's participation in decisions with respect to their nursing care in Malaysia was explored.

1.4 Research aim and questions

This study has set out to explore how children diagnosed with leukaemia participate in decisions regarding their nursing care in an oncological ward in Malaysia. The aim of the study was to gain an understanding of the participation of children in decisions concerning their nursing care from the perspectives of the children, their parent, and nurses. The study was guided by the following research questions:

> **Research question 1**: How do children experience participation in decisions with regard to their nursing care?
>
> **Research question 2**: How do children prefer to participate in the decisions and what are their information preferences regarding their nursing care?
>
> **Research question 3**: What are the factors influencing children's participation in decisions with regards to their nursing care?

To answer these research questions, a focused ethnographic approach was conducted in two phases within an oncological setting in Malaysia. The methods used in this study were: first, participant observation to observe the interactions between the children, their parents, and nurses during the provision of nursing care; second, semi-structured interviews with the participants individually so that they could explore their own experiences; and third, the examination of documents to complement the participant observation and interview findings. The children diagnosed with leukaemia, their parents and the nurses caring for children were purposively selected. This will be discussed further in Chapter 4.

1.5 Structure of the thesis

This thesis is comprised of eight chapters, including this chapter (Chapter 1). This Chapter introduces the study. The aims and research questions are provided along with my own personal reflections on the research problem and an overview of the research context.

Chapter 2 provides the contextual background for the study and an analysis of the relevant literature in the Malaysian context. Included in this chapter is an overview of the multi-cultural backgrounds in Malaysia, and the cultural orientation in Malaysia and its impact on the perception of children's rights. This is followed by a discussion of studies around patient's participation in decisions in Malaysia. The policy documents reviewed in relation to children's rights and participation in Malaysia are also presented.

Chapter 3 provides a review of the relevant literature and situates this thesis in relation to theoretical debates. I provide an overview of the theoretical context and current empirical research in the study of children's participation in decisions in health care. This is followed by a discussion of studies around children's participation in decisions. This chapter then presents the findings of the review in relation to: how children prefer to participate in decisions; how children experienced participation in decisions; factors influencing children's participation; and the impact of children's participation on the children. Towards the end of this chapter, the overall gaps in knowledge that arise from the current literature on children's participation in decisions in healthcare are presented.

Chapter 4 presents the methodological approach taken in this study. I explain the rationale for choosing the adopted methods to meet the research objectives. This includes: the justification of the constructivist perspectives and ethnographic design, and the rationale for choosing a focused ethnographic design, study setting, and sampling strategy. The explanations of the recruitment of participants, the data collection process, data analysis, methodological rigour, ethical issues within the research process, reflexivity and limitations are also outlined.

Chapters 5 and 6 present and discuss the substantive findings of this research. In chapter 5, I explore the way in which children in this study participate in decisions. I draw attention to the actual experiences of children in participating in the decisions relating to their nursing care including the three different patterns of participation: being physically present, being informed, and being consulted about the nursing care provided. I then explore the ways in which different choices are made available to children during the provision of nursing care, and how parents and nurses play their role in offering choices to children. Toward the end of this chapter, the situations where children can express their views, and how their expressions are being ignored or respected by the adults are discussed.

In Chapter 6, I explore this complexity further by looking at the triad of communication (nurse-child-parent interactions). I draw attention to the roles of parents in the communication process and show how these roles facilitate or constrain the participation of children in communication and decisions. While drawing out the salience of how adults control information sharing with the children, I also recognize the way in which children in this study preferred the information concerning their care to be delivered. Towards the end of this chapter, the roles of children in communication processes are discussed.

In Chapter 7, I discuss and summarize the seven key elements identified from the analysis of the two findings chapters by connecting them to the existing literature and theories. This chapter begins with discussions of seven main elements: (i) the dynamic of interpersonal relations in the child-parent-nurse interactions; (ii) the attitudes of nurses; (iii) the roles of parents; (iv) the ward policy; (v) diverging and fluctuating preferences of participation; (vi) shifting degrees of participation; and vii) participation around minor decisions. A diagram was developed through the integration of the key elements analysed in the previous two finding chapters to explain the dynamic process of children's participation in decisions with regards to their nursing care. I draw out that whether children experience a meaningful participation or lack of substance of participation in decisions is highly dependent upon each individual involved in the triadic interaction (mainly nurses, children, and parents). The way in which children participate in decisions can depend on the child's experiences and personal preferences as well as their interaction with others. Also, the child-nurse interpersonal relations, the attitudes of nurses, the roles of parents, and the ward practice are important for children's experiences of participation in decisions relating to their nursing care in the oncological setting.

In Chapter 8 I provide the conclusion of the study. This is followed by the implications and recommendations that arise from this research for nursing practice, nursing education, and nursing policy. The recommendations for future research are provided before finally moving on to the conclusion of the study.

Chapter 2: Contextual background

2.1 Introduction

In this Chapter, I attempt to discuss children's participation from a Malaysian perspective. I begin by providing an overview of the multi-cultural background in Malaysia, and Malaysian perspectives of children and childhood. The main three ethnic groups' beliefs towards children and childhood, including Malays, Chinese, and Indian are discussed in section 2.3. I then discuss the cultural orientation in Malaysia and its impact on the perception of children's rights, before discussing the UNCRC and children's rights in Malaysia. This is followed by a discussion of studies on the context of patient's participation in Malaysia by exploring and discussing empirical studies around patient's participation in decisions in Malaysia. The policy documents reviewed in relation to children's rights and participation in Malaysia are then presented. Subsequently, I provide an analysis of the context of patients' participation in Malaysia by exploring and discussing empirical studies around participation in decisions. Finally, I summarise the gaps in knowledge from existing literature on children's participation in decisions regarding healthcare in Malaysia.

2.2 Multi-cultural background of Malaysia

Malaysia is a multi-ethnic country located in Southeast Asia with a population of 26.26 million (Keshavarz, & Baharudin, 2009). Malaysian citizens comprise of three main ethnic groups; namely, Malay, Chinese and Indian. The Malays constitute about 65 percent of the Malaysian population; the Chinese form about 25 percent of the population, and about seven percent of the Malaysian population is Indian (Department of Statistics Malaysia, 2010). The oldest inhabitants, the tribal peoples, account for about five percent of the total population and mainly live in East

Malaysia (Krishnan, 2004; Keshavarz, & Baharudin, 2009). Regarding religious practice, Islam is the most widely professed religion (60.4%, mostly practiced by Malay ethnic groups). Malaysia also has other religions such as Buddhism (19.2%), Christianity (9.1%), Hinduism (6.3%), and Confucianism/Taoism/other traditional Chinese religion (2.6%) (Department of Statistics Malaysia, 2010).

While the Malays are considered the primary local population, the Chinese and Indian are descendants of Chinese and Indian immigrants who began settling in Malaysia in the 19th Century (Krishnan, 2004). The Malaysian population, therefore, has a wide-range of cultural and ethnic backgrounds that provide an opportunity to understand the different role of cultures and beliefs in relation to children and childhood and its impact on children's participation in matters affecting them. The three major ethnic groups' beliefs about children and childhood in Malaysia are discussed in the next section.

2.3 Beliefs about children and childhood

As elaborated in section 2.2, Malaysia is a multi-racial and multicultural society, which may determine different beliefs about children and childhood. As each ethnic group has distinct values and belief systems, this section discusses each ethnic group's beliefs about children and childhood and the expectations of adults towards children. These views about children and childhood and adults' expectation give a better understanding of how children are supported in participating in the decisions. This section provides a discussion of the beliefs about children and childhood from the different ethnic groups of Malaysians that was based on commentary articles.

2.3.1 Beliefs about children and childhood in the Malay culture

Children are believed to be immature, naive and unable to care for themselves among the Malays (Mohd & Kadir, 2012). This belief indicates that children need care, attention, supervision and protection from adults. The family is considered the starting point for providing guidance and protection to children. Family members are constantly involved in children's activities that help the learning process of the children. Therefore, a strong sense of familyism prevails in Malay culture (Krishnan, 2004). The children who need care and protection are also expected to have good behaviour and obedience to their parents (Kling, 1995). This is consistent with the qualities of filial piety and a sense of obligation to family that has been emphasized among Malaysian children. In Malay culture, these moral principles are to be followed by all family members and undesirable behaviour would affect family reputation (Winskel, Salehuddin & Stanbury, 2013). In addition, despite the patriarchal structure in the Malay family, mothers are particularly honoured. Malay children are taught that 'paradise lies at the feet of mothers' (Krishnan, 2004: 20). The parents are regarded as authority figures in the Malay society, and are obeyed without question (Keshavarz, & Baharudin, 2009). Thus, Malay children are given no self-determination but are expected to accept discipline without question (Krishnan, 2004; Lin & Lian, 2011).

Although Malay children are expected to be obedient and respectful, research indicates that not all Malay parents expect obedience from their children. For instance, Noh, Yusoff and Hasim's (2013) quantitative study of Malay families in Terengganu, a north-eastern state of Peninsular Malaysia involving 435 children and 577 parents, found that there are different expectations of Malay parents towards their children. The findings indicated that only twenty-four percent of the parents expected obedience from their children, while nearly half of the respondents (44%) expected an open discussion with their children, with some regulations that must be followed by the child, so as not to violate the norms and ethics of religion and culture. Other parents (18%) did not share problems with their children. Children felt more comfortable communicating with their peers rather than with their parents. Finally, only a small number of parents (15%) would give full freedom to their children to give their opinion and express their views. This study highlighted different expectations of Malay parents towards their children. However, the findings of the study may not represent and explain how Malay parents expected their children to behave towards them because the study of Noh and colleagues (2013) was conducted on Malays from the rural area and thus the respondents were mainly from low-income groups including respondents who are fishermen and self-employed.

In summary, this section highlighted that Malay children are perceived by adults as immature, naive and unable to care for themselves. Thus, they are thought to need care, attention, supervision and protection from adults. Despite needing care and protection from adults, Malay children are expected to have good behaviour and be obedient to their parents, because the parents are regarded as authority figures in the Malay society.

2.3.2 Beliefs about children and childhood in the Chinese culture

Most of the Chinese in Malaysia are Confucian or Buddhist. The nature of the child in the Chinese culture has been captured similarly such as "children are like white paper," indicating their innocence, lack of knowledge, and innate goodness, which is consistent with Confucian and Buddhism (Chao & Tseng, 2002: 60). Children are regarded as naturally good unless ruined by their environment, in which children cannot be spoiled by their nature, but only by the adults (Chao & Tseng, 2002). Consistent with these beliefs, infants or young children are treated with toleration by their parents because they are believed to be too young and incapable of understanding (Keshavarz, & Baharudin, 2009; Rao et al., 2003). In contrast, older children are treated differently; they are treated in a harsh manner and a strict discipline is enforced (Keshavarz, & Baharudin, 2009), because older children are expected to learn to control or inhibit the impulses of earlier years (Krishnan, 2004). In addition, independence is not always emphasised in the Chinese culture (Krishnan, 2004). Parental authority is important in the Chinese family, which could be linked to the Confucian philosophies regarding filial piety and respecting parents (Chao & Tseng, 2002). In the Chinese family, the parent has great authority, especially in relation to decisions. For instance, major decisions such as education, careers and sometime even marriage choices are made for the children by their parents or at the very least need approval from the parents (Krishnan, 2004; Keshavarz, & Baharudin, 2009). Similar to the Malays, Chinese children are also expected to be obedient to their parents and children’s expression are more likely to be prohibited (Rao et al., 2003). Indeed, children are generally taught to control their emotions and to avoid expression of thoughts and feelings from a young age (Rao et al., 2003).

Research strongly supports that the concepts of adherence and obedience are greatly emphasized in Chinese culture. For instance, a pilot study by Voon and Pearson (2011) was conducted among three Malaysian-Chinese families living in the Australian metropolitan city of Sydney with at least one child within the early childhood age range of four to eight years old. The study used an individual interview approach with the father and mother interviewed separately to identify the beliefs about ethnic identity and cultural maintenance in children’s socialisation. The main finding of this study was the importance of respect and filial piety, where familial responsibilities and interdependence of family members is essential in the Malaysian-Chinese society. This finding highlighted the practice in the Chinese family that the child accepts what the parents say, and thus children who show respect and do not challenge their elders are considered to be good children. However, there is one set of parents (father and mother) within the study who felt that their children have the right to voice their opinions and they perceived that the thoughts of the children might differ to those of the parents. The explanation for this unique finding may be the result of their longer period of residence in Australia, which has made them adapt to the culture of the host society, and thus, their practices may reflect values that are associated with the host culture (Voon & Pearson, 2011).

In summary, the Chinese children were viewed as innocent, lacking knowledge, and having innate goodness. Thus, independence is not always emphasised in the Chinese culture. Similar to Malay culture, the parent has great authority in Chinese culture, especially in relation to decisions. There are different ways of treating children in Chinese Culture; while young children are treated with toleration by their parents, the older children are treated in a harsh manner and a strict discipline is enforced consistent with the beliefs towards children in Chinese society.

2.3.3 Beliefs about children and childhood in the Indian culture

Within the Indian culture, childhood is considered a carefree period, and the child is thought to be innocent and cast in God's image (Rao et al., 2003). Indian children are considered to be born without sin and unable to distinguish between good and evil (Chao & Tseng, 2002). Because children are innocent, they are regarded as dependent. Therefore, a child's independence and non-compliance are considered as a threat to the Indian parents (Keshavarz, & Baharudin, 2009; Krishnan, 2004), and a delay of autonomy in children is essential in Indian society (Rao et al., 2003). Similar to the Chinese culture, parental authority is emphasised a great deal among the Indian; parents generally exercise a considerable amount of control over their children's lives, and the children's desires are usually decided by the parents (Krishnan, 2004).

The important assertion in Indian culture is that there is a clear role differentiation, delineating expectations and type of interaction in families based on gender (Krishnan, 2004) and thus, children are treated differently (Keshavarz, & Baharudin, 2009). While the father is considered to be the dominant figure in the family, the female is regarded as subordinate to the male (Krishnan, 2004). The father is the primary decision-maker, disciplinarian, and protector of the young, women, and the elderly, whereas the female is expected to be dependent all of her life, first on her father, then her husband, and then her eldest son (Krishnan, 2004; Sala, 2002). As a result, daughters are more protected by the Indian parents than the sons. Indeed, Indian children, particularly girls, are inhibited from showing assertive behaviour and autonomy (Keshavarz, & Baharudin, 2009; Krishnan, 2004).

Similar to the Malays and Chinese, Indian parents place a strong emphasis on respect and obedience from their children. However, research suggested that there are differences in expectations from parents towards their children between Chinese and Indian mothers. For instance, a study by Rao and colleagues (2003) interviewed mothers of 4 and 5-year-old children in Beijing, China (n=205) and Bangalore, India (n=118) to compare cultural differences in parenting practices between Chinese and

Indian mothers. This study found that the Indian mothers were found to be more accepting of individual differences and of children's emotional expression from those of Chinese mothers. It is notable that this study was not conducted among the Malaysian, however, Malaysian share common characteristics with other Asian societies that emphasise the importance of family, kinship systems, and family interdependence (Chao & Tseng, 2002). To a certain extent therefore, this finding could be applicable to the Chinese and Indian population in Malaysia.

In summary, the review highlighted that Indian children are perceived as innocent and dependent. Similar with Malay and Chinese culture, parental authority is emphasised a great deal among the Indian, and independence and non-compliance are considered as a treat to the Indian parents. Indian children therefore, are expected to respect and obey their parents.

2.3.4 Summary

This section has shown that the Malaysian population consists of different ethnic groups, and has different beliefs and practice; however, there are commonalities in relation to the beliefs regarding children and childhood between the three main ethnic groups. These beliefs seem to be in line with the conceptualizations of childhood as welfare dependent from Neale and Flowerdew (2007), where children are perceived to be dependent, incompetent, vulnerable, in need of care and protection and control, and childhood is determined by adults. Consistent with this conceptualization, independence and children's expression are not advocated, but respect and obligations to the parents and parental authority has been greatly emphasized. Put simply, this means that children in Malaysia are expected to be obedient and treat their parents with great respect. Similarly, to other Asian children, Malaysian children have been educated to believe that they should respect and follow the guidance of their parents as well as uphold obligations to their families throughout childhood and adulthood (Chao & Tseng, 2002). Parents are mostly expected to be involved in and responsible for decisions, and caring for their children throughout their lives and, in turn, children are expected to consult with parents or other family members on important decisions (Chao & Tseng, 2002). Children are taught to accept what the parents say. Within the Malaysian culture, the character of a good child is representative of the children who shows respect and do not challenge their elders. It can be concluded that these cultural beliefs regarding children and childhood could impact on parents' behaviour towards their children, and specifically in shaping how parents regard and treat children and how children interact with parents. This suggests that children's participation could be influenced by cultural differences, however, the cultural diversity of the participants in this study were insufficient for cross-cultural comparison.

2.4 Cultural orientations and influences on perceptions of rights

In the previous section (3.3), I have discussed the beliefs according to the different ethnic groups in Malaysia about children and childhood, and that these beliefs have somewhat influenced the adults' views of children; specifically, in shaping how adults regard and treat children. The differences of cultural orientation have also been shown to influence human beliefs and actions (Helwig, 2006; Hofstede & McCrae, 2004). As Cherney, Greteman and Travers (2008) suggest, cultural orientation differences can be expected in the interpretation of the meaning of children's rights, and the way in which the term children's rights is understood can anticipate the basic cultural differences. Therefore, this section elaborates on the cultural orientation and its impact on the perception of children's right in general and children's right specifically, to better understand the practice of children's rights in Malaysia.

There are two cultural orientations, individualism and collectivism, that can be related to the differences in human beliefs and actions (Helwig, 2006; Hofstede & McCrae, 2004; Keshavarz, & Baharudin, 2009). Some researchers contend that perceptions of rights vary between individualistic and collectivist cultures (Cherney & Shing, 2008; Helwig, 2006; Murphy-Berman, Levesque and Berman, 1996). The ultimate individualistic culture upholds that individuals are independent and that the ties between individuals are loose. In contrast, the fundamental assumption of collectivist cultures is that interdependent individuals are bound together (Hofstede & McCrae, 2004). To reiterate, individualistic may have a tendency to support independence, autonomy and the right to privacy, leading to self-confidence and competence (Krishnan, 2004). For instance, in the individualistic cultures, such as those in America and Western Europe, a primary value is placed on the capacity to make individual decisions, regardless of being an adult or child. It implies that judgment and reasoning of the rights are oriented based on the individual rather than the social context or situation, and the protection of individual rights tend to be emphasized (Cherney & Shing, 2008). Correspondingly, in collectivist cultures such as those in Asian countries (e.g. Malaysia), individuals are led to conform to the social roles, and to uphold the hierarchy to maintain social harmony (Helwig, 2006). Collectivists tend to act in ways that maintain group coherence and they also encourage conformity toward their parents, and family, and larger social groups (Keshavarz, & Baharudin, 2009). What this implies is that judgment and reasoning are bound with mutual obligations of individuals within the social context. The care and well-being of the child is guarded by the adults, a great deal of parental control is emphasized, and the rights of the child tend not to be highlighted (Cherney & Shing, 2008).

Nonetheless, literature on human rights suggests that human rights are not of culture per se, or are a Western construct (individualistic culture), but are universally relevant and applicable despite their Western provenance (Franck, 2001; Donnelly, 2007; Cole, 2016). Donnelly (2007: 283) argued that human rights are equal rights because we either are or are not human beings, equally. Moreover, according to the author, human rights are an inalienable fact of nature; they are not things that are earned or can be lost. Human rights are thus ‘universal’ rights in the sense that they are held ‘universally’ by all human beings (Donnelly, 2007). The view that human rights are universal and not only applicable to the West was supported by Helwig (2006), who contended that the rights and conception of personal autonomy are not tied to Western cultural traditions (e.g. individualistic culture), but also appear in Asian society; often characterized as collectivist and oriented to obedience and the maintenance of hierarchy and traditions. This view is also supported in a study by

Cherney and Shing (2008), who examined judgments about self-determination and nurturance rights among 12-year-old children across three cultures: Malaysia, Switzerland, and the United States. Based on the fundamental assumption of individualistic and collectivistic cultures as previously mentioned, it might be expected that adolescents from the strongly collectivistic culture (Malaysia) would be less likely to endorse self-determination rights (self-determination rights pertain to rights to autonomy and control over one's life) than those from the other, individualistic cultures (Helwig, 2006; Hofstede & McCrae, 2004). However, the findings of Cherney and Shing (2008) reported that the Chinese-Malaysian adolescents were no less likely to support self-determination rights, nor were they more likely to support nurturance rights (pertain to rights to care or protection, and include matters such as parental obligations to provide food and clothing or emotional support to their children), than adolescents from the other nations. Indeed, Chinese-Malaysian adolescents endorsed a wide array of self-determination rights. These findings support that the global dichotomous orientation of individualism or collectivism does not fully capture children's perceptions of their rights (Cherney & Shing, 2008).

It can be concluded that as a collectivist culture, Malaysia value interdependence, compliance, and non-assertiveness, and the rights of the child for participation would be less emphasized and difficult to be implemented. However, the review highlighted that human rights are universal (Donnelly, 2007). The research evidenced that there was no difference between children in Malaysia and those of the West in relation to the perception of their rights. Malaysian children were also reported to advocate for many self-determination rights (Cherney & Shing, 2008). It appeared that the different cultural orientations (individualistic vs collectivistic cultures) do not carry much impact on how children wanted to advocate for their rights. Considering this, it is appropriate for this study to explore the participation of hospitalized children in decisions in the Malaysian context, keeping in mind that the cultural orientation might make the application difficult.

2.5 Ratification of the UN Convention on the Rights of the Child (CRC)

The UNCRC serves to improve the quality of children's lives by providing guidelines in defining and implementing children's rights. Malaysia ratified the UNCRC in 1995. The country's ratification, however, contained a number of conditions in the form of 'reservations' to the provisions of the UNCRC. These reservations were put in place since there were discrepancies between these UNCRC articles and some national and Shari'ah laws (UNICEF, Malaysia, 2017). In Malaysia, the law that generally governs Muslims is Shari'ah laws or Islamic law, while the law that governs non-Muslims is Civil law. Following the recommendation by the Committee on the Rights of the Child on the Concluding Observations to review and abolish Malaysia's reservations to the UNCRC, the Malaysian government has withdrawn some of its initial reservations to the UNCRC in 2010. According to the Child Rights Coalition (CRC) Malaysian (2007) status report on children's right in Malaysia, the government lifted its reservations to Article 1 (defining the age of the child), Article 13 (regarding freedom of expression), and Article 15 (regarding freedom to assembly and participation). This shows that the government has taken initiatives to realize the rights of the child in the country including the right of the child to be involved in decisions affecting them.

It may be considered that children's rights in Malaysia have significantly progressed following the ratification of the UNCRC (CRC Malaysia, 2007), however, there are many difficulties arising. Some writers argued that children are still not empowered to participate in programming, planning and services (Nalasami et al., 2015). The main argument was that this could be linked to the inconsistency of the definition of the child in national law with the definition of the child under Article 1 of the UNCRC. For instance, in the Children and Young Persons (Employment) Act 1966 (Act 350), it defines a child as any person who has not completed his or her fourteenth year of age, while the Child Act 2001 (Act 611) defines a child as a person under the age of eighteen years (CRC Malaysia, 2007). The classification of the age of the child in the Act is specifically for the implementation of the Act

(Zainuddin & Rahim, 2013). The inconsistency and contradiction of the definition of the child in the above Act in Malaysia may somehow cause difficulties to empower children to participate in any implementation procedures, because the classification of the age of the child is essential in determining whether a person is capable to manage his/her own matters (Dickens, & Cook, 2005). Indeed, the Committee on the Rights of the Child recommended that the State party take all necessary measures to harmonize the definitions of the child, including the terminology used, in the national laws to eliminate inconsistencies and contradictions (UNCRC, Concluding observations, Malaysia, 2007).

Another important assertion in relation to the difficulty of the realisation of the Convention of the Right of the Child in Malaysia was a lack of systematic and transparent monitoring and reporting on children's rights. In the status report on children's rights in Malaysia by the CRC Malaysia (2007), it was reported that there is a general lack of transparency with government data; this is often not made publicly available. This lack of transparency regarding data collected by the government makes it difficult to assess accurately and completely the state of children's rights in Malaysia. This was apparent during my search for information regarding the rights of the child in Malaysia, in that only a few documents related to children's right were identified and could be retrieved from the government's website (see section 3.7).

It can be concluded that since the ratification of the UNCRC, there has been significant progress regarding children's rights in Malaysia. However, the implementation of the rights of the child in Malaysia appeared to be problematic. Despite the multicultural views and beliefs towards children, it could also be due to a few influences, for instance, the inconsistency of the definitions of the child in legal documents, and the lack of systematic and transparent monitoring and reporting on children's rights by the government.

2.6 Research on patients’ participation in decisions in Malaysia

The review of the empirical studies of patients’ participation in decisions in Malaysia found that there was a scarcity of evidence, particularly with children. Most of the empirical studies (n=4) on patients’ participation in decisions were conducted among adult patients, and only one study was found that was conducted among adolescents, however, this study was conducted among adolescents in a school setting. This study was included in this section because it explored the preferences of adolescents (who could be considered as children, who are aged under 18) for shared decisions regarding the use of antibiotics, which is related to healthcare decisions. There is a relative absence of research in the field of children’s participation in Malaysia.

The existing research on patients’ participation in decisions indicates that patients were largely limited in terms of participation in decisions concerning their care. While this field of research primarily explores the adult patients’ experiences in the adult setting, only one study was found to seek children’s experiences in the decisions. The cross-sectional study by Ngadimon and colleagues (2015) included 1,105 children, aged between 13 and 17 years from 14 secondary schools across 14 states in Malaysia, to explore the knowledge, attitudes and experiences regarding antibiotic usage among adolescents and their parents, and their preferences for the style of the shared decisions. This study used questionnaires and the majority of adolescents in this study reported playing an active role in decisions regarding their antibiotic usage, as compared with collaborative or passive roles. The findings also indicated that there were opposing preferences between the adolescents and their parents. While a high number of adolescents preferred an approach to decisions that was not collaborative (joint decisions with their parents), the parents preferred a collaborative decisions approach for their child, and they were also more willing to be collaboratively involved with their clinicians. Nevertheless, this study explored the perception of adolescents from secondary school who may not have actual experience in healthcare decisions, and used a quantitative design which may not be able to provide a full picture of the nature of hospitalised children's participation in the decisions.

Similar findings were reported in studies conducted among adult patients. Ambigapathy and colleagues (2016) explored patients' role preferences in decisions in a primary care setting. This cross-sectional study used questionnaires with patients above 21 years of age attending the clinic and physicians working in the clinic. They found that the majority of patients played and preferred an autonomous (active and shared) role in the decisions and there were differences between patients' expectation and physicians' perception of patient's role preferences. In addition, this study highlighted that the physicians (urologists and oncologists) of their study appeared to underestimate patients' preference, and often played an autonomous role, which might be linked to the paternalism behaviour among physicians in Malaysia.

In contrast, Ambigapathy's (2016) findings were different to those of a study by Mah and colleagues (2016), who studied a different population with a smaller sample size of hypertension patients in a teaching hospital in Kuala Lumpur, Malaysia. This study showed that the perceived level of involvement in treatment decisions among patients varied. Some patients reported that they preferred passive decisions, either through physicians making treatment decisions entirely by themselves or after talking to the patients. Few patients indicated their preferences to make treatment decisions on their own. Nevertheless, both studies showed similar results, in which the patients preferred a collaborative role in the decisions, one group of patients preferred the involvement of their family (Ambigapathy et al., 2016), and another group of patients preferred to make treatment decisions together with their physicians (Mah et al., 2016). These findings indicated that the high preferences for a collaborative role was relatively linked with a high involvement of the patient in the management of their illness.

Considerable similarity was found in a qualitative study by Lee and colleagues (2015), who interviewed 22 patients (aged 28 – 67 years) with type 2 diabetes in a hospital setting in Malaysia. The findings showed that: the majority of the patients preferred to make decisions themselves; some patients indicated that the clinician should make the decision because they trust the physician; and only one patient expressed a preference for a collaborative role. This study identified factors such as: trust in clinicians, responsibility for diabetes care, level of knowledge and awareness, involvement of family and personal characteristics as important factors that influence patient decision role preferences. Similar to Ambigapathy and colleagues' (2016), this study supported the notion that the healthcare professionals preferred to be the main decision maker, with some perceiving that their role was to guide patients' decisions, or act as a facilitator to family involvement.

2.6.1 Summary

The above elaboration of research on patients' participation in decisions in the Malaysian context indicates that there were limited studies on patients' participation in the decisions, especially among children. The review of the existing studies in Malaysia has highlighted the complexity of patients' involvement in decisions, and provides a description of how patients perceived their involvement in decisions, and their preferences for involvement in decisions. To some extent, these studies have shed light on patients' role preference and its associated factors in the context of Malaysia.

Overall, this review drew two important findings. Firstly, patients' experiences and preferences to be involved in decisions vary. Secondly, there was no study that had been carried out in Malaysia on children, their parents' and nurses' experiences and perspectives on children's participation in the decisions. Therefore, understanding how Malaysian hospitalised children, their parents and nurses' experience children's participation in decisions is beneficial to uncover details of how children should be encouraged and supported in the clinical practices in Malaysia.

2.7 Policy document review and analysis

The existing research on patients' participation in decisions in Malaysia has revealed a discrepancy between patients' desire to be involved and their actual involvement in healthcare decisions. This could be a link to the limited enforcement of the policy or guidelines of patients' participation, which might influence how healthcare professionals play their role in involving patients in their care and decisions. It was therefore important to investigate the relevant policies available in Malaysia. The aim of the policy review was to explore policy relating to children's (patient's) rights generally, and children's participation specifically.

A general search on Google was conducted to explore potential websites associated with healthcare policy in Malaysia. On the websites of the Ministry of Health (MOH) Malaysia, the Malaysian Paediatric, keywords used individually or combined were: children's rights, patient rights, patient's participation, children's participation, involvement, decisions, healthcare decisions, adolescent, children rights, Malaysia. Reference lists of included reports and studies were inspected to capture relevant references. In addition, the well-known documents relating to children rights such as Child Act, Child Protection Policy, and the Committee on the Right of the Child's Concluding Observations for Malaysia were identified. Documents between the year 2000 and 2016 were included because they are more likely to reflect the current practices of children's rights. A range of different documents were identified from this website ranging from Child Act, national policy, clinical practice guidelines, and health services policy. Eight documents were identified which were read and analysed (Table 1).

Out of the eight documents identified, only two documents including the Child Act 2001, and the Patient and Family Rights Policy of the hospital (the research setting) were directly related to children's participation in decisions. The Committee on the Rights of the Child Concluding Observations for Malaysia (2007) was also included in this section because it clarifies the implementation of the Convention in Malaysia. The Child Act is discussed and compared to the Committee on the Right of the Child Concluding Observations for Malaysia, in the following section.

Table 1: Included policy documents

Title	Year
Laws of Malaysia: Act 611 – Child Act 2001	2001
Laws of Malaysia: Act 676 – Evidence of Child Witness Act 2007	2007
The Committee on the right of the Child Concluding Observation for Malaysia	2007
National Child Protection Policy 2009	2009
Country Health Plan: 10th Malaysia Plan 2011 – 2015	2011
Ministry of Health Operational Policy: Paediatric Service	2012
Achieving Universal Access to Quality Healthcare – Strategy Paper: 11th Malaysia Plan 2016 – 2020	2016
Patient and Family Rights Policy (of the hospital – study setting)	2010

2.7.1 The Child Act 2001

The most important document to protect children’s participation rights is the Child Act 2001. The provisions of the Child Act are based on the four core principles of the UNCRC that is, non-discrimination, best interests of the child, the right to life, survival and developments and respect for the views of the child. According to the Child Act 2001, a child in Malaysia refers to a person who is under the age of 18 years (Child Act, 2001). The Child Act 2001 has 15 parts and 135 sections and is considered the most comprehensive act the country has ever produced to give better protection to children (Sayed Abdul Rahman, 2000). The Act reflects new thinking about the relationship between children and their parents, encourages cooperation and partnership between families and the agencies charged with the duty of safeguarding and promoting the welfare of children and aims to provide an effective legal framework for the protection of children (Sayed Abdul Rahman, 2000). However, this Act has been criticised as being paternalistic with no indication in the stated provision that the views and opinions of the children will be taken into consideration or given priority (Zainudin & Rahim, 2013). In fact, the Committee on the Rights of the Child reported that they regret that the Child Act 2001 (Act 611) does not contain a specific provision on children’s participation. Indeed, the Committee recommends that the State party should strengthens its efforts, including legislative, to ensure the active participation and involvement of children in all decisions affecting them in the family, schools and other institutions and local communities, in accordance with article 12 of the Convention. It also recommends that children's views be systematically heard and taken into consideration in all judicial, administrative and other decisions affecting them, in accordance with the child's age and maturity (Concluding Observations of the UNCRC for Malaysia, 2007)

It can be concluded that in compliance with its obligation under the CRC, Malaysia has enacted the Child Act 2001 (Act 611). Although the Act does not contain a specific provision on children’s participation, its intention is that the children will be provided with necessary care and protection, including the rights for participation.

2.7.2 Patient and Family Rights Policy of the hospital

The only policy available in the research setting directly related to children's participation is the Patient and Family Rights Policy (2010), which is summarized in Table 3 below. The policy was located in the ward (on the notice board). It is reachable and readable by the patients and families at any time. This policy was formulated based on the Operational Policy for Paediatric Services produced by the Ministry of Health Malaysia. The Operational Policy for Paediatric Services of Ministry of Health Malaysia (2012) is mainly to provide quality care by incorporating aspects of promotive, preventive, diagnostic, curative and rehabilitative care, which is intended to be child and family friendly to all children up to 18 years of age.

The essential explanation pertaining to patient and family rights are in section 3 of the policy, which state: 'Parents/guardian and patients shall be given appropriate information to encourage and permit them to participate in the care given. They shall receive updates regularly and whenever the condition of their child changes. All information shall be given in a language they can understand in as simple a manner as possible. (…) The Baby and Child Friendly Policy shall be in practice. The mothers shall be encouraged to room in. A carer shall be allowed to be with the child at all times. Beds shall be provided for their night stay' (Ministry of Health Malaysia, Operational Policy for Paediatric Services, 2012: 18 - 21).

According to the policy, the healthcare professionals are required to provide patients with quality medical care, respect and dignity; patients and family have the rights to participate actively in the treatment including the decisions regarding treatment plans; and the patient and their family are encouraged to be involved in information exchange and collaboration with the healthcare professionals in their treatment plans (see Table 5). One of the family members, particularly the mother, is to be with the child at all time; beds are provided for her night stay, and the family is to be involved in information sharing and decisions regarding the child's care and treatment. It can be seen that the policy encourages patients and families to be involved in the care of the patient. This appears to be in line with the core concept of FCC including dignity and respect, information sharing, participation, and collaboration (as illustrated in section 3.5, Table 5). Nevertheless, there were no guidelines or policy available concerning FCC identified in Malaysia generally, and the research setting specifically. In addition, there are no guidelines or standards of procedure available to guide nurses on how to support or encourage the patient and family to participate in decisions. In the absence of guidelines and training on the participation of shared decisions in Malaysia, the only source available is the guidelines published by the Malaysia Medical Council on the responsibilities of physicians in shared decisions (Ng et al., 2013). However, it does not relate to the context of this current study as it does not cover the responsibility of nurses.

Table 2: Patient (child) and Family Rights Policy

The hospital management and clinical staff shall work collaboratively to protect and promote patient and family rights by doing the following:

- To provide patients with quality medical care, respect and dignity
    - Patient has the right to participate in making informed decision
    - Patient has the right to accept or refuse medical care or recommended treatment and service
    - Patient has the right to be informed about the outcome of their care/treatment
- To maintain privacy and confidentiality of patients' medical records
- To make known the identities / roles of each patient's healthcare team
- To provide information and counselling (where necessary) to patients
- To provide a channel for patients' feedback

Patient and family responsibilities:

- Provision of Information
    - To provide complete and accurate information about their health
    - To provide complete and accurate personal particulars
    - To ask questions if they do not understand either the diagnosis or the treatment plan being recommended or undertaken
- Compliance to the recommended treatment
    - To participate actively in the treatment including the decisions regarding treatment plans, compliance to medicine, follow up plan.

(Source: Patient and Family Rights Policy of the Hospital, 2010)

2.7.3 Summary

Overall, the review of policy documents in this section indicated that there is a lack of specific provisions on children's participation in the existing legislation in Malaysia. Whereas, in the hospital setting, although there is a policy on patient's and family's rights, there are no guidelines or standards of procedure available to guide nurses on how to encourage and support the participation of children in decisions specifically.

2.8 Chapter summary

The reviews of literature presented in this Chapter have shown that there are commonalities in relation to the beliefs regarding children and childhood between the three major ethnic groups in Malaysia. It appeared that these cultural beliefs regarding children and childhood have a direct impact on parents' behaviour towards their children, specifically in shaping how parents regard and treat children. Nonetheless, there is evidence of a shift from the traditional view towards the more contemporary view of children's status, which would enhance the participation of children in decisions.

The review of the cultural orientation, and its impact on the perception of children's rights, has demonstrated the significance of cultural orientation in Malaysia, that is, a collectivistic culture is less likely for children in Malaysia in terms of being encouraged or supported to participate in decisions. However, the human rights are not cultural by themselves, but are universal. Thus, there is the likelihood that the rights of children for participation in decisions will be encouraged and supported, as Malaysia is a developing country that is moving towards modernity. Recognition that Malaysia has ratified the UNCRC, means the rights of children for participation are applied within the country. Hence, it is considered applicable for this study to examine the children's participation in decisions in the Malaysian context even though it is a collectivist country.

In the policy document review, I revealed that in compliance with the obligation under the UNCRC, the Child Act 2001 (Act 611) was introduced as one of the initiatives to realize and uphold the rights of children including the rights for participation. However, it seems that the Act does not contain a specific provision on children's participation, which makes the implementation of the rights of the child for participation in decisions concerning them difficult. In the hospital setting, I have shown that there is a policy on patient and families' rights that encourage the patient and their family to participate in the patient's care, however, there are no guidelines with regards to encouraging and supporting the participation of children in decisions in the hospital setting.

Within the Malaysian context, the review of the literature indicated that there was no research evidence published regarding the experience and perspective of children's participation in decisions relating to nursing care, and there was no study on children's participation in decisions from the perspective of children, parents and nurses conducted across the paediatric setting. These significant gaps indicated the need for a study that explicitly focussed on the experiences of hospitalized children in participating in decisions in Malaysia.

Chapter 3: Literature review

3.1 Introduction

In this chapter, I provide an overview of the theoretical context and current empirical research in the study of children's participation in decisions in health care. To set this study in context, I first present a summary of the theoretical perspectives underlying studies on children's participation to better understand children's participation in decisions. This is followed by a discussion of studies around children's participation in decisions. In the discussion, I draw out the following: how children prefer to participate in decisions; how children participate in decisions; factors influencing children's participation; and the impact of children's participation on the children. With regards to the standard of care provided to children in the paediatric setting, I then provide some information and consider tensions around the Family Centred Care (FCC) - which is a vital element of care in a paediatric setting that emboldens parents' participation in the care of the child - to better understand the challenges to children's participation. Finally, the final section of this chapter provides a summary of the overall gaps in knowledge that arise from the current literature on children's participation in decisions in healthcare.

3.2 Comment on searching the literature

The literature review was undertaken in two stages: the first (initial) review and the second stage review (a more recent review). The first review was conducted during the preparation of the research proposal for the first-year examination board. The aim was to identify gaps in the subject being studied, helping to define the research questions and a suitable methodology for exploration. The first review was conducted based on the search terms used by Coyne (2006a) because it is a leading study in the field (see Table 3). During this stage, I reviewed the theoretical perspectives underpinning existing studies on children's participation in decisions, followed by a critical analysis of the relevant available research on children's participation in decisions. This literature review was intended to overview the knowledge regarding different aspects of children's participation in decisions in health care.

The second stage of the literature review, the updated review, was conducted with an improved search strategy of the initial review (see Table 3) during the later phase of the study, to examine and analyse literature which informs the discussion of this study's research findings within the wide evidence base. The review of literature in this phase can be considered as a repeat process including literature (identified in initial review) and synthesis in discussion with the wider relevant research. Subsequently, I compared the categories developed from this study with the existing literature.

3.2.1 Search strategies

With regards to the aim of the thesis, studies specifically addressing children's participation in decisions were identified. The search terms and inclusion criteria applied to the reviews are listed in Table 3. Studies published between the years 2000 and 2016 were included because they are more likely to reflect the current state of children's experience of participation in decisions. Reference lists of included studies were inspected to capture additional relevant references. Following this, a snowballing technique was used, which encompassed searching identified articles reference lists, author publications, citation searches, and repeating the process for each identified article. Studies were limited to the English/Malay language due to a lack of translation resources meaning that I would be unable to analyse those in other languages. Studies were excluded if they were not peer reviewed articles and not published in English/Malay.

Table 3: First and second stage literature reviews relating to children's participation in decisions

	First reviews (2000-2013)	**Second reviews (2010 – 2016)**
Data Bases	CINAHL, PubMed, MEDLINE, COCHRANE LIBRARY and SEARCHER of the University of Edinburgh. Google scholar and digital thesis were also used to identify the relevant articles and studies.	CINAHL, ASSIA, PsyINFO, PubMed, MEDLINE,
Keywords	Children, decisions, decision-making, nurses, nursing, parents, participation	Children, adolescence, participation, decisions, decision-making, childhood cancer, healthcare, parents, nurses, healthcare professionals, paediatric, oncological, hospitalized, qualitative studies.
Inclusion criteria	Peer reviewed articles published from 2000 – 2013, Study relating to children's participation, full text, and English/Malay language publications	Peer reviewed articles published from 2010 – 2016, study relating to children's participation, carried out among children (aged 0 – 18 years), and/or parents, and/or healthcare professionals in healthcare setting, full text, and English/Malay language publications
Exclusion criteria	Review articles, children's participation was not the focus of study, did not publish within 2000-2013	Review articles, children's participation was not the focus of study, studies conducted in other setting rather than healthcare setting, and were not published within 2010-2016
Total of studies included in the final analysis	35	27

3.2.2 Outcome of the reviews

The review of the literature presented in this section is based on the analysis of both the first (initial) and second stage literature review. The first stage review identified 829 articles, screened 162 abstracts, and identified 61 full text articles for inclusion. The second stage review identified 859 articles, screened 211 abstracts, and identified 41 full text articles for inclusion. Figure 1 and 2 show the flow diagrams of search strategies used in the first and second stage literature review respectively.

There were articles excluded from the reviews. The justifications for the exclusion of articles in both reviews are as follows:

- the articles did not relate to children's participation in decisions/ were not published within 2000-2013 (first review) or 2010-2016 (second review),
- were not focused on children's participation,
- were not conducted in health care
- were review articles,
- were not in English/Malay,

As the first review finally included 35 articles, another 27 articles were included in the second phase of the review. A total of 2 studies were duplicates (found in both reviews), and ultimately 62 articles were included in the final analysis. In addition, I sourced and drew on relevant literature from reference lists of the studies reviewed and literature to contextualise important background information from grey literature and reports. The thesis reference list gives a sense of the literature examined during the development of this thesis. Data extracted from each included study were study design, sample size, study setting, findings of the study, and a theory or framework developed by the study.

Figure 1: Flow diagram of search strategy: first stage literature review (children's participation in decisions)

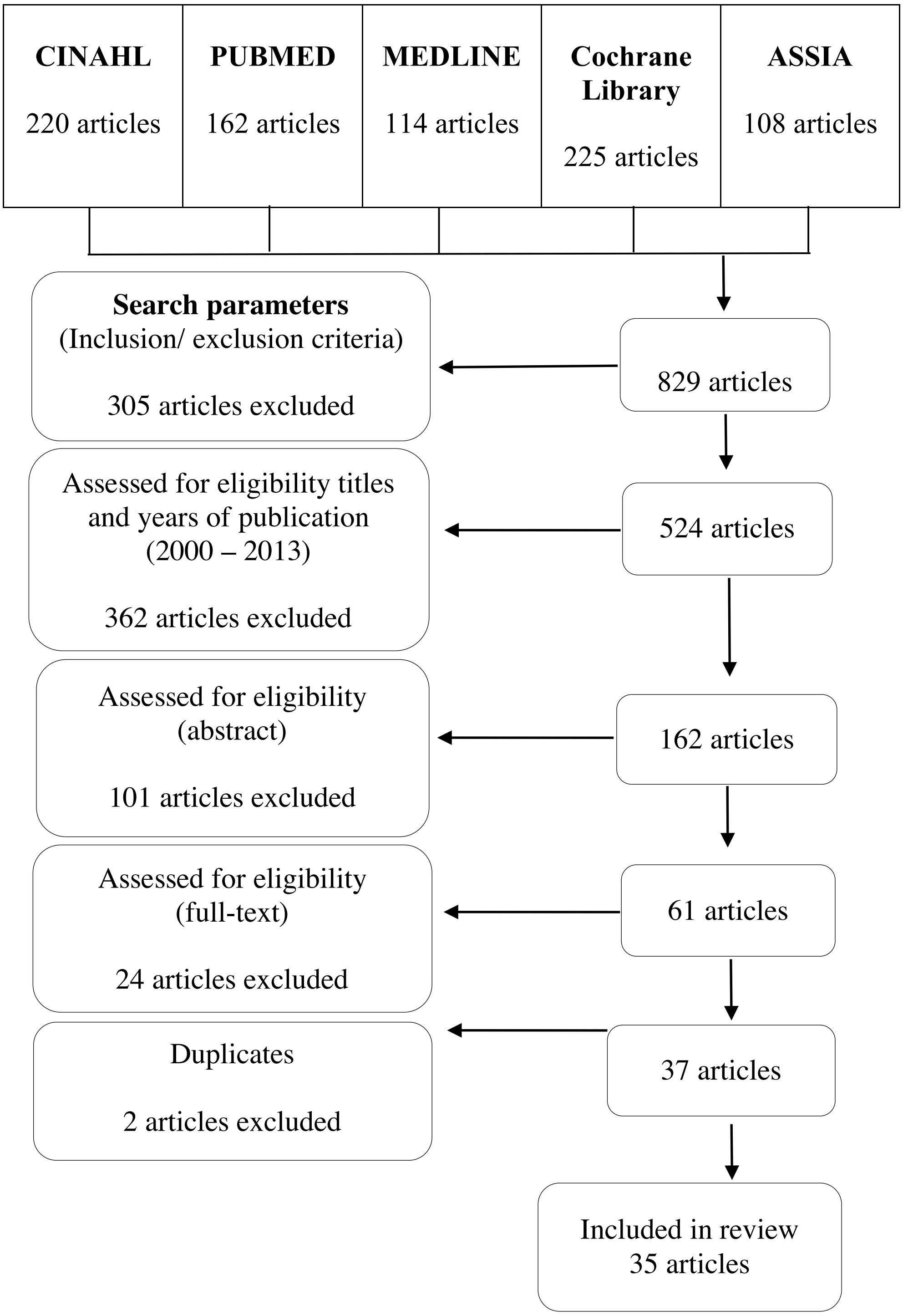
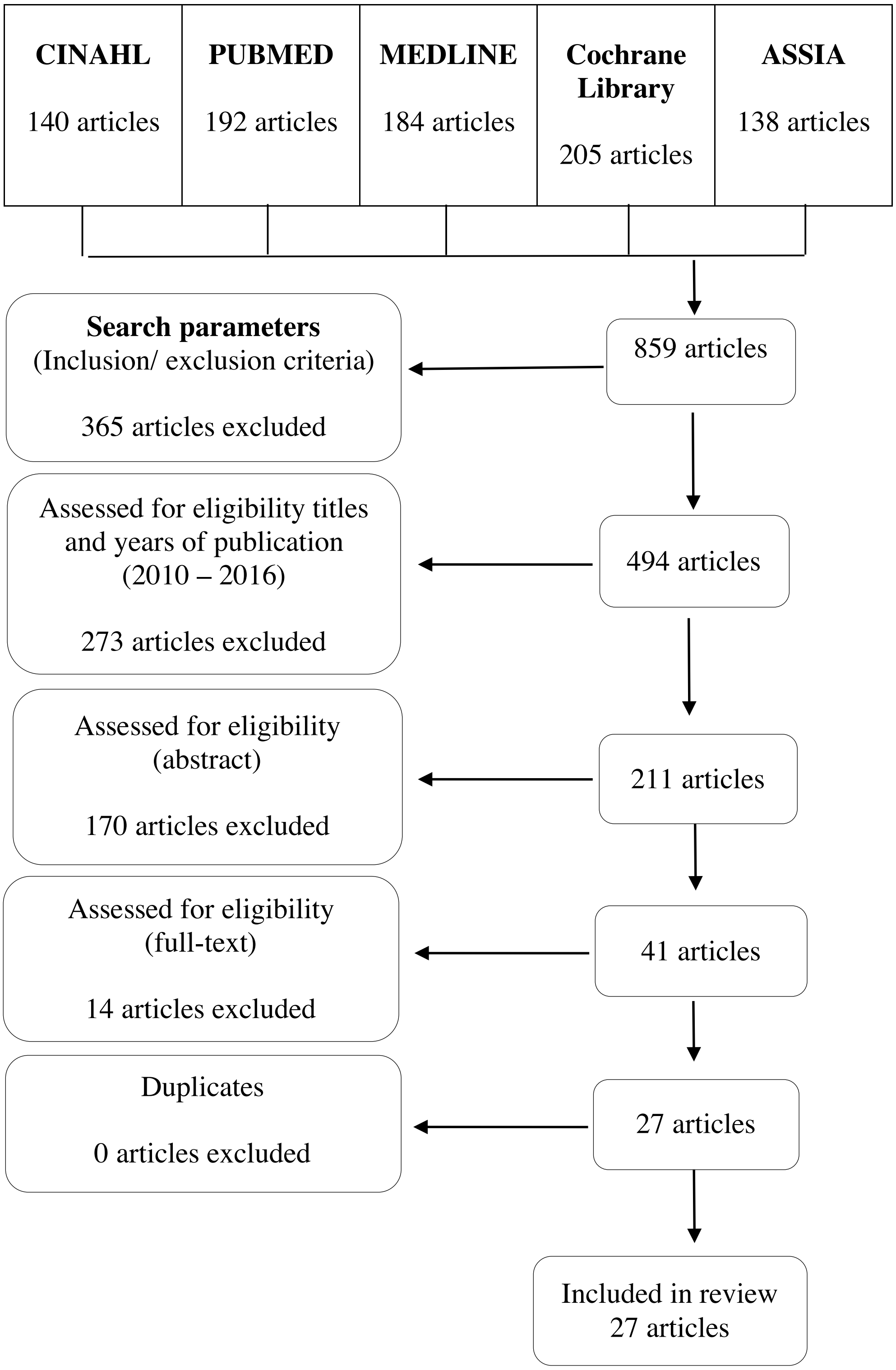


Figure 2: Flow diagram of search strategy: second stage literature review (children's participation in decisions)



3.3 Approaches for understanding children’s participation

The purpose of this section is to debate the variability within the literature of the definitions and approaches used to define and explain children’s participation. The section begins with analysis around the definitions of participation. This is followed by analysis of the relevant and significant literature on the different models of levels of participation that are used to explain the level of children’s participation in this present study. I then provide an insight into how children’s participation can be influenced by different conceptualizations of childhood, namely the *children as welfare dependent*, and *children as young citizens*. Finally, this section then provides some information on the UNCRC that is relevant to children’s participation.

3.3.1 What is meant by participation?

The term participation covers a broad continuum of involvement in decisions as it involves many different processes (Kirby et al., 2003; Sinclair, 2004). Hart (1992: 5), an influential author, argued that participation is a fundamental right of citizens and involves a ‘process of sharing decisions which affect one’s life and the life of the community in which one lives’. This definition highlights the interactivity of children in their everyday lives in society. Although Hart’s definition has been critiqued for failing to consider the impact of participation (Tisdall, 2011), his ideas were linked to different definitions of participation and general discussion around participation (Lansdown, 2001). For instance, Lansdown (2014) suggests that participation is still too often characterised by only seeking information from children that is related to a pre-determined adult agenda. For Thomas (2012: 463), participation is not just about talk or ‘voice’, but shared action among children and adults. Other authors claimed that the term participation does not simply mean ‘taking part’ or ‘being present’ but as having some influence over decisions and action (Kirby et al., 2003: 5). Simply put, it can represent a transfer of power so that children’s views influence decisions (Franklin & Sloper, 2007), and has the advantage of placing emphasis on the process and the outcome of participation (Thomas, 2007). This implies that participation can be considered an ongoing process in which the child can expect to have a say in some, if not all, of the issues being addressed (Littlechild, 2000); which is in line with the participation right of Article 12 (UNCRC, 1989), that the views of the child are to be taken into consideration and could influence decisions.

Despite the differing definitions of the term participation, there is a variation of opinions on how children's participation in decisions in practice can be understood. For instance, Thomas (2007) put forward that participation may vary depending on how much children: understand and own the goals of the activity; are able to make choices and take initiative; and contribute to achieving the goals. Franklin and Sloper (2006) suggested that for children to participate in decisions, first, the child needs to have information to understand what the content of the decision is about and what the arguments and options are. Secondly, the child has an opportunity to express his/her own wishes and views. Third, the child's opinions are considered and have an impact on the decision being made, which are based around Article 12. Sinclair (2004) however, argued that in practice, participation often simply means being listened to, without children having reason to believe that their involvement will make a difference. The key issues involved in understanding the concept of participation in practice, according to Sinclair (2004), are the levels of engagement, the focus of the decisions, the nature of the activity, and the children involved.

From the discussion around definitions of participation, it can be concluded that the term participation does not simply mean just being present, but that children participate in the decisions if they are taking part, or are being involved or consulted and have an influence on the decisions (Kirby et al., 2003; Franklin & Sloper, 2006). In the following section, I examine several models that have been developed that seek to conceptualise different levels of engagement for children in participatory processes ranging from non-participation through consultation to full participation.

3.3.2 Typologies of children's participation

Several writers have developed typologies to determine participation. For instance, Arnstein (1969) first developed the ladder of participation in relation to citizen involvement in community development. Further, the influential author, Hart (1992), borrowed the metaphor of a ladder to illustrate the dissimilarity between a number of types of children's level of 'non-participation', and different degrees of 'participation'. The ladder of participation enunciates different levels at which children are enabled to exercise power in decisions, ranging from tokenism in the inclusion of children, to shared power between children and adults (Mason & Bolzan, 2009). Shared power is typically conceptualised in these typologies as a 'high point' for participation, but different levels of participation are considered as appropriate to different activities and situations (Thomas, 2007). It is to be noted that this ladder places value on children having the power to determine processes and outcomes of decisions (Thomas, 2007). Nevertheless, the ladder has been criticized for suggesting lower and higher levels of participation, with the higher levels often valued more positively (Lansdown, 1995, Alderson & Montgomery, 1996; Franklin & Sloper, 2006). Hart's (1992) ladder of participation has been the most important model in the field of children's participation (Shier 2001), however, it concerns collective decisions, and is not constructed specifically to be utilized within the health care context, which is intended primarily for use with children in society (Runeson et al., 2002a).

In relation to making decisions with children in healthcare, Alderson and Montgomery (1996) outlined four levels of involvement in the decision process: (i) being informed, (ii) expressing a view, (iii) influencing a decision, and (iv) being the main decider. All levels of participation within this model seem to be important methods of participation, with the first three preceding the fourth if the child is to make an informed choice. The first three levels are contained within the UNCRC and include any child who firstly, is given information, secondly, forms a view, and finally, is considered to be able to form a view which can usefully inform the decisions process (Franklin & Sloper, 2006). As Lansdown, (2010) suggests, Article 12 implies that all children capable of forming a view are entitled to the first three levels; but it does not extend rights to the fourth level. In other words, it can be concluded that the responsibility of the adult for the actual decisions are retained, while being informed and influenced by the views of the child (Lansdown, 2010). This indicates that this model is primarily used to evaluate children's participation in decisions about themselves individually, and thus, it has been suggested it could be a useful framework to examine the evidence of children's participation within healthcare settings (Franklin & Sloper, 2006).

As I analysed the data, I continued to read the literature and identified a Swedish study by Runeson and colleagues (2002a) that used a scale of participation by Hermeren (1996) to explain the participation of children in decisions during hospitalization. I found that this model was useful for analysing and interpreting my data. I could see some parallels and associations between what I was identifying in my own data and what was reported in the study. Therefore, I am going to illustrate my data in relation to this model to demonstrate the similarities between my data and that which has been argued by the Swedish study (Chapter 5 to 7).

This instrument was developed in Sweden; it applies to situations where the member of staff acts in accordance with the child's wishes:

> Level 1: A (A = member of the staff) does not listen to B's (B = child) opinions, wishes and valuations.
>
> Level 2: A listens but refuses to discuss the opinions of B with B; no consultation, no two-way communication takes place.
>
> Level 3: A communicates with B but does not care about B's answer; B's opinions, wishes and valuations do not influence the actions of A.
>
> Level 4: A cares about what B says but acts only partially in accordance with B's opinions, wishes and valuations.
>
> Level 5: A acts in accordance with B's opinions, wishes and valuations.

According to Runeson and colleagues (2002a), level 1 was characterized by the fact that there was no communication between the children and staff members. Second, level 2 was characterized by the fact that children were informed about what was going to happen, but often only in a brief way. There was no assessment to see if the children had understood the information. The lowest levels (1 and 2) of participation in decisions are considered as non-optimal; normal conversation between children and adults do not take place (Runeson et al., 2002a). These levels could be considered as ‘non-participation’, similar to the model of Hart (1992). Third, level 3 was characterized by communication between the children and the healthcare staff. The staff listened to the children’s views, answered their questions and provided explanations and motivation for them to participate in the planned procedure. Nevertheless, the staff do not care about the child’s answer or opinions and the child’s wishes do not influence the actions of the staff. The children’s involvement in this level could be considered as tokenism, a way in which children are able to formulate and express their own opinion but have no impact on decisions (Hart, 1992). Fourth, level 4 was characterized by the fact that children received information about what was going to happen; the staff listened to the children’s views, carried on a dialogue with them to check that they understood, but, acted only partially in accordance with the child’s opinions and wishes. Lastly, level 5 was the higher level where children made their decisions, in which the children either agreed to what was planned after receiving information or expressed a wish that was respected. The highest levels of participation are considered as optimal: children received information, took part in the decisions, compromises were made and appropriate alternatives to what had originally been planned were suggested (Runeson et al., 200a2). The levels 3 and above of this model were contained within Article 12, which states that children’s views are given ‘due weight’, thus explicitly, children have the right to have their views listened to by adults who make decisions.

3.3.3 Conceptualizations of childhood

Several theoretical influences regarding childhood are closely related to the understandings of children as having strengths and competencies that have transformed how children are perceived, from invisible objects into subjects with their own expression (Prout & James, 1997; James, Jenks & Prout, 1998; Neale & Flowerdew, 2007). In this section I show how the conceptualization of childhood has contributed to shaping understandings of children as having a voice and thus capable of participation in various aspects of their lives including decisions concerning their nursing care.

The developments in children and childhood research were in part informed by new sociological understandings of childhood (Prout & James, 1997). As part of these developments, two ways of conceptualizing children have been summarized by Neale and Flowerdew (2007: 26) as follows:

Children as Welfare Dependent

- Children are dependent
- Children are incompetent and vulnerable
- Children need care, protection and control
- Children's childhoods are determined by adults

Children as Young Citizens

- Children are people
- Children have strengths and competence
- Children need recognition, respect, and participation
- Children influence their own childhoods

These conceptualizations of childhood provide two very different pictures of the perceptions of adults towards children. Firstly, the welfare paradigm sets out a protectionist framework, which sees children as relatively incapable and vulnerable to harm, and thus in need of adult protection, support and control (Neale & Flowerdew, 2007). This was consistent with the views that children are different from adults and subordinate to adults, and the consequent need for adults to take on some measure of control over children's lives, which consolidates the dependency of children on adults (Mayall, 2012). Similar to the protectionist framework, the welfare paradigm leads to arguments that children should not participate in the decisions in relation to their care because participation places undue burdens of responsibility and guilt onto children (Neale, 2002). Thus, in this formulation, adults (including parents and healthcare professionals) are considered best placed to evaluate children's best interests and to speak on behalf of children (Fitzgerald, 2009).

Secondly, the lens of 'children as young citizens' gives a different picture of how children are perceived. Here they are recognized as children with strengths and competencies. According to Neale & Flowerdew (2007), competency and maturity within this framework is not linked to age, but is understood as resulting from social experiences and interactions, and thus can be nurtured in all children. Similarly, the 'new' sociology of childhood emphasises the social construction of childhood (Mayall, 2012), and that children should be perceived as social actors and holders of rights rather than seeing them as passive and dependent on the family (Mayall, 2002). When children are defined in this way, citizenship applies equally to children and adults, and it suggests new ways for adults and children to relate to each other in their daily lives (Neale & Flowerdew, 2007). Within this conceptualization, children are more likely to be involved in their interactions with others and to participate in decisions concerning them.

In summary, the conceptualization of childhood within both formulations as illustrated above have an impact on children's opportunity to participate in various aspects of their lives generally, and decisions concerning them specifically. It is worth noting that when children are perceived as young citizens, they are entitled to respect and participate in all matters affecting them, and not simply seen as welfare dependents who need care and protection by adults. The relevance of the conceptualization of childhood in explaining the study findings is discussed in Chapter 6 (Section 6.3).

3.3.4 The United Nation Convention on the Rights of the Child

The recognition of participation rights for children in the United Nation Convention on the Rights of the Child (UNCRC, 1989) can be considered as a major influence on conceptions of children as participants in decisions concerning them. As Vis and colleagues (2011) suggest, the identification of children's participation in decisions affecting them as a fundamental principle was theoretically driven in a children's right framework introduced by the UNCRC. Article 12 is recognised as a general principle in the UNCRC, and it states:

> State Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child (Article 12(1)).

Several other articles give expression to children's participation rights, including: Article 13 (the right to freedom of expression), Article 14 (the right to freedom of thought, conscience and religion), Article 15 (the right to freedom of association and assembly), and Article 17 (the right to information). Taken together, these articles recognize the right of children to form an opinion, make it known to others and have it considered (Fitzgerald, 2009). The General Comment on Article 12 by the UNCRC noted that these articles do not provide a specific age range to determine the capacity of the child. Indeed, studies on children's participation in decisions suggest it is difficult to use age as the criterion to determine the child's capability to participate in the decisions (Alderson et al., 2006; Lambert et al., 2008).

There is an argument that the UNCRC does not directly provide competent children the right to give their own consent, and at the same time it does not provide absolute rights to the parents to make decisions on behalf of their children (Zainudin & Rahim, 2013). However, it recognises the right of parents to give direction and guidance to their children (Zainudin & Rahim, 2013), subject to the child's evolving capacities (Article 5, UNCRC). Therefore, in relation to children's participation in decisions in healthcare, it can be summarized that children's right to participation should be respected, and parents and healthcare professionals working with children have a responsibility to encourage, support and ensure that children are able to exercise their participation right. In other words, the UNCRC recognizes children as subject of rights and that those rights impose obligations on adults to ensure their execution (Lansdown, 2001). In this way, children's participation could be acknowledged as the way in which children are understood and valued and are involved in any matters affecting them.

3.3.5 Summary

The findings of the review in this section have demonstrated that there are debates around the term participation. It can be concluded that the term participation does not simply mean just being present; children are participating in decisions if they are taking part, or being involved or consulted and having an influence on the decisions (Kirby et al., 2003; Franklin & Sloper, 2006).

As illustrated in section (3.3.2), there are many models of levels of participation that have been developed to determine the extent to which children participate in decisions. Nonetheless, I have shown that Hermeren's (1996) model of participation was considered to be used as a guide to define children's participation in decisions in this current study.

There are two conceptualizations of childhood within the body of research on how children and childhood are understood: i) children as welfare dependents, and ii) children as young citizens. The conceptualizations of childhood reviewed in this section gives a different picture of how children are perceived by adults, which influences the way children are treated in relation to their participation.

Research on children's participation is framed following the recommendations of the UNCRC regarding the children's rights to participation. This section has demonstrated that the UNCRC recognized the rights of children as a group to whom human rights legislation applies by stressing that children are entitled to participate in any matters concerning them.

Overall, the analysis in this section can be considered as framing my background knowledge regarding the context of studying children's participation, and has led to the development of the research aim and research questions for the current study. It also provides a holistic understanding and interpretation of the context of this current study. In the following sections I analyse the literature in children's nursing in order to examine how children experience participation in decisions and identify the gaps from this body of work.

3.4 An examination of research elaborating on children's participation in decisions

In the previous section (see section 3.3), approaches for understanding children's participation were presented. This work identified two key areas:

i. There are variations in the definitions and theories used to explain children's participation.
ii. There are different models of participation that have been used to examine children's participation in decisions.

This section turns to the relevant literature in nursing children in order to examine how children experience participation in decisions and the contextual factors that influence children's participation in an international context. I begin to analyse literature examining children's participation in decisions in healthcare settings. I then synthesise the evidence to illustrate how children want to participate in communication and decisions concerning them. In the later section, I discuss factors influencing children's participation, including both the facilitators of and barriers to children's participation. The important factors influencing participation and decisions identified from the literature were categorized into three categories, including: healthcare professionals, parent and child factors. Finally, I attempt to glean an understanding of the impact of children's participation on the children, stating the benefits and disadvantages of participation.

3.4.1 Children's preferences for participation in communication and decisions

In this section, I discuss some key studies which have explored the extent to which children want to participate in communication and decisions.

The existing literature on children's participation strongly suggests that children have a commonality of preferences for participation in decisions concerning them. For instance, research involving children from similar age groups (8-12 years) in various settings, such as outpatient clinic (Savage & Cellery, 2007), paediatric medical and surgical wards (Pelander & Leino-Kilpi, 2010; Coyne & Kirwan, 2012), and perioperative care (Sjoberg et al., 2015) shows that children want to have more information and want to be able to participate in their own care and decisions concerning their care.

Similar findings were reported in research that used an observation approach. A qualitative study by Bjork and colleagues (2006), in Sweden, used non-participant observation over 10 months, to describe the needs of 12 children under the age of seven by observing their behaviour, body language and verbal expression (see Table 4). This study found that children expressed their needs for participation in care and treatment. The wish of the children in this study to participate in care and treatment was consistent with an ethnographic study by Lambert and colleagues (2008), with 49 children aged between six and 16 years conducted over four months, found the children wanted to participate in the communication and decisions concerning their care, and the study noted that there are times when children choose to be less involved, for example, in the situation of one child who was in pain.

Comparable findings were reported in research where children were being interviewed, for instance, Coyne (2006a) interviewed 11 children from four paediatric wards in two hospitals in England (see Table 4). The study found that children expressed the need for consultation and information so that they could understand their illness, to be involved in their care, and to prepare themselves for the procedures. This finding was consistent with a qualitative study conducted in Ireland of 51 children between the ages of 5 and 14 years, which shows that children want and need to be involved in consultations and decisions around their healthcare and to be respected as having opinions about their care and treatment (Kilkelly & Donnelly, 2006). Similar findings were also reported in a study that used a phenomenological approach, where 10 children aged between 13 and 16 years in a paediatric ward in a District General Hospital in the South West of England were interviewed (Kelsey et al., 2007). The children in this study stressed the importance of being able to make choices and to be involved in making decisions that would have an impact on their own health.

Studies also suggest that children prefer their parents to be present during care provision, and that the parent's presence helped them to express other needs. For instance, the study of Bjork and colleagues (2006), as illustrated above, identified the need to have the parent close by as the most prominent finding of the study, and that the presence of the parents is necessary for the children to express their other needs. The children expressed that they wanted to have physical and emotional contact with their parents, to be comforted, to have the parent as a facilitator, and to use the parent as a secure base. Consistent with these findings, Kelsey and colleagues (2007) reported that some children needed their parents to be with them, and that the parents' presence enabled children to give their expression. Correspondingly, a qualitative study by Runeson and colleagues (2007), who interviewed 23 children aged between 6 and 11 years (9 boys and 14 girls), who had been admitted to a paediatric day care department for a planned procedure, reported that the children in this study preferred support from their parents or the healthcare professionals during the decisions.

Nevertheless, there were different findings identified in the previously mentioned observational studies in relation to the need of parents' presence for children to be able to express their view. In contrast to Bjork's (2006) study, the need for a parent to be present was not reported in this study (Lambert et al., 2008). The explanation for this finding could be explained by the fact that both studies involved different age groups and diagnosis. The children in Bjork's (2006) study were aged below seven, first time diagnosed with cancer, and was their first experience of hospitalization. These groups of participants may have less knowledge regarding their illness and treatment and fear the hospital environment, and thus, require their parent to be close to them, as compared to those in Lambert's study (2008), who were aged above six, diagnosed with various medical and surgical problems, and more than half of the participants had previous hospitalizations.

Studies on children's participation suggest that children have different preferences for participation in the consultation and decisions concerning them. For instance, a qualitative study in Ireland of 55 children, aged between seven and 18 years, reported that many children wanted to make 'small' decisions related to everyday care such as in relation to their diet and medications. Some children would prefer to leave the serious decisions (i.e. surgery) to parents and health professionals, because they perceived the healthcare professionals and their parents as the experts who know best. Only a few children wanted to make those decisions, whilst others preferred such decisions to be shared (Coyne & Gallagher, 2011). Correspondingly, another study involved a similar age group of children with cancer and survivors (aged 8 – 17 years), and it reported that, while most children preferred decisions about treatment to be a collaboration between patients, parents, and healthcare professionals, few children in their study wanted to be involved in less important decisions regarding their care (Zwaanswijk et al., 2007). Zwaanswijk and colleagues (2007) argued that the absence of children during consultations directly affects the role of parents as managers of what their child is told about the illness, and when and what information is provided.

The same findings have been reported in Switzerland, in a study by Ruhe and colleagues (2015), who interviewed seventeen children aged 9-17 years with cancer in an oncological unit to explore children's experiences of participation in discussion and decisions surrounding time of diagnosis and treatment as well as opinions more broadly on their participation in health care (see Table 4). Using purposive sampling, the study employed face-to-face interviews with children and parents at three weeks after the initial diagnosis to give the family time to come to terms with the diagnosis. The key finding of the study was that children have little involvement in decisions. While the children in the study valued their participation, and their preferences for participation are vacillated across time, the authors claimed this as a complex pattern of participation. The main argument was that the children might appreciate involvement in some decisions while choosing to remain in the background for others. Thus, they called for a flexible model that does not involve a hierarchical form of participation to represent children's involvement in discussion and decisions in paediatric oncology. The authors suggested the need for considering Hart's (1992)

Ladder of Participation because it has had considerable influence in the literature on children's participation in various settings. Nevertheless, it is worth noting that Hart's (1992) model was not developed specifically for healthcare. Thus, researchers within a healthcare setting should use the ladder with caution.

In relation to children's communication preferences, the literature revealed that children have multifaceted preferences regarding their needs in communication. The result of the online focus group study of seven children with cancer and 18 survivors (aged 8 – 17 years), and 11 parents reported that children's communication preferences are associated with interpersonal and informational aspects of communication (Zwaanswijk et al., 2007). The participants of the study valued honesty, reassurance and support from healthcare providers, sufficient time for communication, and the continuity of healthcare providers. The participants also expressed the need to be informed fully and to be allowed to ask questions.

In summary, this section has identified a body of research which suggests that children wish to be involved in discussions about their care; however, their preferences differ from one another. Few children wanted to make their own decisions in relation to their care, some preferred their parent or healthcare professionals to make decisions for them on their behalf, and others preferred to work together with their parent or healthcare professional during the decisions. Nonetheless, the consistency of children's preferences for participation were identified in that most children preferred their parent to be present to enable them to express their views. Finally, this section suggests that children wanted information regarding their care in order for them to participate in care and decisions.

Table 4 provide the summary of key empirical studies included in section (3.4.1 - 3.4.3).

Table 4: Summary of key empirical studies included in section (3.4.1 – 3.4.3)

Author	Title	Methodology	Setting and sample	Key findings	Contribution
Bjork et al., 2006	Needs of Young Children with Cancer During Their Initial Hospitalization: An Observational Study	An Observational Study Non-participant unstructured observations	Oncology ward, university hospital in southern Sweden 12 children, under the age of seven	Five themes were identified: i) 'need to have the parent close by' was the most prominent. The results indicate that the children needed their parents and the parents' presence helped the children to express other needs. Other themes are: ii) 'need to play and feel joy'; iii) 'need for participation in care and treatment'; iv) 'need for a good relationship with the staff'; and v) 'need for physical and emotional satisfaction.'	The study implies that it is important for the professionals to support the child and his or her parents so that the parents in their turn can support and alleviate their child's hospitalization and cancer treatment.
Coyne, 2006a	Consultation with children in hospital: children, parents' and nurses' perspectives	Grounded theory method. In-depth interviews, Questionnaire, and Observation	Four paediatric wards in two hospitals in England. 11 children, 10 parents and 12 nurses	Children expressed the need for consultation and information so that they could understand their illness, be involved in their care, and prepare themselves for procedures. However, children's own opinions and views were underused and they had varying experiences of being consulted about their care and treatment. Parents felt that children should be involved in the decisions thereby enhancing and promoting children's self-esteem and positive self-regard,	The study implies that: 1) Health professionals' communication behaviour may influence by their perceptions of children's cognitive abilities rather than the children's ability to understand. 2) In the absence of a reliable framework in clinical setting, children's nurses appeared to make decisions about involving children in decisions.

				which would consequently enhance their overall welfare. Nurses appeared to hold varying and discrepant views on the involvement of children in decisions and for some nurses, the child's involvement seemed to be dependent on the child's cognitive maturity and being defined as a rational subject.	
Coyne et al., 2006.	Giving children a voice: Investigation of children's experiences of participation in consultation and decisions in Irish hospitals	Focus groups and single interviews with acute and chronically sick children in hospital.	The sample was comprised of children aged 7-18 (n = 55), drawn from the population of children in three hospitals.	The children had varying experiences of being involved in consultations and decisions. Some children had positive experiences of being involved, consulted and heard in relation to their information needs. The children liked receiving information because it helped prepare them for what to expect and thus ameliorated their worries and provided reassurance. Receiving information and having their views respected enhanced children's understanding and adaptation to the hospitalisation. The overall effect of being involved in the consultation process was that the children reported feeling valued, involved, comfortable and less anxious.	Three areas of critical importance were identified by children and young people in respect of the decisions: - they reported that information provided should be tailored so that it is accessible and appropriate according to the individual's level of understanding. - children and young people reported that sufficient time needs to be given to them to consider the information provided and to be able to talk to health professionals and others so that clarifications can be sought. - assumptions about the ability or willingness of individual children to participate should be based on the needs of the child.

Coyne & Gallagher, 2011	Participation in communication and decisions: children and young people's experiences in a hospital setting	Qualitative study Focus groups Individual interview	Three hospitals in Ireland 55 children (aged 7-18 years)	Children wanted to be included in communication exchanges but appeared to occupy a marginal role with discussions largely carried out between parents and health professionals. Children wanted to participate in 'small' everyday decisions about their care and treatment but were constrained mainly by adults' actions.	This research contributes to the literature on children's participation by identifying that children's preferences can vary; although children want to be included in the decisions, some prefer to leave the more 'serious' decisions to parents and health professionals, whilst others prefer to share the decision. Therefore, it implies that decisions should be seen as being on a continuum rather than an 'all or nothing' basis.
Coyne et al., 2014	Children' s participation in shared decisions: Children, adolescents, parents and healthcare professionals' perspectives and experiences	A qualitative study Interviews	Haematology/ oncology unit, Ireland Children aged 7-16 years (n = 20), their parents (n = 22), healthcare professionals (n = 40).	Parents' and children's roles in decisions were significantly influenced by the seriousness of the illness. Cancer is a life-threatening illness and so the treatment 'had to be done'. Children were not involved in major decisions (treatment decisions) as refusal was not an option. They were generally involved in minor decisions (choices about care delivery) with the purpose of gaining their cooperation, making treatment more palatable, giving back a sense of control and building trusting relationships.	This research contributes to the literature on children's participation by identifying that healthcare professionals and parents controlled the process of shared decisions. While children held a minimal role, adults held responsibility for the major treatment decisions.

Lambert et al., 2008	'Visible-ness': the nature of communication for children admitted to a specialist children's hospital in the Republic of Ireland	Ethnographic study. Semi participant observation, interview, draw and write technique and a child-friendly 'stick a star' quiz.	Six children ward in the Republic of Ireland 49 children (aged from 6 – 16 years)	The core concept to emerge was that of 'visible-ness'. 'Visible-ness' existed along a continuum consisting of two polar ends, 'being overshadowed' and 'being at the forefront'. These polar ends illuminated the degree to which children were, or wanted to be, included in the communication process and the extent to which children's agenda was addressed.	This study provides empirical insight into children's experiences of communication in an inpatient hospital setting. A key recommendation calls for the development of communication assessment strategies to determine the 'ideal' position children would like to occupy, at any given point in time, along the 'visible-ness' continuum.
Ruhe, et al., 2015	Participation in paediatric oncology: views of child and adolescent patients	A qualitative study Semi-structured interviews	Paediatric oncology ward, Switzerland. 17 children and adolescent, aged between 9 and 17 years.	Overall, there were few accounts of involvement in decisions. Participants highlighted how their roles in health care discussions varied from direct participation to indirect involvement. Challenges with regards to completely understanding the information provided and making decisions were identified. While they generally valued their participation, the preferred level of involvement oscillated between participants as well as within one and the same child across time.	This research contributes to the literature on children's participation by identifying the complex pattern of participation in which a patient may appreciate active involvement in some decisions while choosing to remain in the background for others, and thus calls for a flexible model of involving children and adolescents in health care that accounts for the varying roles and preferences that they manifest.
Runeson et al., 2001	Professionals' perceptions of children's participation in	A qualitative study	Four country hospital, Sweden 92 Swedish	The factors affecting children's participation in decisions were grouped into six categories: the child's protest, the child's age and	This research contributes to the literature on children's participation by identifying that in certain cases children can affect

	decisions in healthcare		healthcare professionals (81 nurses, 8 physicians, 2 play therapists, and 1 psychologist.	maturity, the role of parents, attitudes of staff, the time factor and alternative solutions to the problem	their situation, but also that impertinent actions are also performed on children.
Runeson et al., 2002a	Children's participation in the decisions during hospitalization: an observational study	A qualitative study Observations over 135 hours	University hospital, Sweden 24 children (aged of 5 months – 18 years)	Children are not always allowed to participate in decisions to the extent that is considered optimal. Parents do not always support their children to make decisions in difficult situations and that health care staff often inform children about what is going to happen without presenting alternatives or asking for their views.	This research contributes to the literature on children's participation by identifying a basic prerequisite for children to be able to participate is that they have knowledge about what is going to happen and why.

3.4.2 Children's experiences in decisions

In the previous section, I have summarized studies which have sought to explore children's preferences for participation in decisions regarding their care. In this section, I provide examples of studies that have investigated how children actually experience participation in communication and decisions concerning their care in a healthcare setting.

The analysis of the literature reveals that research that seeks to determine the extent to which children are involved in actual decisions is remarkably small. The most common approach used to investigate the participation of children in the communication and decisions in health care is through the interview approach (Runeson et al. 2000; Beresford & Sloper 2003, Young et al. 2003, 2006; Coyne et al., 2006; Kilkelly & Donnelly, 2006; Kelsey et al., 2007; Runeson et al., 2007; Savage & Callery, 2007; Coyne & Gallagher, 2011; Coyne et al., 2014; Ruhe et al., 2015; Sjoberg et al., 2015; Schalkers et al., 2016); to a lesser extent observation is used as a method, either non or semi-participant observation (Runeson et al. 2002a, 2002b; Hallstrom & Elander 2004; Coyne 2006a; Lambert et al. 2008, 2011), and participatory-based techniques (Gibson et al., 2010).

In studies where children have been interviewed, children were reported to have varying experiences of being consulted and involved in the decisions. In a different study, Coyne and colleagues (2006) used focus groups and individual interviews to investigate 7-18-year-old children's experiences of participation in consultations and decisions in three hospitals in Ireland. The study describes how children occupy a marginal position in consultations, without direct access to information about their healthcare, and with consultations being largely carried out between parents and healthcare professionals. Overall, the study shows that the children felt that their contributions were not given due weight and consideration. Some children preferred to receive information because it helped prepare them for what to expect and thus decreased their worries and provided reassurance. The authors argued that children receiving information and having their views respected enhanced children's understanding and adaptation to the hospitalisation (Coyne et al., 2006). The same findings have also been reported in a study by Ruhe and colleagues (2015) (see 2.4.1).

This is in contrast with the findings of Sjoberg and colleagues' (2015) qualitative study of 10 children aged between 8-11-year-old, who explored the experiences of participation in decisions in relation to perioperative care in Sweden. The study found that the children were receiving information regarding the preparation of the operation, but, receiving a lack of information regarding the post-operative care. Thus, the children expressed that they wanted to have detailed information regarding both the preparation and postoperative care because they perceived the information to be important for their participation in their care and decisions. The children in this study expressed positive experiences of participation when they were listened to and had the opportunity to ask questions. The study demonstrated how healthcare professionals acted as facilitators for participation through their role in creating security for the child in uncomfortable situations, and making the children feel comfortable and safe. The authors argued that a poor adaptation of the care environment to the children's needs, feeling uncomfortable while waiting and needs for distraction are examples of how the environment and the care in the operating theatre influence the children's experiences of participation. The study also highlighted that children's interaction with healthcare professionals, in terms of being listened to, and being involved is important for children's participation in the decisions.

In observational studies, the existing literature on children's participation in the decisions strongly suggests that children have limited and differing levels of participation in the decisions about their care. For instance, in Sweden, Runeson and colleagues (2002a) conducted an observational study with 24 children (aged 5 months to 18 years), and 21 parents and nurses to observe the interaction between parents, children and nurses in relation to consultations and decisions during hospitalization. Key findings from the study are that children had limited involvement in decisions, parents did not always support their children's participation in difficult situations, and healthcare professionals frequently informed children without eliciting their views or presenting alternatives. Another important point is that in Runeson and colleagues' study (2002a) (see Table 4), there are different levels of participation which are observed and graded on the Scale of Participation in Decisions developed by Hermeren (1996) (see section 3.3.2). The findings of the study found that, level 5 applies to situations where the member of staff acts in accordance with the child's wishes and this is reported as occurring in 48 of 137 situations. It is to be noted that these decisions mainly occurred during daily activities such as how they would like to eat and drink, and whether their parents should be present during the procedure. Conversely, 43 out of 68 situations were judged as belonging to level 3 and 4. The children's participation was considered as meaningful participation, which is defined by the authors as situations where the children receive information, take part in decisions and sometimes compromises were made and appropriate alternatives were suggested (Runeson et al., 2002a: 593). Whereas the remaining 21 situations classified as level 1 and 2, which was not considered as meaningful participation because normal conversation between the children and staff did not even take place.

Using the same data, Hallstrom and Elander's study (2004) further explored how decisions were made and found that children and parents made few decisions themselves and even if one or more persons protested the decision made, decisions were seldom reconsidered. Overall, these studies concluded that children are not always given the opportunity to be involved in decisions regarding their care to a desirable level, which could be influenced by the wide age range of the participants.

The differing levels of the participation of children were confirmed by Lambert and colleagues' (2008) ethnographic study with forty-nine children, ranging in ages from 6 – 16 years with a variety of medical and surgical conditions in a children's hospital in the Republic of Ireland, to explore the nature of communication for children in the hospital (see Table 4). The research involved various modes of data collection, including observation, interviews, and participatory activities (including draw and write techniques and a child friendly ‘stick a star’ quiz), and documentary evidence. Like the previous studies, it found that the children occupied varying degrees of participation in the communication process. The key finding of the study was the emergence of the core concept of the child’s ‘visible-ness’, which existed along a continuum, consisting of two polar ends, ‘being overshadowed’ and ‘being at the forefront’. The ‘visible-ness’ illuminated the degree to which children were, or wanted to be, included in the communication process and the extent to which children’s agendas were addressed. It explains that children did not exclusively occupy any one position in the communication process; rather they move in constant motion, back and forth, along the continuum between the two extreme poles of ‘being overshadowed’ and ‘being at the forefront’ (Lambert et al., 2008: 3096). This suggests that the same child could occupy both positions throughout their hospitalization, where the child may occupy the background and at other times he/she may occupy the forefront of the communication process.

Using the same data (of Lambert et al., 2008), a further analysis of this ethnographic study reported that healthcare professionals positioned children as either ‘passive bystander’ or ‘active participants’ in the communication process (Lambert et al., 2011: 573). These two positions signified the extent of children’s inclusion or exclusion in the communication process and the degree to which children’s communication needs were met or not. Another important finding of the study was that the children’s preferences resulted in oscillating between a passive bystander and active participant position within the communication process, and this depended on their needs at any given point in time. Therefore, the Child Transitional Communication (CTC) Model was developed to provide plausible explanations of why healthcare professionals placed children in one of two position (e.g. passive bystanders or active participants) within the communication process, which was linked to the concept of ‘visible-ness’ (Lambert et al., 2011). The authors suggest that the term transition was used within this model to refer to the temporary and ever-changing state of children’s positioning within the communication process. This model suggests that children remained marginal in the communication process as passive bystanders when health professionals did not communicate directly with them, but rather directed any interaction to the child's parents. This often resulted in the healthcare professional and parent conversing about the child in his/her presence, with the child eavesdropping in the background. Conversely, children became active participants in the communication process, when healthcare professionals interacted directly with them (either in the presence or absence of their parents), listened to them and gave them an opportunity to ask questions (Lambert et al., 2011). The authors further suggest that the extent of children's inclusion or exclusion in the communication process and the degree to which children's communication needs were met or not, depended on their needs at any given time.

Lambert and colleagues' (2008; 2011) findings are echoed with the finding of a study which used a participatory-based approach (Gibson et al., 2010) with 38 children with cancer (aged 4 – 19 years) from three Principal Cancer Treatment centres in the United Kingdom. Some findings confirmed previously reported issues, such as young children's inabilities to voice their preferences, and the importance of familiar environments and parental support for all ages. New findings of the study suggested children worry about the permanence of symptoms, and older children are unhappy about their parents leading communications with health professionals. The findings suggest children's preferences for communication and information are not static; they change over the course of their illness. Drawn from Lambert and colleagues (2008) 'visible-ness' on a continuum, Gibson and colleagues (2010) propose a conceptual model of communication roles of children, their parents, and health professionals to illuminate communication patterns. The model suggests children (aged 4–12 years) reside in the background of information sharing with health professionals until they gain autonomy as young people (around age 13). Nevertheless, when they move into the foreground, and their parents' transition into a supportive background role, the healthcare professionals constantly remain in the background. The model highlights the age of the child as an important factor to determine children's communication role either in the background or forefront position, because they associated the age and movement of children with gaining autonomy. Nevertheless, it could be argued that to be in the forefront or background depends on children's dominant perspectives of their own ability surrounding their illness, as well as those of others. The main argument is that the participation of children in decisions may not purely be influenced by the age of the child; it could be due to other child related factors such as children's understanding, emotional state, personality, illness state, and children's preferences, which have been reported in other studies (Alderson et al., 2006; Coyne 2006a; Coyne et al., 2014; Coyne et al., 2016; Lambert et al., 2008; Runeson et al., 2002a; Ruhe et al., 2015; Schalkers et al., 2016). In addition, the movement of children in the forefront or background could also be explained by the social cultural aspect that children learn through their interaction and communication with others (as illustrated in section 2.3.3). The more activities and interactions that children participate in, the greater will be their understanding, which results in greater participation (Smith, 2002). As such, children with greater understandings are mostly likely to move into the forefront rather than stay in the background.

3.4.2.1 Summary

The review has revealed that children's participation in decisions in healthcare settings are varied. Children appeared to value their participation; however, they are not always given the opportunity to participate in decisions regarding their care, with discussions mostly carried out with their parents. As a result, children mostly occupy a minimal role in communication and decisions regarding their care. Nevertheless, the review highlighted that children possibly occupy two different positions in communication and decisions: as passive bystanders and active participants. The passive bystander position is when the children are not directly communicated to by the healthcare professionals, with the children overhearing in the background. Active participant relates to the children being directly communicated with by the healthcare professionals. The patterns of participation are differing and fluctuate between the children and within the same child throughout their hospitalization, depending on the participating child, their preferences, and requirements at a particular time.

3.4.3 Influential factors on children's participation

From the analysis of the literature, it is evident that children are rarely involved in communication and decisions regarding their care, and that they mostly occupy a marginalized position during healthcare consultations. Research that explores factors influencing children's participation in decisions strongly suggests that healthcare professionals, parents and children play a significant role in whether children's participation is supported or hindered in the hospital setting. Taking this into consideration, in the next section, the factors influencing children's participation are discussed according to healthcare professional, parent and child factors.

3.4.3.1 Healthcare professional factors

The existing research on children's participation agreed that the participation of children in decisions regarding their care is associated with healthcare professionals. Research reveals that healthcare professionals can both facilitate and block the participation of children in decisions. The factors associated with healthcare professionals that influence children's participation were mainly associated with attitudes and behaviours of healthcare professionals, communication skills of healthcare professionals, and the role of power (Runeson et al., 2000; 2001, 2002a; Coyne, 2006a; Hallstrom & Elander, 2005; Schalkers et al., 2016).

The attitudes of healthcare professionals are of utmost importance regarding children's participation in decisions regarding their care (Hallstrom & Elander, 2005). It has been argued that if a healthcare professional values a child as a person with the right to hold an opinion, he or she listens to the child and tries to satisfy the child's wishes as far as possible (Hallstrom & Elander, 2005). For instance, Runeson and colleagues' (2001) study, involved 92 Swedish healthcare professionals (including: 81 nurses, 8 physicians, 2 play therapists, and 1 psychologist). The participants were asked to write about situations in which a child (aged 5 months – 15 years) was allowed or not allowed to participate in decisions regarding their care. Ninety-two written narratives about children's participation in decisions in their own care were analysed, and they found six factors that affected children's participation in a positive or negative direction. The factors include: protests of the child, age and maturity of the child, role of the parent, attitudes of staff, time factor and alternative ways to solve problems. Overall, this study shows that children's participation is highly dependent on adults and their attitudes towards children. This is consistent with an observational study of Runeson and colleagues (2002a), which described how nurses may allow children to participate in their own care and decisions. The results of the study showed that in 72 situations out of 137, nurses did not pay attention to the child. In the remaining 65 situations, staff listened and respected the child's points of view, totally or partly. This finding indicated that nurses played an important role in permitting children to participate to different degrees. While in some situations, children are allowed to participate to a higher degree, in other cases, children's wishes were ignored or sometimes not even sought. Similar results were reported in a study by Coyne (2006a), where 12 nurses viewed children's involvement in their own care as dependent upon cognitive maturity, and suggested that professionals might feel threatened by children who are knowledgeable about their care and who might question the views and approaches of professionals, which seemed to influence their efforts to support children's participation. This was supported by the most recent research on children's participation from the perspective of healthcare professionals that interviewed 32 healthcare professionals from 10 hospitals across the Netherlands including teaching and regional hospitals (Schalkers et al., 2016). The aim of the study was to investigate healthcare professionals' perspective on children's participation in paediatric hospital care. Shier's (2001) Pathway to Participation model was used to guide the interviews. The findings of the study substantiate the claim that when the professionals believe that high levels of participation are possible in basic care for children, they were more likely to enable a high level of participation of children in decisions that has a relatively low impact on the child's health. In addition, the participants considered participation in medical decisions as more complex and subject to a number of reservations and restrictions.

The attitude of healthcare professionals is not the only barrier to children's participation; the communication styles of healthcare professionals also impact on children's participation in consultation and decisions regarding their care (Bereford & Sloper, 2003; Coyne, 2006a; Coyne & Gallagher, 2011; Ruhe et al., 2015). A study of 55 children aged 7-18 years, by Coyne and Gallagher (2011), examined factors that may enhance or hinder children's participation in communication and decisions in Ireland. Although there were many factors that appeared to obstruct children's participation, the key factors were healthcare professionals' communication styles and behaviours. Overall, children in the study reported that healthcare professionals tended to do things to them with very brief explanations or no explanations. Many children in this study reported that they were relying on their parents to be their advocate and interpreter in the communication process because they have difficulty communicating with healthcare professionals. Some children reported that they are being rushed by the healthcare professionals during their interactions with them. They also reported that the healthcare professionals directed information to the parents, which meant that children were often relegated to a non-participant status in communication and decisions. Correspondingly, Ruhe and colleagues (2015) identified few obstacles related to the way in which healthcare professionals communicate with children, where the children in their study reported that they have difficulty understanding the terms used by the healthcare professionals. For example, one of the children in this study mentioned how she did not understand her diagnosis, because the healthcare professionals use the term 'tumour' when conveying the information. These findings corresponded with the findings of Coyne (2006a), who confirmed that the lack of communication skills of the healthcare professionals influence the extent to which children participate in the decisions regarding their care. The use of medical terminology by the healthcare professionals results in children not being given, or not understanding, the information which they need to be able to play a meaningful role in the consultation process, which in turn will influence the extent to which children are participating in the decisions (Coyne, 2006a). The healthcare professionals' communication style of the use of medical terms was also highlighted by Migone and colleagues' (2008) study that the nurses are familiar with the medical jargons, and thus, they tend to use it when communicating with children and parents during the provision of care, without realising that the way they communicate is unclear for the children.

The power imbalance in the relationship of the nurse, parents, and child was also being reported as an important factor for children's involvement in the decisions. For instance, a study by Young and colleagues (2006), who conducted semi-structured interviews with 11 children with cerebral palsy and 12 of their parents and two focus groups with 10 physiotherapy practitioners, showed how power imbalances between the healthcare professionals and children influence children's participation in decisions regarding their care. In this study, the healthcare professionals, who were in the powerful position, were mostly responsible for making decisions about the interventions, while children (who are perceived to be less powerful) were mainly restricted to being involved in discussions regarding the interventions. It has been argued that nurses hold the ultimate power in the caregiving relationship, because they have the knowledge regarding medical and nursing care, as compared to the children who are sick and vulnerable, and, as a patient, children are often dependent on those in charge of their health care, such as nurses in the provision of their nursing care (Newton, 2000). Hence, if the nurse chooses not to negotiate or support the children, it is very difficult for children to participate in their care and decisions.

In summary, the review highlighted three healthcare professional factors including: first, the attitudes of the healthcare professionals; when the healthcare professional values a child as a person with the right to hold an opinion, he or she is more likely to get children involved in the decisions regarding the child's care. Second, the communication style of the healthcare professionals; the use of medical terminology by the healthcare professionals result in children not understanding the information, which in turn will influence the extent to which children participate in decisions. Finally, the power imbalance between health professionals and children; the healthcare professionals are often in a powerful position and are responsible for making decisions about the care for children, while children frequently were marginalised in the discussions and decisions regarding their care.

3.4.3.2 Parental factors

Compared to the healthcare professional factors, parental factors were more often discussed in the research studies. The existing studies reported that parents can both facilitate and hinder children from participating in discussion and decisions (Runeson et al., 2001; Tates et al., 2002; Bereford & Sloper, 2003; Young et al., 2003; Coyne, 2006a; Savage & Callery, 2007). For example, from an observational study of 24 children by Runeson and colleagues' (2002a), as discussed above (see section 3.4.2), the child's opinion was ignored in 72 of 137 situations, while in the remaining situations, staff listened and acted according to the child's desires. The role of parents was one of the important factors reported in the study as factors constraining children's participation. The parents of the study showed no sign of supporting their child in most of the situations. Not in one single case did the parents take their child's side to protect him/her, or demand a new approach to be implemented for their child, despite the fact that they saw that the child was having a difficult time. The authors argued that this could be because the parents have a lack of medical knowledge and are in a new and unfamiliar environment, and the dependent position perceived by some parents, where they have the idea that healthcare professionals know best and the planned procedure is good for their child, even if it is unpleasant or painful (Runeson et al., 2002a). This could have influenced the children's opportunities for participation in decisions.

Correspondingly, Young and colleagues (2003) undertook research on children's and parents' accounts of communication about cancer in the United Kingdom, involving 13 children (aged 8-17 years) with a brain tumour and 19 of their parents. The research concluded that most parents described how they manage their children's information needs, because of their concerns to manage their identity as strong parents and to protect their child's wellbeing. The researchers argued that the roles of parent in managing the child's information needs can contribute to the marginalisation of children and hamper the development of successful relationships between themselves and children. This finding may have been influenced by the fact that the children in this study had cancer, which is a life-threatening disease, and thus parents may have felt that they had to manage the information conveyed to the children which might distress the children (Young et al., 2003). A similar finding was reported in another study conducted in a children's ward. Coyne's study (2006a) found that several children spoke about how their parents inhibited their attempts to participate by various actions, including: answering questions on their behalf; telling them to stay quiet; reprimanding them for interrupting discussions and withholding information. Coyne's (2006a) main argument is that parental wishes were important in determining child participation, with health professionals sometimes seemingly feeling unable to go against parental wishes. Similar to Young and colleagues' (2003) findings, Coyne (2006a) argued that although most children seemed to value their parents' role in the consultation process, some children expressed unease with the constraining aspect of it.

Similar findings of parents controlling the communication between their child and healthcare professionals were reported in a study by Savage and Callery (2007), who employed interviews and participant observation during clinical consultations with 21 children with cystic fibrosis. The study found that parents interrupted children's responses, which led professionals to redirect conversations to parents, thereby continuing to marginalise the children's role in the consultation process. The researchers argued that parents acted in such a way because they believed that they were principally responsible for their children's diet and for consultations with professionals.

While the above findings suggest that parents constrain their child from participating in decisions regarding their care, there are studies that have found that the presence of parents during the consultation process supports children's experiences of communicating with the healthcare professionals. In participatory research with children aged 4-19 years with cancer, Gibson and colleagues (2010) reported that children rely on their parents to communicate with health professionals. The children aged 8-17 within the study described five communication roles their parents undertake, as below:

(i) Facilitators of communication (e.g. parents forging communication between health professionals and children);

(ii) Envoys (e.g. parents being briefed by children and young people to seek information for them);

(iii) Communication buffers (e.g. parents shielding children or young people from information);

(iv) Human databases (e.g. parents being relied upon to remember details of treatment);

(v) Communication brokers (e.g. parents clarifying or reiterating information so children can better assimilate what health professionals have said).

Respectively, such roles are broadly grouped together under advocacy by other studies. For instance, Coyne's (2006a) and Coyne and Gallagher's (2011) studies agreed that children used their parent to be their advocate and interpreter in the communication process because they had difficulty communicating with healthcare professionals. In another study, Lambert and colleagues (2008) argued that the interruption of parents in the communication process of children and healthcare professionals could enhance the communication process; for example, the 'quiet children' can be supported and the passivity of children can be reinforced when parents interrupt the communication between the children and healthcare professionals. There was also an argument that the presence of the parents in the communication process with the healthcare professionals may increase the confidence level of the children and, thus, they can take a more active role in the communication and decisions regarding their care (Beresford & Sloper, 2003; Young et al., 2003).

In summary, the review in this section revealed that not all parents support their children to participate in decisions; nevertheless, if the parents support their child, he/she is more likely to be allowed to take part in decisions, and vice versa. Overall, it can be concluded that parents can both facilitate and hinder their children from participation in communication and decisions.

3.4.3.3 Child factors

The most common child factors identified in the literature were related to the knowledge and experience of the child regarding his/her condition and treatment, the age and maturity of the child, the seriousness of their illness, and the type of decision being made, which are discussed as follows.

The knowledge and prior experiences of children regarding their illness and care have been reported as two factors influencing their participation in decisions regarding their care. For instance, Coyne (2006a) suggested that children who are more knowledgeable and informed about their condition, care, and treatment are more likely to be involved in decisions with more weight being accorded to their views by healthcare professionals and their parents. This was supported by the study of Alderson and colleagues (2006), who investigated the views of children with type 2 diabetes about their condition and the ways in which they share the management of their medical and healthcare with adult patients. The study found that the children could make informed decisions about their treatment from around the age of four. Alderson and colleagues' (2006) main argument was that the ability of children to consent and make decisions developed through experience rather than age. This is in contrast with the findings from Lambert and colleagues (2008), who found that prior experience of hospitalization did not influence the ability of children to participate in the communication process. The authors found that there were situations where the children with previous experience of hospitalization did not participate in the communication process, while in other situations, the children with no previous hospital experience played an active role in the communication process with the healthcare professionals. Therefore, the authors argued that the prior experiences of the child could not be the criteria used to determine the child's level of involvement in communication processes. The differences of the finding of those studies could be because the studies were conducted among different samples with different illnesses and used different methods in their research. Alderson and colleagues' (2006) study for example, was conducted among children with chronic illness (diabetes). This means that the children in this study may have knowledge of the illness and treatment because they have experienced their illness for a long period of time. As compared to those in Lambert and colleagues' (2008) study, which involved children with medical and surgical problems who had experienced their first hospitalization and previous hospitalizations; which probably affected the findings of the study. The experiences of hospitalization of the children could be due to the same illness or a new diagnosis, which may affect their understanding of the illness and treatment, and in turn influence their preferences for participation in the communication process. In terms of a methodological approach, both studies used a different approach. On the one hand, Alderson and colleagues (2006) used an interview approach, where the participants may not convey the actual information regarding their experiences to the researchers. As Runeson and colleagues (2002a) argued, children or parents sometime convey different types of information to a person who is not involved in the care. On the other hand, Lambert's (2008) ethnographic study combined an interview and observation approach, which may report the real experiences of children in the decisions rather than the study which used an interview approach. An observation approach could provide the possibility of viewing interactions between various participants and gives an overview of the whole picture of what is happening (Runeson et al., 2002a). In addition, the combination approach enables researchers to record what is actually happening and knowing what is behind the actions of the participants. This could perhaps explain the contradictory findings of both studies.

The age and maturity of the child has been reported as one of the factors influencing children's participation in decisions. Runeson and colleagues (2001) suggested that children of school age are more likely to be involved in discussions with healthcare professionals, and, thus, decisions can be made which are satisfying to both sides. This is consistent with other studies that reported that children of an older age would be more likely to participate in the discussion and decisions (Beresford & Sloper, 2003; Coyne et al., 2006; Coyne & Gallagher, 2011; Kilkelly & Donnelly, 2006). The children who were older, or more experienced in hospital or their illness, could be more assertive and thus gain greater participation in their healthcare (Beresford &

Sloper, 2003; Coyne & Gallagher, 2011). Moreover, Schalkers and colleagues (2016) reported in their study that professionals are more likely and more accustomed to asking the opinions of older children because communicating with them is assumed to be ‘easier’, less complicated and less time consuming. However, findings of those studies were in contrast with the finding of Lambert and colleagues’ (2008) ethnographic study, which found that not all children of an older age participated in communication processes. They reported that the younger children (aged 6-11 years) were involved in the communication process with the healthcare professionals, and there were instances where the older children (12-16 years) were not involved in the communication process concerning their care. Lambert and colleagues (2008) argued that it is difficult to use age as a criterion to determine the degree of children’s participation in the communication process. Differing beliefs surrounding specific age competencies were also highlighted by Young and colleagues (2003), who confirmed that age was not particularly useful in explaining children’s preferences for information. There is uncertainty of whether it is due to the age of the child, or could be influenced by other external factors such as the child’s condition, types of decision, surroundings and interactions with the healthcare professionals and their parents. It is noteworthy, however, that the differing findings of those studies could be because the studies involved different age groups of participants which makes the comparison difficult. For example, Beresford & Sloper, (2003) involved children aged 11 – 16 years; Coyne and Gallagher (2011) studied children aged 7 – 18 years; Kilkelly & Donnelly (2006) conducted research among children aged 5 – 14 years; Lambert and colleagues (2008) conducted research among children aged 6 – 16 years; and Young and colleagues (2003) involved children aged 8 – 17 years.

Other than the prior experience and age and maturity of the child, the seriousness of the child’s condition has been reported as one of the factors influencing their participation in decisions. For instance, a recent study by Coyne and colleagues (2014) explored children’s participation in shared decisions from multiple perspectives from one oncological unit in Ireland. This qualitative study interviewed children aged 7 – 16 years, their parents and healthcare professionals. They found that the role of children in the decisions was significantly influenced by the seriousness of the child's illness. They argued that when children were acutely ill, they were less receptive to receiving information, participating in shared decisions and became more dependent on their parents. In this case, the healthcare professionals and parents appeared to control the process of shared decisions and the children held a minimal role. This was supported by another study that explained when the children's medical condition is acute or severe, they are less likely to participate in discussion and decisions, and the professionals are more likely to take the child's views into account if the child is in a less critical condition (Schalkers et al., 2016). The child factors such as the child's medical condition and age and maturity of the child were reported to greatly influence the extent to which professionals are willing to involve children in healthcare decisions (Schalkers et al., 2016).

In summary, the review in this section revealed that the child factors that influence children's participation are knowledge and prior experience, age and maturity, seriousness of the child's condition, and the type of decisions. The review highlighted that there were contradictory findings which were found in some studies in relation to knowledge and prior experiences of hospitalization, and the age and maturity of the child in influencing children's participation, however, most studies agreed that children who have knowledge regarding their illness and treatment, and children with previous experience of hospitalization are more likely to participate in decisions. Additionally, the participation of children in the decisions was reported to be considerably influenced by the seriousness of the child's illness. The research suggested that when children were critical, they become dependent, and thus, healthcare professionals and parents were more likely to control the process of decisions.

3.4.3.4 Type of decision

Despite the healthcare professional factors, parental factors and child factors previously discussed, issues relating to the type of decision being made were highlighted across different studies as a factor influencing the participation of the child in decisions (Runeson et al., 2001; 2002a; Beresford & Sloper, 2003; Coyne &

Gallagher 2011; Coyne et al., 2014; Schalkers et al., 2016). The existing research studies that have explored children's preferences for participation, have characterized decisions into two categories: 'small' and 'serious' (Coyne & Gallagher, 2011) or 'minor' and 'major' (Coyne et al., 2014), as illustrated in section (2.4.1). Children were reported as wishing to be involved in small decisions (Coyne & Gallagher, 2011), that have less impact on the child's condition (Coyne et al., 2014). This became evident when the children, parents and healthcare professionals in the study of Coyne and colleagues (2014) agreed that children should be involved in minor decisions, usually associated with the timing and delivery of procedures (e.g. medication, blood test, dressing), which is perceived by the adults to not deteriorate the condition of the child. Consistent results were reported in the recent study by Schalkers and colleagues (2016), who found that the healthcare professionals were more likely to enable a high level of participation of children in decisions that have relatively low impact on the child's health.

The review highlighted two different decisions within the healthcare setting, that are, major and minor decisions. Medical decisions are considered as major decisions. Minor decisions are decisions that most children were reported to be involved in, that are related to the delivery of the procedure or daily living activities that have less impact on the child's condition.

3.4.4 Impacts of participation

After reviewing the factors influencing children's participation, in this section, I review studies that have sought to explore the impact of participation on children. I begin by drawing on the benefits of participation, before moving on to discuss the research exploring the disadvantages of participation at the end of this section.

The existing research on children's participation in healthcare agreed that children benefit from being able to participate in healthcare and decisions. Studies on children's participation in health matters and decisions have demonstrated an increasing sense of control and ability (Tiffenberg et al., 2000), promote preparedness (Coyne & Gallagher, 2011), cooperation with their care (Coyne, 2006a), decrease in fears and concerns (Runeson et al., 2002a), gain in knowledge and skills and responsibility in their own care (Alderson et al., 2006), increased adherence (De Winter et al., 2002), promote satisfaction with health care (Alderson et al., 2006) and enable children to becoming competent decision makers in the future (Miller, 2001). These findings resonated with the study by Coyne and colleagues (2014), who reported that the participation of children in decisions led to increased cooperation between the children and healthcare professionals, better coping, patient satisfaction, and trusting relationships. The participation of children also helped to make the treatment more palatable and less likely to result in children's resentment and non-adherence. In addition, parents in Coyne's (2006a) study felt that respecting their children's abilities to participate increased their self-esteem and accrued to them positive self-regard, thus enhancing their overall well-being. Moreover, the paediatric nurses in Miller's (2001) study, perceived that it is important for young children to participate in decisions regarding their care, which will enable them to become competent decision makers in the future.

Children's participation was not only beneficial to the children, but also favourable by the healthcare professionals. Trollvik, Ringsberg and Silen' (2013) explored the participation and responses of children to an asthma education programme. This exploratory qualitative study used observation, tape recordings of the conversations and notes of the interaction between the 21 children and 2 healthcare professionals in an urban hospital in Norway. The study found that children learned about asthma and its treatment from their interaction with the healthcare professionals and vice versa. Their findings highlighted the positive impacts of children's participation on children themselves and healthcare professionals. On the one hand, the healthcare professionals learned and understood children's asthma in a new way from the children's point of views to develop a child centred programme. On the other hand, children received education from their own perspectives because they were involved in the development of the education programme, which makes their understanding of asthma clearer, which in turn, would increase their adherence to the treatment plan (Trollvik et al., 2013).

In contrast, there was no research identified specifically that explored the disadvantages of children's participation to children themselves. However, there were several commentaries on the potential shortcomings identified in this review. While some writers worry about the effect of participation on children, others are concerned about the parents. For instance, Coyne (2006a) and Terry and Campbell (2001) pointed out that children may feel pressured to participate, as adults increasingly expect them to participate in decisions, whereas Alderson (2000) and Lansdown, (2001) were concerned with a lack of respect for adults especially parents, resulting from children's participation. As LePoire (2006) suggests, protecting one's child is an innate need central to being a parent and fulfilling parental responsibility. Therefore, parents who are perceived to be principally responsible for their child's best interests may feel that their child has a lack of respect for them when the child expresses their view. In other words, the way in which children express their wish or opinion could be interpreted as a quarrel from the children, which leads to the perception that children are disrespecting their parents.

Although there is lack of evidence in terms of the outcome of participation, the limited studies reviewed in this section indicates that the participation of children in the decisions regarding their care appears to be beneficial to the children themselves and healthcare professionals. Nevertheless, it is unclear to what extent the participation of children in decisions improve the child's health outcomes.

3.5 Care delivery in paediatric care: Family centred care

Given the focus of this thesis, my main interest in this section lies in the standard of care provided to children in a paediatric setting. Nursing literature has shown that practice family centred care (FCC) concepts currently form the foundation of paediatric nursing in many countries around the world (Butler et al., 2014). It has been argued that FCC is a crucial element in the delivery of quality care for children that recognize a child as central to the concept of FCC, being the person on which care and treatment are focused (Kelly et al., 2012), while the parent is acknowledged as the expert in the care of their child (Shield et al., 2006). The practice of FCC emphasises the concept of partnership between the healthcare team, and the child and/or family (Frank & Callery, 2004; Mikkelsen & Frederiksen, 2011). In other words, the family and child would be supported in their participation and partnership in care. This gives the impression that FCC may be considered as an appropriate mechanism to promote children's participation in their own care and decisions. Therefore, in this section, I review the literature on FCC in paediatrics to provide information on the FCC practices. I am particularly interested in how the FCC literature describes how nurses are encouraged to support hospitalized children in participating in their care and decisions. This section begins by providing insights into debates on the definitions and concepts of family centred care in the wider nursing literature. I then discuss the challenges and areas of tension identified in the literature in relation to the practice of FCC and children's participation in decisions.

3.5.1 Defining family centred care

The literature has yielded that there is no consistent definition of the terms FCC; different definitions are being used, reflecting different perspectives of FCC. The most well-known and commonly cited definition of FCC was of the institutes for Family-Centred Care (IFCC, 2005: 4), defined as 'a modernisation approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care patients, families, and providers'. Within the IFCC framework, relationships in health care are redefined, emphasizing the partnership between patients and families and their caregivers (Conway et al., 2006). In order to provide a framework to guide healthcare providers in the provision of care to patients and families, IFCC constructed four important core concepts of FCC that are: dignity and respect, information sharing, participation, and collaboration. Correspondingly, eight important elements of FCC were proposed to be implemented in the model of care (see Table 5). These elements of FCC emphasize the involvement of family in the patient's care, in which families are considered full partners in the provision of health care to patients and are of equal status in the relationship (Harrison, 2010).

Recent decades have seen heated debates about the definitions and concepts of FCC in healthcare practice. While some authors have suggested that FCC is a philosophy of care that is widely used in children's nursing for providing care for children and families in hospital and community settings (Jolley & Shields, 2009), others have criticized the model as being espoused rather than enacted in every day practice (Coyne et al., 2013). Indeed, Franck and Callery, (2004) suggested that a reconceptualization of FCC is required to clarify its implications for practitioners, children, and their families, and to provide a firmer basis for the development and evaluation of the practice. The main argument was that FCC contains broad constructs, ill-defined in precise terms, making evaluation difficult, particularly in terms of whether FCC improves outcomes for the child and family (Franck & Callery, 2004).

Alternatively, Brown and colleagues (2008: 38) defined FCC as "an approach that recognized family members as the constants in the patient's life and specific to the paediatric setting, acknowledges the strengths they bring to their child's health care experience". This definition acknowledges the important element of parents in their child's care specifically in a paediatric setting, but does not provide reasons for what it means for children and families or the role of health professionals. Shield, Pratt & Hunter (2006: 1318) provide a definition that is more concise and encapsulates the meaning for children, families, and health professionals who work with FCC: 'a way of caring for children, and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognised as care recipients'. It is noteworthy that there are commonalities between various definitions including: respect for children and family, recognition of the importance of the family to the child's wellbeing, concepts of partnership between the health team, and the child/family, parental involvement, and parental participation (Frank & Callery, 2004; Mikkelsen &

Frederiksen, 2011). Indeed, these definitions indicate that children and families are professionally supported in their journey through hospitalization.

Table 5: Elements of FCC as proposed by the IFCC (Shelton et al., 1987: 76)

- Recognizing the family as a constant in the child’s life
- Facilitating parent-professional collaboration at all levels of healthcare
- Honouring the racial, ethnic, cultural, and socio-economic diversity of families
- Recognizing family strengths and individuality and respecting different methods of coping
- Sharing complete and unbiased information with families on a continuous basis
- Encouraging and facilitating family to family support and networking
- Responding to child and family developmental needs as part of health care practices
- Adopting policies and practices that provide families with emotional and financial support
- Designing health care that is flexible, culturally competent, and responsive to family needs

3.5.2 Teasing out challenges and tensions in family centred care

It is generally accepted that families have the best interests of their children at heart (Ross, 1997) and that it is within the family unit that children's participation are encouraged and supported. FCC may be considered an appropriate model of care to promote children's participation because the emphasis of FCC is particularly on the partnership between patients and families and their caregivers (Conway et al., 2006). Additionally, a number of authors considered that FCC can address children's rights since it deals with children's needs (Newton, 2000; Corlett & Twycross, 2006; Kelly et al., 2012; Shields et al., 2006). Nonetheless, as I further read the central ideas surrounding FCC and children's participation, competing elements became apparent. It became clear that adherence to FCC per se could not be anticipated to promote children's participation in their care and decisions. In the following text, I identify some challenges of its implementation before discussing the areas of tension within the literature concerning FCC.

Firstly, some authors argued that challenges remain in translating the concept of FCC to actual care delivery (Franck & Callery, 2004). This claim is supported by Coyne and Cowley (2007) who argued that the attainability of FCC as a model of care is doubtful. This is also supported by a survey from Petersen, Cohen, and Parsons (2004) to determine nurses' perceptions and practices of identified elements of FCC. This cross-sectional study involved 62 nurses (37 nurses from NICU, 25 nurses from paediatric or PICU). The findings indicated that although nurses agree that the identified elements of FCC are necessary, they do not consistently apply those elements in their everyday practice. Studies have suggested that challenges to implement FCC lie with the fact that there is a lack of training in relation to FCC. For instance, a qualitative study by Higman and Shaw (2008) interviewed seven nurses providing neonatal care in the United Kingdom. The nurses were asked to identify key areas related to the delivery of FCC. The findings found that none of the nurses interviewed had received specific training regarding this area of practice and all felt more could be done to improve nurse education in this area. The nurses also described a lack of confidence, associated with less experience, as having an impact on the capacity in providing FCC. Similar findings were reported in another qualitative study by Mackay and Gregory (2011), who interviewed 20 nurses from a western Canadian children’s hospital to understand the experiences of paediatric oncology nurses in relation to FCC. The study reported that nurses have insufficient training in relation to FCC and most of them stated that they would appreciate further education on the philosophy of FCC. The participants voiced how the lack of training affected their skills and the knowledge needed to fully implement FCC into their practice. In contrast, a survey of 750 nurses across Ireland by Coyne and colleagues (2011) did not support this conclusion. Instead the nurses of the study showed that they have a good understanding of the components of FCC which were consistent with the eight elements of FCC but they indicated that they encounter difficulties because of a lack of organizational and managerial support, and inadequate resources. This is in accordance with a qualitative study of Baird and colleagues’ (2015), who used a grounded theory approach with 19 participants (7 parents, 12 nurses) from a single PICU in an urban teaching hospital in the western United States, to identify the effect of FCC on the family's ability to receive care that was attentive to their needs. The study reported that nurses were in a challenging position of providing the elements of FCC in their practice. The nurses expressed that they have a lack of sufficient support from the organization to effectively integrate the demand of the model of care. This review indicated that without the support, guidance and direction from the organization, the implementation of FCC into practice can be difficult.

Secondly, tensions were reported in the practice of FCC resulting from the different perspectives between the parents and healthcare professionals on the care delivery. Research agreed that both healthcare professionals and parents have different requirements and expectations in relation to involvement in the care of their child. For instance, Martens and colleagues (2008) conducted a survey with 53 mothers and 47 nurses, and reported a mismatch between parents’ and nurses’ expectations on care provision. While the mothers often want to take on more technical aspects of care, nurses were unwilling to allow the participation of mothers in their child’s care. Correspondingly, the case study of Gill (2005) in the USA reported that medical staff, especially physicians, were unwilling to allow parents to make decision and felt that parents were emotionally ill-equipped to handle negative news. The similar finding was reported in a qualitative study by O'haire and Blackford (2005), which used a grounded theory approach with nine nurses to investigate issues for nurses in facilitating parental participation in Australia. The findings showed that nurses acted in the child's best interest, and disagreed with parents about their child's care.

Thirdly, the existing research demonstrates that there can be conflict between the child's desires and those of the family and the issue arises of whose views should be acted upon. Disagreements are partly a question of whose priorities are addressed or even acknowledged (Kelly et al., 2012). The review suggests that healthcare professionals often given priority to the parents' wishes rather than children's expressions. An example of this was given by Hallstrom and Elander (2004) in their discussion of conflicting wishes between children and their parents. They point out that, children's protests or requests are reduced to childish complaints rather than reasonable objections, and parents' wishes are given precedence. In addition, parents tended to take the side of the health professionals in conflicts between the child and professionals (Runeson et al., 2002a). It is noteworthy that such tensions present a challenge to nurses to find a balance working within a FCC model of care delivery and ensuring that the rights of children to participate in their care decisions are met.

Finally, it would be problematic to permit parents to decide on behalf of their children as it may not always be what children want. For instance, Coyne and Gallagher (2011), in their discussion of decisions made by the parent on behalf of children, argued that the decisions made by parents may not always be what children want, or in the children's best interest. Indeed, they pointed out that the parent's judgement of what is best for children is not necessarily equal to the child's best interests.

3.5.3 Summary

As outlined at the beginning of this section, there are debates around the definition of FCC, and challenges and tension in its implementation in practice in upholding children's participation in their care and decisions. This section has demonstrated that FCC is the model of care that has recognized parents as the key players at the expense of children, and certainly, in practice, the parents' experiences are given more priority than those of children. Therefore, it can be concluded that the practice of FCC may limit the role of children in care and decisions, because when the emphasis moves to parents as consumers of paediatric health care, children are at risk of being objectified or even marginalized (Kelly et al., 2012).

3.6 Chapter summary and gaps

This Chapter has provided an overview of the theoretical perspectives and underlying studies on children's participation to better understand children's participation in decisions. It can be concluded that children can be considered as participants in decisions if they are taking part, or being involved or consulted and have an influence on the decisions. There are different models of participation that have been identified that can be used to examine the extent to which children are participating in decisions. This section highlighted the contribution of the UNCRC in framing the right of the child to participate in any matters concerning the child, as well as how the ways children are conceptualized carries an implication on children's participation.

In section 3.4, I have reviewed the relevant literature regarding children's participation in decisions in the context of health care internationally. The review of the empirical studies in relation to children's participation in decisions in health care revealed that children's experiences varied internationally. As outlined at the beginning of this section (3.4.1), there were different findings found in the literature as to whether children prefer to participate in decisions. While some children wanted to have more information, and wish to participate in their own care and decisions, others wanted to leave the decisions to parents and health professionals, because they perceived the healthcare professionals and their parents as the experts, and some children preferred to collaborate with their parents.

In terms of children's experiences of participation in decisions regarding their care, the review demonstrated that children's experiences are varied (see section 3.4.2). Although the studies reviewed in this section have acknowledged that children should participate in their health care and decisions, what many studies have in common is that children sometimes are excluded from discussions, and other times occupy a marginal position in consultations, with consultations largely being carried out between parents and healthcare professionals. Only a few studies reported that children's views and opinions were sought by the healthcare professionals.

The studies highlighted that children's participation may be considered transitory and dependent upon many factors (see section 3.4.3). Studies reviewed in this section agreed that children, parents and healthcare professionals have a significant influence on whether children are allowed to participate in their care and decisions. Parents and healthcare professionals were reported to play a key role in the consultation process and have the power to either facilitate or constrain children's participation. However, the research evidence suggested that healthcare professionals generally have difficulty facilitating or supporting children's participation. While the review highlighted that there are several benefits associated with participation, there is no study that directly explores the disadvantages of children's participation for children specifically.

Overall, the findings of the reviewed literature have demonstrated that the studies on children's participation have mainly focussed on the view and experiences of children, parents and healthcare professionals. In addition, there are methodological issues which have been highlighted in this review. While many studies focus on the perspective of healthcare professionals and parents by using an interview approach, few of the studies explore children's perspectives, when they do, they mostly use interviews, and few use observation, rather than a combination approach (interview and observation), as such they may not provide a complete picture of events. An observation approach has been shown to provide an opportunity of observing children, parents and professionals in different situations and uncovers behaviour and practices of which the participants themselves sometimes were unaware (Mays & Pope, 1995).

Finally, in section 3.5, with regard to the standard of care provided to children in a paediatric setting, the concept of FCC was discussed. As outlined at the beginning of this section, there are debates around the definition of the concept of FCC, and challenges and tension in its implementation in practice in upholding children's participation in their care and decisions. Overall, the review in this section concluded that the practice of FCC which emphasises and recognises the role of parents in the care of their child leads to the marginalization of the children and their role in their own care and decisions. The review in this section has influenced my thinking of the care delivery in a paediatric setting in Malaysia that incorporates some of the elements of FCC in practice.

After reviewing the relevant literature on children's participation in decisions in relation to their nursing care, it thus appears that there is a lack of research which:

- Uses a combination of interview and observational approaches to investigate the ways in which children participate in decisions, to give an overview of the whole picture of what is happening between the various groups of participants and enables the researcher to ask participants the reason for their actions.
- Pays attention to what happens during communication and decision making.

In the following Chapter I will discuss the ontological, epistemological and methodological approaches that I have adopted in this study to investigate and answer these questions.

Chapter 4: Methodology

4.1 Introduction

In Chapter 1, I acknowledged that children's, parents' and nurses' perspectives must be understood in facilitating children's participation in decisions relating to healthcare. Chapter 2 highlighted that the absence of information on children's participation in decisions relating to nursing care in Malaysia has created uncertainty. This uncertainty relates to whether interventions and approaches to care, largely derived from western medical culture, are appropriate and transferable to Malaysian children. From this evidence, it is noted that the problem appears to relate to the lack of meaningful studies and practical information in Malaysia that could help develop more appropriate policy and practice. As such, children's, parents' and nurses' perspectives in Malaysia and their understanding of children's participation in decisions relating to nursing care should be explored if appropriate approaches are to be developed.

This Chapter discusses the justification for choosing the adopted methods to answer the research questions. I begin by outlining the research questions and aims of the study, followed by the epistemological perspectives which frame this study and shape its focus. I then discuss how the principles of a focused ethnography approach have been practically applied in this study. It begins with a description of the research context, practical issues in the process of negotiating access, the study sample, and the fieldwork conducted for the study. A demonstration of the data analysis process is then presented. Finally, this chapter discusses ethical considerations, reflexivity, and the limitations of the study.

4.2 Research aim and research questions

The aim of the study was to gain an understanding of the participation of children diagnosed with leukaemia in decisions relating to nursing care; from the perspective of children diagnosed with leukaemia, their parents, and nurses. To fulfil this aim, the study was guided by the following research questions:

> **Research question 1**: How do children experience participation in decisions with regard to their nursing care?
>
> **Research question 2**: How do children prefer to participate in the decisions and what are their information preferences regarding their nursing care?
>
> **Research question 3**: What are the factors influencing children's participation in decisions with regards to their nursing care?

4.3 Epistemological considerations

This section considers the epistemological considerations that inform my research. For this research, I wanted to explore the perceptions and experiences of the participants. As such, I considered my participants as a source of information, who have knowledge and experiences which would help me to answer my research questions.

The principle of constructivism is that realities are constructed by the individual person or collectively constructed by groups (Guba & Lincoln, 1994). The constructivist perspective stresses that people are constantly engaged making sense and constructing realities through their lived experiences, social interactions and understandings (Lincoln & Guba, 2000).Hence, by adopting a constructivist epistemology, I perceive the knowledge and meanings of children's participation to be constructed by people through their experiences, interactions and understandings.

Each individual has his or her own understanding and interpretations of children's participation. Therefore, there are multiple interpretations of social realities. Thus , I did not want to gain 'knowledge' only from children, I also wanted to learn from the interpretations of parents and nurses who were involved directly and indirectly with children, to create a wider understanding of the children's participation in decisions regarding nursing care.

Within constructivism, social phenomena are produced through social interactions and thus researchers' own accounts of the social world are constructions (Bryman, 2012). This approach involves interactions between the researcher and the participant so that 'the findings are laterally created' during the process of the study (Guba and Lincoln, 1994: 111). As such, I decided that immersion in the social world of children diagnosed with leukaemia in the oncological setting was essential to understand how these children participate in decisions regarding their nursing care. This would allow close interactions between the participants and myself, enabling me to observe the activities of the participants and allowing them to tell their stories in their own words (Crabtree & Miller, 1999). Nevertheless, I am aware of the impact my perceptions can have on this research: thus, the use of reflexivity is beneficial, which will be discussed in section 4.13.

Moreover, in line with a constructivist epistemology, I adopted an ethnographic approach with several methods of data collection. Roper and Shapira (2000) point out that ethnographic study describes various perspectives of the participants within an interactive social context. Fetterman (2010: 1) adds that ethnography gives 'voice' to people to tell their story as they pursue their daily lives in their own communities. In reference to that, my research acknowledges participants' perspectives and experiences, recognising the importance of how they construct knowledge regarding children's participation in decisions relating to their nursing care.

4.4 Research design: focused ethnography

As reported in Chapter 2, there is a lack of research conducted about children's participation in decisions in relation to nursing care. Thus, this study intended to understand the experience of children with leukaemia in an oncological setting in Malaysia. Deliberating on the epistemological stance, I have chosen to conduct this research through a focused ethnographic approach. In this section, I provide an explanation of why the focused ethnographic approach is the most appropriate methodological approach for this study.

Among qualitative approaches, case study and grounded theory would potentially be the appropriate designs of choice in this study, as they allow the exploration of how children participate in decisions bounded within the social context. Upon further reading, I realised that this present study may not fit with one of the above approaches. Case study designs, for instance, may give productive information through multiple sources of data collection, including thorough observation (Merriam, 2009). It may also provide a sufficient understanding of the children's participation phenomenon within real child contexts. However, I realised the complexity in determining the 'case' for this current study. The case study literature suggested that the boundary is recognized as a key to determine a case. For instance, Stake (2000: p. 436) states that "not everything can be a case, a child may be a case, a physician may be a case, but his doctoring probably lacks the specificity, boundedness to be called a case". For this reason, I realised that it is inappropriate for a child to be the 'case', and problematic to have the involvement of children in the decisions as the 'case' because decisions are a relational process with parents and nurses. The boundaries of when it starts and ends make it hard to determine if the child or decisions are to be chosen for the 'case'. Therefore, it was inappropriate to use a case study approach in this study due to the difficulty in selecting the case, particularly because the case is key to this approach (Stake, 2000; Meriam, 2009).

Grounded theory may also allow for the exploration of the surrounding context of individual lives (Charmaz 1990). Grounded theory is not compatible with the aim of this research: to understand children's participation in decisions concerning their nursing care in Malaysia, from the perspectives of children, their parents, and nurses. In other words, the primary focus of this study was not on building theory, but exploring and understanding how children diagnosed with leukaemia participate in decisions based on my observations and participants' descriptions. Thus, a grounded theory approach was not a suitable method for this study.

With further reading, I came to realise that this study required focused ethnographic research as highlighted in Shapira and Roper's descriptions: i) focus on specific problem, ii) within a particular context, iii) among a small group of populations, and iv) to answer the questions that are formulated before going into the field (Roper & Shapira, 2000). The justifications for adopting a focused ethnographic approach as the methodology for this study are explained below.

4.4.1 Why focused ethnography?

A focused ethnography is an adaptation of traditional ethnography that addresses a phenomenon as it is experienced by a particular group in a specific context (Erikson, 2011; Knoblauch, 2005). There were several reasons for this focused ethnography. Firstly, since the aim of the study was to gain an understanding specifically about the participation of children diagnosed with leukaemia in decisions relating to nursing care in one oncology ward setting and from the perspectives of children diagnosed with leukaemia, their parents, and nurses, a focused ethnographic approach was appropriate as its emphasis was on the social context of the oncology ward, participant interaction and experiences. Thus, a focused ethnography was considered an appropriate methodological approach as it had a specific focus (Knoblauch, 2005; Roper & Shapira, 2000; Howard et al., 2016). The predetermined focus of this ethnographic study is that of a specific problem (children's participation in decisions) within a particular context (the oncology and haematological ward) among a group of populations (children, parents, and nurses) (Erikson, 2011; Knoblauch, 2005; Roper & Shapira, 2000). It focused on a group of children diagnosed with leukaemia, and their parents, and nurses who provide nursing care to the children; thus, the selected participants having specific knowledge regarding the research problem is an essential element of a focused ethnography (Roper & Shapira, 2000).

Secondly, focused ethnography is distinct from traditional ethnography by paying specific attention to a selected phenomenon, and therefore the researcher should be familiar with the area of investigation (Knoblauch, 2005). In this study, my professional background as paediatric nurse and experiences of caring for children diagnosed with leukaemia enabled me to converse with and observe the children as well as those with whom they interacted. This provided a multidimensional view of how children diagnosed with leukaemia participate in decisions regarding their nursing care.

Thirdly, the literature review on children's participation in consultation and decisions (see Chapter 2, section 2.5) identified that there is a lack of research which: i) uses a combination of an interview and observational approach to investigate the ways in which children participate in decisions, and ii) pays attention to what happens during the decisions concerning children. To bridge these gaps, this study attempted to use the combination of observation, interviews and the examination of documents, which are the methods appropriate for a focused ethnography design (Roper & Shapira, 2000).

Fourthly, the answers to the research questions in this study can be well explained through multiple ways of conducting focused ethnography including: participant observation, interviews, and the examination of existing documents (Roper & Shapira, 2000). Conducting intensive participant observation activities within the naturalistic setting, asking questions to learn what is happening, and using other available sources of information enables the researcher to gain as complete an understanding as possible of people, places, and events of interest (Roper & Shapira, 2000; Knoblauch, 2005). An observational approach gives an overview of the whole picture of what is happening in the decisions between the groups of participants (e.g. children, parents, nurses) and enables the researcher to ask participants about the reasons for their actions. In other words, adopting a focused ethnographic approach in this study enables an in-depth understanding of the individual child, their parents, and nurses' own meanings, and understandings of the participation of children diagnosed with leukaemia in decisions about their nursing care in a natural setting. Furthermore, it conveys how these meanings and understandings were transformed into meaningful thoughts within their social world.

Lastly, the main participants of this study are children. An ethnographic approach is popular among childhood and youth researchers (Punch, 2004; Gallagher, 2009). According to Punch (2004), ethnography is a means of engaging with the experiences and lives of children and young people in a specific context. It is a particularly useful methodology for studies involving children as it can employ children's own account within the analysis because it allows children a more 'direct voice and participation' in the production of data (Prout & James, 1997; 8).

As previously mentioned, I have an interest in the participation of children in decisions with regards to their nursing care from the perspective of children, their parents and nurses, who experience it. A focused ethnography design would be the most appropriate approach to study children's participation in decisions, as its intent is to concentrate on a specific social unit or identifiable activity within the social ward, thus, it enables a detailed description of a research problem (Roper & Shapira, 2000; Fetterman, 2010). This approach allowed me to explore the account of children's, parents', and nurses' stories in their own words to better grasp the meanings behind their social behaviour, which has the potential to provide a rich picture of the children's participation in decisions within the specific context of the oncological ward in Malaysia.

4.5 Study setting

The study primarily aimed to gain an understanding of the participation of children diagnosed with leukaemia in decisions relating to nursing care; from the perspective of children diagnosed with leukaemia, their parents, and nurses. To fulfil this aim, a setting that catered for the key informants (e.g. children diagnosed with leukaemia, their parents, and nurses) had to be selected to gain insight into the phenomena under study. Therefore, one of the public hospitals in Malaysia was chosen as my research setting because it has more cases of children diagnosed with leukaemia than elsewhere in Malaysia. The setting was chosen to obtain information from the participants with a good knowledge of children diagnosed with leukaemia and their participation in decisions regarding their nursing care. The oncology ward of the hospital receives around 180 – 200 new childhood cancer cases a year (information gathered from the ward census of 2015).

This study took place in a 32-bedded paediatric oncology-haematological ward of one of the public hospitals in Malaysia. Patients of the ward were aged sixteen and below. Based on the ward census of 2014, ethnicities of patients in the ward included Malays, Chinese, Indian, and other ethnicities such as Iban; most of the patients were Malays. The patients in the ward consisted of children diagnosed with various types of childhood cancer, including hematologic cancer and solid tumours (see Table 1). The ward census of 2014 also indicated that the majority of the children admitted to the ward were diagnosed with leukaemia, at fifty-six percent (56%). The length of treatment depends on the type of cancer. For example, the treatment for acute lymphoblastic leukaemia is usually 2.5 years for boys and 2 years for girls. However, 18 months of this is maintenance treatment, which means that patients will attend the hospital (for treatment) once a month for chemotherapy. The first year of treatment is usually intensive with numerous hospital admissions. According to the head nurse of the ward, most of the hospitalised children were accompanied by their mother, only a few children were accompanied by their father or other family members such as siblings or cousins.

Generally, there are several levels of the nurses in Malaysia: community nurses, registered nurses, nurse-midwives, and head nurses. A community nurse (CN) is a person who has undergone a formal course of community nurse education (two years training in the community nursing college). A registered nurse (RN) is a person who has undergone a formal course of nursing education (either three years diploma or four years degree programme), and is registered with the Malaysian Nursing Board

(Malaysia Nursing Board, 2015). A nurse-midwife is a registered nurse who has successfully completed a one-year course of studies in midwifery, and has acquired the requisite qualifications to be registered, and legally licensed to practice midwifery (MOH Malaysia, 2013). A head nurse (HN) is a registered nurse or a nurse-midwife who generally has had 15 years' experience working in clinical practice.

With regards to the research setting, there are different levels of nurses (RN and CN) who work collaboratively to manage children with different illnesses. There were also ancillary staff (also known as nurse's aides) assigned in the setting – who do a non-nursing job and assist RNs and CNs in the care of children in the ward. In total, there were 25 RNs, all were female, with two (2) CNs, and six (6) ancillary staff, which were led by two HNs (see Table 5). The ethnicity of the RNs of the ward were Malay and Indian.

The team nursing care delivery model was adopted, whereby a small group of nurses worked together, guided by a team leader, which uses a group of healthcare workers with diversity in education, skills/abilities and licensure (Tiedeman & Lookinland, 2004). The nursing duty was divided into three shifts: morning shift (0700 – 1400hr), afternoon shift (1400 – 2100hr), and night shift (2100 – 0700hr). The official nurse allocation for each shift are six (6) RNs, with four (4) RNs taking charge of the patients (maximum of 8 patients per RN), one (1) RN assigned as a team leader and another as a runner. The runner can be the RN or the CN. However, the nursing staff shortage was critical during the data collection period at the setting; frequently, there were only 4 to 5 RNs on duty. At the time, one RN was assigned a dual role, working directly with patients and acting as team leader. According to the sister in charge of the ward, they could work well with the nurse coverage of six RNs per shift. Despite the ward sister making a formal work distribution, I observed nurses working together covering all patients during the administering of medication and routine vital sign checks. RNs were regularly in direct contact with the patients and performed most of the nursing interventions, including those for children diagnosed with leukaemia.

For this study, the children, parents and nurses were sampled from the oncology and haematological ward of the study setting. The inclusion of children diagnosed with leukaemia and their parents who accompanied them, and the nurses who work in the oncology and haematological ward of the hospital allowed for an investigation into their experiences of caring and their involvement in the decisions concerning children. It would allow the participants in this setting to provide rich information for this study. In the next section (4.5.1), I provide information regarding ethical approval and negotiating access.

Table 6: Summary of the research context

Name of Hospital	A public hospital
Ranking	Tertiary
Number of staff	
Head Nurse	2
Registered Nurse	25
Community Nurse	2
Ancillary staff	6
Major cases in year 2014 (%)	
Acute Lymphoblastic Leukaemia (ALL)	50
Acute Myelogenous Leukaemia (AML)	6
Neuroblastoma	14
Retinoblastoma	18
Medulloblastoma	12
Average number of leukaemia cases (2014)	3,000 (mix of new and old cases)
Description: The hospital is a comprehensive Public hospital. It is a leading Public hospital with prevailing advanced medical technology and a well-known, high quality medical service. There are nine wards, including, surgery, medical, orthopaedic, oncology haematological operation theatre, paediatric intensive care unit (PICU) and neonatal intensive care unit (NICU). The hospital providing various subspecialty services, serves as a tertiary referral centre for the country, while continuing to provide core services in general paediatrics and the neonates. The hospital also serves as a referral centre for paediatric surgery, oncology and haematology, orthopaedics, child psychiatry, and paediatric intensive care throughout Malaysia. All children aged sixteen years and below are rightfully placed under the care of the paediatrician in the hospital.	

4.5.1 Ethical approval and negotiating access

Ethical approval was sought and granted from two main research ethics committees: The Ethics Committee of the School of Health in Social Science in the University of Edinburgh and the Malaysian Medical Research Ethics Committee (MREC).

Upon approval from the Ethics Committee of the School of Health in Social Science, University of Edinburgh (Appendix 12), the ethics approval from the Malaysian National Institute of Health Research (NIHR) and MREC were applied for through online registration with the Malaysian National Medical Research Register (NMRR). The process of application was monitored at the NMRR website. The final decisions were notified by the MREC through email to inform the status of the application (Appendix 13). Approval from the Economic Planning Unit, Department of Prime Minister Malaysia was also sought in order to obtain the research pass as this research was considered to be an application from outside Malaysia. Prior to submitting the study for ethical approval, permission from the authority of the study site was first sought. The application letter details the study was sent to the director of the hospital and the head of department of the study setting for their willingness for me to undertake the research in the setting.

Overall, the process of negotiating access was time consuming and challenging, but, clarity in describing how the study would be conducted was essential for protecting the participants' rights and wellbeing. Once approval for the study was obtained, I then sought permission from the relevant gatekeepers to access their practice and gain their support throughout my data collection period. I arranged a meeting with the head of the department and the director of nursing of the setting. The purpose of this meeting was to re-familiarize them with an overview of the study and the planned process of conducting the research. The major challenges of the main fieldwork study site included obtaining permission from the management of the study setting. There were two meetings which were held with the administrators on October 2014 before part one of data collection began, and another meeting in June 2015 (before the beginning of part two of data collection) (see Figure 2). The meetings reviewed the research purpose, the research methods and the feasibility of the study. Prior to part one of data collection, an overview of the study was presented to the team of physicians and nurses in the ward in order to gain their feedback and facilitate access to potential participants. The outcome of both meetings was positive as the Head of Department verbally endorsed the research proposal and offered to be the on-site contact person for the research project if required.

4.6 Sampling strategy

It was my responsibility, as the principal investigator, to recruit individual participants to take part in the study. In this study, purposive sampling was employed. Purposive sampling is the most common sampling method used in qualitative research (Bryman, 2012). Participants in this study were selected because they held particular characteristics, which enabled a detailed exploration and understanding of children's participation in decisions in Malaysia. The aims of this type of sampling are to ensure that all the relevant areas involved in the participation of children in decisions are covered, and to include some diversity, so that the perspective of children's participation is comprehensively explored. Chapter 2 recognized that children's participation could be influenced by cultural differences, however, the cultural diversity of the participants in this study was insufficient for comparison.

4.6.1 Study sample

The potential participants for this study were determined by the research questions and characteristics of the population. The study population was decided upon based on the central interest of this study: children diagnosed with leukaemia, their parents who attended the oncological care at the chosen hospital, and nurses who work in the hospital and take care of children diagnosed with leukaemia. Recruitment of the participants was conducted in the oncology and haematological ward of the hospital. Three groups of participants were identified to answer the research questions: i) children diagnosed with leukaemia, ii) parents of children with leukaemia, and iii) nurses with experience of caring for children with leukaemia. The inclusion and exclusion criteria for each group of participants are as follows.

4.6.1.1 Inclusion and exclusion criteria: children

Setting up a selection criterion in the early stage of the research is essential in purposive sampling (Ritchie, Lewis and Elam 2003). The inclusion criteria for the children in this study were: having a diagnosis of leukaemia, aged 7-12 years, and sufficiently fluent in Malay or the English Language to participate in the interview. To be noted here is that there was a child who did not fully understand Malay (see Chapter 6, section 6.2.2) but was included in the observation to observe how nurses support the participation of children with language barriers in decisions. It could be argued that children should be encouraged and supported to participate in their care and decisions regardless of their ability to speak and understand a certain language. Nurses working in a paediatric ward should be competent in communicating with children of all ages (Royal College of Nursing, 2010), and must be able to listen to children, to respect their needs for information and to be prepared and able to give the correct amount of such information (Donnelly & Kilkelly, 2011). The exclusion criteria included the children who were: in a critical condition (confirmed by the physician in charge), receiving palliative care, and not fluent in Malay or the English Language.

With regards to the age group of children selected for this study, I acknowledged that there is a pattern of development that children are expected to follow based on their age, however, each child develops in a unique way. A literature review on the participation of children in decisions indicated that the involvement of children in decisions is not mainly influenced by their age (Alderson, 1993; Runeson et al., 2002a). A study found that children as young as four are capable of being involved in their care and discussing issues that are of importance to them (Alderson, 1993). Indeed, Alderson and Goodey (1996) suggest that children with health problems may mature more quickly and their experiences increase their understanding even at a young age. In addition, the UNCRC sets no minimum age at which children can begin expressing their views freely, nor does it limit the contexts in which children can express their views. The Convention acknowledged that children can and do form views from a very early age and refers to children's developing capacity for decision- making. Thus, any child, regardless of age, could be involved in the decisions concerning them. Taking this into consideration, I decided to restrict the age range for participants in this study to school-age children between the ages of 7 to 12 years, as the majority of children with leukaemia admitted to the research setting are within this age range. This would influence the recruitment of children, who are the main participants of this study. This justifies the age group selection for this study. Furthermore, this study excluded children who received palliative care because palliative care occurs at a time that can be extremely distressing for children and families (Jackson et al., 2007; Coyne et al., 2016), thus the children and parents were excluded from the sampling frame because the focus was on ordinary everyday situations in clinical care.

4.6.1.2 Inclusion and exclusion criteria: parents

The mother or father who has been taking care of a child diagnosed with leukaemia in the oncology and haematological wards of the study setting were recruited. The inclusion criteria for the parents in this study were those who have a child aged 7-12 years and diagnosed with leukaemia, and sufficiently fluent in Malay or the English Language. The exclusion criteria for the parents were thus, those who have a child diagnosed with other types of childhood cancer or those who had a child diagnosed with leukaemia, but aged less than 7 or more than 12 years, and those who do not accompany their child in the ward, and are not fluent in Malay or the English Language.

4.6.1.3 Inclusion and exclusion criteria: nurses

The nurses were recruited from the oncology and haematological ward of the study setting. The inclusion criteria for the nurses in this study were those who work in the ward, and who are sufficiently fluent in Malay or the English Language. The exclusion criteria for the nurses were those who do not work in the oncology and haematological ward, and those not fluent in Malay or the English Language. The selection of nurses who had been working in the oncology and haematological ward, without limiting the years of experience was to ensure a diverse range of seniority of nurses to capture a wide range of their views and experiences in relation to the participation of children diagnosed with leukaemia. Although the ward managers were the RNs, they were excluded from this study because their job scope mainly covers administration work rather than providing the direct care of children with leukaemia.

Table 7: Summary of the inclusion and exclusion criteria for study participants

Participants	Inclusion criteria	Exclusion criteria
Child	• Child, who is currently diagnosed with leukaemia • Age of 7 to 12 years old • Sufficiently fluent in Malay or English Language to participate in the interview.	• Child diagnosed with leukaemia, who is in critical ▪ Child diagnosed with leukaemia, who is in critical condition ▪ Not fluent in Malay or English Language
Parent	▪ Father or mother of a child aged 7-12 years, and diagnosed with leukaemia, ▪ Father, mother or carer who accompany their child in the ward ▪ Sufficiently fluent in Malay or English Language to participate in the interview.	▪ Father or mother of a child diagnosed with other type of childhood cancer. ▪ Father or mother of a child diagnosed with leukaemia, but aged less than 7 or more than 12 years. ▪ Father or mother of a child with leukaemia aged 7-12, but does not accompany their child in the ward. ▪ Not fluent in Malay or English Language
Nurse	▪ Registered nurse (RN), currently practicing in the ward. ▪ Sufficiently fluent in Malay or English Language to participate in the interview.	▪ The ward managers ▪ Not fluent in Malay or English Language

4.7 Recruitment of participants

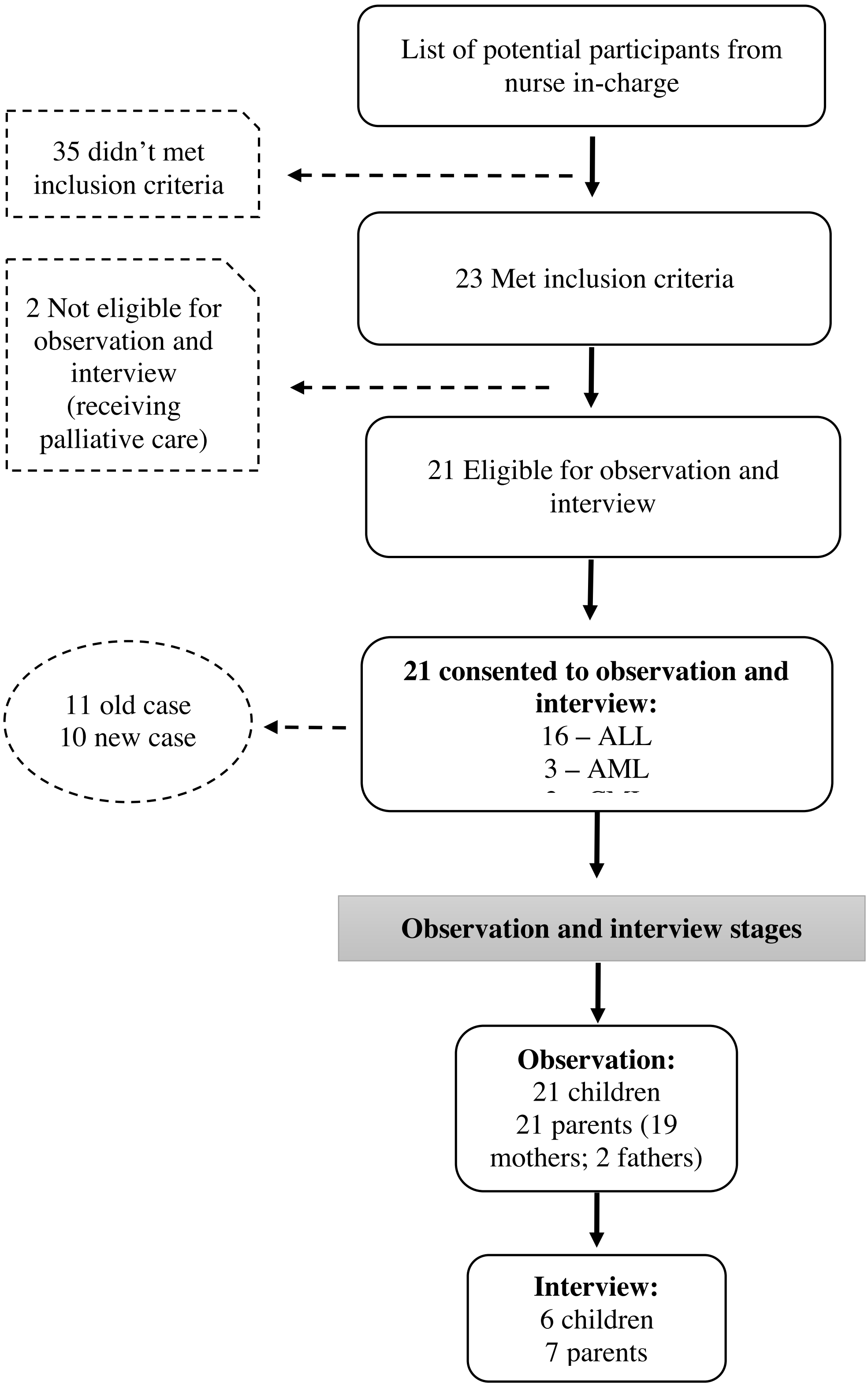
As illustrated previously, there were three groups of participants recruited in this study: children diagnosed with leukaemia, parents of children diagnosed with leukaemia, and nurses who work in the oncology and haematological ward. The process of recruitment of the participants is explained as follows.

4.7.1 Recruitment of Child and Parent Participants

The recruitment of children diagnosed with leukaemia and their parents began with the invitation to participate in the study. Initially, the nurse in charge provided me with a list of potential participants. I then personally met those who fulfilled the inclusion criteria to explain the nature of the study, making it clear that their participation was voluntary, and that refusing to participate in or withdrawing from the study while it was in progress would not affect their care in any way. The parents were given the Participant Information Sheet (Appendix 2), details about the research and invited to participate in the study. The children were given a different version of the Participant Information Sheet which had less words and was colourful (Appendix 1). With awareness of the potential ethical issues at the initial recruitment, I spent time explaining the nature of the study to the children. Written consent from the guardian was obtained for the child participants. The children were asked for their assent to participate in the research (Peart & Holdaway, 2000). Before the fieldwork began, I reassured their confidentiality by informing them that a pseudonym would be used, to ensure their identity was kept a secret and that the information would not be used to identify them or describe their life but rather to explain the experiences of a child in their community. I also tried to establish rapport with child and parent participants by attending to them and having an informal conversation pertaining to them a few times before my fieldwork began. Also, I spent time playing with the child whenever they were free (e.g. jigsaw, colouring book, and educational games (mathematic) using an iPad).

Over the course of the study, the 42 participants of 21 children and 21 parents were recruited. The children were between 7 to 12 years of age; the majority were diagnosed with ALL; only three were diagnosed with AML, and two children were diagnosed with chronic myelogenous leukaemia (CML). Overall, eleven children were old cases of leukaemia and ten children were newly diagnosed clients (Appendix 9). For parent participants, 19 mothers and two fathers, with an age range of 33 to 58-years-old were recruited (Appendix 10). The majority of children were accompanied by their mother. This explains why the recruitment of parents were mostly mothers. The next section (4.7.2) details the process of recruiting nurse participants.

Figure 3: Summary of recruitment strategy of child and parent participants



4.7.2 Recruitment of nurse participants

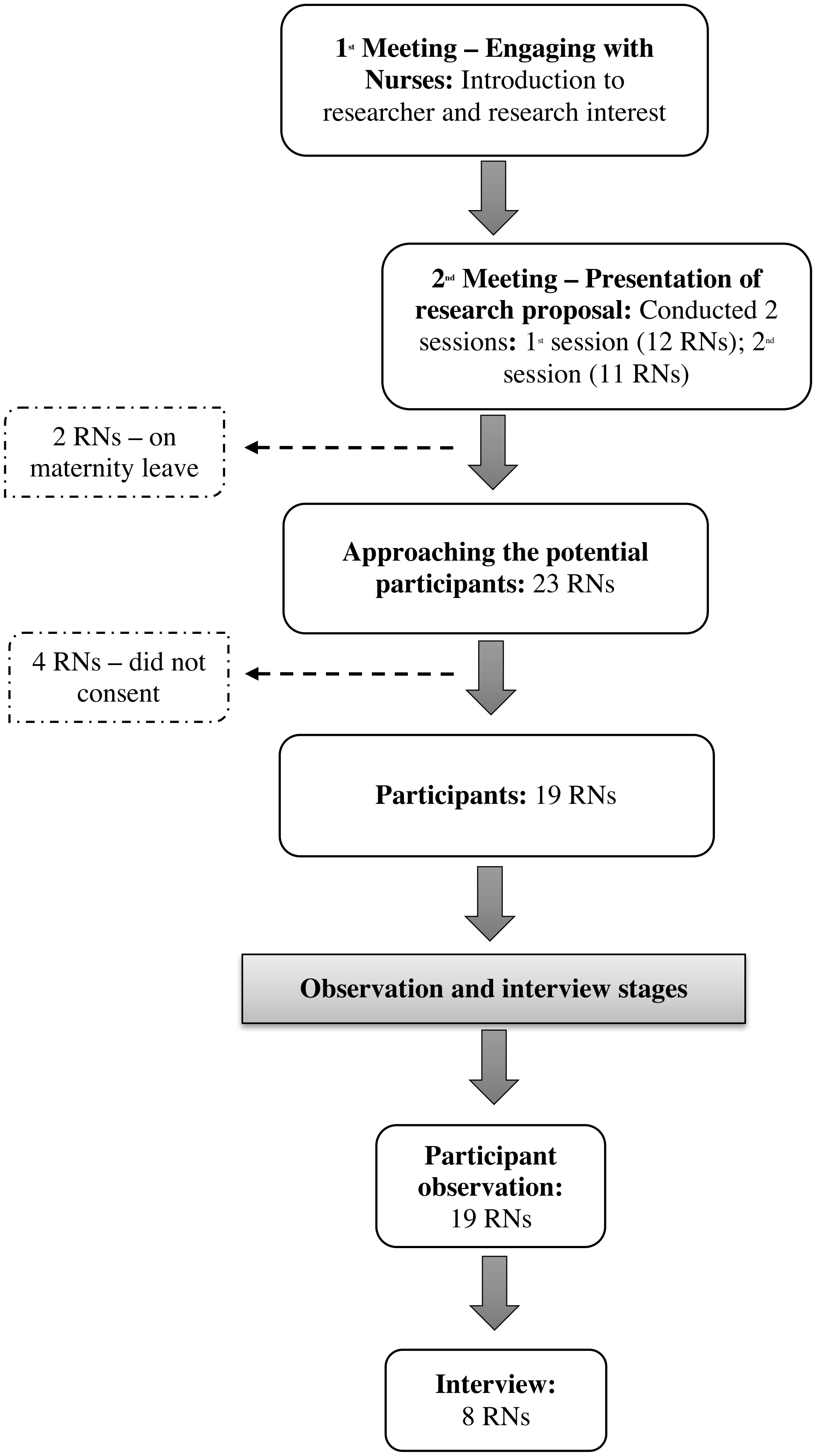
The goal to recruit nurse participants was to include the nurses who delivered the most care for children with leukaemia in order to analyse how they involved children in their care and gain their perspectives on the participation of children in decisions relating to nursing care. As illustrated in Figure 2, with the assistance of the nurse managers, two meetings were organized in the unit to inform all members of staff about my study. The purpose of the meeting was to establish rapport with the nurses thereby allowing researcher-participant engagement. At the end of the first meeting, the nurse managers were approached to arrange the second meeting. The second meeting was divided into two sessions to include all nurses from the ward. The aims and the processes of the study were presented to all nurses in the second meeting. At the end of the second meeting, the nurses were given a flyer (Appendix 4) and the Participant Information Sheet (Appendix 3). They were asked to provide their name, years of working in the ward and contact number if they were interested in participating in the study. The nurses were given at least 24 hours before the eligible nurses were approached about whether they wished to participate in the study.

I am aware of the possibility that some of the nurses may have felt authoritative pressure from the managers, because to some extent the gatekeepers may have enhanced the research credibility with their support (Sixsmith et al., 2003), and such recruitment may also influence the way in which the participants provided information (Orb et al., 2001). Keeping this in mind, I tried to gain access to the nurse participants for observation and semi-structured interviews through my personal contact at the stages of fieldwork. Although I had not known the participants previously, I had to be mindful of such potential ethical issues during the initial recruitment process. Before the observation and interview session, the nurses were informed that they had the right to withdraw from the study at any time without the need to give a reason and I assured them of their anonymity and confidentiality. Subsequently, the nurse participants were verbally asked for their consent prior to the interview session. None of the nurse participants who consented at the earlier stage of recruitment withheld their consent for the interview session. It should be noted that different nurses provide different nursing care to the same children during each shift. Hence, I intended to obtain informed consent from all RNs on duty during my fieldwork to enable the observation of the nurses that were involved with the child and parent participants (Appendix 6). However, four nurses who were newly graduated and who had worked in the ward for less than a month withheld their consent for both observation and interview. Those nurses were ensured that the provision of their nursing care to the children in the ward would not be observed and recorded. They were also reassured that if I indirectly observed them, their activities with the children would not be used for analysis. Considering this, I always kept in mind those nurses and tried where possible not to observe their nursing care activities with the child participants.

Throughout the fieldwork, out of 25 RNs, 19 RNs were recruited. The nurse participants had a range of years of experience with the majority having served for longer than five years; six participants had less than five years of experience, 14 participants had between five and 10 years of experience and five had over 10 years' nursing experience. There were six nurses who were ineligible to participate in this study: two RNs were on maternity leave, and another four RNs refused to participate in this study. These nurses' refusals derived from them believing that they did not have enough experience to share with me. I came to realise that although they were newly graduated, these nurses might have had some interesting data which I was not able to capture in this study. For instance, they might be more compassionate than those more experienced nurses, which might influence their ability and willingness to get children involved in decisions. Studies have found that the more recently the nurse has graduated, the higher their levels of empathy (Forsyth, 1979; Shapiro, 2008; Ozcan, Oflaz, & Sutcu Cicek, 2010).

In total, 61 participants including: 21 children, 19 mothers, 2 fathers, and 19 nurses were recruited and all completed their written consent to participate in the study. The profiles of the nurse participants are summarised in Appendix 11.

Figure 4: Summary of recruitment strategy of nurse participants



4.8 Fieldwork

The main method of data collection for this ethnographic study was participant observation. As part of the data generation process, I triangulated participant observations, interviews, and the examination of documents to investigate the context for children's participation in decisions for children diagnosed with leukaemia in an oncological setting (refer Table 8). I conducted fieldwork in the Public hospital from October 2014 until January 2015, and continued this from June 2015 until August 2015. In total, six months of fieldwork were conducted in the study setting in 2014 – 2015. The data collection was divided into two phases because when the analysis of data collected from the first phase was completed, I realised that I did not have enough evidence to support the discussion of the emerging themes. Therefore, the data collection was extended for a further 3 months to generate more evidence.

Table 8: Summary of the data collection

Method	Fieldwork Date	Sample	Setting
Pilot study Participant observations Individual interviews	2 sessions in October 2014	2 nurses 2 children 2 mothers	Oncology and haematological ward
Main study Part one Participant observations Individual interviews Examination of document	November 2014 to January 2015	15 nurses 9 children 8 mothers 1 Father	
Main study part two Participant observation Individual interviews Examination of document	June 2015 to August 2015	19 nurses (the same 15 nurses involved in part one + 4 new nurses) 10 children 9 mothers 1 Father	
Nurse participants	19 nurses		
Child participants	21 children		
Parent participants	19 mothers; 2 fathers		

4.8.1 Participant observation

Participant observation was the main method of data generation in this research. In health settings, participant observations are suitable for research that involves children and their families (Carnevale et al., 2008). In this study, participant observation involved spending time with, observing, and talking with children, parents and nurses in the oncology and haematological ward.

My fieldwork began with an informal observation during the first three days in the field. The observation was conducted for 3-4 hours per shift for three days. These observations were to gain a feel for the setting, such as the layout, staffing, model of care delivery, nursing routine, and types of patients. The purpose of this was to establish familiarity with the ward layout and daily routine, the staff and the families, to identify the desired sample characteristics, to minimize misinterpretation of contexts that were observed during the data collection period, and to work out the important questions to be asked (Coyne & Gallagher, 2011).

I then conducted two sessions of participant observation and individual interviews with two children, two parents and two nurses, which took place over two days. The purpose of these sessions was to test the observation tools and interview questions. A checklist for participant observation (Appendix 7) was prepared prior to the fieldwork, however, during this session, I realised that it was not possible for me just to rely on the checklist. I came to see that some things were not captured in the checklist, and for these a reminder was needed, which is time consuming but gives richer data. I came to realise that I should be more open and not constrained by the checklist during the observation, and began doing observation without the checklist, so that I did not miss out on some interesting data (Fetterman, 2010). This helped me to be more prepared for my fieldwork.

In terms of interview questions, some of the participants, especially children and parents, had some difficulty understanding some of the questions I asked during the interview process. Some of the questions had to be rephrased and some examples of situations had to be given to increase the participants' understanding of the questions

(Christensen, 2004). For example, some children had difficulty understanding the phrase ‘participation of children in decisions’ in Malays, and thus, an example of a situation was given, for instance, *‘Do you ever get involved in discussions or decisions about, for example, when to take your medication, or when to do your dressing, or about what you want to have for your lunch or dinner?’*. This session was very useful because it prompted me to find a way that better corresponded with the children’s understanding.

The subsequent participant observation was non-continuous and was spread out throughout my fieldwork (Fetterman, 2010); it continued three days per week (alternate days). I attempted to observe each child and parent for at least three days, to see the progression of involvement of children in decisions relating to nursing care. The child participants all routinely received nursing care from the nurses in the unit. I observed several client consultations between the nursing team, children and parents. Each time nurse participants attended to the child participants, I followed to observe the interaction between them. I spent time observing consultations between nurses, children and parents in the ward, to see for myself the benefits and challenges of involving children in decisions relating to nursing care. The daily observations included all activities the nurses delivered to the child in addition to formal situations such as nursing rounds, serving medication, checking vital signs, performing dressings, taking blood specimens, and informal situations such as small talk during procedures. Nonetheless, as previously mentioned (see section 4.7.2), the provision of nursing care by the four nurses who did not consent for observation were not observed or recorded.

4.8.1.1 The role of researcher

According to Roper and Shapira (2000), there are four roles of involvement in the participant observation continuum: participant, participant-as-observer, observer-as-participant, and observer. The aims of this study were to understand the children’s participation in decisions and to explore this from the perspectives of children, parents, and nurses. In this case, neither participant nor observer were applicable.

Most ethnographic information is collected when the researcher is in the role of participant-as-observer or observer-as-participant (Roper & Shapira, 2000). Adopting the role of observer-as-participant would have limited my involvement in the ward activities, and thus, there would have been less chance for validation of observations with the participants and more opportunity for bias to influence the interpretation of events, actions, and behaviours (Roper & Shapira, 2000). This role does not fit with the aims of this study, as there was a need for full involvement in the interactions of the participants.

Rather, I positioned myself as participant-as-observer, that is, as fully involved in the interactions in the setting, but at the same time explicit about my status as a researcher (Parahoo, 2006). This role best fit with the aims of this study because by employing this role, I could get involved in the ward activities and see events and actions from an insider's point of view, and it enabled me to validate observations with the participants while observing, interpreting, and recoding to have a better understanding of children's participation in decisions (Roper & Shapira, 2000).

With no previous experience of the setting, my fieldwork commenced with some nervousness. From the beginning, I was aware that to research children, it was important to establish relationships with children so that they would want to continue throughout the research process (Christensen, 2004). In the early stages of my fieldwork, I introduced myself as a nurse researcher, and explained the aims of the study to the children by saying, for example, 'I am interested in how children diagnosed with leukaemia experience the hospital, especially, how the children get involved in their care and decisions.' I further explained that it was important for me to get a better understanding of what it means for children themselves, by knowing what they think and do, with the hope to convey to the children the emphasis I put on their own perspectives in the research process (Christensen, 2004). I always introduced myself as nurse researcher, so that the participants knew that I was an active observer. My previous experience of working in a paediatric ward with children with leukaemia provided me with interpersonal skills to communicate with nurses, children and their parents, who came from a mixture of ethnic and educational backgrounds with a range of experiences.

As previously mentioned, my role as participant-as-observer meant being involved in most of the nursing care provided to the child participants, however, I did not perform any activities that are part of the legally defined role of the nurse (e.g., giving medication, administering treatments). I participated whenever appropriate, as judged by the nurse in charge, in non-legally defined roles as might be performed by a care assistant. Like other ethnographers in the field, I willingly became involved in the ward activities involving my participants. I also talked and played with the children, helped with the meals, accompanied the children to various parts of the hospital (such as the radiology department, and clinics), and assisted with the nursing procedure (dressing, blood taking). My participation with the activities involving the participants allowed me to ask questions when I needed to clarify why a child, parent or nurse did a particular action (Roper & Shapira, 2000).

Although the focus of my role was to participate and observe the social interaction between children, parents and nurses around the participation of children in decisions, I did not want to start with a preconceived idea of what was meant by this. Thus, I began by recording everything I could about what happened when nurses provided nursing care to the child within the ward. This unfocused approach is common at the commencement of this form of research (Mason, 2002). As my fieldwork progressed, I came to recognise that observations are necessarily selective. I also had to be aware that my focus should not be too constricted, which can lead to missing something important in relation to my study context.

During my time as a participant observer, my role gradually became that of part volunteer, occupying my time helping nurses in activities such as feeding patients, and assisting patients to the treatment room or washroom. I also helped with certain aspects of patient care in the presence of a nurse, such as transferring a patient from one room to another. However, I was fully aware that my priority objective was to do participant observation.

As I was essential to the data collection, it was sometimes uncomfortable being neither a client nor a practitioner. The nurse participants sometimes involved me in their client's consultations, and the parents always questioned me regarding the care and treatment of their child; this is where I faced ethical dilemmas in giving advice. It was challenging to determine how this would have disturbed the data collection; although the nurses, children and parent participants accepted my presence without query, the care of children might have been different to the usual standard.

One main concern often raised in relation to observational research is the effect of the observer on the observed (Fetterman, 2010). My presence in the setting could disturb the natural environment and trigger a change in typical human behaviour (Lambert et al., 2008). It is possible that at times the nurses, parents and children could have altered their behaviour in my presence. However, it is believed that my ad hoc coming and going, the busy noisy real-life environment in the setting and the prolonged time spent on the oncology and haematological ward combated any sustainability in behaviour changes (Lambert et al., 2008). As Fetterman (2010: 39) contends, 'given time, people forget their 'company' behaviour and fall back into familiar patterns of behaviour'.

4.8.1.2 Recording observation data

Data produced from participant observation mainly consisted of fieldnotes, taken in handwritten form in a fieldwork notebook. I had selected manually writing in a notebook because it allowed me to write immediately after each observation, and to be quicker at handwriting than typing on a tablet or laptop. As the nursing procedure or care session for each child was usually around thirty minutes to an hour, it was practical for me to make all my notes after each session. Normally handwritten notes were scribbled down to record data about the event to focus on each session to help me to recall and write about the events later in more depth (Emerson, et al., 2011). Writing the notes immediately after the event helped me to recall the situation and this was useful for prompting me to reflect analytically on my notes. Taking into consideration the reliability of the human memory, fieldnotes were written timely, consistently and in an organized manner based on what had been observed

(Fetterman, 2010; Bryman, 2012). What was done and what was said by participants was recorded in as much detail as possible, including the words, or approximate words used by those participants as these vocabularies can be used in understanding the participation of children in decisions in this setting (Hammersley & Atkinson, 2007). The observation and informal interview notes were recorded in my notebook, jotting down the participants' sentences that concisely described their experience. I was clear in my notes whose expression was being represented and whether I was directly or indirectly citing a participant. However, in the situation where direct communication could not be recalled, paraphrasing or indirect citing was used (Emerson et al., 2011). This was followed by typing up a more formal note, then, jotting was done, which I would use to restructure my observation of what I had seen and heard in more detail. The set of field notes were typed up as a Word document within 48 hours to avoid missing information. These full field notes were completed before I re-entered the field again to prevent the possibility of confusing events and to ensure the field notes reserved the freshness, excitement and nuanced detail (Emerson, et al, 2011), and to prevent unrecorded information being overshadowed by subsequent events (Fetterman, 2010).

4.8.2 Semi-structured interviews

Another form of data collected and analysed in this study arises from semi-structured interviews with children, parents and nurses in the setting over the six months research period. While observations and informal conversations formed an important part of the study, it only provided a partial insight into the participation of children diagnosed with leukaemia in decisions relating to nursing care. Semi-structured interviews were incorporated into my methodological approach to supplement and verify the participant observation data. The interview was designed to facilitate a discussion of the participants' individual understanding and experiences of children diagnosed with leukaemia's decisions relating to nursing care, to reflect upon what they do and why they do it in the setting. It also gave me an opportunity to verify details that I was unsure of during my observation (Fettermen, 2010).

4.8.2.1 The interview guide

Prior to the interview process, an interview guide was developed to facilitate the semi-structured interview process (Appendix 8). In this study, the interview guide consisted of several specific questions to be asked of every participant; questions based on participant observation, as well as open-ended questions depending on participants' responses. As this study employed a focused ethnographic approach, the topic and issues listed are focused specifically around children's participation in decisions. The topic guide was used regularly in the first few interviews, but when I became more familiar with the listed issues, it was only used to confirm that all topics had been covered. As mentioned earlier, after the pilot study, some modifications were made according to participants' responses to the questions to ensure the clarity and understanding of the language and concepts (see section 4.8.1).

4.8.2.2 Interviews with children, parents, and nurses

After three weeks in the field, I began to conduct semi-structured interviews with some of the children, parents and nurses. The individual semi-structured interviews were carried out as informal conversations to probe the participants' interpretation of their practice and experience relating to children's participation in decisions.

During my fieldwork, I spent time interacting and in conversation with the child participants. I am fully aware that some children appeared shy and would refuse to talk at times because of their illness, but, could communicate well at other times and on different days. When the children were given the opportunity to communicate they would often become more talkative. For example, Alexis was generally a quiet boy but could voice his opinion when he was asked for his views. Therefore, children who could freely interact and communicate with me, without being influenced by their parent(s) were invited to participate in a semi-structured interview.

I tried where possible to interview the children immediately after the observation session. Although the location had been set up (a meeting room in the respective ward), the children could choose the location in the hospital for interviewing as they wished to provide comfort during the interview process. Also, this would ensure that children felt they had control over the interview location and duration so they were not tired. Children who agreed to be interviewed in the meeting room were transported to the meeting room with the awareness of the nurse in charge. All children agreed for the interview to be conducted in the meeting room, but one of those who had a few IV infusions, requested that the interview be held in his unit as he is the only patient in the room (4 beds sharing room). Taking into consideration the tiredness that the child may experience, I considered his request and he agreed to my suggestion for his mother to leave the room while the interview was conducted. This may not affect the overall quality of the data; however, concerns about being alone may have influenced the children's responses throughout the interview session.

For parent and nurse participants, the interviews were conducted in the meeting room in the ward. The interviews with parents were conducted immediately after the observation session, where possible, while the nurses were interviewed after their morning shift. Although they were tired, it was more convenient for them and they could reflect upon behaviours in the preceding nursing care to the children. This allowed for the discussion of behaviours to be more evident.

The interviews were recorded using an audio recording device with participants' consent. Each interview lasted from 30 to 90 minutes depending on how much time the participants had and how much they had to say on each topic area, however, interviews with children lasted less than 60 minutes. All interviews were transcribed verbatim to facilitate an analysis of what the interviewees said and how they said it (Bryman, 2012). Interviews were all transcribed verbatim by myself. Self-transcribing allowed close interaction with the data set, which enabled me to be more sensitive to the underlying sense of participants' meaning. These were written in word format and were organised according to participants' pseudonyms in a computer to facilitate the analysis process.

4.8.2.3 Translation considerations

All interviews in this study were conducted in the Malay language. Taking into consideration the ability to maintain accuracy in representing people's views and perspectives when the research project is conducted in one language and then analysed and synthesized in another (Temple & Young, 2004), attention was given to whether the original Malays version or English translation was to be used for analysis. Although translation and back translation by two competent bilingual translators who are familiar with the research has been suggested as a good practice for translation, he/she may not be able to wholly capture the languages used by the participants by only reading the transcribed text (Harrington & Turner, 2001). In addition, this process is time consuming and expensive which is beyond my capability as a student researcher. With careful consideration, I decided to analyse the transcriptions in the English version. I consider myself as proficient in the language of the communities I am researching, and fully understand the context of the interviews. This offered me the opportunity for close attention to the meanings and interpretations and potentially brings up any problems of meaning within the research process (Temple & Young, 2004). To ensure the consistency of the translation, I was the only translator and undertook all the translations for the study. In considering the issues of translation such as wording, terms and meaning, and the need for understanding the data for this study, the raw data were kept in place for further checking and comparison. I constantly revisited the raw data and compared them with the developed codes. To ensure the validity, accuracy and readability of the translation, a bilingual colleague was referred to during translation and assisted me in checking a selection of the translations independently. The translated excerpts and the developed codes were shared with the supervisors to facilitate the analysis process and supervision.

4.8.3 Examination of documents

A third source of information for this study was the examination of the existing documents. Roper and Shapira (2000) suggest that examination of the existing documents pertinent to the research focus is useful to understand the community and to validate the participant observation and interview findings. They recommend that ethnographers should be creative in identifying the documents that will help with the study completion. Thus, my aim was not only to identify the relevant documents, but also to explore how the documents were taken up and how they impacted on the children's participation in decisions relating to nursing care.

The documents in the context of this research included:

- Patient case note,
- Patient nursing report,
- Standard of Procedure (SOP) – Nursing procedures,
- Policy statement of the ward,
- Patient and Family Rights Policy, and
- Census figures.

The examination of these documents was to capture relevant information relating to the participation of children in decisions with regards to nursing care, to prevent researcher observation bias, which may occur during the process of observations and interviews (Alaszewiski, 2013). The documents were treated like detailed descriptions of observations and transcriptions of interviews for analysis.

In summary, triangulation of data sources including participant observation, interviews, and the examination of existing documents were used in this study. The triangulation of research methods has been shown to aid conceptual understandings and improve validity, and compares information sources to test the quality of the information (Fetterman, 2010). The use of these three forms of data provided a holistic picture of children's participation in decisions from the perspectives of children, parents and nurses and served to validate each other (Roper & Shapira, 2000).

4.9 Data management

Observation, informal conversation, semi-structured interviews, and examination of documents were converted into field notes, and tape recorded interviews were transcribed. My personal comments, reflection, mood, attitude, and judgement during specific stages of the research were kept separately from the observation and interview notes. To ensure participants' anonymity, all potential identification of individual information was removed, or an alternative description was used to ensure participants' anonymity. The qualitative research data analysis package NVivo 10 was used to manage the data, organise my analytical work and store files and documents related to the study. A file was created for each participant case containing individual observations and conversations pertinent to that participant, which were jointly examined to identify comparable and contradictory issues. This software provided a useful tool to assist in managing my data by coding the data, making comparisons between the codes and sorting for pattern or categories, and recording the research memos.

As the analysis precedes and is concurrent with data collection in an ethnographic approach, (Fertterman, 2010), when I left the field, a number of themes had already been identified. Negotiation around the children's participation in decisions was an obvious area to be explored, as most of participants' reactions and expressions related to this concern. Keeping this in mind, I moved onto the process of familiarisation of the data, which is a fundamental element of the analysis process (Roper & Shapira, 2000). In addition to NVivo, I started to print out the observation data, and these were organised according to the child participants. The interview data were organised according to participant groups (child, parent and nurse). This allowed me to get familiar with the data by reading and rereading it, and also enabled a comparison of the information within and between the groups. Where possible, any significant issues from the data were compared. This allowed familiarization of the data. The recurring patterns and ideas were recorded.

4.10 Data analysis

Drawing on Roper and Shapira's (2000) focused ethnographic data analysis techniques, this section discusses the approach used for data analysis in this study, including a description of the systematic steps taken to produce the study findings. In most research, analysis follows data collection. In ethnographic research, analysis constitutes an overlapping continuous process beginning during fieldwork and extending into the process of writing (Davis et al., 2008; Punch, 2009). Thus, analysis is not a separate stage of the ethnographic research process, but permeates it throughout. Similarly, my analysis began while data was being collected, and the analytical procedure started with fieldnotes and a review of the first fieldnote.

Applying the data analysis to this study, I followed the steps as suggested by Roper and Shapira (2000): i) coding of descriptive labels; ii) sorting for pattern; iii) generalizing constructs and theories; and iv) memoing to note personal reflections and insights. While the steps are presented sequentially in the following text, it is to be noted here that in reality the process was not linear; I moved back and forth between the steps to have a deeper understanding of culture and richer descriptions (Roper & Shapira, 2000).

4.10.1 Coding for descriptive labels

Coding was the initial stage of data analysis, during which the data were separated into smaller chunks that have meaning within the specific research context (Roper & Shapira, 2000). As previously mentioned, the data collected for this study consisted of observation field notes, informal conversations, interview transcriptions and the examination of documents. Initially, the observations, informal conversations, and the examination of the documents that were converted into fieldnotes and interviews were transcribed. I then began to read through the data and add memos, annotations and links (functions of the NVivo 10 programme), in order to keep a record of my thoughts and ideas. When I embarked on a process of coding, I tried to add particular codes to significant data segments or 'chunks' of words, sentences, or paragraphs of the data (Miles & Huberman, 1994; Roper & Shapira, 2000). The codes were first grouped into meaningful segments, and were then, organized to compare and contrast within and between the groups of participants, and sources of data (e.g. observation, interview, and document) in a table, before identifying the patterns that shed light on the beliefs and practices of the participants of the study. At this point, I struggled with the temptation to add an infinite amount of codes, and with the difficulty to find codes that were broad enough to be applied to different data extracts. In order to ensure robustness of my findings, I looked for commonalities as well as contradictions or conflicting examples. During the analysis process, I paid close attention to examples that appeared striking or deviant with respect to my expectations or other observations in the field (which in turn also highlighted what I considered to be 'common' practices). This process of coding helped me to see the nuances in the data, and allowed me to retrieve all information related to the specific topics (Roper & Shapira, 2000), but also to remain critical about it by keeping myself from being so immersed in the participants' standpoints.

4.10.2 Sorting for patterns

Sorting for patterns or categorisation was the second stage of focused ethnographic data analysis, which was to sort or group the descriptive labels into a smaller number of sets (Roper & Shapira, 2000). Miles and Huberman (1994) argued that patterns become apparent as data are sorted into groupings or piles of things that are alike or unlike each other. For this study, each code identified in the coding process that explained regularities in the behaviours and beliefs of participants were categorized into a pattern, becoming more general and abstract (Miles & Huberman, 1994). Following this, themes were developed from the data to gain a more all-embracing picture of why things happen and to shed light on recurring relationships between participants in the study. During this stage, I began to develop a mind map for the emerging patterns. I looked for links between the codes then the themes. This mapping helped me to examine the relationship between the patterns and themes. Each emerging theme was given a label reflecting its content and making sure the patterns suited the raw data. Table 9 illustrates the examples of emergent patterns of themes from codes. This process allowed me to structure my themes under five main categories which roughly reflected the content for each of the following two chapters: (1) children's experiences of participation, and (2) the nature of communication for children.

4.10.3 Generalizing: constructs and theories

The next step was generalising. Generalising in focused ethnographic research means to find linkages between the emic meanings and worldview of study participants and my (researcher's) etic interpretations of those meanings, and then constructing theoretical understandings that take both perspectives into account (Roper & Shapira, 2000). It is worth noting that a significant aim of ethnographic analysis is to discover an ever expanding and ever more abstract interrelation of concepts to explain the events and activities that are witnessed through ethnographic methods (Roper & Shapira, 2000). Therefore, the findings of this study were linked to theories that make sense of the rich and complex data collected. During this stage, I continuously reviewed the literature to find more abstractions that explained and linked understandings to themes that emerged from the data. The mapping that developed during this stage of sorting for patterns was very helpful for me to construct theoretical understandings of the relationship between the patterns and themes which emerged.

4.10.4 Memoing: reflective remarks

Memo writing worked throughout the analysis process. Ideas about the data that were forms of coding that made connections between pieces of information were written in the memo (Roper & Shapira, 2000). This technique allows a researcher time to reflect on issues raised in the setting and how they related to larger theoretical as well as methodological and substantial issues (Merriam, 2009). Written memos also served as a reminder of further reflection and testing, which provided the basis for my deep and meaningful understandings of the data (Roper & Shapira, 2000). Throughout the study, memo writing was very helpful; it produced a summary of the research efforts during various stages of my field work. Moreover, it enabled me to record my analytical thinking, to reflect and refine the research procedure and to gain deeper insights into the participants' experiences, perceptions and behaviours in relation to the research inquiry (Fetterman, 2010).

As a result of the above process, five overarching themes were identified in relation to children's participation in decisions: i) children's experiences of participation, ii) choices versus expression, iii) the role of the parent in the communication process, iv) adults controlling information sharing, and v) the children and their roles in the communication process. These are explained in detail in Chapters 5 and 6.

Table 9: **The examples of emergent patterns from codes**

Transcripts raw data	**Codes**	**Theme**
'… it means that I would have been informed and asked for my opinion… Umm, I want to know about what is going on, what decision will be made. I also want to tell them what I prefer...' (George, child)	Informed and asked for opinion	Being consulted
'Usually nurses will ask me if I want to remove a plaster during dressing procedure…' (Jane, child)	Asked for opinion	
'My mum also will ask me what I want to do for today or what I want have for my lunch' (Phoebe, child)	Asked for wishes	
'They should be given all information about what is going to be done to them, so that they understand… and they should be able to tell us what they want… and we…' (Jess, parent)	Give information to children	
Even though most of the time parents make decision for them, it is their bodies, so, they should be informed and asked what they like…' (Alina, nurse)	Children were informed and asked for what they like	

4.11 Methodological rigour

Ensuring the trustworthiness of data collection was important. Holloway and Wheeler (2010) explain trustworthiness and rigour in qualitative research by relating these to the terms commonly used in quantitative research. They suggested practical ways to demonstrate trustworthiness in qualitative research through developing credibility (or internal validity), dependability (or reliability), transferability (or external validity).

4.11.1 Credibility

Credibility or internal validity is the accuracy of the findings, which address the issue of 'fit' between respondents' views and the researchers' representation of them (Tobin, & Begley, 2004). To achieve the credibility of this current study, several strategies were used, including: i) development of an early familiarity with the setting; ii) establishing prolonged engagement with the potential participants; iii) triangulation including different methods, and a wide range of participants; iv) ensuring honesty in participants' descriptions and responses by explaining their right to refuse to participate in the study; v) identifying my initial impressions before each observation and interview session and then later comparing and contrasting these with the participants' experiences and transcripts; and vi) providing a thick description of the phenomenon under study.

The development of an early familiarity with the setting before the first data collection dialogues take place was essential to improve the credibility of the study (Shenton, 2004). As mentioned in section (4.8.2), the fieldwork began with an informal and unstructured observation during the first three days before the actual data collection started. The unstructured observation was conducted for 3-4 hours per shift for three days. The non-systematic observations had given me an opportunity to gain an understanding of the setting, such as the layout, staffing, model of care delivery, nursing routine, and type of patients in the setting. This informal and unstructured observation also allowed me to build familiarity with the ward layout and daily routine, the staff, patients and the families, and thus, minimize misinterpretation of contexts that were observed during the real data collection period.

In the beginning, relations with child and parent participants were established through the information provided by the nurse in-charge regarding the potential participants, while contact with nurse participants were established through meetings in the selected ward, and these were followed by face to face final meetings with each participant (see section 4.7). It should be noted that although the data collection was divided into two phases, the fieldwork took a total of six months, which enabled me to establish a good rapport with the participants. This was apparent when some of the nurses involved me in their patient's consultation (e.g. how to maintain aseptic techniques during a dressing procedure, and side effects of chemotherapy), parents shared their problems, which is out of the study's scope, throughout the fieldwork (e.g. dietary intake suitable for their child, and handling the side effects of the chemotherapy), and children shared their hospitalization experience (e.g. their Eid celebration in the ward). This also means that they identified me as a nurse.

Despite employing several methods of data collection including: participant observation, interviews, and examination of documents, this study also involved a wide range of participants such as children diagnosed with leukaemia, their parents, and nurses working in the selected ward. This strategy is supported by Fetterman (2010) who pointed out that triangulation of research methods has been shown to aid conceptual understanding, enables comparing information sources to test the quality of the information, and improves validity (Fetterman, 2010). Also, Shenton (2004) ascribed that the use of a wide range of participants provides opportunities to check parts of information across participants and verify them against one another's viewpoints and experiences.

There were several methods employed to ensure honesty in participants' descriptions and responses by explaining their right to refuse to participate in the study. These comprised of an explanation of their right to refuse to participate without requiring to disclose the reason for their refusal. These strategies aimed to include only those who were genuinely willing to take part and who were prepared to contribute ideas and talk of their experience freely.

As this study is an ethnographic study, I played a major instrumental role in data collection and analysis. To improve the credibility of the study, I was aware that I should minimise my personal emotional and intellectual biases thus my initial impression before each observation and interview session as well as the examination of documents were noted. Then, these were later compared and contrasted with the participants' experiences and transcripts. The detail of the reflexivity of the study is further explained in section (4.13).

As this current study employed ethnographic methods, a thick description and verbatim quotation of the situations or events are provided, for instance detailed excerpts of the events are presented and discussed throughout Chapters 5 and 6. This strategy was supported to promote the credibility of the study as it helps to convey the actual situations that have been investigated and, to an extent, the contexts that surround them, which enable the reader of the final account to determine the extent to which the overall findings are credible (Shenton, 2004).

4.11.2 Dependability

Dependability refers to the extent to which the study, if it were to be repeated in the same context, with the same methods and with the same participants, similar results would be obtained (Shenton, 2004). In order to address the dependability issue of this study, the following strategies were employed: the research design and its implementation (see section 4.4), the operational detail of data gathering (see section 4.8), and the analysis process (4.9) are explained in detail. The reflective appraisal of this study is elaborated in section (4.12). These strategies have been applied to improve the dependability or consistency of the study (Shenton, 2004).

4.11.3 Transferability

Transferability or external validity is concerned with the extent to which the findings of one study can be applied to other situations and populations (Shenton, 2004), and giving readers enough information for them to judge the applicability of the findings to other settings (Finlay, 2006). For this purpose, a detailed description of the study setting and participants has been explained in section (4.5 – 4.6) in order to provide contextual information about the fieldwork sites. Nevertheless, it seems difficult to generalise the findings of an ethnographic study to another setting, as this study selected participants through purposive sampling and aimed to select the participants with some level of knowledge and experience to explore their particular knowledge and experience in order to answer the research questions. After all, similar to other types of qualitative research, the aim of an ethnographic study is not the generalization of the findings, but to understand better the processes and meanings of the phenomenon under study (Herbert, 2000).

4.12 Ethical considerations

The application of appropriate ethical principles in research for the protection of human subjects is important (Bryman, 2012). In using the ethnographic approach as a methodology, I was directly involved with those participants under study. Thus, I needed to ensure the integrity of my work and to minimise the potential risk and harm to the participants (Wolcott, 1992). The next section details a specific account to address the ethical considerations of the study. There are four important ethical issues considered in this study, and these are discussed in the following section.

4.12.1 Informed consent and voluntary participation

Participants in a research study must be provided with comprehensive information about the research and must be adequately informed of the potential risks, so that they have the power of freedom of choice to decide whether to participate or decline

(Polit and Beck, 2006). Thus, a thorough explanation regarding the research process was given to the potential participants before obtaining their agreement to participate in this research.

All participants were required to provide written informed consent, except for the child participants, whereby the written informed consent was obtained from the parent. For this purpose, the potential nurse participants were approached individually, while each child and his/her parent were approached together and explained the purpose of the study and data collection process. They were informed that as their participation was voluntary, they could refuse to participate or withdraw from the study at any time while it is in progress. They were informed that their refusal or withdrawal from the study would not affect their care or job in the respective ward in any way. They were given an appropriate time to ask questions and address any concerns.

A participant information sheet was provided to further explain the study to all potential participants. The potential participants were given appropriate time (up to three days) to read the information sheet and to decide whether they wanted to participate in this study. The nurse and parent participants who agreed to participate were asked to sign the informed consent form before the observation and interview to indicate their permission to be part of the study. As a different nurse provided nursing care to the same children each shift, informed consent was obtained from all nurses in the ward to ease my observation process. All participants fully understood that their participation was on a voluntary basis. However, as noted earlier (see section 4.7.2) there were four nurses who refused to be observed; their names were noted so that the observations did not involve them. Participants that agreed to take part in the study were asked to sign the written consent form before the observations commenced. The participants, who already signed the consent, were asked once more for their agreement upon beginning the interview session.

Before approaching the potential child participants, I asked the parents first. It has been argued that children are generally taught from a very young age that they must obey adults (Morrow, 2009). This may mean that it could be difficult for the children to refuse to participate in my study. Thus, my attention was on the three main elements of informed consent: adequate information, voluntariness and capability to understand the information (Morrow, 2009). The nature of the study was explained in simple language so that children could understand. Pressure was not put on them to participate in my study; reassurance that their participation is voluntarily and that they can withdraw from the study at any time without needing to give a reason was given. They were also reassured that their decision about whether to participate or not would not affect their treatment and care. The written consent for children was obtained from their parent; however, children were constantly asked for their agreement to continue as a participant throughout the data collection period.

An explanation was clearly given to potential participants that they had a right to withdraw from the study at any time during the fieldwork even after the informed consent had been signed. Consent for audio recording during the interview session was asked from them prior to the interview. The participant's information sheet and informed consent was available in two languages: Malay and English.

4.12.2 Anonymity and confidentiality

The anonymity and confidentiality of the participants was preserved by not revealing their names and identity in the data collection, analysis and reporting of the study findings. Privacy and confidentiality of the observation and interview environment were managed carefully during the participant observation, interview session, data analysis and dissemination of the findings.

To ensure the anonymity and confidentiality of the data, the participants were informed that only I had sole access to the audiotapes and fieldwork notes; that participants' individual identities would not be linked to the information they provided; and pseudonyms would be substituted for names to prevent any breach of confidentiality.

For child participants, explanations of anonymity were really challenging. Prior to my data collection, I produced a chart containing clear written information outlining my approach in a simple language. During the interviews, I gave the child participants reassurance regarding confidentially. I explained the concept of anonymity in words the children could understand. All participants were informed that their identity and family members would be kept a secret and that the information would not be used to identify them or their life. Preserving participants' anonymity would also encourage them to express their opinion freely (Morrow, 2009). The participants were also informed that the name and full description of the hospital would not be revealed. They were reassured that the information they provided was securely stored and that backup files were created; the original reports and files were stored on a password-protected computer; all hard-copy files were stored in a lockable cabinet and all could only can be accessed by me; and I kept the keys to the cupboard holding all of the research materials. Excerpts of anonymised data were shared with my PhD supervisors during the analysis process.

4.12.2.1 Participant observation

Since the participant observations were conducted in the ward that involved other children and their parents other than the participants, suitable safeguards were put in place. Participants were reassured that their participation would not be disclosed to other children and families in the ward. There were a few cases where my identity was asked about by other children and parents in the ward. In this situation, I did not expose details of the study. Instead, I explained that the purpose of my presence in the ward was to observe the nursing care provided to the patients in the ward in order to improve the quality of nursing care.

4.12.2.2 Interview Sessions

Each interview was conducted individually in a private and quiet room in the respective ward without access to outsiders. There was one child who requested that I conduct the interview in his room because he was on several types of infusions. I agreed to his request since he was the only patient in the room. During the interview, his parent was asked to leave the room. I am the only one who should be able to match the identity of the participants and the voice recordings.

4.12.2.3 Examination of documents

All information gathered from the document examinations were managed in the same way as with the field note data and interview transcriptions, and were stored on a computer with no access by anyone other than me. Client's records were anonymised; the identities of participants were removed, and their pseudonyms were used. I am the only one who should be able to match the identity of the participants and the records.

4.12.2.4 Data analysis and dissemination of the findings

The transcription of the data was conducted in a private room using earphones to avoid the possibility of the recordings being overheard by others. The identities of participants were removed during the transcription, including their names or any significant aspect of identity. These were referred to by their pseudonyms in the verbatim quotes that are presented in Chapters 5 and 6. Nevertheless, participants were informed that their actual age would be used for reporting the data from the observations and interviews.

All documents containing the participants' personal details, such as written consent, were kept in a locked cabinet with no access by anyone other than me. This personal information will be destroyed in accordance with the university research governance procedures.

Data were shared with PhD supervisors for reaching the agreement of the interpretation without exposing the participants' detail at any stage. Participants were informed about the supervisors' access to the data and their consent was obtained.

4.12.3 Data protection

Data analysis was conducted simultaneously with data collection. The observation fieldnotes, interviews, and examination of the documents were transcribed and analysed by myself and was supervised by my two PhD supervisors. Data were stored in devices which were password protected. The information was stored in the university computer, personal laptop, and memory sticks were protected by using passwords that were only held by me. Written material of the data was kept in a secured cabinet in a locked room with no access to by others. Both electronic and written data from this study will be retained in line with the University policy. The interview recordings, however, will be disposed once they are no longer needed.

4.12.4 Harm and child protection

Since this study involved children, special precautions were taken in relation to harm and child protection. The protection of research participants from risk of significant harm, both during the research process and as a consequence of the research, is the key ethical consideration (Morrow, 2009). As such, I had to ensure that my research would do no harm to the children, while at the same time ensuring sufficient study data were gathered.

I was aware that involving children diagnosed with leukaemia as participants might cause distress during the data-collection process. The child participants were determined as either being off limits or could be approached only following an agreed upon approval process by the primary physician or nurse in charge (Carnevale et al., 2008). I ensured that all child participants were in a stable condition throughout the data-collection process. Vital signs of the children were checked prior to the interview session, as children are transported to a meeting room for the interview. The observation and interview were stopped immediately if the child showed signs and symptoms of deterioration. In one case, a child who had agreed to participate in the study suddenly deteriorated during the observation. She suddenly complained of chest pain, and her blood pressure and heart rate dropped. Therefore, the observation was stopped immediately to avoid any adverse effects and possible distress. However, the observation of this child was continued after four days when her condition improved, and upon her agreement.

It has been argued that unequal power relations exist between children and adults throughout the research process (Punch, 2002). This typically leads to concerns over how free children feel they are to refuse to participate in the study, to withdraw during the research, or even to give their own views and experiences to an adult researcher (McCrum & Bernal, 1994; Kirk, 2007). Taking this into consideration, to allow children to feel part of the research process, and to enable them to provide their views, several ways were employed to manage the power differential between children and adults in research. I was aware that with working with children, they may potentially be afraid to express their refusal to participate to me as an adult researcher. As applied to all participants, children were also advised that they could withdraw from the observation and interview at any point. I continually checked the willingness of children to participate in the study throughout the data collection process by verbally asking for their willingness to continue as a participant of the study (Kirk, 2007). To ensure that children did not feel themselves to be under duress to answer all questions, I reviewed with the child how to say "no" for any questions that they did not wish to answer. The use of green and red cards was implemented, whereby the child simply shows a red card for questions they do not want to answer. I also showed children how to turn the recorder on and off, so that when they felt that the information given should not be recorded, they could freely turn off the recorder. These methods have been proven to inform the children that they do not have to answer certain questions and do not feel pressured and thus enables them to talk freely during the interview session (Kirk, 2007). To ensure that the child's views and feelings were respected, the child participants were reassured that their description should be in their own words and that there are no right or wrong answers. The child participants were also reassured that they would not be required to answer all questions for their interviews to be considered valid; for example, the child may be reluctant to speak about a sensitive topic, and, in this instance, their wish would be respected. I was also aware that I had to be sensitive to children's body language and tone of voice to recognise their willingness to continue to participate in the interview or observation (Morrow, 2009).

Dealing with issues of harm and child protection became more problematic when I witnessed a child restraint during my observation. I found that it is a normal practice in the setting where parents as well as healthcare professionals would restrain uncooperative children during a procedure. Although restraint is commonly used in a clinical setting to successfully carry out therapeutic or diagnostic procedures to a child, it is unlikely that the nurse would restrain the child without the parent's consent; however, this may conflict with the child's own wishes. I decided not to be involved in child restraint activity. I was aware of ethical issues concerning the need to challenge or report unprofessional practice to the manager. The nurse manager was consulted regarding this, and with the awareness of the nurse manager, discussion was held with some of the nurses. The practice of child restraint was discussed, such as the child should be aware of why and how this happens, and how other kinds of interventions that are appropriate to individual children's needs before resorting to restraint should be considered by the nurse when dealing with a difficult child (Alderson, 2007; Clarke, 2011). The importance of consent from the children and their parent to the use of restraint before the procedure begins, as it is considered as good practice, were also discussed (Darby & Cardwell, 2011; Alderson, 2007). However, I was informed by the nurses and nurse manager that it is the normal practice to gain cooperation during the invasive procedure with the children. As such, it was difficult to determine how this would impact on the data collection; there was the possibility that nursing care would be delivered differently from the norm following my action.

4.12.5 Feedback and dissemination

It is arguably necessary if the research is to be regarded as ethical to disseminate the research findings to research participants (Morrow & Richards, 1996). It was therefore important for me to disseminate to children, their parents and relevant nurses. However, due to the timescale of this research, I have at the stage of submission of this thesis not yet been able to provide formal feedback to the participants. Nonetheless, I have devoted to making this thesis, as well as a short summary of it, available to children, their parents, and nurses involved in the research. I have agreed with the Director of Nursing of the hospital that after completion of the research I will arrange to return to the hospital to present my findings to the nurses. The findings of this study are not only beneficial for the nurses who took part in this study, but, also for all nurses of the hospital, thus, this might take the form of a presentation to the whole hospital during the continuing nursing education session held there. Furthermore, findings from the research have been presented at various international academic conferences and will be published in nursing journals.

4.13 Reflexivity

The concern when ethnography is the methodology of the investigation is the role of the researcher as an instrument for data collection. Thus, reflexivity, or the process of reflecting critically on the self as researcher as a human instrument in their study, is essential to minimise personal emotional and intellectual biases or influence that they may have on participants at each stage in the study development process (Finlay, 2002; Meriam, 2009). Therefore, qualitative researchers should openly communicate their own personal motivations, values and assumptions regarding the research undertaken to make explicit how intersubjective elements impact on data collection and analysis of their research (Finlay, 2002). In this way, they can be considered consciously aware of how any of these factors have shaped their collected data (Finlay, 2002; Finlay & Gough, 2003; Bryman, 2012). In the following text, I demonstrate how I ensure that the reflexive process was applied in this current study.

At the beginning of the participants' recruitment, I introduced myself as a nurse researcher. Nevertheless, throughout my field work, my professional status (as a paediatric nurse) became identifiable to the participants, especially nurses. When this discovery happened, I emphasised that although I am a paediatric nurse, my latest job scope was more on teaching and research instead of directly caring for children in clinical practice.

It is noteworthy that my participants were not only comprised of adults, but also children; thus, I acknowledged the possible power imbalances between the child participants and myself as adult researcher. I also recognized that it is not always possible to neutralize the power dynamics between child and adult researcher

(Spyrou, 2011). Atkinson and colleagues (2014) suggested that anthropologists do not have to turn native in order to argue from the native's point of view. Thus, it is clear also that a childhood researcher need not pretend to be a child when researching children. Indeed, as Mayall (2000) argues, the inevitable differences between children and researchers have to be accepted. I was aware that my role as an adult researcher and the power imbalance that existed between me and the children may have influenced the child participants; for instance, children may feel pressured to answer certain questions during the interview. To minimise this, several strategies were adopted to enable them to talk freely during the interview session, as discussed in section (4.12.4).

In addition to the possible power imbalance between the child and the adult researcher, I was also concerned about how I as an adult researcher would be accepted by the child participants. I undertook measures to establish a good rapport with the children by having an informal conversation pertaining to them a few times before my fieldwork began and spent time playing games with the children whenever they wished to throughout the data collection period (see section 4.7.1). However, I began to realise that our first encounters had been conditioned by children's initial discomforts, as could be seen from their facial expression and non-verbal communication during the interaction with me. Nonetheless, it was difficult to determine to what extent this impacted on the data collection; there was the possibility that my role as adult researcher and 'stranger' may have influenced their behaviour and expression during the research process.

Despite positioning myself as researcher, there were situations where researcher-nurse conflict occurred. For instance, when I witnessed a child restraint during my observation (see section 4.12.4). I took the step of discussing this matter with the nurse manager and decided not to have any involvement in child restraint activity. However, I was informed that it is the normal practice to gain cooperation from the children during the invasive procedure. Rather, she expressed that I should be aware of this as I had also previously experienced working in a paediatric ward. What I have learnt from this is that some nurses may be reluctant to change their practices which are considered as their norms, although their reluctance could jeopardise the child's health. I had the impression that if the nurse manager took this matter into consideration seriously and advised her staff, the nurses would be willing to change their practice in a better way, and improve the quality of nursing care. This perception somewhat influenced my thoughts throughout the data collection process. It was difficult to determine how this impacted on the data collection; there was the possibility that nursing care may have been different from the norm following my action.

As previously mentioned, field notes were written as soon as each participant observation and interview ended (see section 4.8.2.2). I included participants' verbal conversation and non-verbal communication such as the facial expressions of all participants involved in the interaction (as much as it could be recalled), and my own insights. It is to be noted that although I do not know any of the participants, some subjective bias could occur due to my previous experience as a paediatric nurse. This process of writing my thoughts, feelings, questions and insights all allowed me to attach emotional meaning to what I had observed. This helped to evaluate my response to specific observations and interviews; for instance, anything that could affect my emotional and intellectual balance should be considered (Roper & Shapira, 2000). This was to ensure all important data were included in data analysis, and to support the trustworthiness of this study (Bryman, 2012).

As mentioned above, I was aware that some of my thoughts seemed to be challenged during my field work; this nevertheless, became clearer when I analysed my data. For instance, I expected the children would focus more on the authority of adults, especially their parent, and may not acknowledge their right to participate or their preferences to be involved in any discussion about their care or decisions. I presumed this because of the culture in Malaysia that regards parents as authority figures, thus children are expected to accept the discipline without any questions. This however was not the case. Rather, few children acknowledged the role of their parent; in fact, some of them mentioned their rights to be involved in their care and expressed their need to be part of decisions. Throughout the data analysis process, memo writing helped me to record my personal feelings and ideas about the participants' experiences, expressions and themes (see section 4.10.4). Writing these notes not only helped me to provide transparency in the study development, but also made me aware of my personal growth in the research process.

To summarise, although it is challenging and not always possible to examine my preconceptions, I made many efforts to ensure all thoughts, feelings and activities associated with the study were recorded along the research process. These reflexive practices somewhat helped me to develop self-awareness, and provided the basis for deep and meaningful understandings of the data (Roper & Shapira, 2000), as well as providing credibility and accuracy of the study (Fetterman, 2010; Shenton, 2004). Although I was aware that my personal experience could influence how I interpreted the participants' experience, I believe that it boosted my interest and passion, rather than inappropriately carrying my personal and professional bias into data collection and inappropriately influencing data analysis and interpretation.

4.14 Limitations

The limitations of the study need to be acknowledged. Firstly, as this study has a broad range of inclusion criteria for nurses, the nurses who are newly graduated and worked in the ward for less than a month refused to participate in this study. Their refusal was mainly due to their limited experience as a nurse. At some point, these nurses might have had some interesting data in relation to this research that was not captured. Thus, for future research it is recommended that researchers consider the inclusion of this group of nurses.

Secondly, this study involved child participants, and the interviews with this group of participants were conducted purely by questions and answer. It could be more productive if 'creative' methods, which are appropriate for the purpose and nature of the research such as writing, telling story, drawing, or taking photographs are employed. Therefore, future research could consider the use of creative methods to allow new insights to emerge from the perspectives of children. Using ‘creative’ methods that are child-friendly in studying children has been suggested to encourage children’s active engagement with particular issues of the research and enable them to use a diversity of means to express themselves in the communication between them and researchers (Christensen, 2004).

Thirdly, because the researcher is the main research instrument of data collection and analysis in qualitative research, the qualitative research may be too subjective (Bryman, 2012). In this current study, I was the only researcher; thus, researcher bias could be seen as a significant shortcoming. In order to minimise this potential limitation, various forms of triangulation have been incorporated into this study (Bryman, 2012) through bringing in the different data resources and different data collection methods as well as comparing findings with existing literature, as detailed in Section (4.11.1).

Finally, there have been critiques of qualitative research in terms of generalisation, particularly from the quantitative researchers’ perspectives. However, qualitative researchers have argued that qualitative study research is intended to generalize to theory rather than to populations (Bryman, 2012). Likewise, this focused ethnographic study aimed to find linkages between the emic meanings and worldview of study participants and researcher’s etic interpretations of those meanings to construct theoretical understandings that take both perspectives into account (Roper & Shapira, 2000). In addition, as qualitative research focuses on a small number of subjects located in a certain setting, it is argued that the findings cannot be generalised to other settings (Bryman, 2012). Equally, as the current study was conducted in a specific geographical area of Malaysia, findings could not necessarily be generalised to other populations or to the wider context without any problems.

4.15 Chapter summary

This chapter has outlined an overview of the methodological approach adopted for this study. As highlighted in the beginning of the chapter, the aim of the study was to gain an understanding of the participation of children diagnosed with leukaemia in decisions relating to nursing care; from the perspective of children diagnosed with leukaemia, their parents, and nurses. This chapter then provided the justification for choosing the constructivist approach to conduct a focused ethnography study to achieve the research objectives. I selected focused ethnography to gain an in-depth understanding of the etic and emic perspectives of children's participation in decisions, which allowed participants to tell their own stories. The use of focused ethnography allowed for a period of time in the field, which enabled me to meet with a range of children, parents and nurses from different backgrounds. Triangulation of methods were used to ensure the robustness of the data. Roper and Shapira's (2000) focused ethnographic data analysis technique was described, leading to the findings discussed in the next chapter. The ethical issues presented were considered as they arose in the findings. In the following Chapters, 5 and 6, I move on to the substantive findings of this research.

Chapter 5: Children's experiences of participation in decisions

5.1 Introduction

An international review found that the participation of children in their health care is considered an important value in the provision of their treatment (Runeson et al., 2002a). Many studies that have been conducted with children in hospital indicate that children have varying experiences of being consulted and involved in their care, and that the children experience marginalization in decisions (Beresford & Sloper, 2003; Coyne, 2006a; Coyne & Gallagher, 2011; Runeson et al., 2002a; Schalkers et al., 2016; Vaknin & Zisk-Rony, 2010). In one of the most cited studies, Coyne (2006a) found that children wanted to participate in their care and decisions, but their own opinions and views were often underused by the adults. Thus, this Chapter takes an already established staring point that children can participate in decisions with respect to their nursing care.

Exploring how children would participate in decisions regarding their care was a central research question. Although commonly reported in nursing research literature that it is often difficult for children to participate in decisions (Coyne, 2006a), a more detailed analysis of the circumstances in which children can participate in decisions is limited. Notable influences on this include the role played by adults, particularly parents and healthcare professionals (Savage & Callery, 2007). Therefore, the aim of this chapter is to contribute to the broader literature by exploring children's experiences of participation in decisions with respect to their nursing care.

This chapter is the first of two chapters that analyse the findings of this ethnographic study. Here, I draw on fieldnotes, interviews, and the examination of document data to analyse how children diagnosed with leukaemia experience participation in decisions in respect of their nursing care. I contextualise each subsection firstly with a particular fieldnote and interview excerpt that serves to illustrate the data and exemplify the themes and draw the reader into the children's participation in decisions regarding their nursing care. In the first section (5.2), I analyse the experiences of children in participating in the decisions relating to their nursing care. I reflect on the three different patterns of children's participation: i) being physically present, ii) being informed, and iii) being consulted about the nursing care provided. In the second section (5.3), I examine the ways in which different choices are made available to children during the provision of nursing care, and how parents and nurses play their role in offering choices to children. I then evidence the situations where children are able to express their views, and how their expressions are being ignored or respected by the adults. As previously mentioned, the levels of participation of Hermeren (1996) will be used to discuss the data of this study. Thus, the analysis of the data that have association with the model are discussed, where appropriate, in this chapter.

5.2 How do children participate in decisions?

In this section, I take a closer look at how children participate in the decisions during the provision of their nursing care. Using observation data in the form of fieldnotes and interviews, excerpts are presented to illustrate my argument about children's experiences of participation in their care during hospital admission to an oncology ward in Malaysia. I evidence how children are engaged in decisions about their care.

5.2.1 Children being physically present

> Friday afternoon, Ray, a 9-year-old boy is readmitted due to the infection of the central venous line (CVL). He is under the care of Irene. He requires a peripheral line before the insertion of the new CVL. Ray is lying down on a bed. Irene comes in the room; she wants to apply the anaesthetic cream on Ray's hand in preparation for the IV-line insertion.

> Irene holds Ray’s hand and says: Mum, I will put this cream on both of his hands, so that he will feel no pain during the injection. [Mum is the terms used by nurses of the ward to address the mother of the child.]
>
> Rachel (Ray’s mother), in a very firm voice, replies: Nurse, no need, it’s useless, because the pain is still there, like last time, even though the cream was applied he could still feel the pain.
>
> Irene: But this cream will make him feel numbness, so he will feel less pain during the injection.
>
> Rachel: Less pain? No! Still pain, no need!
>
> Irene then told the mother to bring her child to the treatment room for the insertion of the IV line, since she refused the application of the cream.
>
> (I feel now I have to say something as I cannot enable the lapse in providing appropriate care)
>
> I ask: Ray, do you want the nurse to put the cream on for you?
>
> Rachel turns to Ray and says: Hah, do you want it?
>
> Ray keeps silent, looks at me and shakes his head [indicates he does not want it].
>
> Rachel: Okay, let’s go to the room then!
>
> Rachel helps Ray to get out of his bed and all of them walk to go to the treatment room.
>
> [Excerpt from fieldnotes, 16 January 2015]

The excerpt demonstrates that Irene (the nurse) first communicated with Rachel (the mother) instead of Ray. Rachel decided on Ray’s behalf that he would not have the cream, based on her subjective belief that the clinical treatment was not effective, Ray was not asked for his views on what was planned. It appears that, despite being physically present in the midst of the narrated interaction, Ray's presence was ignored by the nurse and his parent. He was excluded from the discussion, and thus from the decisions concerning his care, even when I intruded by asking him directly – he merely corroborated his mother's decision.

In this situation, Rachel appeared to be the decision maker, establishing a dominant role in the decisions. Her interruption appeared to have an impact on the nursing actions, which suggests that it was a remarkable command when Irene followed her instruction and administered care in a way clinically considered to inflict more pain, particularly when one considers Ray was a paediatric patient. Rachel, however, may not understand how the anaesthetic cream works to ease the pain, which explains why she apparently obstructed the pain relief of her child. As a nurse, Irene could have informed her and Ray that the effect of the anaesthetic cream can be enhanced by leaving it to work for a longer time prior (and subsequent) to the procedure. However, in the event, Irene followed Rachel's instructions of not wishing to have this non-invasive pain treatment applied to her child's hand. This interaction appeared to largely focus on helping the nurse attempt to complete her task, rather than being an intervention (by the parent) specifically personalised to Ray's needs. While Ray may be afraid and have anxiety about how he will experience the procedure, which might not be being understood by the nurse and his parent, the nurse seems anxious to complete her task in a timely fashion; thus she ignored the child's fears. It appears that Irene did not take the initiative to reduce Ray's fear. In an attempt to disperse any fears or worries, for instance, Irene could have worked harder to reassure Ray, for instance by stating 'don't worry... you'll be okay.'

When I asked Ray about his preferences, Rachel appeared to realise the importance of Ray's choices on whether or not to have the cream applied on his hand, which she demonstrated by asking Ray about his preferences. Ray remained silent, giving non-verbal assent to his mother's decision by shaking his head to indicate he did not want the cream. This could indicate that he might be aware of and understand the feeling of insertion, and may not require the cream to be applied, since this is his second experience of IV insertion. However, his non-verbal response – looking fearful, could be due to fear of the procedure, as procedures involving needles are almost universally regarded as a negative experience for most children (Forsner, Jansson, & Sorlie, 2005; Lindeke, Nakai, & Johnson, 2006). In addition, when at first Rachel interrupts the interaction between nurse and child, she could have compelled her child to stay silent in the discussion, or Ray may prefer to be silent because he might be afraid to tell his preference as it would contradict his mother's prior instruction to the nurse not to apply the cream. Alternatively, Ray might learn not to interrupt the parent and nurse interaction, which could be a link to his cultural background. It is worth noting that Ray is an Indian boy, from an Indian family. Within the Indian culture (see Chapter 2, section 2.3.3), parents generally exercise a considerable amount of control over their children. Moreover, a child's wishes are usually decided by the parents in Indian culture. Children often follow the instructions of adults, and they are inhibited from showing assertive behaviour and autonomy (Keshavarz, & Baharudin, 2009; Krishnan, 2004).

This first observation, equates to level 1 and 2 of the Hermeren's (1996) model of participation (as illustrated in Chapter 3, section 3.3.2). Not only does the nurse not listen to the child, she also refuses to talk to the child. There was no communication between the child and the nurse and no consultation takes place in this example. It appears that children are merely physically present in the decisions concerning them, whereas, the adults talk over them and do not even address them superficially, demonstrating children's marginalization in decisions. The excerpt also resonates with many other fieldwork observations I undertook, wherein parents took the initiative to dictate care actions impacting on the child, with little respect for nurses' clinical judgment or children's concerns and wishes. Nevertheless, there are parents who appeared to encourage their children to get involved in decisions concerning them (such as the example of George, which will be explain in section 5.2.3). As a result, a few children were able to decide on their own care, but the majority exhibited agreement with their parents, as in the example of Ray.

5.2.1.1 The role of parents and nurses in promoting the participation of children in their care

The above example of Ray being physically present in decisions could be greatly enhanced by the nurse and parent giving the child a chance to contribute, indicating how the attitudes of nurses and parents are of essential importance in facilitating or inhibiting the opportunity for children to participate in the decisions (Runeson et al., 2002a). Events such as when nurses address direct communication to parents, and parents try to answer on behalf of their children (even when the question was directed to the child) were found to be very common during my fieldwork. Ray's situation demonstrates that when the parent continued to interrupt children, the nurse was observed to realign to discuss with parents. As a result, Ray was disregarded and excluded from discussion, even though he is at the centre of the provision of the nursing care. This corresponded with previous studies which suggested that most of the parents managed their children's information sharing, with several children speaking about how their parents inhibited the children's attempts to participate in various ways, including: answering questions on their behalf; telling them to stay quiet; reprimanding them for interrupting discussions; and withholding information (Beresford & Sloper, 2003; Young et al., 2003; Coyne, 2006a; Zwaanswijk et al., 2007).

It could be argued that if Irene and Rachel discussed Ray's preferences to have the cream on his hand and subsequently supported his own view, Ray would realise a more participatory role in the decisions. For instance, when Rachel asked Ray about his choice in the later stage, it can be seen that Ray was involved, although his participation was limited. This situation demonstrates that Ray could occupy different degrees of participation in the decisions, and that it fluctuates in particular situations. Initially, Ray appears to be involved in the decisions, but his role was catalysed by my artificial intervention; he, then, appears to have minimal participation when asked about his preferences. This is in line with Ruhe and colleagues (2015), who concluded that children could move freely from lesser degrees of participation to more intense participation and the other way around, or maintain the same degree all the time. Such degrees of participation allow children to occupy different roles in their care based on their preferences (Ruhe et al., 2015).

During fieldwork, I gained the impression that the participation of children in decisions was uncommon in the ward. Therefore, I conducted more informal conversations with the nurses and parents to explore their understanding of children's participation. The parents and nurses identified the presence of children during decisions as an important aspect of participation, apparently without awareness that they generally ignore the children in their discussions. When asked specifically what children's participation in decisions means to them, most parents were keen to emphasise that participation means their child should be present during the discussion of decisions; for example, Vicky (the parent) informed me: *'It means that children need to be there, they have to be available when the decision is made, that's more than enough'*, and Violet (the nurse) added *'I think it is when children are available and become aware about the decisions'*. These statements demonstrate that the parents and nurses considered children to be participating in decisions when they are simply physically present.

Reflecting on the way in which Ray was treated; Irene explained that children's participation could mean more than just the presence of the child:

> Children are participating, when they are there, they also listen to the discussion. As long as they are there and aware of what happens. It is not necessary for them to decide. (…) I am sure that Ray was aware of what was going to happen…
>
> [Interview, Irene, Nurse, 15 January 2015]

Irene described children's participation as being present, as she suggests that they are there and listening to the discussion regarding their care. Irene's choice of words, such as 'not necessary for them to decide', explains how she views the role of children in the decisions as passive compliance. Amongst some adults, there is an idea that children just need to be present, listening to and generally aware of what is being discussed, without the burden of participation such as expressing a personal view or preference. This indicates that participation is simply listening to adults, without children having reason to believe that their involvement will make a difference (Sinclair, 2004). In this sense, the term takes on a very passive connotation (Lundy, 2007), whereby the role of children in the decisions has no substance. This could suggest that some parents and nurses in this study might have perceived the presence of children as reassurance that the views of children are being considered, without any attempts to include them in the decisions (McNeish, 1999). This could explain Irene's reaction towards Ray as illustrated in the above example.

5.2.1.2 Summary

The section has demonstrated that children can be physically present during decisions. Reflecting on the example of Ray, even though children are present, they may not be involved in decisions about their own care. The fact that he is excluded from the discussion, results in his marginalised role in the decisions. It is noteworthy that the understanding of nurses and parents regarding children's participation as being physically present during the decisions gives an insight into how children are treated in the decisions, and that, this participation is not reflective of the appreciation of children as the centre of their care.

5.2.2 Children being informed

> During her first day of admission, Nurse Doreen obtains Nita's history from her parent, Rena.
>
> Doreen gives an orientation to Rena. Information regarding the unit, such as the routine of the ward, visiting hours, the dietary schedule, the use of facilities in the pantry, and child safety was conveyed to Rena.
>
> Doreen then informs Nita about the procedures being carried out, such as vital sign checking and physical examination. Doreen also informs her of the preparation needed for CVL insertion. First, she tells Rena that Nita has to fast starting from 4am, and she then tells

> Nita to start fasting from 4am. Nita and her parent nod in agreement.
>
> Doreen explains once, and leaves. Nita and Rena look confounded, seeing Doreen leave.
>
> [Excerpt from fieldnotes, 22 June 2015]

This excerpt illustrates a way in which children are informed regarding the care provided. As noted earlier, this is the first admission for Nita. However, she seems to receive limited information regarding the procedure to be carried out on her during the orientation process and was not given an orientation to the ward; instead the orientation was given to her parent. It can be seen that Nita was not given any options or encouraged to make a choice of how she prefers the procedure to be conducted on her. While information was conveyed, Doreen did not seem to check whether Nita and Rena understood the important information. Doreen appeared preoccupied with delivering directions, without providing an opportunity for Nita to think or ask questions. It appears that the decision of how the procedure should be conducted was mainly decided upon by the nurse, and Nita was left to adhere to the nurse's instructions. This situation is congruent with level 2 of Hermeren's (1996) model (also see Chapter 7, section 7.7). This can be explained by the fact that although Nita was informed by Doreen about what was going to happen, it was in a very brief way. In addition, there was no check to see if Nita had understood the information, thus, no consultation took place.

Such interaction was frequently observed during the provision of nursing care to other children. Most nurses in the study were repeatedly observed to give instructions on what to do, rather than explaining in detail how and why certain procedures needed to be done, or encouraging children to decide how they prefer a procedure to be done. For example, during the blood taking procedure, Doreen informed Nita that she was going to draw a blood specimen without informing her of the purpose of the procedure or giving an option for her to choose which hand she preferred to be used. It is noteworthy that the majority of children in this ward are re-admission cases with prolonged periods of stay. Thus, nurses may assume that children already fully understand their illness and treatment plan. Some nurses may forget which child is new and which child is a re-admission, which is why they appeared to be administering this care to patients in a habituated manner assuming familiarity with the procedure from repeated admissions. This could be acceptable for re-admitted children, who may have some degree of familiarity with the ward environment and the staff members; however, it may not be suitable for new admissions such as Nita. Being admitted for the first time, there is a possibility that Nita requires detailed information during orientation to allay expected feelings of fear and anxiety in a new clinical environment, surrounded by unfamiliar people (Coyne & Kirwan, 2012). Thus, the welcome and orientation is of immense importance to the initial interaction between patients and the clinical environment. Nevertheless, it is unclear in the example whether the parent and child are satisfied with the information they have received. As first timers in the ward, Nita and Rena appeared bewildered and apprehensive, without substantial information being communicated to them.

During the informal conversation, Doreen informed me that it is normal practice on the ward to give the orientation to the parents rather than the child. Doreen rationalizes that the orientation is mainly about the layout and routine of the ward, and that the parents thus require more information compared to the child, because the hospitalized children in the unit are assumed to be very sick, have limited movement, spend most of their time in their beds, and presumably all their activities are assisted by the parent. Doreen's explanation indicated that she does not seem to acknowledge the fear the children can experience being in a new clinical environment, surrounded by unfamiliar people, not to mention the anxiety of being diagnosed with cancer. Additionally, her explanation suggests that the practice of the ward does not value children as an individual within their own rights to participate in the matters affecting them. The practice seems to perceive the sick children as vulnerable, incompetent, and thus needing care and protection, which is consistent with Neale and Flowerdew's (2007; 26) conceptualization of children as welfare dependent, as discussed in Chapter 3. Thus, the care and well-being of the children is guarded by their parent, and children's participation in their care and decisions tend to be less emphasized (Cherney & Shing, 2008).

5.2.2.1 Nurse's role in conveying information

Children's experience of participation as being informed could potentially be influenced by the nurse. For instance, in Nita's situation, while she received limited information, and with no options given, Doreen seems to be in a position to control the information administered to children and parents, indicating how some nurses use their power over the children and their parents (Lowes, 1996). In comparison to Nita and her parent, Doreen, who went for training (nursing) and who is used to caring for sick children has information relating to the child's condition, was in the position to decide whether or not to share information with the children and their parents (Corlett & Twycross, 2006).

During my informal conversations with some of the nurses, their explanations indicated that they were aware that they conveyed limited information to children. For example, while Violet declared, *'Yes, we tell them'*, Alina stated, *'Normally, we inform them, but most of the time we just tell them what we want to do'*. Amelia added, *'If we are busy, we just give them instructions'*. Vivian explained that the ability to follow the instructions is important for child patients for expedient health care processes:

> If they want to know more, they should ask (smiles). Most importantly, we inform them what they need to do, as long as they understand and are able to follow the instructions, that's the most important. This will be easy for everyone.
>
> [Excerpt from fieldnote, 23 June 2015]

The statement of Vivian indicates that she would expect or rely on the children to be proactive. It appears that she had a pragmatic approach calibrated to enable the expedient administration of nursing care. For her, informing children was necessary only to ensure their cooperation, which she felt was conducive to an easier working situation for nurses as well as children and their parents. Again, this showed how most nurses in this study are particularly task oriented, without considering the needs of children for information. This could be the explanation for Nita and most children of this study who received limited information, with no option being given. Reflecting the situation of Nita, I would argue that children might not always know what questions to ask or may not know what information they need. For instance, during the vital sign checking and blood taking procedure, despite receiving limited and simple information, Nita was not given an option to choose (e.g. which hand she preferred for the blood taking procedure and vital sign checking). She appears to accept what she is being told and acts according to the nurse's instructions. Thus, it could be argued that when a child has limited information and options, it is difficult for them to be involved in discussions and to make decisions about his/her care. Franklin and Sloper (2006) suggest that children (and indeed any patient group) cannot participate in decisions if they are not fully informed of the care provided, options available to them, and the implications of those options.

5.2.2.2 Summary

In this section I have analysed how the children come to occupy a marginal position in decisions, without direct access to information about their care. Although children appeared to be informed, they essentially received very limited information, with information sharing largely carried out between parents and healthcare professionals, which limits the possibility of participation in decisions regarding their care. On many occasions, it could be argued that children should be fully informed to improve their understanding and increase their participation in care and decisions (Franklin and Sloper (2006). It is certainly a nursing responsibility to assess the information requirements of children and their parents. For example, nurses could share information with children about their condition during the decisions, such as the purpose of treatment, timing and the nature of treatment or investigation, risk involved and possible harm and inconvenience, including prospects of pain (Alderson & Montgomery, 1996). These ideas are linked to how children were being consulted, as discussed in the following section.

5.2.3 Children being consulted

> George is under the care of Gail. George has yet to register for the ‘school’ (a one-to-one learning session, which is held in the unit and taught by a qualified schoolteacher). All children that are admitted to the unit are encouraged to attend the learning session.
>
> Gail says: George, do you want to attend school tomorrow?
>
> George looks at his mother. He does not give any verbal response. His facial expression looks as though he is asking for his parent’s opinion.
>
> Jess (George’s mother) looks at George and asks: Are you interested?
>
> George asks Gail: Do I need to attend every day?
>
> Gail: You need to register if you are interested and you are allowed to not attend if you are feeling unwell and unable to do so. I can register your name if you want to.
>
> Jess suggests to George that he could register first and then the decision whether to attend can be made later depending on his condition.
>
> George looks at his mother and is silent. He seems to be thinking. Then, George with a steady voice, confidently tells Gail to register his name for the session.
>
> [Excerpt from fieldnotes, 5 January 2015]

Initially, George was asked by the nurse whether he wanted to attend a learning session, and the information regarding the session was given. When the nurse directed the question, George seemed uncertain about the decision to attend the ‘school’. He appeared to seek his parent’s opinion. From his facial expression, George seems to be trying to seek support from his parent, when he tried to inspect his parent's behaviour when asked for his own opinion by the nurse. His reaction could reflect his attempts to identify signs or opinions from his parent to determine his own course of action, or to form his own opinion. George, then, directed questions to the nurse. He seems to be seeking clarification from the nurse, before he can make his own decision. This situation demonstrates a child being consulted during decisions about the learning session: first, George seeks further information regarding the learning session whether factual or relational (e.g. what his mother wants), second, he was given information regarding the learning session by the nurse, and third, he can express his views (Savage & Callery, 2007), which finally, enables him to make his own decision. In this situation, George can be considered to participate at the highest levels of participation of Hermeren's (1996) model (see Chapter 7, section 7.7). This could be explained by the fact that George received information about the learning session. This means that a two-way communication and consultation takes place between the child and the parent and nurse. It can be seen that the nurse and the parent carried on a dialogue with him, his opinion was listened to, and he made his own decision to attend the learning session and finally, the nurse acted in accordance to his wishes.

In this situation, Gail appeared to spend time explaining and discussing the session with George, and she gave an opportunity for George to think and ask questions. It appears that when Gail was willing to give information, options, and an opportunity for George to ask questions, he was able to be involved in the consultation, and, finally, make his own decision regarding his preferences to attend the learning session. This suggests that when children are consulted in their care, they will be able to be involved in the decisions, because being consulted would improve their understanding, and thus, promotes their participation in care and decisions (Franklin & Sloper, 2006). This could be the reason why most of the children in this study tend to prefer discussions with either their parent or nurses during decisions about their care. Reflecting on his experience, George said:

> I usually discuss with my mother for certain things that I am not sure of…like…about the *school*; I have no idea about it. That is why I asked the nurse about it and discussed with my mother.
>
> [Interview, George, Child, 5 January 2015]

Not only did George state that he needed support from his parent during the decisions, it was also mentioned by other children. For instance, Amanda stated:

> I would prefer my mother. I think she knows what is best for me. Most of the time, the physicians and nurses also talk to her. Anything about me, they ask her. Maybe because she knows everything about me. (…) I am also afraid I don't understand what they say. Sometimes, they talk like an adult, difficult to understand. If they inform my mum, she will explain to me, and it is easy for me to understand.
>
> [Interview, Amanda, Child, 26 July 2015]

The views of George and Amanda indicates that they prefer to consult with their parent during decisions. Amanda rationalised that, for her, her mother knows what is best for her. Her statement demonstrates that she has an appreciation of the role of her parent in the decisions. Drawing on her hospitalization experience, Amanda perceived that her mother has a fuller understanding about her when the healthcare professionals always direct questions to her mother. This corresponds with the findings of a qualitative study by Coyne and Gallagher (2011), who found that children perceived the healthcare professionals and their parents as the experts who know best, and, thus, favoured such decisions to be shared. In addition, Amanda seems to locate the cause for this effect with the way in which the physicians and nurses of the ward frequently convey information and obtain clarification from the parents; indicating that parents are experts about their child. For Amanda, nurses and physicians are most likely to communicate in an adult way which makes it difficult for her to understand, and that this is why she needs to rely on her parents because she needs reassurance and support in the decisions. This supports the findings of

Bjork and colleagues (2006), that some children needed their parents and the parents' presence helped the children to express other needs. Also, Runeson and colleagues' (2007) study reported that some children preferred not to be left to make decisions without the support of the parent or health care professional.

5.2.3.1 Parents' role in promoting consultation

The fieldnote about George demonstrates that the parent plays an important role in supporting consultation with the child, which in turn enables the child to participate in the decisions. It appears that Jess (George's parent) suggested to George to first register and then to decide later whether or not to attend depending on his condition (see above excerpt, page 11). The role of Jess in this situation could be considered as an advocate in the consultation process or as communication brokers, the term defined by Gibson and colleagues (2010), when she clarifies information so George can better assimilate what the nurse has said. In addition, the presence of Jess and the way in which she discusses it with her child seems to increase George's confidence level and, thus, he can take part in the decisions and finally make his own decision (Bereford & Sloper, 2003; Young et al., 2003). It can be seen that the parent assisted in the child reaching a decision, and thereby affected the decision; this was through engagement in discussion with the child. This interaction endorses the distinction between decisional priority and decisional authority made by Whitney et al. (2006); the person who has decisional priority takes the lead in the process of choosing between possible options, resulting in a recommendation, which prepares for the proposed option to be made by the person who has decisional authority. In this case, although the parent may have the decisional priority, George appears to have decisional authority when he makes his own decision to attend the session.

Some parents in this study appeared to agree that children's participation entails some element of being consulted. The reaction of Jess can be interpreted in light of this; indeed, her action toward her child was in line with her explanation:

> Actually, they should be given all information about what is going to be done to them, so that they understand… and they should be

> able to tell us what they want… and we… as parents, we should listen to them, and if possible follow what they want… I personally try my best to fulfil my child's request…
>
> [Interview, Jess, Mother, 7 January 2015]

This statement emphasises the relevance of children being consulted. Jess appears to acknowledge that information is essential in order for children to be aware and understand the decisions made and, thus, they can be involved in the decisions. Reflecting on her own experience, she seemed to desire that all parents would listen to their children's voices, and take into consideration and fulfil their children's wishes where possible. Her explanation appears to consider children as individuals with their own ability and need for participation and respect. This was in line with the conceptualization of 'children as young citizens' by Neale and Flowerdew (2007: 26), who argued that when children are defined in this way, adults will treat children equally to adults, and thus, children are more likely to be encouraged and supported to be involved in their interaction with others, and participate in the decisions concerning them. This could best explain her reaction in promoting consultation involving her child. This highlights the significance of parents' views towards children and such perceptions condition the ways in which parents respond differently towards their children.

5.2.3.2 Nurses' role in consultation

In addition to the role played by parents in promoting consultation, the role of nurses can also be considered as essential in promoting consultation with children. Several nurses in this study expressed opinions that children should be involved in decisions about their care. For example, Nurse Hilda exclaimed that, *'Of course we should include them, because everything is about them'* and Nurse Alina added, *'Even though most of the time parents make decisions for them, it is their bodies, so, they should be informed and asked what they like'*. Hilda explains that because the care concerns children directly, children should be involved. Although Alina acknowledged that parents play an important role in their child's care decisions, it appears that most nurses hold a view of children having a right for getting information regarding their care. They were adamant that children should be consulted in the matters concerning them, implying that children should be part of the consultation, and their views should be solicited and heard (Savage & Callery, 2007). However, these explanations seem to contradict some of my observations. Not all children in this study were treated in such a way. Some children were treated differently, for example, the situation of Ray (see section 5.2.1), and Nita (see section 5.2.2). Both of these examples showed that children were not informed, or if they were informed, it was only with limited information. In other situations, children were not given a chance to ask questions or express their opinions (see example of Nita in section 5.2.2), or if they were able to express their opinion, they were being disregarded by nurses (see example of Noah in section 5.3.2.1). In these examples, children were required to adhere to the nurse's instructions regardless of whether they liked it or not. This could link to the views of some nurses that children's participation should be minimized in order to avoid undue stress on the children. For instance, Irene states:

> (…) I know that children should be involved in the decisions about their care, because it is about them. (…) They are sick, they should rest, and they are just a small kid, we should not burden them. Let their parents take the responsibility; as parents, they know best about their child and they know what is best for their child. You know, when we ask them so many questions, it may be stressful for them. So, for me, it is better if they just know what they have to do, I guess it is better that way.
>
> [Excerpt from fieldnote, 22 January 2015]

This statement indicates that she acknowledges that children should be part of their care, and that children should participate in their care decisions, but she appears to prefer to restrict this to a need-to-know basis to avoid the burden of stress caused by participation. She clarified that it is not appropriate to involve children in complicated decisions about their illness, as this would be highly stressful for them.

She assumed that parents are the best people to decide for their child, because they know what is best for their child. She acknowledges the importance of the parental role in the decisions of the child's care, when she expressed that she would rather let parents take responsibility to make decisions for their children. Her expression also indicates that she is doing what she thinks best for children in terms of holistic care (e.g. sparing the feelings of the child by avoiding the discussion of complicated issues), which results in not eliciting children's preferences and effectively curtailing their involvement in care decisions. This was evident in the way in which she treated Ray (as illustrated in section 5.2.1), where she directed communication to the parent and let the parent decide for her child. Furthermore, the characteristics ascribed to children in the above extracts (e.g. 'small kid' and 'sick') convey a construct of vulnerability and dependency. Children are thus assumed to be dependent on their parents. This was consistent with the conceptualization of 'children as welfare dependent' (Neale & Flowerdew, 2007: 26), which leads to her argument that children should not participate in the decisions in relation to their care because participation places undue burdens of responsibility onto children (Neale, 2002). This conceptualization also considers the adult (including parents and healthcare professionals) as the best person to evaluate children's best interests and to speak on behalf of children (Fitzgerald, 2009). This could best explain her reaction towards Ray (see section 5.2.1). Again, this highlights the significance of nurses' views towards children and such perceptions influence the ways in which nurses respond to children in particular situations.

Children's participation in decisions are complex and adults could not activate children's involvement in decisions without the readiness and willingness on the part of the child. Ray, for instance, (as illustrated in section 5.2.1) despite a question being directly addressed to him, was evidently unwilling to be drawn into the discussion. Thus, his participation did not materialize. In contrast, George (as illustrated in section 5.2.3) appeared to be ready and willing to be involved in the discussion with his parent and the nurse, and thus his participation was apparent. In fact, his reaction directly resonates with his comments regarding what participation means to him:

> If I participated in the decisions about my care, it means that I would have been informed and asked for my opinion… Umm, I want to know about what is going on, what decision will be made. Like I said just now, the nurse should tell me, so that I know what is going on. I also want to tell them what I prefer.
>
> [Excerpt from fieldnote, 28 December 2014]

In this excerpt, there appears to be an agenda to convince me as well as himself of his hope to have a full understanding of decisions. His statement highlights that he desires information from nurses in order to be able to understand what is happening, he wants to express his opinion, and if he participates he would feel he was being consulted. Indeed, the necessity for children to be consulted was also mentioned by most children in a qualitative study of Savage and Callery (2007), who desired information, wanted to express their views, and who wanted their own wishes to be taken into consideration in the decisions.

5.2.3.3 Summary

In this section, I have discussed some of the ways in which children are consulted during decisions. I have shown that when two-way communication and consultation takes place between the children and nurses, children can be considered to participate at the highest level which parallels with level 5 of participation by Hermeren (1996) when they are able to express their wishes, and the nurses acted according to the children's request. This section also analysed how the children prefer to be consulted in relation to their care decisions. Already it has become apparent that the children were in need of parental support in decisions, and the consequences of being consulted, was that, children can ultimately contribute to making decisions about how they are cared for in hospital.

In chapter 3, I have drawn on authors such as Neale and Flowerdew (2007) in order to suggest that children's participation is influenced by the way in which adults conceptualise children. This section addressed this conceptualization of children by nurses and parents, as either ‘children as welfare dependent’ or ‘children as young citizens’, conditioning the ways in which they respond to children in decisions.

5.3 Choices versus expressions

In this section, I discuss the children in this study being offered choices and given opportunities to express their views with regard to their nursing care. This involves examples of different choices being made available to children during the provision of nursing care, and situations where children are able to express their views, and how they are either being ignored or respected by nurses, which may or may not influence the final decisions. It resonates with debates from the literature, reviewed in Chapter 3, on the options available for children including something related to their daily routine, not distressing to their condition, and does not interrupt the treatment plan.

5.3.1 The choices available to children

> Alexis is taking his oral medication, Tab, Prednisolone, 60mg (total of 12 tablets). His parent, Jenny, is assisting him.
>
> At 10.30am, as I walk past them, Jenny looks at me and says: This is supposed to be taken at 8am, but, just now, he refused.
>
> I ask: Alexis, is there any reason why you delay your medication?
>
> Alexis: I’m too full just now, after I had my breakfast, it difficult for me to swallow it, too much! But… I know I have to take it, sooner or later.
>
> I ask: You think so?

> Alexis: Yeah, I have cancer, without medication I will be sicker. Even though I have to take a lot of medication each day, and I don't like it, really, I don't like it, but I have to!
>
> Jenny: You know, he has to take all 12 tablets at the same time, twice a day. Just now, he is too full, if he takes it, he will definitely vomit. That is why I'm not forcing him, because if I do, he might totally refuse the medication. Usually, the timing is up to him, he is the one who takes it, as long as he takes the medication, it doesn't matter; for me, later is better than not taking it at all. And he also knows that he has to take all his medication. He understands, for him to get better, he has to follow all the treatment plan.
>
> [Excerpt from fieldnotes, 24 December 2014]

This excerpt illustrates that Alexis was given an option of when (immediately or later) he would prefer to consume his medication. Alexis seems aware that he is allowed to choose the timing of taking his medication when he initially delays consuming it. Although Alexis appears to dislike the medication, as he initially refused it, ultimately, he takes it because he realises its therapeutic importance: 'I have to.' He eventually engaged and complied with the treatment plan, although certain phrases indicated an element of compulsion (e.g. 'I have to'). Alexis seems to have a constrained option and decides to comply with the medication regimen, while his action of deferring the timing of medication could be his personal preference that does not substantively alter the course of the prescribed treatment. The excerpt indicates that Alexis appears to understand the seriousness of his illness, which requires him to comply with the treatment plan. He seems to know that the treatment is necessary for his condition, with no absolute right of refusal, when he stated that the only chance of getting better was to follow the prescribed treatment protocol, and thus, try to work within the parameters given.

The phrase 'I have to' was repeatedly used by most of the children to refer to health behaviours, as evidenced by the following excerpts:

> George states: I was being told like 'If you don't want to get sicker, you have to do this, or take that medication', so I have to follow what they (nurses) say.
>
> [Interview, George, Child, 7 January 2015]
>
> Kate informs: I know I have cancer, so, I have to follow everything that the physicians and nurses ask me to do (…) it is important for my health. If not, I will not get better…
>
> [Interview, Kate, Child, 20 Jan 2015]

These statements of George and Kate indicate that they mostly have no choice in relation to their treatment. They are typically complying with their care plan because they are being influenced by others. George, for instance, indicates that he is continually reminded to follow all the treatment plan for his survival, while Kate's quote suggests she has awareness of the importance of adherence to the treatment plan, which is essential for her condition.

Alexis', George's and Kate's expression regarding choices for children suggests that they were not always offered choices mainly due to their illness, and thus, the treatment plan had to be followed. It appears that the limited options that were made available for the children appear to influence the role children play in decisions. As Franklin and Sloper (2006) suggests, children cannot participate in decisions if they are not fully informed of options available to them.

Nevertheless, there were a few children who felt that they had general daily choices; for example, Jane told me, *'Usually nurses will ask me if I want to remove a plaster during dressing procedure'*, and Phoebe added, *'My mum also will ask me what I want to do for today or what I want to have for my lunch'*. These statements indicate the options available for children appeared to be something related to their daily routine, something not distressing to their condition, and did not interrupt the treatment plan. This could have suggested that the alternatives offered could be something with less impact; however, children appeared to welcome and appreciate the choices.

While some children perceived that they have no or limited choices in their care delivery, others perceived that sometimes they were offered choices. Nurses and parents agreed that children are mostly able to make a choice, and at times children have the opportunity to make a decision. The following excerpts are noteworthy statements representing the views of nurses and parents:

> Actually, children decide simple issues, they may have some say for example in their food intake, they normally can choose what they like and dislike. Unlike in the big decision especially about the treatment protocol, usually, the parents together with the physician will decide for them.
>
> [Interview, Violet, Nurse, 10 January 2015]
>
> Yeah, in terms of everyday decisions, like about something that has not affected her condition, she chooses when she wants to take her medication, or what she would like to have for her breakfast, but not the chemo.
>
> [Interview, Teri, Parent, 22 December 2014]

These excerpts illustrate that the parents and nurses appeared to agree that children were offered choices and were able to make decisions concerning their care. They tried to distinguish between the different types of decisions that involved children. This statement can be seen as a powerful illustration of Coyne and colleagues' (2014) classifications of decisions, as 'minor' and 'major' decisions. Their explanations indicated that the minimal impact or minor decisions are the choices related to everyday events such as diet and times for procedures to be carried out, which children are mostly involved in, while the major decision such as the treatment decisions are mostly made by the health professionals and the parents. It is illustrated in the statements that the major decisions are made by adults, frequently by the physician and nurses together with the parent/s, and could be done with or without involving the children. This could suggest that the focus on the best treatment in the child's best interests resulted in adults ultimately maintaining decisional authority over serious care issues (Whitney et al., 2006).

5.3.1.1 The role of parents in offering choices to the child

In the situation of Alexis, Jenny (Alexis's mother) played a role in allowing choices around the timing of medication to her child. Jenny tried to fulfil the wish of Alexis by allowing him to consume his medication at his preferred time. She may be aware that Alexis' wish to delay the medication will not change the whole course of treatment protocol, and she may expect that finally Alexis will take his medication. In addition, Jenny seemed practical as she understood that it would not help Alexis's treatment plan if she forced Alexis and he vomited out the medicines. This situation can therefore be seen as an example of how the parent tries to fulfil their children's requests. Nevertheless, it could be part of a strategy to promote ultimate compliance with an essential treatment plan, because the treatment could be considered to be vital for children in life-threatening illnesses such as cancer.

Reflecting on this situation, Jenny indicated that it is important for her child to take the medication on time: to sustain the effectiveness of the medication. However, according to her, the most important thing is the adherence with the treatment plan. This confirms that she fulfils her child's wish mainly to promote compliance to the treatment.

With respect to the choices available to the children, Jenny gives the following explanation on the matter:

> Jenny states: Hmm, maybe, maybe choices are there for them, as you can see, but most of the time they couldn't choose what they want. You may have realized about the chemo, it's important for them, for them to be cured, without it they wouldn't survive, regardless they like or dislike they have to take it, and they cannot

> refuse, if not they become sicker… Even to delay, they are not allowed. They just need to keep going.
>
> [Interview, Jenny, Mother, 24 December 2014]

Jenny's statement reveals that the optional components might be things not considered essential for the child's survival, for example the timing of medication elaborated upon with regard to the above situation (but not the timing of chemotherapy). It appears that, according to her, chemotherapy is considered as an essential treatment for the survival of the children with cancer. Similar to Alexis, George and Kate, Jenny appears to be aware that children were not always offered choices, and non-adherence was not an option in serious circumstances because of the binding nature of the treatment plan, which is ultimately instituted for children's best interests and survival (Coyne et al., 2014). This could be due to the life-threatening diagnosis, urgency, and seriousness of the illness, which required a strict protocol to be followed (Coyne et al., 2014). Nevertheless, to some extent it does allow the children some sense of control over their care although not total control, for instance, Alexis is able to decide the timing of his medication according to his desire. This finding supports the studies that reported that when choices were made available to the children, they are able to make a choice, and in turn, improve outcomes such as medication compliance (Runeson et al., 2001, 2002a; Alderson, 2007; Coyne & Gallagher, 2011).

5.3.1.2 Nurses' role in offering choice to children

The above example indicates that parents and children were in agreement that choices were not always made available for children. This is supported by some nurses who state that offering choices to children is not always possible:

> Yes, I'm sure there are options for them, and they can choose the timing of certain procedures, but I would say it depends, if it is not urgent, it's okay to delay, but if it is urgent, the answer is 'NO' (…) for example blood test, blood transfusion or any other procedure that needs to be done immediately, if it is for a lifesaving reason,

> we will not compromise. At the end of the day, they may not be able to choose what they want, but they just need to follow what has been set up for them.
>
> [Interview, Amber, nurse, 11 December 2014]

Amber appears to agree that there are choices for children, and usually children are allowed to select their options according to their wishes. However, Amber stressed that nurses are responsible for making the final decision for the children. She explains that the decision was considered if it does not affect the child's condition or disrupt the treatment plan. This indicates that, despite the lack of choice or opportunity to decide about care for children, decisions regarding their care are largely determined by the nurse (Runeson et al., 2001; Coyne & Gallagher, 2011; Coyne et al., 2014; Ruhe et al., 2015). It gives an impression that children seemed to have the options but in reality, it seems that they actually did not have any real choice.

The following excerpt is an example of a nurse offering choices to a child and acting as a main decider in the situation:

> Albert is under the care of Bella. Albert is on RT (Ryle's tube, a narrow bore tube passed into the stomach via the nose) because he refuses oral medicine.
>
> In this case, the tube is mainly for the purpose of giving oral medication. He is scheduled for the change of RT.
>
> During the removal of the tube, Albert appears calm, he follows Bella's instruction to breath in and out, and he does not struggle or cry. The tube was successfully removed without difficulty.
>
> When Bella prepares to reinsert the new tube, Albert starts to cry, and he refuses the reinsertion. He pushes Bella's hand away.

> Bella, with a firm voice, says: If you are willing to take your medication orally, I will not insert the new tube.
>
> Bella gets ready to reinsert the tube. Albert continues crying. Bella repeatedly tells Albert that the RT will not be inserted if he is willing to take his medication by mouth.
>
> A bit later, suddenly Albert in a crying tone says: I will take the medication by mouth.
>
> Bella with a strong voice asks: Are you sure that you are going to take it? I will insert the tube if you don't.
>
> Albert nods and agrees to take the medication by mouth. In a high tone of voice, his parent, Ezra, stresses that the nurse will insert the tube if he does not take his medication. Albert promises that he will take it.
>
> Finally, Bella decides not to reinsert the tube and gives Albert time to take his medication. Before leaving, Bella reminds Albert that she will come back to check if he has taken his medication.
>
> [Excerpt from fieldnotes, 3 July 2015]

Initially, Albert refuses the reinsertion of RT, exhibited in highly emotional behaviour (crying and pushing away Bella's hands) as soon as she began preparing for the procedure. Albert's response could mean that he seeks to register his disapproval of the reinsertion of RT, or he fears pain caused by the procedure. As this is not the first time, he might anticipate the uncomfortable feeling of insertion. It can be seen that Bella is offering the options of taking medication orally or to insert the new tube to Albert, which enables Albert to make his own decision.

It was unclear from the situation why Albert suddenly agreed to take oral medication, which was his original difficulty. During my fieldwork, Ezra and the nurses in the ward indicated that prior to the incident, Albert often had difficulty in consuming his oral medication, and his parent had to continually persuade him to take it. He usually took a long time to consume a single dose of oral medication. After the incident, I noticed that his parent and nurses repeatedly use a RT as a tool to threaten him in order for him to take his medication.

His response could be made under duress (i.e. under threat, or being forced or manipulated). The procedure of RT insertion can be an unpleasant experience for children, causing discomfort during the insertion. This could be the reason why Albert made the decision to comply with the oral medication, although he found taking oral medication difficult. However, there is also a possibility of his own free will because he might understand the importance of taking medication orally, as he needs to consume medication in the long term, and it is needed for his health. Another reason could be the way in which Bella communicated with Albert. She appeared to use a firm voice while communicating with Albert, which might cause Albert to feel threatened, and therefore comply with what he knows to be the treatment option preferred by the nurse. It can be seen that, although Albert seemed to make his choices, ultimate control of the final decision rested with the nurse; it was Bella who effectively decided whether to insert the RT or allow Albert to consume medication orally.

It seems that Bella uses her interpersonal skills such as, explaining, reassuring and listening, in this triadic interaction, which makes the exchange of communication become effective (Lambert, 2012). Initially, Bella is explaining about the reinsertion of the tube to Albert and his mother. Reassurance was given when she announces that Albert does not need the tube which can be unpleasant for him, if he is willing to take medication orally. Finally, she appears to be listening to Albert when she makes a decision that accommodates his request, which is conditional on his choice and action (to take the medication). Although Bella appeared to exert her power towards Albert by using a strong tone of voice, she seems to be trying to establish rapport with Albert when she spends time carrying on a dialogue with him and not hurrying the procedure. Bella appears to recognize Albert as a valid partner in his care, whose opinions and wishes were taken into consideration. In addition, the flexibility of

Bella in negotiating the nursing care appears to motivate Albert to make his own choice, which ultimately resulted in gaining the child's cooperation and acceptance of care (Coyne et al., 2014), although Bella's concern could mainly be related to promoting the compliance of the child with treatment. Despite Bella using threatening behaviour towards Albert (using a high tone of voice), the interpersonal skills used by Bella when she is negotiating with Albert, influence the degrees to which Albert participates in the decisions. In other words, Albert received information about the need of the insertion of RT. This would mean that there was a two-way communication taking place where the nurse carried on a dialogue to negotiate with him, and finally, the nurse made the decision according to his wish. Thus, Albert's participation was congruent with level 5 of Hermeren's (1996) model (see Chapter 7, section 7.7)

5.3.1.3 Summary

In this section I have discussed some of the ways in which children are being offered choices in relation to their nursing care. Already it has become apparent that children were provided with choices which are not distressing to their health outcomes or disrupted their treatment plans. By looking at everyday interactions in detail I have shown how lack of choice or opportunity to decide about care being offered for children and final decisions regarding their care are being mostly regulated by the adults.

The section has shown the importance of the role of nurses and parents in offering choices for children. The way in which adults draw attention to fulfil the wishes of the children, have implications for children and decisions. When Jenny permitted Alexis to delay the timing of his medication according to his desire, it allowed him to have some sense of control over his care although not total control; Alexis is able to decide to delay the timing of his medication. When Bella made decisions according to Albert's wish, this had an impact on her decision, which was different to the one that was initially anticipated by her.

The analysis of these examples echoes the classification of decisions discussed in Chapter 3 which include: (i) minor decisions, which are considered as having less impact by nurses and parents, mainly related to their daily routine, such as, the timing and delivery of the procedures (e.g. medication, dressing, blood test, food intake), which children are mostly involved in, whereas, (ii) Major decisions, such as treatment decisions are mostly made by the health professionals and the parents, which was welcomed by most children. Thus, decisions are complex and for the most part are controlled by nurses and parents.

5.3.2 The expressions of the child

In this section, I illustrate the situations where children were able to express their requests and opinions during the provision of nursing care. I begin to discuss the ways in which children are able to express their views, and how they are at times ignored by nurses. I then explore the situation where children's expressions are respected by nurses and influence the decisions.

5.3.2.1 Expressions being ignored

> In the morning shift, Nita is under the care of Alison. Nita is due for her second CVL dressing, which was conducted in the treatment room.
>
> Initially, Nita is allowed to remove a plaster herself; she slowly removes the plaster covering the CVL on her chest. Suddenly, Alison pushes Nita's hand away. She pulls the plaster roughly and very fast.
>
> Nita appears shocked when Alison pulls the plaster off. She screams.
>
> Alison tries to defend her action. She informs Nita that it will cause more pain if she pulls slowly, and will have less pain when the plaster is pulled off fast.

> Nita, with an angry face, screams and says: No, it is not that painful if you pull it slowly, you do it very rough, and luckily my skin is not pulled off!
>
> Nita seems very angry and unhappy. Nita repeatedly argues that Alison's action caused more pain compared to her first dressing.
>
> Rena (the mother) appears surprised seeing Alison's action. She says in a high pitch tone: During the first dressing, the nurse pulled it very slow, and it caused no pain.
>
> Alison continues to defend her action.
>
> Nita seems unhappy and dissatisfied. She shows a sour face and keeps silent throughout the procedure.
>
> Alison continues doing the dressing without any conversation with Nita.
>
> [Excerpt from fieldnotes, 26 June 2015]

At first, Nita expresses her preference to remove the plaster, and Alison appears to respect and consider her wish to remove the plaster herself. Then, again she expresses her opinion when her hands were suddenly pushed by Alison. Nita expresses her dissatisfaction with the way Alison conducted the procedure, stating that the procedure carried out by the latter was painful, but this time, her expression was disregarded by Alison. It appears that Nita is very brave in expressing her disapprobation with Alison's action, even though this is her first admission to the ward. This could be because Alison's action caused excruciating discomfort to her. Despite being able to express her disagreement (indeed, a complaint of pain) towards the way Alison conducted the procedure, Nita expresses her preferences for the procedure to be done in a similar way to what she experienced during the first dressing, and she appears to prefer the plaster to be pulled off slowly. It appears that there was no consultation or two-way communication taking place when the nurse refused to discuss and consider the child's opinion.

Alison appears defensive and unapologetic, ignoring Nita's expression of dissatisfaction. The behaviour of Alison might suggest similar dismissive and disrespectful attitudes and practices toward other children, failing to perform the nursing role of supporting children's participation in their own care (Runeson et al., 2002a; Hallstrom & Elander, 2005), which results in a marginal role of children in decisions regarding their care. The way in which Alison refused to communicate with Nita during the remainder of the procedure could mean that she is dissatisfied with Nita's reaction. Alison might feel threatened by Nita, who appears to be familiar about the procedure and questions the way Alison is conducting the procedure. Similarly, as reported in Coyne's (2006a) study, it was suggested that professionals might feel endangered by children who are knowledgeable about their care and who might question the views and approaches of professionals, which seems to influence their effort to support children's participation. Nita may be considered as an aggressive child and a problem patient following her behaviour, which might challenge her professional conduct. Again, it shows how the attitudes of nurses are of greatest importance regarding children's participation in decisions. Consistent with this finding, previous studies have reported that children were seen to have little active involvement during the discussions and decisions regarding their care, and nurses often play a significance influence on whether children's efforts to participate are facilitated or supported in the hospital setting (Reneson et al., 2001; 2002a; Hallstrom & Elander, 2005; Coyne 2006a; Savage& Callery, 2006; Alderson, 2007; Coyne & Gallagher, 2011; Schalkers et al., 2016).

This excerpt serves as a powerful illustration of level 3 of Hermeren's participation model (1996). It appeared that there was communication taking place between the child and the nurse. Alison communicated with Nita, but she did not seem to care about Nita's opinion and Nita's opinion does not appear to influence her action. Although Alison directly communicated with Nita, the participation of Nita can be considered as non-participation or tokenistic, as it is a way in which children are able to formulate and express their own opinion but have no impact on decisions (Hart, 1992). Nita appeared to be angry and unhappy when she was pushed away, and her wishes were disregarded, which could indicate that she was disappointed with the nurse’s action (Young et al., 2003). In contrast, it can be seen that she appears to be pleased and confidently removes the plaster when she was allowed to do so at the beginning of the procedure.

The excerpt resonates with my other fieldwork observations among re-admitted children, as illustrated in the following:

> Wednesday morning. Noah is under the care of Alma. Noah is scheduled for a blood taking procedure [drawing blood specimen from the CVL port, which does not involve a needle procedure].
>
> Noah is lethargically lying on a bed. His cousin looks at me and says: Last night he had a spike of fever, he is tired and very sick.
>
> Alma comes in and says to Noah’s cousin: Could you please bring him (Noah) to the treatment room for the blood taking procedure.
>
> Noah tiredly says: Just do it here, I’m so tired!
>
> Alma looks at Noah, with a firm voice and says: No, you have to walk to the treatment room, otherwise you will be sicker and weaker, and because of that you cannot go home. Do you want to stay in the hospital forever?
>
> Noah looks unhappy, he looks down and keeps silent, and he does not give any verbal response.
>
> Alma: I’ll be there waiting for you okay. Alma walks out.
>
> [Excerpt from fieldnotes, 26 November 2014]

This excerpt is similar to the above interaction between Alison, Nita and Rena, but this time Noah is a readmitted child. In this situation, Noah voices his request for the procedure to be conducted at his unit. Despite ignoring Noah's request, Alma appears to remind Noah that the cause of his fever and weakness was his refusal to walk around, walking she said would have a positive effect on his recovery. This could be a means to gain Noah's obedience, both promoting the positive benefits of walking and cautioning that refusal could result in prolonged hospitalization. Similar to George's statement (see section 5.3.1), Noah is also being reminded to follow the treatment plan for his own benefits. Hospital can be considered as a stressful place, and hospitalization is a stressful experience for most children (Gibson et al., 2010; Coyne 2006b; Coyne & Conlon, 2007; Coyne & Kirwan, 2012). Thus, Noah was made aware that, if he followed the nurse's instructions, his condition would improve, and he could ultimately go home, which was intended to induce his adherence.

I was informed by the majority of the nurses that it is the practice of the ward that dressing, blood taking, and other invasive procedures have to be conducted in the treatment room. All children have to walk to the treatment room except for those under isolation nursing, those who are sedated, and those who are critically ill (incapable of ambulating to the treatment room). A child who is weak and who feels tired is normally given a wheelchair or is assisted by the parent or family member to go to the treatment room. Based on this information, Noah, however, might not meet the requirements for the procedure to be done at his unit, because he is considered fully conscious, not sedated and not being cared for under isolation nursing. This could be the reason why his wishes were not listened to. Alma might act in such a way because of the rules established in the unit that she is bound to follow, so that she is not reprimanded by the authorities for her action to fulfil the child's request. This indicates that nurses may be facing an ethical conflict in deciding between supporting a child's wish and following hospital routine and rules. However, Alma could have offered Noah a wheelchair because he looked weak and tired. Again, this suggests that the nurse seems anxious to complete her task on time, without assessing the needs of the child, and ignored the child's request.

Like Nita, this interaction exemplifies level 3 of Hermeren's (1996) model of participation because there was a two-way communication between him and the nurse. However, his participation can be considered as tokenistic because he voiced his wishes, but they were not considered and had no impact on the decisions or the action of the nurse. The examples of Nita and Noah as illustrated above, demonstrate an imbalance of power in the nurse-child interactions (Bricher, 2000), whereby the nurses exerted their power over the children by using a firm voice and failed to respect the children's expressions. In both cases, nurses were responsible for making decisions about the interventions, while children were mainly restricted to discussing how the intervention would be implemented. It becomes apparent that although children were able to express their requests and opinions, nurses are in the position to control the decisions and, thus, they are marginalized in the decisions.

It can be seen in both examples (Nita and Noah) that when their expression or requests are disregarded, children appeared to be unhappy and dissatisfied (it is noted through their facial expressions and sullen silence throughout the procedures). Consistent with this finding, previous studies reported that children often feel angry and upset when their expressions are ignored and they are excluded from the discussion (Young et al., 2003; Coyne, 2006a; Kelsey et al., 2007). The way in which the children follow the nurses' instructions without argument are within the culture of Malaysia that upholds the hierarchy to maintain social harmony (Helwig, 2006). As outlined in Chapter 2, Helwig (2006) claims that this culture implies that children who are inferior tend to receive and follow the instruction of the adults who are superior, and the adults tend to give directions and demand for children's obedience. The nurse-child interactions thus appear to be hierarchical, which could lead to the rejection of children's participation in decisions, in which the expressions of the children are disregarded.

5.3.2.2 Expressions being listened to

While the above example demonstrated that the expressions of both novice and veteran children are ignored by nurses, I continued to conduct more observations and had conversations with children, nurses and parents regarding opportunities for children to express their opinions and make decisions. I then began to see some differences in the interactions, such as in the following observation:

> Jane is under the care of Laura, and Jane is scheduled for a blood taking procedure. The procedure is carried out in the treatment room. Jane is accompanied by her parent, Maria.
>
> Laura says to Jane: Can you remove the plaster for me please?
>
> Jane, without any verbal response, removes it herself.
>
> When Laura proceeds with the procedure, Laura asks Maria if she can hold the CVL tube in order for her to draw blood specimen. Maria agrees.
>
> Suddenly, Jane says: Mum, let me do it! (Jane holds the tube).
>
> Maria, without any verbal response, smiles at seeing her child's behaviour.
>
> Laura proceeds with the procedure. When it is completed, Laura asks Jane if she wants to apply the plaster over the port herself.
>
> Jane, with a smiling face, places the plaster covering the port herself.
>
> Laura says: You're ever such a good girl!
>
> Given her age (7-years-old), Jane is a very diligent patient.
>
> [Excerpt from fieldnotes, 10 June 2015]

This excerpt might have some similarity to the above example of Nita and Noah, but this time Jane's voice appeared to be respected. It can be seen that as soon as Laura asked for assistance to remove the plaster, Jane began to decide and act without giving a verbal response. She appears to make her own decision to remove the plaster. When Laura asked for assistance from Maria (the mother) during the procedure, again, Jane was seen to express her wish to do it herself, which was granted by Laura, which was in line with level 5 of Hermeren's Scale of Participation (Hermeren, 1996). Correspondingly, Jane thus appeared to be the main decider in the decisions, and her participation can be considered as being at a high level of participation (Alderson & Montgomery, 1996). This could be explained by the fact that there was two-way communication between the child and nurse, in which Jane was able to voice her wish, and consequently, her wishes were respected (Alderson & Montgomery, 1996, Runeson et al., 2002a).

It is noteworthy that this is her sixth admission; thus, she can be considered as a veteran patient. Children who are frequently admitted to the unit are widely known and regarded as such by nurses and physicians. During my fieldwork, Jane appeared to participate intently in the nurses' routine such as vital sign checking, medication serving and dressing procedures. Jane seemed familiar with most routine nursing care administered to her and she was familiar with the terms usually used by nurses in relation to childhood cancer, such as 'ALL' (acute lymphoblastic leukaemia), 'IT' (intra-thecal), 'LP' (lumbar puncture) and 'MTX' (methotrexate). Indeed, during the interaction with nurses, she often inquired what they were doing and why they did things in a particular way. She would, for example, ask what the medication was for. On other occasions, she read out her temperature reading; when a nurse measured her temperature, Jane would place the thermometer under her armpit and read the temperature reading to the nurse herself. In conversations throughout the fieldwork, Jane indicated that she sometimes performs CVL (central venous line) dressing herself at home. Jane's response, therefore, is probably due to her status as a veteran patient in the ward. She might be familiar with the procedures and staff members. Thus, she knows what to do and was able to express her wish and for it to be accepted by the nurse.

The excerpt illustrates how a nurse played a role in encouraging and supporting the participation of a child during decisions. In contrast to Alison and Alma (see section 5.3.2.1), Laura, who is in a position of power and authority, does not overtly exert this power over Jane; rather she encourages and supports Jane and her parent to be involved in the care and decisions, and respects Jane's desire and acts accordingly without objection. Laura seems to recognise the right for Jane's participation, with a strength and ability, and thus, is capable of participating in and negotiating her own role in her care. Again, this could be linked to the way in which children are conceptualized, as the young citizens of Neale & Flowerdew (2007) (see Chapter 3, section 3.3.3), suggested that when children are defined this way, they are more like to be participants in their interaction with others and participate in the decisions concerning them. This indicates that although Laura has the authority to decide whether to allow Jane to participate in the decisions, she believes that Jane has the right to and is capable of participating in her care, and thus, Jane's participation in decisions was encouraged and supported.

Nevertheless, there were situations where children's requests were being listened to and taken into consideration by nurses, but at the same time the nurses exerted their power and authority over the children, as illustrated in the following example:

> Friday afternoon, Phoebe is eating her lunch. Her parent, Teri, is sitting on a chair and reading a newspaper. Nora, the nurse in charge, comes in and tells Teri to bring Phoebe to the treatment room for dressing.
>
> Teri nods and says: Come Phoebe, you can continue eating after the dressing is done.
>
> Phoebe: Nurse, can it be done after I have my lunch?
>
> Nora: Okay, I'll give you 15 minutes okay, I'll be waiting in the treatment room. Just come when you are done.
>
> Phoebe: Okay, I'll be there soon.
>
> When Phoebe had eaten her lunch, she and her parent walk to the treatment room for her dressing.
>
> [Excerpt from fieldnotes, 12 December 2015]

In this situation, communication was initially directed to the parent. Phoebe, however, was assertive in making her request. She confidently requested delaying the procedure despite having been instructed by her parent to proceed with it. The courage of Phoebe to express her request could be explained through the fact that she has been diagnosed with ALL for three years, and she has been admitted to the unit more than ten times. Similar to Jane (as illustrated in the above excerpt), as a veteran patient, Phoebe became familiar with the procedure through her constant involvement in it (Smith, 2002). It could be argued that the ability to participate in decisions is not something that the children have, but something they do (and constantly re-do) through everyday practices. This means that children's participation in decisions can be determined by the involvement in activities and interaction with others. The more the activities and interactions that children participate in, the greater will be their participation in their care and decisions.

The way in which Phoebe assertively voiced her wish may have been influenced by an effective interpersonal relationship between her and the nurses in the ward. Phoebe could have had rapport with Nora due to her (Phoebe) frequency of admissions. Such rapport encourages children to voice their wishes, and nurses are more amenable to respond positively to the requests of children with whom they have a personal and professional bond. Consequently, when Phoebe tried to make a request, Nora satisfied her needs, and ultimately the child's request was negotiated, contingent on the treatment protocol and patient safety not being affected. Again, this shows that positive interpersonal relations between the children and nurses enable children to voice their wishes and nurses to fulfil the request of the children (Peplau, 1992).

Phoebe's situation can be considered as in line with level 4 of the Hermeren's (1996) model, in which the nurse cares about what the child says but acts partially in accordance to the child's wishes. This could be explained by the fact that Nora cares about what Phoebe says when she is listened to and allows Phoebe to delay the procedure. Nevertheless, she acted only partially when she used the phrases such as 'I'll give you 15 minutes' reiterating that she is the one in control of the situation and holding the power. In other words, the child's wish was listened to but the final decision was made by the nurse. This could be explained through the fact that those in charge of health care tend to have the power to decide which and when care is to be given to a certain patient, and all patients are dependent on those in charge of their healthcare (Hallstrom & Elander, 2005). In this context, the power of the nurses could be interpreted as similar to the concept of owning the patient by Shield and colleague (2003), who suggested that the physicians own each patient who is admitted under their responsibility, and it may be equally true that nurses in charge feel the same way when they provide nursing care to their patient.

5.3.2.3 Summary

In this section, I have shown how in different situations, requests by children were listened to or respected by the nurses. On the one hand, some children expressed their opinions or wishes, and the nurses listened to them and took their voices into consideration. While on the other hand, children's requests were disregarded, which limited their participation in decisions regarding their care. In this section I have shown that although children's expressions were listened to, this does not necessarily mean that their wishes or opinions were acted upon accordingly. There was the possibility for the wishes of the children to be partially or fully fulfilled depending on the nurses who hold the authority over most situations. The varying ways of children's participation in their care and decisions raise questions about nurses' roles in supporting children's participation. Rather than the power and authority held by nurses, I have shown that it is highly dependent on the way in which nurses perceive children, which impact on whether children's expressions are listened to or are taken into consideration.

5.4 Chapter summary

In this chapter, I have presented the multiple ways in which children experience participation in decisions regarding their nursing care. By presenting examples from the children diagnosed with leukaemia in an oncology ward, I have given insights into the salient degrees of children's participation, at different times and in different situations. I have illustrated how the degrees of participation of children in this study were parallel with the model of participation by Hermeren (1996).

In section 5.2 I illustrated that children's experiences of participation were evident in many ways. Even though I have drawn out the significance of the children's experiences including: being physically present, being informed, and being consulted, in each section I have shown the ways in which children's experiences of participation are complex and highly dependent on the situation, and rooted in and shaped by the people (e.g. nurse and parent) involved in the interaction.

In showing how children are physically present during the decisions (section 5.2.1), I have highlighted the ways in which parents take a dominant role in the decisions regarding the care of their child, and how nurses can be task oriented, and anxious to complete their task, without considering the needs of children, resulting in children being excluded from discussion and decisions. This highly related to the way in which nurses and parents perceived children's participation in decisions when children were physically present during the decisions.

In section 5.2.2 I have illustrated that children receive information but, they essentially received very limited information. Children were informed about what was going to happen, but often only briefly. Most importantly, nurses were in a position to decide the amount of information to be communicated to the children and their parents. I have shown that inadequate information to the children restricts the possibility of participation in decisions regarding their care. Children cannot participate in decisions if they are not fully informed about the care being provided, options available to them, and the implications of those options (Franklin & Sloper, 2006).

By illuminating how children are consulted regarding their care, (in section 5.2.3), I have shown that children welcome consultation in the decisions, and they prefer joint discussion with their parents. I have shown that the children's participation in being consulted is grounded in complex contextual factors, rooted in and shaped by the children, parents and nurses, who focused on the need, and sometimes the demand for recognition – of who the children are, and of what they have to say (Graham & Fitzgerald, 2010).

In section 5.3.1 I have shown what choices are allowed, how choices are being altered for children, and how the concept of choice permeates the everyday interactions of some children, parents and nurses. The analysis in this section has distinguished between the minor and major decisions that involve children in decisions. The decision related to everyday events such as diet and times for procedures to be carried out can be considered as minor decisions, while the major decisions are the treatment decisions. Children were mostly allowed to decide the timing and delivery of the procedures, which are considered as having less impact. Ultimately, the nurses and parents maintain decisional authority for the major decisions, and children are mostly involved in the minor decisions. Most importantly, this section highlighted that although there are choices for children, and usually children are allowed to select their options according to their wishes, nurses and parent are responsible for making the final decision for the children, suggesting a lack of choice or opportunity to decide about care for children, and decisions relating to their care being largely determined by the nurse.

In section 5.3.2 I have illustrated that children experienced different ways of expressing their requests and opinions regarding their nursing care. I have indicated that in many situations, children are able to express their opinions and wishes. For some children, their expressions are often disregarded by the parents and nurses, and thus limits their involvement in the decision regarding their care. While for others, their expressions are listened to and are able to influence the decisions. This section also highlighted the consequences of participation, in which, children were happy and glad when they were able to express their wish and opinion and their expressions were respected and taken into consideration by the nurses and their parents (e.g. Jane in section 5.3.2). In contrast, when their voices are ignored, and they are excluded from the discussion, children often feel angry and upset (e.g. Nita and Noah, in section 5.3.2).

In various ways, in this Chapter, I highlighted that the attitudes of parents and nurses towards children and participation are the most instrumental factor determining the participation of the children in decisions. Rather than the power and authority held by adults, I have shown that it is highly dependent on the way in which children were conceptualized (as discussed in Chapter 3), when a nurse values children as people with the right to express a view, rather than as vulnerable dependents (on their parents), she would attempt to involve them in discussion and decisions about their care (Hallstrom & Elander, 2005). For example, in the situation of Ray (as illustrated in section 5.2.1), Irene held a view that parents know what is best for their children, are deeply relational and thus these views had implications on her actions towards children (such as towards Ray, in section 5.2.1). While some parents, for instance Jess (George's mother), recognized that children have a right to voice their expressions, this enables their child to be actively involved in the discussion and decisions with the nurse, although in Jess' case, the nurse directly communicated with her, instead of her child. This section has confirmed this conceptualization of children by nurses and parents which condition the ways in which nurses or parents respond to children in decisions.

Overall, the analysis in this chapter indicates that children participate in decisions concerning their care to different degrees. In most situations, children often receive desirable advice from their parent during the decisions. I now move on to explore the role played by the parent in the communication processes, and draw out their role as: i) facilitators of communication, ii) communication brokers, and iii) communication buffers in the communication processes in which decision can be made.

Chapter 6: The nature of communication for children

6.1 Introduction

In Chapter 5, I discussed how the children in this study participate in decisions with respect to their nursing care. The examples analysed in Chapter 5 have given insights into how children participate in decisions with regards to their nursing care: children being physically present during the discussion and decisions, being informed but with limited information, and being presented with choices but only about minor aspects of care and that they did not have a choice to refuse, and nevertheless, some children had the opportunity to express their requests and opinions but usually the final decisions were made by the adults.

It has been argued that the participation of children in communication and decisions in paediatric oncology is complex (Ruhe et al., 2015). Various studies reported that children play different roles in communication and decisions (Coyne, 2006a; Lambert et al., 2008; 2011; Ruhe et al., 2015). The most remarkable effects of this are the differing preferences of participation among children (Lambert et al., 2008; Ruhe et al., 2015), the physical state of the child (Coyne et al., 2014), and those of others involved in the interaction (Gibson et al., 2010). Therefore, this chapter attempts to explore the nature of communication for children in communication and decisions about their care and to contribute to the broader literature.

In this chapter, I take this analysis further to look at the triad of communication (nurse-child-parent interactions) by using examples from fieldnotes and interviews with children, parents and nurses. Firstly, resulting from the analysis of findings in Chapter 5 – that the majority of the children frequently asked for advice from their parent during the decisions – I explore how parents play their role in the triad, and show how these roles would facilitate or constrain the children's participation in communication and decisions regarding their care (section 6.2). Secondly, I then investigate further the ways in which adults control information sharing with the children. This provides an insight into the significance of full and understandable information for the children for them to better understand their illness and treatment plan (section 6.3). Finally, in section 6.4, I discuss the different roles of children in communication processes by exploring what role children usually employ.

6.2 The role of parents in the communication process

As discussed in Chapter 5 (section 5.2.3), the majority of children in this study expressed that they need advice from their parent during communication and decisions. This is particularly interesting because it reflects children's own expression of preferences and the need for parental support in communication and decisions, especially in the presence of nurses. In this section, I further explore the situations where parents played their roles in the communication processes between nurses, children and parents. Various themes emerged from the communication role of parents in the triad. These are drawn from Gibson and colleagues' (2010) model of communication, describing the communication roles undertaken by parents during communication processes. This section sets out to describe the roles of the parents in this study including their roles as: (i) facilitators of communication, (ii) communication brokers, and (iii) communication buffers for their children in the decisions.

6.2.1 Parent as facilitators of communication

> After the physician's morning round, I join nurse Alina, attending to George and his parent, Jess. George and Jess are sitting on a bed and watching television.

> Alina informs Jess that one of her son's tablets has to be changed to syrup form due to the unavailability of the tablet in the pharmacy.
>
> Alina: Mum, can George take syrup? [*Mum* is a commonly used term in the unit when nurses address the parents of patients in front of them].
>
> Jess: Last time he used to take it, but now I'm not sure whether he wants it or not, you know how the taste is, can you ask him?
>
> Alina: Oh, okay. George, can you take syrup medication?
>
> George, smiles and looks at his mum without any verbal response. Alina also turns to Jess; she seems to be expecting Jess to give the answer.
>
> George then says in a soft tone: Syrup medication is for small kids, I'm not a small kid any more, but okay, I can take it.
>
> I assume he is right, since he is twelve, and syrup medication is generally prescribed for small children for whom the tablet is not suitable. I wonder if he understands why his medication has to be changed.
>
> [Excerpt from fieldnotes, 5 January 2014]

In this situation, Alina directs the question of whether George can take medication in syrup form to the parent (Jess). However, Jess appeared to facilitate Alina to communicate directly with George about the type of medication he preferred. Jess did not speak on behalf of her child, but recommended Alina ask George himself. This excerpt illustrates how Jess plays her role as facilitator of communication, when she forged communication between the nurse and her child (Gibson et al., 2010). It can be seen that, initially, George engaged in what Gibson and colleagues (2010: 1404) term 'actors in the background' of the communication when his mother directly speaks to the nurse, but, he then engages with the role as 'actors in the foreground' of communication when his parent facilitates the communication between the nurse and him, and he speaks directly with the nurse. At the same time, his parent transitioned into the background of the communication process when the nurse directly communicates with him. This suggests that when the role of one participant changes, it affects the role of other members of the triad interaction. During my fieldwork, I noticed that it is not unusual for Jess to ask George for his opinion when the issue at hand is anything concerning her son. For example, the situation where a nurse asked her whether George wanted to join the learning session (as illustrated in 5.2.3). At this stage, Jess may have been aware that she may not be able to know everything regarding her child's likes or dislikes, allowing him to make decisions about what he wanted to do. Jess's reaction in this context possibly reflects her appreciation that not all parents know what is best for their child, and the child's preference may change over time. As discussed previously, the parent may not be able to decide what exactly children want (Coyne & Harder, 2011).

In addition, children sometimes appear to use their parents to facilitate communication with nurses, as illustrated in the following example:

> Ruby (8-years-old) was admitted with a swollen neck and intermittent fever she had for more than two weeks. [This is her first admission to the ward]
>
> Ruby was brought to treatment for a venepuncture. While waiting for the physician, Rita (the nurse) asked her which hand she preferred to be punctured.
>
> Ruby, without answering, turned to her parent (Damia). Damia smiled and asked Ruby to answer the nurse.
>
> Rita held both of Ruby's hands and said: Which one do you like? This hand or this? [Holding up left and right hand for Ruby to choose].

> Ruby extended her left hand and said: This hand.
>
> Damia smiled and said: Err... or should we let the nurse do it on your right hand? You are left handed, remember? (...) and how can you sleep without your left thumb?
>
> Damia, stroking Ruby's head, informs me that Ruby usually sucks her left thumb at bed time. Ruby appears shy when her parent tells me about this.
>
> Rita says to Ruby: Okay, should we do your right hand? Easier for you to move, and you can do anything freely.
>
> Ruby smiles and nods. Then she says: This hand [now extending her right hand].
>
> [Excerpt from fieldnote, 1 December 2014]

This excerpt illustrates that at the beginning the nurse communicated with the child by asking her which hand she preferred for inserting an IV line. Ruby's facial expression and reaction of turning to her parent makes it seem that she wants her parent to answer on her behalf. However, Damia did not try to overshadow her child's presence by blocking the conversation between the nurse and Ruby. Rather, she facilitated Ruby to engage in the communication with the nurse by encouraging Ruby to think about her options and choices (possibly not with everything). Certainly, this example showed the child that she has some influence in the decision about her care. Damia explained to Ruby the need for the IV line to go in the right hand to make sure that Ruby is aware of the consequences and, thus, she needs to think through the consequences of her decisions. Additionally, this excerpt represented a willingness among some parents to allow questions directed at them to be answered by their child, highlighting the parent valuing and respecting the child. This could be explained by the fact that some parents might be aware that it is their child's body and life, they are the ones who are sick, and they might know better about what they want.

It is noteworthy that Damia's presence and response as facilitator of communication appeared to enhance the confidence levels of Ruby to ask or answer questions, and thus, to be a part of the communication process (Young et al., 2003). Subsequently, Ruby expresses her preference, which is not a wrong answer, but it is not supposed to be thus, because by getting an IV line in her left hand she may experience difficulty in performing her daily activities. Ruby answering in such a way might be because she forgets that she is left handed or, more likely, she does not know the consequences of the IV line being established in her dominant hand. The comfort of the IV is important in ease and comfort of sleep, which is central to general recovery, health and wellbeing. The response of Ruby could indicate that children may not think about such rudimentary considerations unless choices and consequences are explained to them. However, Ruby finally extending her right hand for the venepuncture after the consequences of having the insertion on her left hand were explained to her by her parent. This indicates that if a full explanation is conveyed to the child, she will be able to understand, and thus, is able make her own decision of which hand to be used for the IV line.

It appears that some children in this study recognize the role of facilitator of communication that their parent undertakes. Children who recognized the role of their parent often gave great detail about how they felt about the role undertaken by their parents. Amanda provided one of the most detailed explanations of how she feels about her parent's role during the communication process:

> Most of the time when the physicians or nurses asked me, and if I don't know how to answer them, my parent will help me. (…) I like it that way, because if you do not know how to answer, it is good that your parent is there to help you.
>
> [Interview, Amanda, 8-year-old, 26 July 2015]

The quote suggests Amanda is very pleased with the support of her parent as a facilitator in the communication process between herself and the healthcare professionals. She later explains that she preferred her parent to be with her when information or questions were addressed, especially when she had trouble in answering or not understanding the information. It appears that Amanda acknowledged the presence of her parent, especially when she was experiencing difficulty during communication processes with the healthcare professionals. Her expression indicates that she may worry or fear when having trouble to communicate with the healthcare professionals. Thus, the company of her parent helps make the environment less frightening (Shields, 2001).

For many children, the expression of preferences for the parent to be facilitators of communication highly link to the use of medical terms by the healthcare professionals. The majority of children in this study express that they have difficulty understanding the medical terminology used by the nurses. During my fieldwork, Ruby and Bob (see section 6.3.2), for instance, seemed to be reluctant to communicate with nurses when the nurse used acronyms (e.g. LP, IT, and FBC) in conversation with them; they would rather let their parents communicate with the nurses instead. This is particularly fascinating because it is associated with the children's preferences for understandable information (see section 6.3.2).

During my fieldwork, I frequently observed that the children in this study did not only need their parent to facilitate their communication with the nurses, but, they also appeared to rely on their parent to clarify the information by nurses during the provision of nursing care. As I will discuss later, there are children who seems to require their parent to reiterate the information from the nurses so that they can better understand what the nurse has said.

6.2.2 Parent as communication brokers

> Tina is scheduled for blood investigations, and at the same time her peripheral IV line on both of her hands has to be removed.
>
> Vina (the nurse) informs Tina's parent (Fida) in Malay that she is going to withdraw Tina's blood specimen and then she will remove the IV line on Tina's hands. Vina wants to proceed with the

procedure. Suddenly, Tina cries and pushes Vina's hand away when Vina tries to hold Tina's CVL.

Seeing what happened, Fida, in a very firm voice, informs Tina in Mandarin about what the nurse is going to do, and she also asks Tina to stop crying and tells her to stay still when the nurse performs the procedure (I am able to understand Mandarin).

Vina appears shocked, and asks Tina why she is screaming. Tina, without answering, continues crying. Fida informs Vina that her daughter does not understand Malay.

Vina asks for Fida's assistance to inform Tina in her native language. Vina explains what the procedure involves and how it will feel, including that the blood will be drawn through the CVL, and she will not puncture Tina's skin. She also informs her that she will remove the IV line from both hands after she finishes the blood-taking procedure.

Vina repeats the information to Tina in Mandarin, with the notable exception of the information that the blood will be drawn from the CVL, and that her skin will not be punctured.

Tina, with a crying voice, yells: No! Mummy, no... It's painful... no, I don't want... mummy, I don't want (she continues crying).

Vina asks Fida why Tina is still crying, and asks whether she informed Tina about the procedure.

Fida, holding the CVL, says: the nurse will draw your blood from here!

Tina: are you sure? Just now she said she wants to take my blood? Of course, she will puncture me!

> Fida, in an angry voice, says: yes, she will draw your blood, but from here! [Gestures to the CVL line] not puncturing your skin! Don't move, just bear with her, she knows what she is doing, she will do it slowly. Not painful, okay?!
>
> Vina asks Fida if she can proceed before she starts.
>
> [Excerpt from fieldnote, 29 July 2015]

The excerpt illustrates that Vina (the nurse) did not specifically direct her communication to Tina; rather, she conveyed the information regarding what she was going to do to Fida (Tina's parent). Initially, Fida did not provide information to Tina until the difficulty was evident. Fida acted in such a way perhaps because she thought that her child could predict what the nurse was going to do, or she might have thought that the procedure would not cause pain and that her child would give her full cooperation. However, that was not the case, Tina refuses the procedure to be done on her when she cries and pushes away Vina's hand. Tina's refusal could be related to the language barrier, or perhaps to the use of medical terms and the use of lengthy sentences (Coyne & Kirwan, 2012). Fida later explained that her child has difficulty understanding Malay, which confirmed that Tina's refusal is due to the language barrier. However, in this stage, the role of the parent as a communication broker (beyond rudimentary translation) is not apparent. Subsequently, when Tina exhibited her refusal of the scheduled treatment, the nurse and parent jointly intervened to overcome this barrier by endeavouring to gain the cooperation of the child. Noting that Tina was having difficulty understanding Malay, Vina asked assistance from the parent. Vina provided the information to Fida, who translated it into Mandarin for Tina. At this stage, Fida appears to employ the role of what Gibson and colleagues (2010) term communication brokers, in which she explains and repeats the information for her child by translating the information ad hoc. Eventually she manages to convey information to the child on behalf of the nurse (although the parent omitted important information initially). When Tina wished to double-check that no puncturing would be involved: *'Are you sure? Just now she said she wants to take my blood? Of course she will puncture me!'* Tina appeared to depend on her parent in this communication process, because she did not, for the most part, see herself as having direct access to information, particularly from the nurse. Again, Fida repeated information so that Tina could better integrate what the nurse had said. Nevertheless, this example indicates that the parent's role as communication broker (by translating and repeating information) does not always promote children's understanding. Fida did not convey the information in full to Tina (particularly regarding the fact that puncturing of the skin was unnecessary for the procedure). This suggests that it is possibly challenging for the parent to be the interpreter in the child's care. Indeed, while parent interpreters are widely useful to healthcare practitioners, it cannot be expected that parents universally function in this way to provide complete information to their children. This was also reported in a study by Raval (2003), who employed a qualitative methodology and used Interpretative Phenomenological Analysis to elicit an in-depth understanding of child and adolescent mental health practitioners' experiences in carrying out assessments and therapeutic work with the help of an interpreter (both professionals and family members). The study found that the process of communication lost important attributes through translation because intervention and information by the interpreters tended to become simplified (Raval, 2003). This could be the case for Tina, whereby Fida might decide to simplify the information based on her preferences, resulting in omitting some important information.

The roles undertaken by the nurse in this situation appear to either facilitate or constrain children in the communication process. For example, the nurses could try to convey information to the child in a suitable manner. However, it was observed in this situation that Vina was unaware of the difficulty faced by Tina, because she seemed shocked when Tina started screaming and pushed her hand away; alternatively, she may have been aware, but decided to communicate based on the presumption of the parent's interpretation on her behalf. Vina's decisions and actions could be related to a number of factors that include particular attitudes and behaviours of the nurse, which appear to influence children's participation in the communication process and understanding (Hallstrom & Elander, 2004).

During my fieldwork, it became evident that parents played a different role in the communication process between the nurse and child. As illustrated above, some parents tried to facilitate their child in the communication process with the nurse, and some appeared to act as communication brokers by clarifying and reiterating information to the child to increase the child's understanding. There are also parents that shield their child from certain information, as illustrated in the following section.

6.2.3 Parent as communication buffers

> Ralph is a 7-year-old boy, newly diagnosed with ALL. During my fieldwork it is his second day of his first admission to the ward. He is on schedule for CVL insertion the next day. He is under the care of Nurse Vivian.
>
> Ralph's parent, Nancy, has been informed of preparations for the insertion.
>
> When Vivian left, Nancy informed Ralph: Tomorrow, the physician will give you a 'necklet', for the purpose of medication administration. After that, you will not feel any pain during the blood taking and administration of medication.
>
> Ralph: Necklet, but why did the nurse say I have to fast?
>
> Nancy: Oh! Before that, the physician is going to give an injection that is why you have to fast. You have to fast because the physician has to give you an injection.
>
> Ralph nods, and appears to understand. Nancy looks at me and smiles.
>
> [Excerpt from fieldnotes, 16 June 2015]

This excerpt illustrates how parents protect their child from information in the communication process. It appears that Nancy does not give particular information about what is going to be done to her child. She seems to be trying to shield the information regarding the CVL insertion from her child when she named the CVL insertion as ‘Necklet’. Necklet is the term used by the majority of parents in the ward to refer to the CVL which are kept in a small pouch that dangle on the child’s neck. In this situation, Nancy can be considered as a communication buffer, as articulated by Gibson and colleagues (2010), which is when parents shield their children from distressing information. Alternatively, Nancy could explain to Ralph that the physician will insert a tube into his chest for the purpose of medication administration, rather than label the CVL as a necklet, which may cause more confusion to Ralph. Ralph appeared to be dissatisfied with Nancy’s explanation and in need of more information, which was evident in his attempts to clarify the reason why he needed to be fasting. Again, Nancy seemed not to tell the exact information to Ralph when she explained that the requirement for fasting is because the injection is going to be administered by the physician. It appears that Nancy tries to filter and conceal some information from her child.

It can be observed that where the parents tried to selectively withhold some information from the child, it is mainly due to their assumptions of the consequences of conveying full information. Some parents felt that this would protect their child, whilst others felt the practise could be upsetting for the child. Nancy provides clarification regarding her decision to shield information from her son; she stated:

> I’m scared if he knows, he will have fear and anxiety. Most importantly, when he’s scared, he will refuse the procedure. I’m sure he will, I know him! I can confirm that he will refuse. So, it will make it more difficult.
>
> [Parent, Nancy, 17 June 2015]

Nancy explains that her decision to shield her child is because she fears that her child will experience distress and will refuse the procedures if he knows exactly what will be done to him. Nancy has confirmed that she did this because she feared that Ralph would experience unnecessary anxiety or fear if she told him the blunt facts. Nancy may instinctively try to protect her child from information, which may worry or upset her sick child. It is not unusual for a parent to act as such because, generally, when parents were told that their child had an incurable cancer, their first thought was to protect their child's life, and to keep their child comfortable and happy (Kars et al., 2011; Matsuoka & Narama, 2012). The excerpt can serve as an example of how information sharing with children becomes more complicated because of issues such as the adult's desire to protect children from distressing information (Coyne et al., 2014). This finding corresponds with a study by Young and colleagues (2003) who concluded that most parents act in an executive-like capacity, where they manage their children's information needs, because of their concerns to protect their child's wellbeing. The researchers argued that the role of the parent can contribute to the marginalisation of children and hamper the development of a successful relationship between themselves and children.

Most parents in this study took a similar approach to Nancy, however, there are a few parents who preferred to be transparent and to tell the exact information to their child. For instance, Becky, Jess, Jenny, Rena, and Vicky all agreed that they give full information of what and how certain things are going to be done to their child, especially regarding procedures to be done to them, in order to gain cooperation from children. In talking directly about their role in communicating information to their child, most parents were keen to emphasise that giving the full information to children is essential; for example, Jess told me: *'Of course I have to tell them what exactly is going to be done'*. Jenny explained: *'If not, they (children) will be upset with what happens and definitely will give a hard time during the procedure'*. Parents, who perceived it was their role to convey the full information, often gave details about their role and the impact of telling lies (or concealing information) from their children. Olive provided one of the most detailed explanations of the decision to communicate the exact information to her child:

> Hmm, like my child, it is going to be difficult if he does not know what the nurses will do to him. He normally will fight if he doesn't know what will be done to him. It is really important to inform him

> beforehand regarding how the procedure will be conducted. (…) especially if the procedure is new to him. The repeated one is okay, they know when you tell the name of the procedure, because they used it already, but the new one, it has to be explained in detail (…) if he experiences something different from what you tell him, you will get it [reprisals] from him…
>
> [Excerpt from fieldnote, 2 January 2015]

This statement suggests that Olive's view of how important it is to give full information to children is to increase their understanding as well as to gain cooperation and compliance with treatment regimens. According to her, by telling the child exactly what was going to happen, the difficulty of the child such as refusing, struggling, or not giving full cooperation (as she mentioned as 'he will fight') can be avoided. However, if incomplete information is given to the child and he experiences something different from what he has been told, he may make difficulties for the nurses. This suggests that conveying the actual information is important to gain full cooperation from the children. In addition, when she mentioned *'You will get it from him'*, it appeared that the parent has learnt from not having told the full information previously and now knows this is not a good way forward to avoid it. Olive later explained that information regarding repeated procedures is not essential compared to new ones, because usually the child is aware of how the repeated procedure will be done and will have more information as a result of familiarity.

This example demonstrates how parents play an important role in meeting the communication needs of children. Parents usually, though not always, act as the gatekeepers or conduits of the communication between healthcare professionals and the sick children (Scott et al., 2003). The accounts of some of the children suggested that they are aware about their parents' attempt to conceal some information from them. Eva gave an insight to the patterns that some children may experience:

> (…) sometimes, she (her parent) does not answer all my questions. I know, she is not telling me everything (…) err… err… maybe because she doesn't want me to be worried, maybe, I don't know.
>
> [Interview, Eva, Child, 24 June 2015]

In this excerpt, Eva appears to refer to her parent's inability and unwillingness to answer her questions as if she is trying to restrict information from her. This suggests that children perceive that communication is constrained by their parents as a result of the hesitancy of their parents to answer their question (Young et al., 2003). Eva appears not too sure about the reason why her parent acts as such, but presumably it is because her parent tries to protect her from unnecessary worries. This does not mean that children regard the role of their parents in the communication process as inappropriate in principle; their preferences are fluid and depend on context (Young et al., 2003). For instance, some children may think that the boundaries of information sharing set by their parents depend on the quality of the judgement of the parent:

> I didn't really need to know everything, I think my parent knows what is important for me and what is not.
>
> [Interview, George, Child, 28 December, 2014]

George's positivity here was tangible as he continued to support the role of his parent in setting information sharing boundaries. His statement indicated that not all children need all information. Therefore, the language used conveyed strong support for the parent, showing that he was pleased with the role of his parent in sharing information with him.

The example in this section demonstrates the desire of parents to protect their children from the perceived distressing information, which may have carried the consequences on to the participation of children in their care and decisions. Nevertheless, Eva and George's expressions indicate that the children acknowledged and seemed comfortable with their parent's role of filtering and selecting information to be conveyed to them. Thus, the role of parent as communication buffers may not be problematic for some children in this study.

6.2.4 Summary

In this section, I have discussed some of the ways in which the roles of parents become visible in the child-nurse interaction, and analysed how the parents played their role in the communication process between nurse and child. It became apparent that parents in this study employ different roles in the communication process between the nurse and child: as facilitators of communication, communication brokers and communication buffers. The examples in this section demonstrate that the roles undertaken by parents can both facilitate and constrain children's participation in their care and decisions. I pointed towards the importance of the role of parents to facilitate their child in the communication process with the nurse. The ways in which parents managed communication difficulties by translating and repeating information from the nurse to the children have implications on the children's involvement in the communication process. I have shown that the way in which parents filter and shield what children are told might restrict the children's engagement in their care and decisions, although it may not be problematic for some children.

6.3 Adults controlling information sharing

Many examples analysed in Chapter 5 demonstrated that children are provided with limited and simple information. In this section, I further explore how adults (parents and nurses) control information sharing with children and the subsequent consequences.

6.3.1 Selective information

> In the afternoon, Zana (the parent) and Adela (12-year-old, girl) are having a dialogue about Adela's hair loss. Zana is sitting on her

> bed and tries to remove her lost hair on her pillow. She appears worried about it, and repeatedly asks her parent what causes her hair loss.
>
> As I walk past them, Zana looks at me and says: She is worried about her hair. I told her that her hair will grow back soon, but still she does not listen to me.
>
> I ask: What makes you worried about it, Adela?
>
> Adela: I don't know what's wrong with me, my mom said if I take all the medication, I will get better, but now, you see… my hair… my hair… (She prostrates herself on the bed and hides her face with the blanket, but I can see she is sobbing).
>
> Zana looks at me and signals not to tell Adela the fact by putting her first finger to her mouth, shaking her head and whispering: Don't tell her that this is the effect of chemo.
>
> Zana then says: Adela, why are you crying? Don't cry, I told you your hair will grow back, don't worry! If you do not believe me, ask the nurse. (She pointed to me).
>
> At this time, I felt a little afraid about the looming dilemma of what to say if Adela asked me, having been primed to lie by her parent, contrary to professional obligations. Fortunately, I was relieved because Adela ignored both of us and continued covering her face with the blanket. I could hear that she was crying.
>
> [Excerpt from fieldnote, 12 January 2015]

This excerpt illustrates that the parent does not direct a considerable amount of information to her child. Zana appeared to withhold information and did not discuss fundamental treatment issues with her child. Similar to the example in section (6.2.3), this parent was possibly trying to protect her child from distressing information.

Adela appeared to have a lack of knowledge regarding the treatment and its effects and, because she was not fully informed about it, she was distressed. Adela seemed to need more information regarding her illness and what caused her hair loss, and why this was happening to her. In addition, she seemed confused and frustrated about what had happened, stating: *'I don't know what's wrong with me, my mom said if I take all the medication, I will get better, but now, you see… my hair… my hair'*. This could be because of the literal and straightforward thinking that is common with children (Whitty-Rogers et al., 2009), whereby Adela believed that she would simply get better by following the treatment plan, with no concept of nuances such as treatment side effects. However, when she experienced a different situation (which is her hair loss), her confusion and frustration were evident in the way in which she reacted to the changes in her body. Adela appeared tearful. Her reaction could have related to body image issues that are common to teenagers (Whitty-Rogers et al., 2009). Her statement explains that she really cared about her body image: *'my head will be bald, and err… err… it is not beautiful for a girl to have a bald head'*. This suggested that the thought of losing her hair was essentially intolerable. It seemed that for her, hair is an important asset for a girl's appearance. Although her parent seemed to try to reassure her, her mother did not attend to her worries regarding grooming and appearance. Adela appeared to need more than just reassurance; she needed clarification regarding her hair loss. The lack of information may cause further refusal of medication, due to her wish to avoid continuous hair loss. For instance, as treatment continued and hair loss increased, Adela might become angry, and refuse the treatment. Thus, the full information of what is happening to her is essential for Adela, so that she is aware of her own condition, and she needs the information she receives from her parent and health care professionals to become congruent, thereby preventing confusion and frustration (Kreicbergs et al., 2004).

The incident left me feeling dissatisfied and uncomfortable with my own reaction when the parent attempted to coerce me into withholding clinical information from Adela, as well as feeling frustrated on behalf of the child. Besides trying to shield her child from important information that affected her, Zana attempted to enlist me in the conspiracy. I however decided not to tell Adela about what was causing her hair loss, not because I agreed with the parent's action, but, concern that it may cause more chaos if I explained the reality of the situation to her. For instance, the parent would be dissatisfied with my response if it contradicted her wishes, while Adela might get angry with her parent knowing that her parent had been telling lies to her; nurses and physicians in the ward may also be dragged into the chaos as they might be blamed for not fully conveying information to their patients. At that moment, I was fully aware of the ethical dilemma of whether to follow the request of the parent or to tell the facts to the child. I also have the impression that nurses in the ward may experience the same circumstances when providing nursing care to the children. Some nurses may not want to speak up about things that are contrary to the parental wishes. In the informal conversation with some of the nurses, most of them agreed that they frequently experienced such situations, as illustrated in the following example:

> At the nurse's counter, Selena (the nurse) tells: I don't know why Adela's mom don't want her (Adela) to know the cause of her hair loss. Normally, most of the parents will choose to tell only certain information during the early stage of the illness.
>
> Alina (the nurse) explains: I personally will tell the things that the parents want their child to know. Although I know that we shouldn't protect the child from any information concerning them, but if their parents want it that way, we have to respect. (…) what can we do is that just tell them the importance of telling the child the actual fact, like it is for the child is understanding about his/her condition, reduce the child's fear and anxiety, err…err… and… easy for the child to follow the treatment plan.
>
> [Excerpt from fieldnote, 15 January 2015]

The excerpt illustrates that it is not unusual for parents to get the nurses involved in their effort to shield their child from certain information, especially during the initial stage of diagnosis. Alina's expression illustrated that nurses are aware of the importance of conveying the full information to the children, and that they encourage parents to tell the truth as it will increase their child's understanding and reduce the child's anxiety. The explanation of nurses indicated that the parent's request for them not to tell the details to their child seemed to place them in a difficult position, whether to tell the actual fact or follow the wish of the parent to withhold some information from the child. It seems that nurses sometimes face the dilemma of supporting and complying with this type of communication. Surprisingly, it appears that some nurses decided to respect the parent rather than respecting the child's right to have information related to their condition. The main argument is that parental wishes are of utmost important in determining information sharing with children, and thus, nurses sometimes seemingly feel unable to go against parental wishes (Coyne, 2006a). Nevertheless, this practice went against the policy of Patient and Family Rights that has been applied in the ward that requires nurses to provide information to the patient and patients have the right to be informed about the treatment outcome (see Chapter 2, section 2.7.2). It also contradicts the paediatric nurses' fundamental obligation, which is to treat the child, and to balance a duty of care with respect to these children and their parents that include providing support and information to enable them to understand and cope with their illness and the treatment needed (Coyne et al., 2016).

The example of Adela highlights the differences between the parents' preferences to convey information to children and children's information preferences. Children wanted full information regarding their illness and its treatment, while parents seem to pick and choose the information to be conveyed to their children. This resonated with many other fieldwork observations that some children in this study wish to have information concerning their care, for instance, George expressed that he desires information to be able to understand what is happening (see section 5.2.3.2). Whereas, parents adopted the role of defensive gatekeeper when communicating with their children, in most cases deciding the amount of exchange of information between health care professionals and the ill children (e.g. Ralph in section 6.2.3, and Adela in section 6.3.1). Again, this could be linked to the Asian culture in which families tend to protect patients from being given bad news by deciding what, when and how patients should be told about the disease, the treatment and its effect (Lapine et al., 2001; Tse et al., 2003; Eng et al., 2012). In contrast to the Western culture, for instance, in the US, most persons strongly believe that the patients should be informed regarding their diagnosis, and that, the patient should be the primary decision maker in their own care (Phipps et al., 2003; Subone, 2008).

It is noteworthy that the way in which the parents shield their child from distressing information could be due to the seriousness of the illness of the child and its grim connotations in popular usage. Zana chose to be more protective of Adela, as she stated:

> It's not easy for me to tell her everything. Me myself, when I found that she was suffering from cancer, it was so hard for me to accept. The word 'cancer' is so scary! It reminds me of death! It is difficult… until now, it's so difficult for me to say the word 'cancer'. And if possible I don't want to hear about it! …I'm also scared if she knows that, because of chemo, she might protest, and we know that chemo is essential for her life, she really needs it… I know it is not easy for her, but what can I do? She needs to keep going.
>
> [Excerpt from fieldnote, 12 January 2015]

Zana expresses that decisions regarding what to tell the child about the illness and treatment is difficult. She certainly felt ill-equipped to discuss a potentially life threatening disease with her child because of the fear of how this would affect Adela. As a result, Adela was only partially informed about her illness and treatment. This indicates the challenges for parents to cope emotionally when knowing that their child is suffering from a life-threatening disease. Her statement revealed that she herself refused to discuss the illness suffered by her child, and she had a psychological fixation on the negative connotations of the word 'cancer' itself, which is synonymous with 'death' for many parents. In addition, Zana may think that this information could be needlessly upsetting, due to the inevitable need for Adela to undergo the treatment, as she mentioned *‘She needs to keep going’*. This indicates the perception that, regardless of being informed or not informed, Adela has no choice but to follow the treatment plan, as it is needed for her health and survival. Zana may also feel fear that she might ‘break down’ whilst telling Adela, thus distressing her and implying hopelessness (Young et al., 2003). It has been argued that parents are often aware of their imminent loss, the knowledge that their life with the child will end by the child’s death is too much to bear (Kars et al., 2011). In particular, parents were reported to have difficulty in accepting their child’s forthcoming death; their common thought upon hearing that their child had a life-threatening childhood cancer was to support and protect the child (Matsuoka & Narama, 2012). This indicates the significance of how parents face the difficult dilemma of deciding how to explain cancer and its treatment to their child (Clarke et al., 2005).

The above excerpt highlights how parents’ own perceptions of disease and their own information and psychological needs conditioned their information sharing with their children. It has been argued that it is not uncommon for parents and others involved in care for children to acknowledge indirectly the seriousness of the illness and avoid discussing the possibility of death, while others simply find it impossible to broach such subjects at all, despite an awareness of the need to be open and honest with children (Liben, Papadatou & Wolfe, 2008). Zana, for instance, when she implied that cancer was linked to death, she appeared reluctant to discuss it and tended to provide her child with minimal information, professing a wish to shield Adela from the bad news. I should be noted that Zana is Chinese. The behaviour of Zana could be linked to the Chinese culture that is reluctant to disclose the disease and prognosis to the patient (Pang, 1999; Tse et al., 2003). Pang (1999) argued that truth-telling would become an insincere act if patients were to lose hope and confidence after learning of his or her disease. Thus, families usually tried to use every possible means to maintain a hope for life for the patients. For instance, the excerpts illustrated that Zana tried to withhold the information regarding the causation of the hair loss even though she has been repeatedly asked by Adela. Zana repeatedly reminded Adela to not worry because her hair would grow back soon. She may not want her child to lose hope due to the effect of the treatment. Rather, she wanted her child to be confident that her condition would get better after having the treatment. However, in doing so, Zana possibly protected herself from facing the reality of the situation (Tuckett, 2004). Such attempts to protect the children, however, place barriers between the children and the people who can help them understand and deal with their experience, as children are even more anxious and can feel a greater sense of isolation when they are shielded from the actual information (Beala, Baile & Aaron, 2005).

As treatment continued, mounds of Adela's hair would fall out. I formed the view that she would likely become withdrawn as her treatment progressed. After a few days, although Adela did not show any signs of refusal of treatment, she still appeared to worry about her hair loss and she continually asked her parent why her hair fell out each time she combed it. I had an opportunity to have a conversation with Adela regarding her experience of hair loss:

> I ask: Could you please tell me the reason why you look so worried about your hair loss?
>
> Adela: I don't know what's wrong with me, why my hair keeps on dropping, if I continue like this, I will become bald after a few days!... When I asked my mom, she said I will be okay, she asked me not to worry about it, she said my hair will grow back… but why? Why does my hair continue dropping? Tell me… why?
>
> [Excerpt from fieldnote, 16 January 2015]

This excerpt demonstrates that it is very hard for a young girl to accept that she is on treatment and yet still experiencing difficulties. Adela is having treatment so wonders why this 'bad' thing is happening when treatment is about getting better. Her tone of voice and facial expression seemed to suggest that she is frustrated with what is happening, of not knowing why her hair fell out. Her expression indicates that the ways in which the information was communicated to her were imbued with optimism. While she appears aware of her disease, her reaction, however, indicated that she had not received full information pertaining to the nature of her disease, and the purpose and effect of chemotherapy. It appears that she is greatly in need of the straightforward information in relation to her hair loss. Adela wanted the full information regarding her condition and its treatment. This was evident when she repeatedly asked her parent for such information, even though her demands were disregarded by her parent. Nevertheless, it appeared that children's right to information is largely undermined by the adults controlling information to be shared by selecting information to be conveyed to the children.

It has been argued that the adjustment of the children to their illness is related to their early knowledge of the diagnosis and treatment (Clarke et al., 2005). The earlier children learned they had cancer and required treatment, the better they adjusted compared to those who were misinformed initially or learned their diagnosis at a later stage (Hooker, 1997; Clarke et al., 2005). The same principle could be applied to Adela; if she knew about the effect of the chemotherapy at an earlier stage and before her hair loss, she could have prepared herself emotionally and physically and be better able to accept the changes, with less experience of worry and anxiety. Additionally, the child who is not informed or given opportunities to ask questions about illness is not necessarily protected from fear or worry (Clarke et al., 2005). Conversely, children may sense that the illness is a taboo and dangerous secret that should not be spoken about (Claflin & Barbarin, 1991), which may increase their sense of fear and anxiety. Although Zana decided not to tell Adela directly about the effect of chemotherapy, Adela will inevitably be exposed to such information during her hospitalization journey. There is a possibility that Adela could overhear conversations or learn from her peers that the cause of her hair loss is chemotherapy, or she may even deduce her own conclusions about her hair loss. She can still refuse the treatment even if her parents do not tell her about the effect of chemotherapy because she has a lack of information about it. Refusal and non-compliance with treatment in children with cancer has been linked with a lack of understanding and poor communication regarding diagnosis and treatment (Clarke et al., 2005). As DiMatteo (2004) stressed, providing complete information is crucial to fostering adherence and cooperation from the child, and adherence is likely to be distorted when children feel unsupported by either healthcare professionals or their parents.

Research has reported that children who have more information about their disease may be better equipped to cope because they understand the importance of taking medication, they feel able to discuss their worries and concerns with parents, and thus they trust their parents and healthcare professionals (Clarke et al., 2005).

Similar to the frustration experienced by Adela, some other children expressed their frustration due to the unwillingness of some parents and nurses to discuss certain things. According to the children, the parents and nurses were often reluctant to discuss their disease and its treatment. For example, Adela, George, Nita and Edna agreed that their parents were trying to avoid answering their questions, especially when they were asking about their condition. Among others, Nita explains how her parent and nurses were trying to avoid her question:

> They seem not to encourage us to talk about it. When I asked about it, nurses, for example, they would abruptly end the conversation and pretend to do something or, if my mom, she will just change the topic to something else (…) I don't understand why they don't want to tell, just tell, it's about me…
>
> [Excerpt from fieldnote, 23 June 2015]

The statement from Nita illustrates how dissatisfied some children were with their parents' and nurses' avoidance of having discussions with them regarding their condition. Children may feel they need to know and to understand what is supposed to happen to them in treatment. Sometimes, children may fear that they do not have an adequate level of information to be able to cope with their health condition. Thus, they are dependent on both their parents and nurses. Parents might have full information regarding the illness of their child, and nurses know the paediatric oncology. Studies have highlighted that children should be treated with respect and given full information regarding the illness and treatment to enable them to understand and cope with their disorder (Coyne et al., 2016), as well as participate in the decisions (Coyne et al., 2014; Franklin & Sloper, 2006). However, the statement from Nita, and the example of Adela, and Ralph (see section 6.2.3) demonstrate that both parents and nurses appeared to act as protective gatekeepers of information, to choose what to discuss with the children, and that children have limited information regarding their care.

During my fieldwork, I started to notice that not all children wanted to be told everything about their illness and treatment plan. While some children in this study felt frustrated when their parents and nurses were reluctant to discuss or inform them regarding their condition, others did not want to have discussions regarding their treatment and its effect. Kate, for instance, states:

> I don't really like to hear about the chemo, even the name of it, I feel like I wanted to vomit when I hear about it, it makes me sick, really, it reminds me of how I felt when I had them (…) erm, before this, yes, I wanted to know everything about my condition, but not now, not anymore…
>
> [Excerpt from fieldnote, 20 Jan 2015]

This statement of Kate demonstrated that not all children necessarily wanted to have full disclosure regarding their disease and its treatment at all times. This indicates the individuality of each child, in which different children have different preferences. Kate's quote demonstrated that the children's preferences for information may change over the course of the illness and treatment. At particular times and situations, children may be pleased with the information they receive. This corroborates the findings of previous work, which reported that not all children want to know everything (Lambert et al., 2008), and some children find comprehensive information overwhelming (Gibson et al., 2010).

The hospitalization experience of the children, such as novice or veteran, was very salient during the interactions. It is to be noted that Kate was considered a veteran child (9th admission), while Nita is a novice. In addition, although Adela is a veteran, her experience of hair loss was new to her. Children who were new to the illness and treatment appeared to need more information, while the veterans like Kate had more understanding of their condition, and were more selective about the kinds of information they wished to receive. In addition, the novice child had yet to experience some illness-related conditions such as the side effects of treatment, while the veteran might have had more experience of adverse challenges and therefore had improved self-efficacy. Consequently, novice children were visibly more anxious and in need of more comprehensive information regarding their condition compared to veterans.

The examples in this section have given an insight into the significance of full information being disclosed to the children to better understand their illness and treatment plan. I have demonstrated that when children are not fully informed, they have a lack of understanding about their condition and, thus, experience fear and anxiety surrounding their situation. The analysis in this section revealed that the parents desire to shield their child from the perceived distressing information was supported by most of the nurses in this study. These nurses decided to follow the wishes of the parents rather than respecting the children's right to have information related to their condition. What is important in this finding is that children have different needs for information at different times and in different situations, highlighting the need for nurses to listen to and consider children's needs during the care provision to ensure that children are kept fully informed. Listening to and respecting children are the best practice principles in today's paediatric setting (Coyne et al., 2016).

6.3.2 The use of technical terms

The above examples illustrated the situation where children were not fully informed regarding their illness and treatment. I also repeatedly observed situations wherein children were informed with unclear information, with nurses often using short-form terms or medical jargon in communication with children, as illustrated in the following excerpt:

> During the CVL dressing, Nurse Hilda explained to Ruby and her parent (Damia) that she would withdraw Ruby's blood for FBC (full blood count). Hilda further explained that Ruby may need a

> transfusion of platelets if the results indicated that she had a low platelet count. Hilda used medical terms such as ‘FBC’ and ‘platelet’ (in English) in the communication process. Hilda acknowledged Ruby by directing the information to her, but Ruby did not give any verbal response. Hilda then focused her attention on the explanation to the parent, when asked by Damia what platelets are. Now Hilda translated what platelets are in Malay and explained the needs of the transfusion. Ruby heard Hilda inform her parent that she needed to have a transfusion. She appeared confused and nervous about the terms used, and what the nurse was going to do.
>
> [Excerpt from fieldnote, 15 August 2015]

The excerpt illustrates that Hilda informs Ruby and her parent about the procedure by using the medical terms (e.g. FBC, Platelets). Although information regarding the procedure and why the procedure must be conducted was given, because of the terms used, it caused Ruby difficulty in understanding the information. Therefore, she ignored the nurse during the information sharing. Hilda, however, did not explain or ask Ruby whether she understood what she was being told, but continued to explain to the parent. Ruby seems to be excluded from the discussion and her fear was not acknowledged and attended to. This indicates that the presentation of information to the children was mostly based on the use of technical terms, and the ancillary explanation was targeted directly to the parent. It appears that the term used by the nurse not only caused difficulty in terms of the child’s understanding, but also for parents, highlighting the importance for nurses to use easy and understandable terms such as layman’s terms when communicating with their patients and family to promote their understanding.

During my fieldwork, I noticed that most nurses in the ward tended to use medical terms when communicating with children and their parents. The acronyms and medical terminology used by nurses in communication processes with children carry consequences on the necessities of the parent to be the facilitator of communication between nurses and children outlined in section (6.2.1). Ruby's experiences can be interpreted in light of it. In fact, the experiences of some children in relation to the terms used by nurses during the communication process directly resonate with Ruby's expressions:

> A few days back, one nurse mentioned about… IT… yea... IT… LP… err… err… and so many more, I can't remember… Today the nurse explained about plat… plat… I don't even know how to pronounce it… [Platelets] and far away from knowing the meaning! …She should talk to me and explain things in a way that I understand. Like about the thing…IT…LP… just tell me what they are going to do with me, instead of using words I don't understand.
>
> [Excerpt from fieldnote, 15 August 2015]

Ruby's statement suggests that aside from using technical terms, the nurses in the ward commonly used abbreviations, which might cause most children to have difficulty in understanding the information. Ruby herself observed that nurses should speak in child-friendly language, avoiding technical terms and short forms (Curtis et al., 2004; Coyne & Kirwan, 2012), when she stated: *'She should talk to me and explain things in a way that I understand... instead of using words I don't understand'*, which suggests she wants understandable information.

Such interactions of nurses communicating with children with the use of acronyms was indeed quite common in my fieldwork, as illustrated in the following excerpt:

> Bob is scheduled for his first IT (Intra-thecal) procedure. Nurse Maya asks Bob if he is fasting because the procedure will be carried out soon. Bob, without any verbal response, looks at his parent. His reaction and facial expression appears like he tries to ask his parent to answer the nurse. Seeing her child keeps silent, and the nurse is waiting for the answer, Rita verbalised that the last time Bob has eaten or drank was his dinner.

> A bit later, I ask Bob: Why don't you answer yourself when the nurse asked you just now?
>
> Bob: I let my mum talk to them, cos I hardly understand anything they say. Yesterday she said about LP (lumbar puncture), I wonder what it is, and how they will do it on me.
>
> [Excerpt from fieldnotes, 10 August 2015]

The excerpt illustrates, initially, that Maya directly asks Bob, but he does not give any verbal response. It appeared that because of Bob's unwillingness to answer the nurse, Rita finally did so. Bob acts in a way that could indicate that he deliberately relies on his parent when the nurse directs a question. Bob explains that he has difficulty understanding the terms used by the nurse. Bob further explains that the use of medical jargon (e.g. LP) by the nurse leads to his difficulty in understanding, which was why he preferred his parent to communicate with the nurse. The way in which nurses used the terms could be linked to the familiarity with the medical jargons, and thus, they tended to use it when communicating with children and parents, without realising that the way they communicate is unclear for some of the children (Migone et al., 2008).

The situations of Ruby and Bob demonstrate how children react by not responding or communicating with the nurses when they are hardly able to understand what is being discussed. The similarity of Ruby's and Bob's experiences could be because both are newly admitted patients in the ward, and they are not yet familiar with the common terms used there, which is why they are struggling to understand the new terms. These situations correspond with the findings of Ruhe and colleagues' study (2015), which identified difficulties related to the way in which the healthcare professionals communicate with children, where the children in their study reported that they have difficulty understanding the terms used by the healthcare professionals. Both examples indicate that because of the use of technical terms, children have difficulties in understanding, as a result, the children most likely rely on their parents to be their advocates in the discussions regarding their care (Coyne & Gallagher, 2011; Coyne & Kirwan 2012).

In contrast to this situation, different responses were observed during the interaction between nurses and children who were considered as veteran patients. For instance, Jane (introduced in 5.3.2) was familiar with most routine nursing cares. Jane certainly had a familiarity with the terms usually used by nurses in relation to childhood cancer, such as IT, LP, MTX, and ANC (absolute neutrophil count). This example appears to suggest that as the children repeatedly stay in the hospital, they become accustomed to medical procedures, and also gradually use medical terminology (Wilson, Megel, Enenbach et al., 2010). This could be explained through the fact that the veteran patients become familiar with the terms commonly used in the clinical setting, learning by observing and listening in on the activities of adults and other children, thus they gradually advance to new levels of learning (Rogoff et al., 2003).

The example of Jane indicates that the longer children are hospitalized, the more they can observe, be listened to and learn from the healthcare professionals' communication. Nurse Nora, who has been working at the ward for more than ten years, commented on this phenomenon: *'The longer they stay, the more sophisticated their conversation becomes, more medical terms they can say, like… they know how to say CVL or chemo-port and the name of chemo'*. Nora's expression suggests that the longer the children stay in the hospital, they start to embellish their speech with medical terms, and, generally, they become knowledgeable about the hospital routines (Wilson et al., 2010; Rindstedt & Aronsson, 2012). In fact, I repeatedly observed children who were considered veteran patients rapidly talk about the nursing procedures, blood counts, names of medications and other generally unfamiliar terms as naturally as if all this had always been part of their native vocabularies. The situation can therefore be an example of how children develop new skills, and knowledge which are transformed on the basis of the child's experiences, skills and knowledge (Tudge & Hogan, 2005).

Although it appears that many children were concerned about the way nurses communicated with them, most nurses considered their communication style to be simple and understandable for children, as Nurse Amelia explained:

> We always explain things in a way that they could understand. The words that we used… it is not difficult for them to pick up… most of them are used to the terms.
>
> [Excerpt from fieldnote, 27 July 2015]

The quote of Amelia suggests that nurses might be aware of the difficulty faced by most children, which is why nurses appear to commonly use terms perceived by the nurses to be more understandable when communicating with children. However, during my fieldwork, the majority of nurses in this study were repeatedly observed to convey limited information, with the use of medical terms, and mostly direct communication to the parents instead of children. This contradicts Amelia's expressions regarding the way in which nurses convey information to the children. This could be explained by the fact that the perceptions of nurses may be misaligned with those of the children, and nurses might perceive that they used appropriate explanations in discussion with parents and children, but they may not be aware that their communication is unclear to the children (Migone et al., 2008). Such ignorance among nurses could lead to non-participation of children in discussion and decisions regarding their care, as illustrated in the above example (e.g. Ruby and Bob), where both children were hesitant to respond during the communication process. This substantiates that the attitudes and behaviours of healthcare professionals influence paediatric patients' willingness to participate and ask questions during the provision of nursing care (Coyne 2006a, Hallstrom & Elander, 2004).

6.3.3 Summary

The examples in this section have given an insight into how adults control information sharing with children. The analysis showed that the adults select information to be shared with children and the use of language (use of medical term) prevents children from fully understanding about their condition or enabling children to be involved in their care. The way in which parents shield their children from distressing information, and the ways in which nurses communicate with the children by using the medical terms and acronyms, have given an insight into the significance of providing full information and communicating in an understandable manner for the children to better understand their illness and treatment plan, which in turn, enables their participation in their care and decisions.

6.4 The children and their role in communication

In the previous section, I analysed how adults played their role in the communication process with children. In this section, I analyse the role of children in communication and decisions by exploring what role and how children take on a role in the communication and decisions, and explore why and when children prefer such a role.

6.4.1 Child as passive participant?

> Monday morning, Alexis is under the care of Alma. At his unit, Alexis is sitting on the bed watching TV.
>
> Alma comes in and informs his parent, Jenny, that they must transfer to a single room because Alexis is suspected of having an eye infection.
>
> Alexis appears distracted by the conversation between Alma and his parent. He stops watching TV and turns to Alma, but does not say any words. He seems interested and continues listening to the conversation.
>
> Jenny: How long do we have to be in that room?
>
> Alma: Until the blood culture result is normal, then you will be transferred back to the shared room.

> Jenny smiles and says: Hopefully not long, I don't like the room because it feels isolated, no friends to chat with.
>
> Without a verbal response, Alexis continues observing the conversation between his parent and Alma.
>
> [Excerpts for fieldnote, 22 December 2014]

In this situation, Alma (the nurse) relayed the information to Jenny instead of Alexis. Although Alexis appeared to be conscious and alert, behaviour associated with receptivity to information, he was not addressed directly by Alma; rather the nurse and his parent conversed about him in his presence. Alexis was visible within the communication process, but the nurse and his parent were essentially ignoring him. He sat mutely in the background within the communication process. Thus, Alexis can be considered to employ a role as passive participant (Lambert et al., 2011) in the interaction because the flow of the conversation was prominently directed towards his parent in his presence (Wassmer et al., 2004; Savage & Callery, 2007; Lambert et al., 2011).

Although Alexis appears to play a passive participant role, to some extent he can be considered as an active observer (Lambert et al., 2011) in the communication process. Alexis listens attentively in the background and overhears the information that he was to be transferred to an isolation room because of a suspected eye infection. He appears interested in the information, as he immediately stopped watching the TV program when he overheard the requirements for his transfer. Presumably, his reaction indicates that he wanted to be party to the information being disclosed (Elwyn, Edwards & Kinnersley, 1999); as research showed that hospitalised children wanted involvement in discussion about their care and an opportunity to have a say about their care plan. However, Alexis did not give any verbal response, arguably because a child who is simply shy may be reluctant to speak to strangers or adults. In conversation throughout fieldwork, Jenny has claimed that Alexis is merely shy. Jenny conveyed that Alexis finds it difficult to have conversations with outsiders. This could suggest that the child's personal character (a quiet child) has reduced his opportunities to seek clarification or to ask questions (Lowes, 1996), and thus, limiting his participation in the communication process.

It is worth noting here that Alexis is a veteran patient in the ward, since this is his 9th episode of admission. However, the excerpt indicates that he is excluded from the discussion and takes a passive participant role in the communication process. This is in contrast with the previous research which suggested that children who were repeatedly admitted to the children's ward would be more likely to occupy the active participant role in the communication and decisions (Beresford & Sloper, 2003; Coyne et al., 2006, Kilkelly & Donnelly, 2006). The finding of this study does not conclusively support this suggestion. There were instances whereby both children who are regularly admitted to the ward (e.g. Alexis), and the first timer (e.g. Nita in Chapter 5, section 5.3.2.1), were disregarded in the communication process, and occupied the observer role, in line with the findings of Lambert et al. (2008). Thus, this finding supports the suggestion of Lambert and colleagues (2008) that it is difficult to explicitly apply prior hospitalization experience as a criterion to determine the extent to which children are or should be involved in the communication process.

The excerpt indicates that the most remarkable influence on the passive participant role of Alexis is the nurse, who initiates the communication, and directly communicates with his parent in his presence. During my fieldwork, I noticed that the majority of nurses in this study often initiated communication with children and their parent during the care provision. However, many nurses seem to communicate mainly with the parent and most of the time the child is in the background of the communication processes. Nurses preferred to convey information by directly communicating with the parent instead of the child, albeit in the presence of the child. In an informal conversation during my fieldwork, Amelia (nurse) gave the most eloquent reason for why nurses frequently directly communicate with the parent instead of the child:

> At the nurse's counter, Amelia states: (...) Parents are more understandable compared to the child, the child, normally when we

> talk to them, they would ask their parent, sometimes, what we tell or ask them, they don't understand, you know, a child is still a child, eventually we have to talk to their parent.
>
> [Excerpt from fieldnote, 31 December 2014]

The statement from Amelia rationalizes nurses' action of directing communication to parents in the communication process. She seemed to question the ability of children to understand the information, and perceived that parents are more able to understand than children are. In this present study, it was noticeable among most of the nurses that directing communication to parents was mainly because the children were perceived to be lacking in the ability to understand information, and thus were dependent on their parent. The nurses' reaction could partly be due to an assumption that children are incompetent, without the ability to understand the concepts being discussed, and thus are dependent on their parent (Christensen & Prout, 2002). It appears that the degree to which children can participate in a situation is dependent on how nurses perceive the child's ability to understand (Alderson, 2007). As discussed in Chapter 2, Neale and Flowerdew (2007) argued that children are perceived as incompetent, relatively incapable of understanding the information, and thus, in need of their parent's support. This perception leads to arguments that children should not participate in the discussion and decisions in relation to their care because participation may place undue burdens of responsibility onto children (Neale, 2002). This suggests that, if the nurse holds the perception that the children have the ability of understanding the information, they are more likely to be encouraged and supported to be part of the information sharing. Equally, if the children were perceived as unable to understand information, they are more likely to be excluded from the process, instead, the information would be directed to their parents.

Amelia's statement indicates that she tried to do the task on time. She perhaps had the impression that the children would slow her down in her job. She appeared to not respect or value the child as her patient. Again, it shows nurses' practice to be 'adult focused' rather than child friendly. The majority of nurses in the ward prefer to communicate with the parents, rather than the children. None of nurses in this current study setting had undertaken paediatric nursing training. It could be argued that the paediatric nurses should be able to speak and discuss things with the children in a language that children understand. As Coyne and colleagues (2016) argue, the fundamental obligation of paediatric nurses is to treat the child with respect; providing support, information and listening to children are the best practice principle of today's paediatric setting. This could explain why nurses are not caring for children in a child friendly way.

Amelia's statement was supported by another nurse, Selena who stated:

> Exactly! In addition, in here, everything that we do to the child, we have to inform their parent and get permission from the parent. If not, we can't do anything. Normally we include all information and treatment plans for their child. (...) and you know, when the parent agrees, it's easy to deal with the child, they will just follow.
>
> [Excerpt from fieldnote, 31 December 2014]

The quote of Selena such as: *'we have to inform their parent and get permission from the parent. If not, we can't do anything'*, describes the practice of the ward whereby nurses are required to convey information to parents as well as obtain permission from them in relation to every procedure to which the children will be subjected. This is due to the practice of the ward in caring for patients, in which parents are considered essential in their child's treatment plan. As discussed in Chapter 2 (section 2.7.2), according to the Patient and Family Rights policy, patients and family have the rights to participate actively in the treatment including the decisions regarding treatment plans, and to be involved in information exchange and collaboration with the healthcare professionals in their treatment plans. It appears that the policy concerns both patients and family. However, the statement from Selena demonstrates that nurses give more attention to the parent rather than the child. Again, this illustrated how practices of nurses are conflicting with the policy of the ward. This could be explained by the fact that parents are considered as experts in the care of their children (Coyne and Gallagher, 2011), and most parents will demand to know all information regarding their child's care, thus telling the child directly would double the work, as nurses have to tell children and then tell their parents. In addition, Selena's expression could be linked to the concept of filial piety which is upheld in the Malaysian culture. Children are expected to be obedient and respect their parents (as discussed in Chapter 2). She might have had the impression that children will follow the instruction of parents. Therefore, telling the parent prior to carrying out a nursing procedure on the child is essential for the nurses in the study setting. Children are expected to agree and cooperate during the procedure if the parent agreed. This example could provide some explanation for some situations that arose during the observations, because there is a risk within the partnership models that by encouraging a parent's involvement in their child's care, the child may become less central (Lambert et al., 2011).

The role of children as passive participant is often viewed as negative and inhibitive to the quality of communication and care (Lambert et al., 2011). Nevertheless, some of the children in this study were not regarded as passive participants in the communication process in terms of being prevented from participating, and rather they took on this role willingly, as illustrated by the following conversation:

> I ask: How do you feel when the nurse is directly communicating with your parent in your presence?
>
> Alexis states: I don't mind, I usually hear what they discussed. I knew it. Even if I don't know, my mum will definitely tell me later on. So, it's okay if nurses do not tell me… and… if I want to know something, I can just ask them…
>
> [Excerpt from fieldnote, 22 December 2014]

This quote illustrates that Alexis appears to be satisfied with his role as passive participant at a particular point in time. His explanation indicated that he was not bothered about getting direct information from healthcare professionals. In fact, what is important for him is that the information still reaches him via his parent or by simply overhearing the nurse communicating with his parent. This suggests that although being excluded from the discussion and employing a passive participant role, a child is satisfied because he desires such a role and his communication agenda is being met in that position (Lambert et al., 2011). This is contrary to studies reporting that some children were dissatisfied with their non-participant status in the communication process, which hampers their ability to make sense of their illness and to have their interests considered (Young et al., 2003; Odigwe, 2004). In addition, Alexis noted that if he wanted more information he could simply ask the nurses, indicating children may have their own preferences about how and when to be included in the communication process. This finding supports the need for each child to explicitly decide upon how and what information they want to receive (Zwaanswijk et al., 2007), because they might have differing preferences at that time (Ruhe et al., 2015). For instance, in certain situations, they might want to play a role of active participant, and of passive participant in other situations. It became clear that the role of the children in the communication process is highly influenced by their desire for information. Alexis, for example, when he desires more information, may take an active role in the communication process by asking for the desired information. Whereas, he might remain unresponsive when he feels he has had enough information.

After a few weeks, and over several conversations, Alexis told me that at times he prefers the nurse to communicate directly with his parent, and sometimes he prefers his parent to convey the information to him. In an excited voice, however, he explained that he was very happy to be part of the communication and he hoped that all nurses would take the initiative to communicate directly with all children in the ward. After learning this information, I began to see interactions such as the following in a new light.

6.4.2 Child as active participant?

> Alexis has a severe mouth ulcer and experiences severe pain. Ann, the nurse in-charge of him, comes in to his unit to commence an IV Morphine infusion for him.

> Ann: Alexis, I’m going to start the medication to ease your pain.
>
> Jenny: Nurse, it is possible to do it after his breakfast? He is just trying to eat.
>
> Alexis: No mum! Nurse, do it now please, it’s so painful! Hopefully I can eat peacefully after the medication is infused!
>
> Jenny, without any objection, just smiles and looks at her son.
>
> Ann: Okay, that’s good.
>
> The infusion is started accordingly.
>
> [Excerpt from fieldnote, 14 January 2015]

In this situation, Ann is directly communicating with Alexis by informing him of what was going to be done to him. However, it appeared that this was largely focused on the nurse’s accomplishment of her routine tasks, and not specifically tailored to Alexis’s agenda. Indeed, when the nurse attempted to communicate with Alexis, the parent interposed not only to answer for him, but also to voice her own preferences to have the procedure after her son had eaten his breakfast. In the beginning, Alexis appeared to employ a position as passive participant when his parent tried to interrupt the conversation; however, from this point he was an active participant, when he voiced his preferences for the infusion to commence immediately. In contrast to the previous example (section 6.4.1), Alexis had a stronger wish to be involved in the conversation when he personally requested pain medication. His response, therefore, may suggest that he was too sore and just wanted the pain to go away, indicating he knows better how he feels. This supports the findings that the physical state of the child could influence their role in communication and decisions (Coyne et al., 2016). This example also supports the argument that the decisions made by parents may not necessarily be what children want, and may not be in their best interests (Coyne and Harder, 2011). Alexis appears to know his pain threshold better than his parent when he stated that he needed the infusion urgently at that time, and thus, takes on the active role. Although the majority of nurses in this study might agree that parents have a better understanding compared to children, and know best regarding their child (see section 6.2.1), this example; however, has shown that this is not always the case, highlighting the need for nurses to examine the individuality of each with regard to their care needs.

Both examples of Alexis serve as a powerful illustration that the same child can play a different role within the communication and decisions throughout the period of hospitalization. Similar to the example of Ray (see section 5.2.1.1), Alexis did not seem to fully occupy a position as active participant or passive observer within the communication process, but his position was constantly changing throughout his hospitalization, oscillating between active participant and passive observer. This ties in with what Lambert and colleagues (2008: 3098) concluded, namely that children did not exclusively occupy a forefront or background position within the communication process; rather they oscillated along the continuum between the two extreme poles of 'being overshadowed' (in this case as passive participant) and 'being at the forefront' (as active participant). The child's involvement in the communication process appears to oscillate throughout their hospitalization. The excerpt indicates that the fluctuation of the role of the child in the interaction could be partly because of the nurse allocating the child opportunities and space within the communication, or partly because of the child taking more initiative (Lambert et al., 2008). Alexis, for example, although the parent interrupted and blocked his interaction with the nurse, when he eagerly tells his preferences to get things done, the nurse stays focused on him, thus his active role was evidenced. It can be seen that, when children suddenly change their role from passive to active role, the role of other members in the triad were affected (Gibson et al., 2010). For instance, when Alexis became an active participant, his parent become a passive one in the background. The nurse, however, remained in the position to decide whether to follow the preference of the parent or that of the child. Again, demonstrating the role of nurses as influencing the child's role in the communication and decisions.

6.4.3 Summary

In this section, I have sought to show how children employ different roles of passive or active participants in communication and decisions. The example in this section demonstrated that children become active participants in the communication process when nurses interact directly with them, in either the presence or absence of their parents, listening to them and giving them opportunities to ask questions. Equally, children are passive participants when nurses do not communicate directly with them, choosing instead to directly interact with the child's parents (Lambert et al., 2008). I have shown that the role of children as active and passive participants are not permanently engaged by individual children, rather their role fluctuates throughout the hospitalization journey.

6.5 Chapter summary

This Chapter has presented the nature of communication for children. By presenting examples from the children's experiences in the oncological ward, I have given insights into the salience of parents' roles in the communication processes, adults controlling the information sharing, and children's role in communication processes, for particular children, at different times and in different situations.

As outlined at the beginning of this Chapter, I have conceptualized the role of parents as facilitators of communication, communication brokers and communication buffers (Gibson et al., 2010). Paying attention to the different roles of parents recognises the importance of the parental roles on the children and their role within communication processes. I have shown how parents play their role as facilitators of the communication process with the child and nurse. I have also shown that the ways in which parents translate and repeat information from the nurse to the children, as well as filter and shield what children are told, have implications on the role of children (either as passive participants or active participants) within the communication process.

Fieldnote excerpts analysed throughout section 6.3 has indicated, first, the way in which parents shield their children from distressing information, have given an insight into the significance of full information for children to better understand their condition. Second, the way in which nurses communicate with the children by using the technical terms and acronyms, have given an insight into the significance of understandable information for the children to better understand their illness and treatment plan. In turn, full and easily understood information would enable children's participation in their care and decisions. What is important from the findings of this study is that the adults always communicate in a way convenient to them rather than trying to be child friendly during the information sharing with children. For instance, nurses often used technical terms when communicating with children, which prevented children understanding. As a result, children must learn to adapt themselves in an 'adult way' of communication to better understand their condition and treatment plan. Thus, the analysis in this section highlighted the value of having paediatric trained nurses in the children's ward. Paediatric training provides additional education and experience for nurses to be competent in communicating effectively with children of all ages (Royal College of Nursing, 2010). Without the paediatric training, the nurses lack the appropriate skills (e.g. communication skill) in caring for children.

Section 6.4 on the children and their role in the communication process has demonstrated the role of children in the communication process, rooted in nurse-child-parent interactions. I have drawn out the significance of the role of children as active and passive participants in the communication and decisions. This section has shown that these roles are not permanently engaged by individual children, rather their role constantly vacillates throughout the hospitalization journey. This Chapter, in line with Lambert's (2008) concept of visible-ness, has shown how both active and passive participant roles are not fully engaged by individual children; rather their role oscillates throughout the hospitalization journey. The fluctuations of a child's role are highly dependent on their preferences: how and when they want to be included in communication and decisions. Children's roles in communication and decisions are also dependent on the particular context, and a child's role in one situation may sometimes contradict their role in other situations. The ways in which the children play their role are thus ambivalent and contradictory.

Chapter 7: Discussion

7.1 Introduction

This study was driven by a lack of evidence about how, when and why children participate in decisions relating to their nursing care. There was a lack of research on children's experiences of participation in decisions relating to nursing care in Malaysia. Previous studies suggest that children's participation should consider the perspectives of children, their parents and healthcare professionals (Coyne, 2008; Coyne & Gallagher, 2011; Moore & Kirk, 2010). The need for research to bridge understandings of children's participation in decisions with regards to their nursing care from children's experiences and the parents and nurses' views was therefore the main driver for this study.

The study aimed to explore how children diagnosed with leukaemia participate in decisions regarding their nursing care in an oncological setting in Malaysia. The first findings chapter (Chapter 5) explored children's experiences of participation in decisions and depicted the marginalized participation of children in decisions relating to nursing care in their current oncological setting. The second findings chapter (Chapter 6) reported on the roles of parents in supporting children's participation, adults controlling information sharing and children's information preferences, and the role of children in the communication processes. The analysis of the findings emphasises that these are important elements that substantially contribute to the participation of children in decisions regarding their nursing care.

In this chapter, I set out to elaborate the key elements identified from the analysis of the two findings chapters. A diagram was developed through the integration of key elements analysed in the previous two findings chapters to explain the dynamic process of children's participation in decisions with regards to their nursing care at the end of the Chapter (see Figure 7).

The findings of this study contribute to the literature on children's participation through seven key elements:

i. Interpersonal relations in the child-parent-nurse interactions were particularly important for the participation of children in decisions relating to their nursing care. Establishing interpersonal relations in the nurse-child relationship impacts on the children's participation in the decisions regarding their nursing care.

ii. The attitude of nurses has been shown to have an impact on children's participation in their care and decisions. There were variances in the views held by nurses about children's participation, that of whether a child is competent to participate in decisions. The nurses' views of whether or not a child is competent has a tremendous significance for the nurses in this study to encourage and support the participation of children in the decisions relating to their care.

iii. The parental role impacts on how children are involved in decisions. Some of the parents in this study protect their child by filtering and withholding the distressing information from their child, while others support the participation of their child by encouraging the child to be involved in information sharing and supporting the child to make his/her own decision where possible. The perceptions of parents towards children affect the way in which they treat their child in relation to the participation of the child in discussions and care decisions.

iv. The analysis of accounts of the nurses in this study indicate that children's care is limited by the guidelines implemented in the ward that they can refer to. Although the ward policy places equal emphasis on both patient and family rights, in practice, the focus is more on the parents rather than the children, resulting in children being marginalized when it comes to decisions regarding their care.

v. The accounts of the children have shown that their preferences for participation in the communication process and decisions about their care shifted during the course of their illness and treatment, leading to the identification of changing patterns of preferences as the key element of this study. The majority of children in this study preferred different levels of participation, and their preferences for participation in decisions were varied and changed throughout their hospitalization. Some of the children wanted more involvement, while others were comfortable with their limited role in the decisions.

vi. The analysis of observation data indicated that children in this study experienced shifting degrees of participation throughout their hospitalization, in which the children occupied different roles, those of either active or passive participants. The role of children within the process oscillated throughout their hospitalization, which could be linked to children's preferences changing. In this section (section 7.7), I attempt to link the key finding of this present study with the model of participation of Hermeren (1996) and have developed a diagram to illustrate the association between this key element of this study and the model (Figure 6).

vii. The analysis of observation data and accounts of participants of this study revealed that decisions can be divided into two: major and minor decisions. Adults (nurses and parents) of this present study were more likely to support children's participation over 'minor' decisions and less so for 'major' decisions.

The following sections discuss the above key elements in relation to existing literature concerning the experiences and understandings of children's participation in decisions regarding their care.

7.2 The dynamics of interpersonal relations

The first finding of this study shows that the dynamics of interpersonal relations between nurses and children create a climate that can either support or impede children's participation in their care and decisions. Drawing on Peplau's (1997)

Theory of Interpersonal Relations, the term, 'relations' here refers to connections, bonds or patterns that develop and are identifiable within the relationship (Peplau, 1997: 162). Peplau (1997) suggested that the relationships between nurse and patient are dynamic, not a relation of equals, and it is an interactive and relational process which develops over time between the nurse and patient, with the goal to promote the patient's well-being and reduce their dependency. As a result, a nurse encourages a patient to make his/her own decision, so that they can become autonomous individuals and assists them by providing the necessary background information, proposing possible alternatives, and explaining the consequences of their choices (Gastmans, 1998). This would mean that this is a relationship where patients are respected and valued as the nurse listens to their concerns, provides information and advice, relieves distress by encouraging the expression of emotion, and encourages the patient to practice self-care (Moyle, 2003). This finding is highlighted in the following explanation.

7.2.1 Relational care

The findings of this current study show that the key aspect of establishing interpersonal relations is the nurses' use of interpersonal skills to communicate, negotiate and take into consideration the children's request. When nurses demonstrated that they knew something about the child, children felt more comfortable with the care provided. When the relations were established between child and nurse, they could more easily work with each other and information was shared with the children regarding their care, resulting in more individualized care. This means that good interpersonal relations between the child and nurse is influenced by the nurse's knowledge of the child, the child's knowledge of the nurse, and their ability to find the common connection between them (Espezel & Canam, 2003). The issue that influences the development of interpersonal relations between the children and nurses in this current study is that either the children are novices or veterans in terms of their illness and episodes of admission to the ward. Although there were few veteran children who were not always involved, this underlying cause, to some extent, has impacted on the child-nurse interpersonal relations, and in turn, influenced the degree to which children participate in the decisions, as evidenced by the following remarks.

The analysis of the observation data of this study indicated that repeated contact of the children with a group of nurses was important in fostering a situation contributing to establishing interpersonal relations. The majority of the veteran children in this study were more likely to have good relations with the nurses in the ward, which was not the case for the majority of novice children. Veteran children comfortably communicate with the nurses, equally, nurses are spending time to have a dialogue with the children during the provision of care. For instance, in Chapter 5 (section 5.3.1.2 and 5.3.2.2), I have shown that the veteran children, who had repetitive contact with the nurses, are more likely to converse with the nurses. These children easily asked questions, or expressed their views and requests in relation to the care provided to them, which could be linked to the interpersonal relations established between them and the nurses in the ward. Specifically, it can be seen in the example of Albert (section 5.3.1.2), whereby the nurse (Bella) demonstrated that she treated Albert as a person, when she spent time negotiating with Albert by explaining the RT insertion, reassuring him that he does not need the insertion if he is willing to take medication orally, and listening to Albert's wishes to take medication orally and taking them into consideration. Eventually, this reached a conclusion that was favourable to both the child and nurse. This finding demonstrates that when the nurse and child have more contact, it develops a better interpersonal relation. As Espezel and Canam (2003) argued, spending time together was important for each party to establish a positive interpersonal relationship and to feel comfortable with each other. It is noteworthy that, when positive interpersonal relations were established, the interaction between the nurse and child became calming, and thus, supported the children's participation. Conversely, there were different observations witnessed between some novice children with the nurses in this study. For instance, as illustrated in the case of Nita (a novice) and Alison (see Chapter 5, section 5.3.2.1), the relationship between the nurse and child was not positive; the interaction appeared to be tense, and there was a quarrel between them. This would suggest that interpersonal relations are difficult to establish during the first contact between the child and nurse. The example of Nita demonstrated that without establishing interpersonal relations, children were not encouraged to participate in their care and decisions, so, the nurse maintained overall control.

In addition, establishing interpersonal relations between nurses and children also involved information sharing. As discussed above, this study highlighted that when good interpersonal relations were established between nurses and children, they could more easily work with each other to share information. On the one hand, children could comfortably ask questions and give their opinions where possible. On the other hand, nurses could educate the children regarding their care according to their needs. This helps children to better understand, prepare for, and cope with their illness and treatment, and the procedure they may undergo. In addition, good interpersonal relations between children and nurses would be beneficial in helping the children to express their views and feelings. Therefore, establishing interpersonal relations that enable information sharing between nurses and children are vital for establishing a strong collaborative relationship, which results in children's greater participation in decisions regarding their care. As Coyne and colleagues (2016) argued, information sharing was the best approach in children participating in the decisions because it enhanced understanding, reduced anxieties, promoted cooperation and helped build trusting relationships.

Studies have shown that the participation of children in decisions could be influenced by numerous factors such as the child's age, child's understanding, emotional state, level of maturity and illness state (Clarke et al., 2005; Zwaanswijk et al., 2007, 2011; Coyne & Gallagher, 2011; Coyne et al., 2016). The findings of this study highlighted that establishing interpersonal relations between nurses and children is needed for children to participate in the decisions regarding their care. Nevertheless, establishing rapport between veteran children and nurses may not fully explain the way in which children participate in decisions because the degree of participation among veteran children in decisions could be due to other influences. As McCabe (1996) argued, children's preferences for involvement in decisions will be heavily influenced by their prior experiences with the disease; relevant experiences include practice in different types of decisions in their daily lives, with health behaviour being the most important. This was supported by a qualitative study that interviewed 24 children aged 3 to 12 years with a chronic disease. The study reported that the children have a high level of understanding, knowledge and skills gained from their previous experience of living with the disease, and the children were able to make decisions about their treatment and care, even at a young age (Alderson, Sutcliffe & Curtis, 2006). This would suggest that it is not only the positive interpersonal relations established between children and nurses that contribute to the degrees of their participation, but also the veteran children's prior knowledge regarding their illness and treatment.

In this section I have shown how repeated contact between veteran children and nurses impact on the child-nurse interpersonal relations, and in turn, influence the degree to which children participate in the decisions.

7.3 The attitudes of the nurse

The second key element of this study is that the most notable influence on children not always being given the appropriate opportunity to participate in their care and decisions was the attitudes of nurses. Attitude is defined as the way a person views something (Lee, 2007). The attitude of an individual often determines how that individual acts in different situations and towards other people (Runeson et al., 2002a). Therefore, the action of individual nurses towards a child can be explained by understanding the nurses' view of children.

The findings suggest that there were variances in the views held by nurses about the children's participation, relating to whether a child is deemed competent to participate in decisions. Beauchamp and Childress (2001) define competence as the ability of the child to perform a task and to make decisions if he/she has the capacity to understand the information, to make a judgement about the information in light of his/her values, to intend a certain outcome, and to communicate freely his/her wishes.

The competence of children is difficult to determine, particularly for children with chronic conditions because competence is not fixed or quantifiable and varies with the context (Kelly et al., 2012). However, in this study, nurses' views of whether a child is competent impacts on their efforts to engage the participation of children in the decisions relating to their care as evidenced by the following remarks.

A large proportion of the nurses in this study initiated communication either with the children or their parents. Resulting from their views towards children and their competency, many of the nurses directed communication to the parent during the provision of nursing care instead of the child. These nurses provided nursing care to the children without explaining the procedure or only providing limited information regarding the procedure to the child. This resonates with assertions by Larsson and colleagues (2011) and Gluyas (2015) in that the nurses demonstrated a lack of engagement with the children during the care process, a lack of understanding and empathy of what is important to the children or a paternalistic attitude where the children are not presented with any options. Also, this corresponds with the finding of Baggens (2001) who reported that most conversations were started by the nurse, and nurses in her study frequently tended to interact with the parent rather than with the child. The accounts of the nurses in this current study indicate that they perceive children as incompetent. For instance, the nurses stated that children lack the ability to perform their activities of daily living due to the seriousness of their illness. They perceived children to lack an understanding of the information regarding their treatment, and thus children were often dependent on their parent's assistance. The nurses also expressed that, although they communicated with the children regarding their care or treatment, the child was usually unable to communicate with them, and so they tended to discuss things with their parents. This group of nurses believe that the responsibility should lie with parents. These perceptions were in line with the conceptualizations of childhood as welfare dependent from Neale and Flowerdew (2007), where children are perceived to be dependent, incompetent, in need of care and protection from adults. This could be linked to the Malaysian culture, where children are expected to consult with their parents on important decisions and follow their guidance; and parents are mostly expected to be involved in and responsible for decision making, and caring for their children throughout their lives (Chao & Tseng, 2002) (see Chapter 2). It could be argued that the ability of children to understand the information and perform their activities could be due to other influences, such as the child's emotions, illness condition or their preferences rather than the competency of the child (Coyne & Gallagher, 2011; Coyne et al., 2016; Ruhe et al., 2015). However, this perspective views children as in need of adult's care and guidance (Alderson & Montgomery, 1996; McNeish, 1999). Therefore, children are relegated to non-participant status in discussion and decisions with information-giving directed at the parent rather than the child (Wassmer et al., 2004). Consistent with this finding, previous research suggests that nurses who view children as incompetent, and dependent, are unlikely to involve the children in the communication process regarding their care, but often involve the parent in the child's care and communication process (Lambert et al., 2011).

Conversely, a small number of nurses in this study communicated with the children in relation to the care provided and involved children in discussions about their care and care decisions; however, the nurses' efforts to include children in discussions and decisions were often interrupted by their parent (e.g. example in Chapter 5, section 5.3.2). When they were interrupted by the parent during the conversation, nurses responded differently. Some of the nurses continued to focus on the child rather than the parent, with some nurses changing their communication style to communicate with the child, while others changed their focus to the parent and left the child excluded from the discussion. The nurses who tried to include children seemed to show their respect for the child's needs. For instance, the nurses were observed attempting to satisfy the needs of the child by offering choices, listening to, and taking into consideration the child's views (see Chapter 5, section 5.3.1). Their explanation indicates that they hold a view that children should be involved in the care and decisions because it is about them, and they strongly agreed that children should be consulted about all matters concerning them. This group of nurses consider children to be competent and hold a view that children can perform their daily activities, such as dressing, and that children are able to understand the information about their illness and its treatment. Therefore, these nurses were directing conversation directly to the child, listening to the child, and informing the child about the care provided to them, and therefore, the children could participate in their care and decisions. Although only a few nurses in this study acted in such a way, this finding may reflect that some of the Malaysian nurses hold a view that children have strength and competence, and thus, need recognition, respect and participation in their own care and decisions concerning them. It can be considered that these nurses respect children's right for information and participation in their care and decisions. This was in line with the conceptualizations of childhood as young citizens from Neale and Flowerdew (2007) but, in contrast with the general beliefs of Malaysians that children are expected to be dependent on their parents, and parents are mostly expected to be involved in and responsible for decision making concerning their children. This suggests that these attitudes may change as societal values evolve with time (Eng et al., 2012)

It becomes apparent that the views of nurses towards children support the way in which nurses' efforts either support or hinder the participation of children in the decisions. It is plausible that when the nurse believes that children are competent and have their own strength, the nurses were more likely to involve the children in their care and decisions. For instance, if the nurses believe that the child is 'competent', they will encourage the child to participate in their care and decisions. Equally, if the nurses believe that the child is 'incompetent', they do not involve the children in the discussion and decisions regarding their care, but involve the parent in the child's care and decisions without consideration of the child's choices and preferences; as a result, the child is excluded from the conversations and decisions.

7.4 Parental role: protection vs support for participation

The third key element identified from the analysis of the findings is the role played by the parents. The role of parents has profound implications for how children are involved in communication and decisions. Chapter 6 (section 6.2) has explained how in various situations parents played different roles in facilitating or constraining children’s participation in communication and decisions. This key finding can be clarified by the following explanations.

The analysis of the findings suggests that the parents in this study acted differently in relation to their child’s participation in decisions. Some of the parents protected their child, filtering and selecting information to be conveyed to their child and acted as decision makers regarding their child’s care. Others seemed to support the participation of their child by encouraging them to be involved in discussions with the nurse and to make their own decisions where possible. The explanation of the dissimilarity of the way in which the parents treat their children in relation to children’s participation in decisions could be explained by understanding the different constructions of children and childhood. There has been much discussion about the different social meaning of childhood (James, Jenks & Prout, 1998; Mayall, 2002; Uprichard, 2008). James, Jenks and Prout (1998) suggested that those differentiations have affiliation specifically with notions of children as ‘being’ and ‘becoming’. Similarly, as discussed in Chapter 2, Neale & Flowerdew (2007) summarized ways of conceptualizing children: first, children as welfare dependant, and second, children as young citizens. These conceptualizations of children provide two very different pictures of adult’s perceptions and actions towards children, resulting in facilitating or limiting the participation of children in decisions, as evidenced by the following remarks.

In Chapter 5 and 6, I have shown that parents of this current study play different roles in the communication processes between the nurses and children, which can both facilitate and constrain children’s participation in their care and decisions. Parents who played an important role in facilitating communication between the nurses and their children encouraged their children to be involved in the decisions regarding their care. These parents often encouraged nurses to communicate directly with the children when the nurses directed information to themselves regarding their children. The way in which parents supported and facilitated their children’s participation in discussion and decisions are linked to the parent's conceptualization of children. For instance, as elaborated in Chapter 5 (section 5.2.3), Jess (George's parent) encouraged the nurse to communicate directly with her child, supported her child in decisions by discussing and giving suggestions to her child regarding the learning session, and, finally facilitated her child to make his own decisions. Jess's explanation gives the impression that children are considered as individuals with their own ability and need for participation, when she emphasised the relevance of children to be involved in the consultation processes regarding their care. This could be linked to the concept of children as young citizens where children are seen as individuals, who are competent and have their own strength, and who influence their own childhood, and who need recognition, respect and participation (Neale & Flowerdew, 2007). Also, in line with the concept of the child as a 'being' is where the children are seen as social actors, who are actively constructing their own childhood, and who have views and experiences about being a child (Prout & James, 1997; James, Jenks and Prout, 1998). As Lambert and colleagues (2011) suggest, parents who see children as beings believe that children are mature, competent and thus can exercise their autonomy. Therefore, with this view, the parent would involve children in discussions or decisions concerning them. This conceptualization of children gives significance to Jess's view towards her child and how such perceptions influence the ways in which she reacts to her child in particular situations.

It could be argued that the way in which parents support their child in discussions and decisions is essential to children's participation. Supportive parents can provide information and help, and facilitate children's participation in decisions, resulting in maximising the participation of their child in discussion and decisions concerning their nursing care. For instance, Damia's (Ruby's parent) presence and response appeared to enhance the confidence levels of Ruby to ask or answer questions, as subsequently, Ruby could express her preference of which hand she preferred to be used for the venepuncture after the consequences of having the insertion on her left hand were explained to her by her parent (see Chapter 6, section 6.2.1). This example indicated the way in which parents supporting their child could help and facilitate the child to make their own decisions. Also, it could help with learning for future discussions and decisions and help the child to participate in future more complex decisions as she becomes older (Runeson et al., 2002a). As research has shown, all of the experiences the child has will further influence his/her action in the future, because how a child acts in any situation depends on the child's earlier experiences of various everyday situations (Soderback, Coyne & Harder, 2011).

Nevertheless, there were some parents in this study who were often observed trying to shield their children from information by selectively withholding information from the child. For instance, as elaborated in Chapter 6 (section 6.2.3 and 6.3.1), some parents of this current study did not communicate full information to their child regarding a procedure that was to be carried out because of their desire to protect their child from distressing information. Nancy (Ralph's parent), for example, tried to protect her child from knowing the facts about CVL, and the reason for the insertion of CVL. Another example was discussed in section 6.3.1, with Zana (Adela's parent), who shielded the information regarding the side effects of chemotherapy and did not discuss fundamental treatment issues with her child. It can be seen in both situations that parents seem to pick and choose the information to be conveyed to their children. The justification of these parents' actions was related to the fear of how the information would affect their children. Consistent with this finding, previous research suggests that parents' desire to protect their child from distressing information may lead to them withholding or providing only partial information (Young et al., 2003; Zwaanswijk et al. 2007).

From the examples of this current study, it can be considered that some parents did not regard their child as having the right to receive actual and full information regarding their condition and the care provided. In fact, the parents made the decision to not communicate the facts to their child. They felt the need to protect their child from distressing information, which was reported elsewhere (Kars et al., 2008; Watanabe et al., 2014; Coyne et al., 2016), indicating the importance of this for parents of children with cancer. The need for the parents in this current study to protect their children from distressing information reflected the conceptualization of children as welfare dependent (Neale & Flowerdew, 2007), in which children are perceived to be incompetent and vulnerable, and thus, in need of care and protection from adults, especially their parents. This conceptualization is consistent with the view of children as 'becoming' with the children being seen as an 'adult in the making', who is lacking universal skills and features of the 'adult' that they will become (Prout & James,1997; James, Jenks & Prout, 1998). As Lambert and colleagues (2011) suggest, parents who see children as becomings believe that children are immature, and in need of adult protection. Therefore, the parent protects their children in various ways. As highlighted in this current study, some of the parents control the information to be conveyed to their children, and others decide on behalf of their children. Again, this is linked to the Asian culture where parents are mostly expected to be involved in and responsible for decision making for their children, and caring for their children throughout their lives (Chao & Tseng, 2002).

These findings generally reflect the idea that parents' perceptions and expectations of children affect the way they treat their child in relation to the participation of the child in the discussion and care decisions affecting them (Clarke et al., 2005). It illustrates that the parent who sees a child as a 'young citizen' or 'being' would listen to, and empower children in the discussion and decisions. Conversely, parents who see their child as 'welfare dependent' or 'becoming' took initiatives to protect their child from distressing information, as well as constraining the child from participating in the decisions concerning them. Furthermore, the role of parents in supporting or constraining the participation of children in the decisions could be linked to the healthcare delivery model practice in the setting, which is further discussed in the next section.

7.5 The ward policy

The findings of this current study have revealed that the role of parents in this setting becomes essential in the care of their child, resulting in marginalizing the role of children in their care and decisions. For instance, the nursing care in the current setting focused on involving the parent in the child's care including educating parents about the short term and long-term side-effects of chemotherapy. The majority of nurses often communicated with the parent, rather than the child, prior to any procedure being carried out on the child. This could be linked to the policy implemented on the ward, which requires parents or families to be involved in the child's care, including decisions about the child's care. In Chapter 2 (section 2.7.2), I demonstrated how the policy of Patient and Family Rights could encourage a high degree of parental involvement. According to the policy, healthcare professionals are required to provide patients with quality medical care, patients and family have the right to participate actively in the treatment including the decision making regarding treatment plans, and they are encouraged to be involved in information exchange and collaboration with the healthcare professionals in their treatment plans. Although the policy emphasized both patient and family rights, the findings of the present study indicate that actual practice seemed to focus more on the parent rather than the child. This finding is clarified by the following explanations.

It is noteworthy that, although the FCC model of care is widely used in paediatric settings worldwide, there were no guidelines or policy related to FCC identified in the research setting specifically. Nevertheless, the elements of the Patient and Family Rights policy implemented in the ward were consistent with the four important core concepts of FCC that are: dignity and respect, information sharing, participation, and collaboration (see Chapter 3). This means that this ward implemented a model of care where parents were acknowledged as central to their child's existence, and therefore vital in the decisions regarding the care of their child (Shields, 2001). This might place the child at risk of becoming less visible, as evidenced in the following remarks.

Firstly, the policy emphasises 'information sharing', where the healthcare professionals are required to provide information, and a channel for feedback to their patient and family, while the family and patient are responsible for providing complete and accurate information about the patient's health to the healthcare professionals (see Chapter 3, Table 5). Information sharing means that nurses share complete and unbiased information with parents about the care of their child on an ongoing basis (Johnson, 1990). Nursing care cannot proceed effectively toward outcomes beneficial for children without the nurses having adequate information about the child as a person and about the prevailing health condition (Peplau, 1997). Equally, without information from the nurse, children and parents are unable to participate in the children's care, decisions for their children, and are therefore unable to form an equal partnership with the healthcare providers (Butler, Copnell & Willetts, 2014). With the most knowledge about their child, on the one hand, to some extent the parents seemed to understand that nurses needed information regarding their child to provide individualized care to them. Thus, they provided information concerning their child to the nurses, while, on the other hand, nurses shared information regarding the child's care with the parents. Nevertheless, the findings of this study indicate that nurses and parents often share information between them, but not with the child (see Chapter 5, section 5.2.1, and 5.2.2). There was only limited and simple information conveyed to the children in relation to their care and treatment plans. When the nurses' accounts were analysed, it was found that this related to the policy of the ward, which required nurses to convey information to parents as well as to obtain parental permission for every procedure to which the children will be subjected to (see Chapter 6, section 6.4.1).

Secondly, the policy of the ward emphasized the participation and collaboration of the parent in their child's care. Parents were encouraged to participate actively in the treatment of their child, and to be included in the decision making regarding treatment plans of their child (see Chapter 2, section 2.7.2). This is in line with the concept of 'participation and collaboration' of FCC, which means that nursing care for a child in hospital can be given by the parents with support and education from the nurse (Shields, 2010). In the present study, parents' participation in their child's care, and collaboration between the nurse and parent, were observed during the provision of nursing care to the child. For instance, most of the parents in this study were educated about, and encouraged to do, dressings for their child while in hospital, as a preparation for continuous care at home after the child is discharged. The participation and collaboration between the parent and nurses appeared to overshadow the role of children in their own care. Thus, children appeared to face challenges in being actively involved in their care, resulting in their limited role in decisions. Consistent with this finding, previous studies suggest that children face challenges in being actively involved in their care because of the role played by their parents (Coyne, 2006; Kelly et al., 2012; Lambert et al., 2008; 2011).

Finally, what is important is that this study shows that the policy emphasis tends to be on parental participation, collaboration, and information sharing between the nurses and parents. This suggests that in the study setting, parents can be considered as the focus of the child's care, with children viewed as an object of concern. This means that children are perceived as being possessions of their parents, and, as such, may have minimal or no input into decisions regarding their health care. Thus, attention was mostly directed toward the parent rather than the child. This was similarly found by Lambert and colleagues (2011), who suggest that the way in which the children were viewed as a subject with their own ability or object of concern could influence the way in which nurses treat the child in their own care. In other words, if children were viewed as an object rather than subject of their own rights, it would hinder their rights to express their views and participate in their own care and decisions concerning them. Communication could largely be directed to the parent. If children were viewed as subjects of their own rights, this could lead to an alternative partnership model of care for hospitalized children and their families. This model requires more equality within child-parent relationships, where children will be more likely to be allowed a certain amount of involvement in decisions. While the parent may still maintain the control over decisions, the possibility for the nurses to involve the child in the decisions directly would be evident (Lambert et al., 2011). Nevertheless, Lambert and colleagues' (2011) work was undertaken in the context of the Republic of Ireland, the focus on parents and marginalization could be further reinforced by how children tend to be perceived in Asian culture. Within the Asian culture, children are largely perceived to be dependent, incompetent, and requiring protection from adults, and, thus, parents are mostly expected to be involved in and responsible for decision making for children, and caring for their children throughout their lives (Chao & Tseng, 2002).

A further explanation given for why the nurses of the ward focused more on the parent rather than the child was that the nurses of the ward were not specifically paediatric trained. It could be argued that children's nurses require excellent clinical skills to provide high quality care to children and young people. Paediatric training provides additional education and experience for nurses to be competent in communicating effectively with children of all ages, and recognition and management of children with different illnesses, and working flexibly in a multidisciplinary team within an environment which can change rapidly (Royal College of Nursing, 2010). Thus, without the paediatric training, the nurses lack the appropriate skills (e.g. communication skill) in caring for children. It could be argued that if the nurses were paediatric trained, they would be able to provide nursing care for children with skill and competence, and, thus, provide nursing care appropriate for children of all ages.

Together these findings suggest that the policy on patient and family rights show some alignment with FCC. Thus, the parental role is crucial to their child’s care and decisions about such care. In doing so, however, the role of children in decisions was marginalised. It is not inevitable within the FCC model that children’s participation is minimal, but it is a risk.

7.6 Diverging and fluctuating preferences of participation

The next key element of this study is that children’s accounts indicated that they had different preferences for participation in decisions regarding their nursing care at different times and in different situations, and these preferences were changeable throughout their hospitalization. Some of the children in this study wished to be involved in the decisions, while others were content with less participation. This finding can be clarified by the following explanations.

The nature of changing preferences due to an illness situation has some resonance with Meleis's (2010) middle range transition theory, which explains how children can transition between being passive participants (situated in the background and not participating in discussion and decisions) and active participants (expressing their requests and preferences) depending on the situation and their preferences. The circumstances of children diagnosed with leukaemia could be linked to the nature of health/illness transition. As Im (2006) stated, this health/illness transition is terminal or chronic, depending on the type, stage and site of cancer for each individual. Transitions theory has a major concept of properties of transitions that include awareness, engagement, change and difference, time span, and critical points and events (Meleis et al., 2000). All these properties can be easily linked to the experiences of children diagnosed with leukaemia. For instance, children in this study were aware that they had been diagnosed with leukaemia. The children were engaged in the diagnosis and their treatment process. Most of the children mentioned that they had to follow the treatment plan because of their cancer. They were also experiencing changes in their physical, psychological, and everyday experiences due to the health/illness transition. Children diagnosed with leukaemia have specific critical points in their transition process (e.g. diagnosis as a start point of the transition, death or ultimate survival as an ending point of the transition). The nature of transition (acute or chronic) can influence the preferences of children for participating in decisions regarding their care. The findings revealed that the illness situation of the child contributed to changes in the child's preferences for participation, as demonstrated in the following remarks.

The illness situation of the child could and did at times determine the child's preferences to participate in decisions at that time. As elaborated in Chapter 6, Alexis (section 6.4) did not verbally respond in one of the conversations between the nurse and his parent regarding his transfer to an isolation room. However, in another situation, when he was experiencing severe pain, Alexis expressed his preferences to have the analgesia immediately, even though it had been suggested by his parent to wait and have the pain medication after his breakfast. It appeared that the child's physical state, particularly pain and discomfort, enabled them to voice their preferences to calm one's self when faced with a stressful situation. This would suggest that the child's physical state such as pain, because of an illness situation (cancer diagnosis – leukaemia), resulted in children more actively asserting themselves in decisions regarding their care.

It became apparent that each individual child had different preferences to participate in decisions, and that preferences changed throughout the course of their hospitalization because they experienced a change in their health and illness status. These findings support the argument that children's preferred level of involvement could move from lesser degrees of participation to more intense involvement and the other way around or maintain the same degree all the time, based on their preferences at that time (Ruhe et al., 2015). This could be because the transition does not follow a chronological trajectory, and learning to live with chronic illness is an ongoing process involving movement in many directions (Kralik, Visentin & Van Loon, 2006). Therefore, it was not surprising that a different child in a similar situation reacted differently.

7.7 Shifting degrees of participation

The previous section (7.6) reported that the child's illness situation could influence preferences for participation, and in turn, the degrees to which they participate. In this section, I attempt to discuss the next key element of this study (from observation data), which is that the participation of children alternated throughout the course of their hospitalization: moving from lesser degrees of participation (passive participant) to greater involvement (active participant) and vice versa. This finding can be clarified by the following explanations.

The nature of the shifting degrees of participation in the decisions relating to their nursing care can be explained by understanding the position of children in the communication processes. Lambert and colleagues (2008) suggested that the position of children in the communication process have associations with the concept of a ‘visible-ness’ continuum. ‘Visible-ness’ continuum consists of two polar ends, ‘being overshadowed’ and ‘being at the forefront’.

The concept of ‘being overshadowed’ can be classified as the position where children were least visible within the communication process, in which the children were marginal to the communication process, standing in the background overshadowed by their parents and nurses (Lambert et al., 2008). This would mean that the children had lesser degrees of participation when the nurse did not communicate directly with them, but instead directly communicated to the parents in the presence of the child. The finding of this study suggests that nurses frequently overshadowed some of the children by directly communicating with the parents. As a result, children were excluded from the discussion, despite being physically present during the communication and decision-making. However, some of the children did not regard their position as passive or negative or felt they were prevented from participating in the decisions. In fact, they permitted this lesser degree of participation willingly because they desired such a position; thus, their agenda was met because they desired this position, and they were satisfied in the position (Lambert et al., 2008).

The way in which children of this study were ‘being overshadowed’ or occupied a passive participant position, matches level 1 to 3 of Hermeren’s participation model (1996) (see Figure 6). In this present study, there were children who appeared to belong to level 1. For instance, Ray (see section 5.2.1) was physically present during the decision regarding his care. In this situation, very brief information was given; the nurse only indicated that something was going to happen. This is more in accord with level 1.

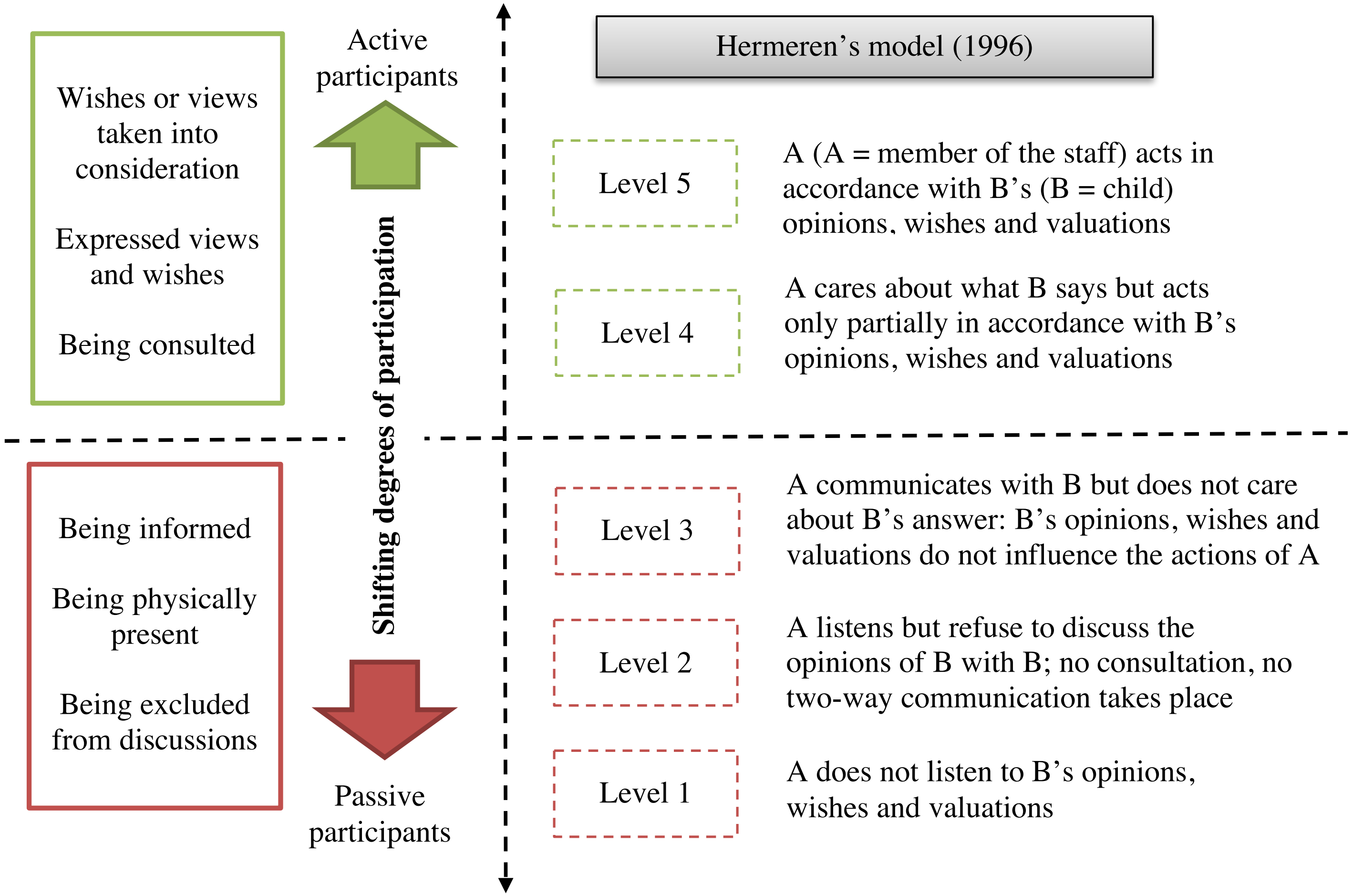
Moreover, for level 2 and 3, there is no two-way communication between children and nurses; nurses refuse to communicate and listen to children, nurses did not care about the children’s wishes or opinion and, thus, the children’s opinions and wishes did not influence the nurses’ actions. In this present study, there were some children who appeared to belong to these levels. For instance, Nita was informed about the care provided, but in a very brief way and the nurse did not check to see if she had understood the information (see section 5.2.2), and Alexis was sat mutely in the background during the discussion regarding his transfer to another room (see section 6.4.1). In these situations, a plan was presented and no alternatives were offered by the nurses; nor were the children asked for their views on what was planned. In most cases, no two-way communication could be seen during the conversation between the nurses and children although the children were present during the discussions and decisions regarding their nursing care. The nurses often communicated with the parents, while the children were physically present but excluded from the discussion.

The concept of ‘being at the forefront’ refers to the position where the children are most visible within the communication process, in which children are the focal point of the communication process, holding a leading position, with the nurse communicating with them, or simultaneously with them and their parents (Lambert et al., 2008). This would mean that children have greater degrees of participation when the nurse interacts directly with them, in either the presence or absence of their parents. In this present study, there were children who appeared to be positioned as being at the forefront during communication and decisions. For instance, some children were observed as being actively involved in communication and decisions, where nurses communicated directly with them. They were informed about the procedure to be carried out on them, and they were also consulted about the care provided to them. The children’s explanation indicated that they believed that their involvement in the decisions is essential because it is about them. With this perception, the children tried to ask questions when they had doubts, they expressed their wishes according to their desires, and they directly communicated with the nurses. This would change the degrees of their participation in the decisions regarding their care.

The way in which children were ‘at the forefront’ or occupied an active participant position, matches level 4 and 5 of Hermeren’s model (1996) (see Figure 6). These levels indicate that there is communication between the staff members and children. The staff members usually act partially or fully in accordance to the children’s wishes and opinions. In this present study, there were some children who appeared to be in these levels. For instance, George (see section 5.2.3), Albert (see section 5.3.1) and Alexis (see section 6.4.2) had conversations with their parents and nurses and could express their opinions and requests during the decisions regarding their care. The nurses in these examples talked with the children about what was going to happen, explained why, and tried to provide an option to make it easier for the child to understand (e.g. Albert). It appeared that these nurses made a real effort to have the children participate in what was happening or at least in the discussion and they finally acted in accordance to the children's wishes. Moreover, the nurses seemed to discuss things with the children as if they were a valid partner whose opinions and wishes were taken into consideration. This would suggest that the nurses care about and respect the children's opinions and wishes. Most importantly, these nurses did not hurry the procedure, they spent time having a dialogue with the children. It can be seen that when the nurses were willing to have a conversation or discussion with the children, children would have greater participation in the decisions compared to situations where nurses did not spend time communicating with them.

It is remarkable that the position of children in the communication process affects the degree of their participation in decisions. What is important in this study is that the individual child does not fully occupy the position as active participant or passive participant within the process, but their position always changes throughout, fluctuating between active and passive participant. Moreover, the participation of the children does not completely belong to any level between levels 1 to 5, but their degree of participation also changes throughout their hospitalization, shifting between levels 1 to 5. For instance, Alexis did not seem to fully occupy a position as active participant (level 5) or passive observer (level 3) within the communication process, but his position was constantly changing throughout his hospitalization, wavering between active participant and passive observer (see section 6.4). Correspondingly, an ethnographic study that recruited 49 children aged 6 – 16 years in one children's ward in a specialist children's hospital found that children did not exclusively occupy a front position or background position; rather they alternated along the continuum between the two poles of 'being at the forefront' and 'being overshadowed' in the communication process (Lambert et al., 2008). There were indefinite reasons for the shifting degrees in participation among the children in the current study. However, this may have been related to the changing preferences of participation in the decisions at the specific time (as elaborated in section 6.4), that the changes in the children's preferences influenced their position in the decisions regarding their nursing care.

Figure 5: Association between the degrees of participation of children and the Hermeren's (1996) model of participation



Level 5
A (A = member of the staff) acts in accordance with B's (B = child) opinions, wishes and valuations

Level 4
A cares about what B says but acts only partially in accordance with B's opinions, wishes and valuations

Level 3
A communicates with B but does not care about B's answer: B's opinions, wishes and valuations do not influence the actions of A

Level 2
A listens but refuse to discuss the opinions of B with B; no consultation, no two-way communication takes place

Level 1
A does not listen to B's opinions, wishes and valuations

7.8 Participation around minor decisions about care

The final key element of this study is that some children are encouraged to participate in minor care decisions. The analysis in Chapter 5 and 6 illustrated that children experienced different degrees of participation in decisions regarding their nursing care. The findings revealed that adults (nurses and parents) were more likely to support children's participation in 'minor' decisions and less so for 'major' decisions. This finding is clarified by the following explanations.

When the issues of decisions were explored, the participants of this study held varying views on decisions and from the analysis, children appeared to be involved about decisions that can be considered as falling into two categories of 'major' and 'minor' decisions. Analysis suggests that the children mostly participated in minor decisions about care. Minor decisions refer to 'having choices' or 'everyday' decisions, which were usually associated with timing and delivery of procedures (Coyne et al., 2014: 5). The observation data revealed that choices are at times influenced by children, especially regarding aspects of care such as the timing of procedures and how they prefer the ways in which the care or procedures are conducted for them. The accounts of nurses and parents indicated that minor decisions were considered as having less impact on the children's conditions, and, thus, children could participate. The involvement of children in minor decisions which did not affect their medical condition had been reported in other studies (Coyne & Gallagher, 2011; Coyne et al., 2014). Nevertheless, this study highlighted that not all wishes by children were always listened to or respected by the nurses or their parent. While some children expressed their requests and the nurses listened and took their voices into consideration, other children's requests were disregarded and thus limited their participation in decisions regarding their care. In this present study, children indicated that they generally had limited or no choice in relation to their care. For instance, George and Kate's (see section 5.3.1) views suggest that children are not always offered choices about their care. The children were typically complying with their care plan because they were being influenced by others (mostly nurses and parents) and, thus, the treatment plan had to be followed. From the adults' perspectives, giving choices was not always possible and non-adherence was not an option due to the life-threatening diagnosis, urgency, and seriousness of the illness, which required a strict protocol to be followed. Most of the nurses in this study held the impression that although children could express their views, they were responsible for making the final decision for the children. Children's views were considered if they did not affect the child's condition or disrupt the treatment plan. It became apparent that children seemed to have some options, but it seems that they did not have real choice because decisions regarding their care were being largely determined by the adults.

Major decisions are similar to 'serious' decisions (Coyne and Gallaher, 2011: 2340). Participants' accounts in this study indicated that major decisions mostly involved the healthcare professionals together with the parents (see section 5.3.1). Most parents and nurses in this study stated that the major decisions were made by adults, frequently by the physician and nurses together with the parent/s, and could be done with or without involving the children. This could suggest that the focus on the best treatment in the child's best interests resulted in adults ultimately maintaining decisional authority over serious care issues (Whitney et al., 2006). This is in line with the findings of previous studies, which state that major decisions (e.g. surgery) were made by the parents together with the healthcare professionals (Coyne & Gallagher, 2011; Coyne et al., 2014).

In sum, the study demonstrated a distinction between decisions that were minor (choices about how care or procedure were delivered) or major (serious decisions about whether life-saving care or procedures would be undertaken). The participation of children in decisions regarding their nursing care fundamentally involved interactions amongst three parties: the child, the parent, the nurse. Children were mostly involved in the minor decisions and the nurses and parents maintained decisional authority for the major decisions, as illustrated in Figure 6.

Furthermore, taking these key elements together, Figure 7 depicts the dynamic process of children's participation in decisions in relation to their nursing care in this oncological setting.

Figure 6: Participation of children in minor decisions

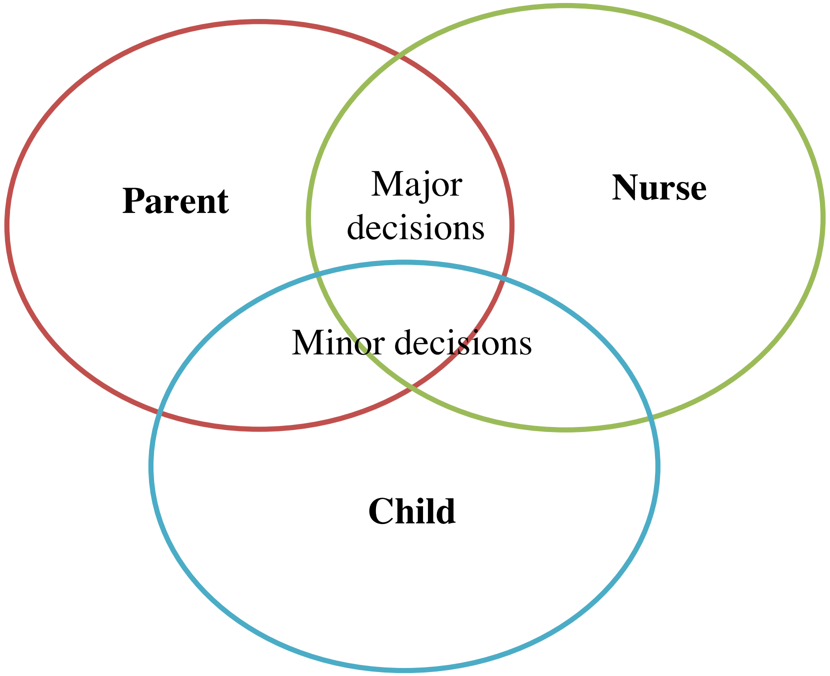
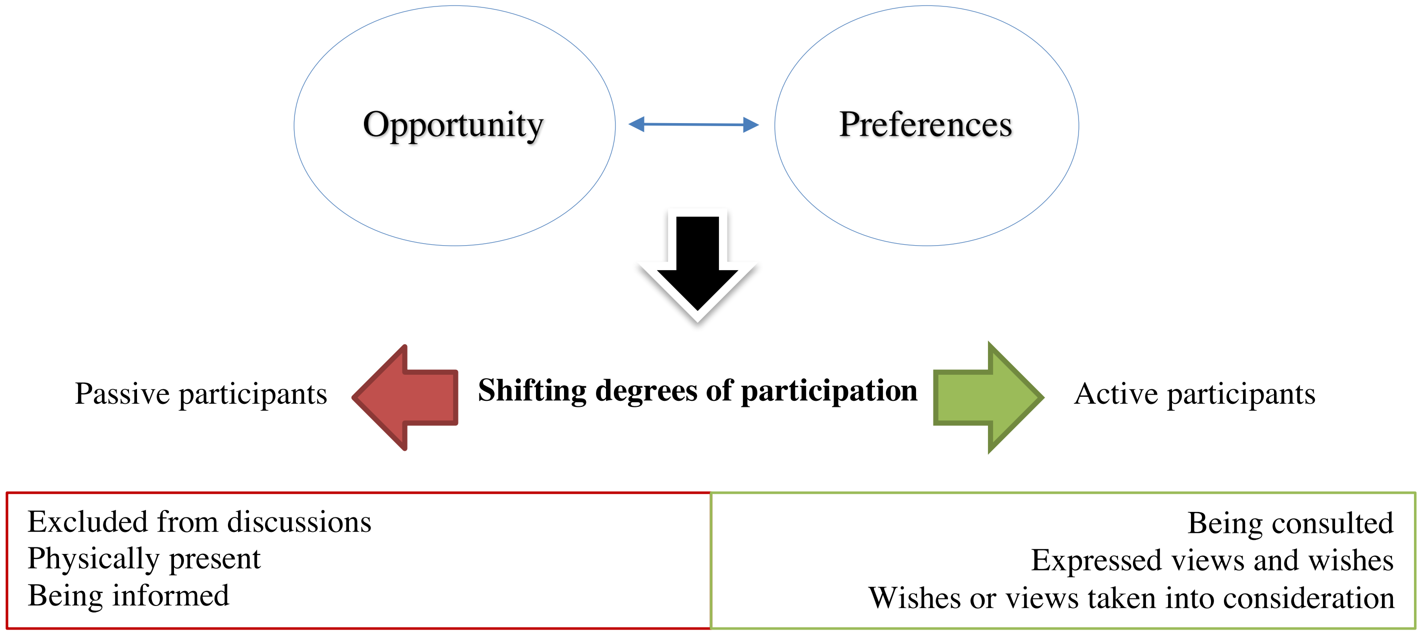


Figure 7: Meaningful participation versus lack of substance of participation



In figure 7, I have developed a diagram to illustrate the dynamic process of children's participation in decisions with regards to their nursing care: Meaningful participation versus lack of substance of participation. Taking the key elements together, it can be concluded that children in this study wanted to participate in decisions regarding their care, but, their participation changed throughout the course of their illness. Participation was highly dependent on the availability of the opportunity and their personal preferences to participate at that particular time. This study highlighted that the children's participation in decisions regarding their care could fluctuate and that the same child could be an active or passive participant and being an active participant or passive participant was highly influenced by the opportunity afforded to them by adults. The findings of this study demonstrated that if the children were given the opportunity by the adults (parents and nurses) to participate in decisions regarding their care, they normally took the opportunity, but not necessarily always. Children generally who were given opportunity by their parents or nurses would participate in decisions regarding their care, and thus, acted as active participants. These children were consulted, able to express their views and opinions in relation to decisions being made, and their expressions were taken into consideration. Likewise, children who were not given the opportunity by adults were situated in the background, excluded from the discussion, and thus, occupied a passive participant role.

Children's personal preferences also influenced the level or degree of children's participation. The way in which children preferred to participate in decisions was highly reliant on the children's personal experiences in the ward setting, for example, how often they had been admitted and were familiar with the ward; whether they were a veteran or novice patient. The veteran children, familiar with the procedures and ward routine often had positive interpersonal relations with nurses and preferred to participate more in discussions regarding their care compared to the novice children who had less familiarity with the ward routine and nurses. Changes in their health and illness status also impacted on their preferences for participation in decisions regarding their nursing care at different times and in different situations. Generally, as the children felt well they were more likely to participate or attempt to participate, but as they became unwell and tired by treatments they would withdraw and participate less. All these factors influenced the preferences of the children to participate in decisions, and resulted in the shifting degrees of participation of children at different times during the hospital admission.

7.9 Chapter summary

In this chapter, I presented the key elements identified from the findings of this study in relation to experiences and understandings of children's participation in decisions regarding their nursing care.

In section 7.2, I have highlighted the importance of interpersonal relations in the child-parent-nurse interaction in the participation of children in decisions relating to their nursing care. Establishing interpersonal relations between nurses and children has played a key role here in enabling or hindering participation, as well as the attitudes of nurses to children. In section 7.2.1 I have highlighted the importance of establishing interpersonal relations, and shown how it enables nurses and children to more easily work with each other in the information sharing. Established interpersonal relations allowed children to feel comfortable enough to ask questions and express their views, and enabled nurses to convey information according to the different children's needs, and improved the children's understanding, and in turn facilitated children's participation in the decisions.

Section 7.3 has discussed how the attitudes of nurses toward children are deeply related to how nurses construct children and participation. I have shown how nurses constructed their views of children through the nurses' perceptions of the children's ability to understand information, and perform their daily activities. The nurses' views of whether or not a child was competent and able to understand the information and consequences of care decisions had a remarkable consequence for the nurses' willingness to engage children in participation about their care.

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In section 7.4, I have drawn attention to the importance of the role of the parent in the participation of children in the decisions regarding their care. I have highlighted how the ways in which the parents perceived their child affected the way they treated their child. I have shown that the way in which parents decide to support or restrict their child from participating in decisions are shaped by the perception of the child as a 'becoming' or 'being'. What it means to be both a becoming and being differs for different parents, and their perception towards children allows them to support their child, or protect their child from information, which constrains the child from participating in the care and decisions concerning them.

Section 7.5, has illustrated how the organizational structure and the policy of the ward, which incorporates some of the elements of FCC, to some extent, constrains the recognition and involvement of children's participation in decisions relating to their nursing care. I have shown that although the policy places an equal emphasis on both patient and family rights; in practice, when the policy is implemented in the ward setting, the focus is more attuned to involving the parents rather than the children. Thus, the child becomes less visible, and their role in discussions and decisions concerning their care is diminished. This section has shown that it is challenging to integrate children's participation in decisions more fully into the practice of the delivery of care model that highly encouraged and supported parent involvement in the child's care. The findings of this study also indicate that, while many paediatric settings in Malaysia adopted the policy that has some alignment with FCC in their setting, in reality, nursing practice does not always meet the ideal.

In section 7.6, I have drawn attention to the pattern of children's preferences for participation, which were quite fluid and shifted often over the course of their illness and treatment. I have shown in this section that the illness situation of children plays a key role in how children prefer to be involved in discussions and decisions relating to their care. These variations resulted in shifting preferences for participation.

In section 7.7, I have discussed how children in this study experience shifting degrees of participation throughout their hospitalization; they occupy different roles in decisions, either as active or passive participants. In this section I have developed a diagram illustrating the association between the shifting degrees of participation and Hermeren's (1996) model of participation to show how the findings of this study parallel with the model and how it can be used to explain the participation of the children in this study. I have also linked my discussion back to the analysis of situations where children play different roles within decisions, and the changing preferences of participation in decisions at a specific time (as elaborated in section 7.5). I have demonstrated that the changes in the children's preferences have an impact on their positions in the communication process, and that positions fluctuated at any given specific time; moving from lesser degrees of participation to greater involvement and vice versa.

In section 7.8, I have clearly distinguished between major decisions (serious) or minor decisions (choices about how care or procedures were delivered). I have demonstrated that children are mostly involved in the minor decisions where they are offered choices, and, the nurses and parents maintain decisional authority for the major decisions, as shown in Figure 6. These findings highlighted that although involvement in minor decisions can be considered as giving children some degree of autonomy and control over a situation, children lack choices or opportunity to decide about their care because the final decisions relating to their nursing care are largely determined by the nurses and parents.

Overall, in Figure 7, I developed a diagram of the dynamic process of children's participation in decisions in relation to their nursing care. This model linked to the key elements analysed throughout this chapter. I have shown that children can experience both a meaningful participation and lack of substance of participation in decisions with regards to their nursing care throughout their hospitalization.

My final point is that everyone involved in the triad of interactions, namely, child, parent, and nurse influence the shifting degrees of participation of children: active participants or passive participants. This study has highlighted the importance of opportunity for children to participate in decisions regarding their care. Thus, it is importance for the parents and nurses to provide opportunities and support children in participating in decisions with regards to their nursing care in an oncological setting.

Chapter 8: Conclusion

8.1 Introduction

This study aimed to explore how children diagnosed with leukaemia participate in decisions regarding their nursing care in an oncological setting in Malaysia. Chapter 7 discussed the findings of this study that contribute to the literature on children's participation through seven key elements. In this final chapter, I provide a summary of these key elements by revisiting them and answering the research questions. This is followed by the implications and recommendations that arise from this research for nursing practice, nursing education, and nursing policy, and finally, recommendations for future research.

8.2 Summarising findings and answering research questions

The study primarily aimed to explore how children participate in decisions with regards to their nursing care in the context of Malaysia. I have investigated this through a focused ethnographic study with 7-12-year-old children diagnosed with leukaemia in an oncology and haematological ward in Malaysia, which addressed the following research questions:

> **Research question 1**: How do children experience participation in decisions with regard to their nursing care?
>
> **Research question 2**: How do children prefer to participate in the decisions and what are their information preferences regarding their nursing care?

Research question 3: What are the factors influencing children's participation in decisions with regards to their nursing care?

These research questions have guided my analysis and discussion throughout this thesis and cannot be condensed to individual chapters. In describing and analysing the context of this research, Chapter 5 has contributed to the first research question, but also to questions 2 and 3 through a continuing concern for the relevant role of parents and nurses in the process of making decisions and the child's preferences for participation. The substantive Chapter 6 has mainly addressed research question 3. However, it has also added to questions 1 and 2 through a concern for the child's role in the communication and decisions and their preferences for such a role. My research strategy throughout was to examine the experiences of children participating in decisions with regards to their nursing care, and focus on children's preferences and factors influencing children's participation.

The important contribution that this thesis makes on the current theoretical knowledge of children's participation in decisions is that it elaborates on the shifting degrees of participation and the diverging and fluctuating participation preferences of children in decisions. This thesis has also extended focus to the influences of the parents and nurses on children's participation. More specifically, the findings of this study contribute to the body of knowledge in understanding the participation of children diagnosed with leukaemia in decisions regarding their nursing care in an oncology setting in Malaysia, and this is expanded upon in respect of the research questions below:

Research question 1: How do children experience participation in decisions with regard to their nursing care?

The findings of this study have shown that children value having the opportunity to participate and want to be involved, but, their opportunities for participation are quite limited. Some nurses and parents enabled the children to become participants in their care and make decisions about their care. When the children were enabled, they usually took up the opportunity but not always, sometimes it depended on their health condition or how well they were.

The findings of this study drew attention to the way children experienced different degrees of participation, including: being physically present, being informed, and being consulted. The ways in which the children were physically present during the decisions highlighted that the parent often takes a dominant role in the decisions regarding the care of their child. Although the analysis of this study revealed that children were being informed about the nursing care provided, they essentially received very limited information, with information sharing largely occurring between nurses and parents. The way in which children are physically present and informed can mean that the children had lesser degrees of participation in decisions regarding their care. In addition, there were few children in this study who were consulted during the nursing care provision. On the one hand, the children were offered choices and asked for their opinion. On the other hand they were able to express their views and make requests, their wishes and opinions were taken into consideration, and the nurses or their parent acted in accordance with them. This would mean that these children had a greater degree of participation. This study highlighted that the degrees to which children participate in decisions fluctuated throughout the course of their hospitalization; moving from lesser degrees of participation (passive participant) to greater involvement (active participant) and contrary wise. Moreover, this study indicated that the majority of the children participated with minor decisions, while the major decisions mostly involved the adults.

> **Research question 2**: How do children prefer to participate in the decisions and what are their information preferences regarding their nursing care?

The findings of this study have shown that there are different ways in which the children in this study prefer to participate in decisions. First, some of the children preferred joint discussions with their parents during the decision. The children in this study were in need of parental support in decisions, and the consequences of being consulted was that children could ultimately contribute to decisions about how they are cared for in hospital. The children's reasons for their need to rely on their parents was that they needed reassurance and support in the decisions. The analysis indicated that the parents' presence helped children to express needs because of the way in which nurses communicate in an adult way which makes it difficult for children to understand. Second, as previously mentioned, some children in this study desired less participation. These children were comfortable with their limited role in the discussions and decisions. Although it may seem as though the children's existence was neglected, their agenda was met because they desired and were satisfied in this position (Lambert et al., 2008). Third, only a small proportion of the children in this study wanted to be included in decisions. These children appeared to be acting as the main decider in the decisions although they were being interrupted by their parents. The children commented that they believed that their involvement in decisions is essential because it is about them, and it is therefore important that they tried to participate in discussions and decisions.

Despite having diverging preferences for participation, the preferences of children in this study also fluctuated over the course of their illness and treatment. The analysis of this study has shown that the way in which children prefer how and when to be included has implications on the extent to which children participate in decisions. For instance, on the one hand, children may prefer and be content with less participation, while at other times, children may want to have a say by expressing their wish or opinion, or make their own decision regarding the care provided to them (e.g. Alexis, see section 6.4). Thus, their participation in decisions were highly influenced by the change of their preferences at any time.

A basic prerequisite for children to be able to participate is that they have knowledge about what is going to happen and understand the rationale behind it. The findings of this study draw attention to the way children receive brief information about what is planned. The way in which the parents filter and shield the perceived distressing information from their child, and how nurses communicate with the children by using the medical terms and acronyms, highlights the need for full and understandable information for the children in this study for them to better understand their illness and treatment plan. Similar to preferences for participation, children's information preferences differ from one child to another, are not fixed, and change at different times and in different situations. The most notable influence on this was the children's experiences (hospitalization or illness). Novice children, for example, are visibly more anxious and need more complete information compared to the veterans (see section 6.3.1). It would be advantageous if the information was adapted to a greater extent to children's needs and wishes, and children were asked for their views on what is planned. Therefore, children's needs should be considered in each situation, in other words, nurses should be sensitive towards children's ways of expressing their information needs and tailor the information accordingly (Coyne & Harder, 2011).

> **Research question 3**: What are the factors influencing children's participation in decisions with regards to their nursing care?

The analysis of this study has identified several factors influencing children's participation in decisions. These factors can be characterized into facilitators of and barriers to children's participation in decisions concerning their nursing care, which are summarized as follow.

Firstly, the interpersonal relations in the child-parent-nurse interactions were markedly important in the participation of children in decisions relating to their nursing care. Particularly, this study has shown that establishing good interpersonal relations between nurses and children is needed for children to be involved in decisions. The interpersonal relations that are established between the veteran children and the nurses enabled children to easily ask questions, or express their views and requests in relation to the care provided to them; enabling their participation in decisions. Conversely, without establishing interpersonal relations between the novice children and nurses, children were unable to participate in decisions, and the nurse maintained overall control.

Secondly, despite the hospitalization and illness experience of the child (veteran or novice) having an influence on children's participation in decisions, the child's situational condition is also the most notable when influencing the participation of children in this study. For instance, the situational condition such as being in pain influenced children to express their wish concerning their care, while when they were not in a distressing situation, such as not in pain, they were more likely to be pleased with their lesser degree of participation in decisions.

Thirdly, the attitude of nurses has been shown to have an impact on children's participation in their care and decisions. The findings of this study have shown that there are variances in the views held by nurses about whether a child is competent to participate in decisions. The nurses' views of whether or not a child is competent has a tremendous significance for the nurses in this study to encourage and support the participation of children in the decisions relating to their care. For instance, if the nurses believe that the child is 'competent', they will encourage the child to participate in their care and in decisions. Equally, if the nurses believe that the child is 'incompetent', they do not involve the children in discussions and decisions regarding their care, but instead involve the parent without consideration of the child's choices and preferences; as a result, the child is excluded from conversations and the decisions.

Fourthly, this study suggests that the marginalization of children's participation is highly relevant to the way in which children are cared for; the way nurses care for the children. The nursing practices of the research setting seemed to have an 'adult focus' rather than being child friendly. The findings suggest that the nursing care in the current setting appear to be regulated by the policy and guidelines implemented in the ward that have some association with FCC. In line with the features of FCC, it puts emphasis on partnership between healthcare professionals and parents in the child's care (Shield & Nixon, 2004). Despite, children having to learn and adapt themselves to the 'adult focused' environment to better understand their condition and treatment plan, their attempts to participate were often thwarted by nurses' actions. As a result, they occupied a passive role, and, thus, their participation in decisions regarding their care was marginalized.

Further, the role of the parent has also contributed to how children are involved in decisions. The analysis of this study has shown that parents employed different roles in the communication process between the nurse and child: as facilitators of communication, communication brokers and communication buffers. These roles of parents can both facilitate and constrain children's participation in their care and decisions. For instance, the role of parent as facilitators of communication between their child and the nurse and, the ways in which parents managed communication difficulties by translating and repeating information from the nurse to the children, improves children's understanding and enables them to be involved in the discussion and decisions. Nonetheless, the way in which parents' filter and shield what children are told has been shown to restrict the children's engagement in their care and decisions regarding their care.

Finally, the findings support the assertion that the perceptions of adults (parents and nurses) towards children affect the way in which children are treated in relation to the participation of the child in the discussion and care decisions affecting the children (Clarke et al., 2005). For instance, the parents and nurses who see a child as a 'young citizen' or 'being' would listen to, and empower children in discussions and decisions. Equally, parents who see their child as 'welfare dependent' or 'becoming' took initiatives to protect their child from the distressing information, as well as constraining the child from participating in decisions concerning them, while nurses who assumed children were 'welfare dependent' or 'becoming', would direct communication to the parent and let the parent decide for their child.

8.3 Implications and recommendations

This study has explored how children diagnosed with leukaemia participate in decisions with regards to their nursing care in the context of an oncological ward in Malaysia. In this section, I discuss the original contributions of this study from four perspectives: its implications for nursing policy, practice, education and future research.

3.6.1 Nursing policy

The findings of this study indicate a need for policy and guidelines to support children's participation in decisions within the Malaysian healthcare system. Although there is a policy for patient and family rights implemented in the ward, which encourages children and families to be involved in their care and decisions, the study illustrates the lack of enforcement of the policy in the reality of nursing practice in this ward setting. For this reason, there should be reinforcement of the implementation of the existing policy to encourage and support children's participation in their care and decisions. A guideline is required to specify the roles of nurses in the facilitation of children's participation that is suited to the individual child. Implementation of the policy and guidelines by the nurses will foster the initiation of approaches and interventions to facilitate the participation of children in their care and decisions.

3.6.2 Nursing practice

The study pointed out that children wanted to be involved and appreciated being able to participate in the communication and decision process but that their opportunities for participation were somewhat limited. Therefore, it is important for nurses and other healthcare professionals to give an opportunity to children to be involved in decisions concerning their care and consider the various ways children can participate as well as allow choices where possible.

The findings of this study indicated that there was a lack of communication skills by nurses working with children in the oncology ward setting. Nurses caring for children will benefit from regular education and coaching to become skilled in facilitating triadic interactions to support children's participation in decisions. Frequently, communication skills are learned by 'trial and error', and information is often imparted by many professionals in an unstructured manner in a busy environment (Coyne et al., 2016). Nonetheless, communication skills training can have a beneficial effect on behaviour change (Moore et al., 2004; Coyne et al., 2016). Therefore, this study calls for a training package or training for nurses, which should include the following components:

i. Training on effective communication skills with children, including workshops on how to encourage children to become involved in decisions regarding their care.
ii. Seminars on understanding children's rights and the right of children to participate.
iii. Continuous nursing education on children's participation related issues.

This study clearly highlights that some action needs to be taken because there is a risk for children to become invisible within the FCC model. The policy emphasis tends to be on parental participation, collaboration, and information sharing between the nurses and parents. Thus, attention was mostly directed toward the parent rather than the child, and the role of children in decisions was marginalised. I suggest that in addition to the adoption of FCC, the setting needs to implement child-centred care and build cultures of participation where participation is firmly embedded, not just a desirable add-on (Sinclair, 2004). Given that children's participation improves the quality of care provided, it is an important investment and one that requires adults to move to a child-centred approach in how they relate to children.

Findings of this current study indicate that children's preferences for a passive or active participant role in decisions are changeable during the course of their treatment for many reasons (e.g. seriousness of condition, type of decisions, status – veteran or novice, their preferences), which means that children's preferences for participation may not always be congruent. Thus, participation of children must be an ongoing process that is both relational and situational (Coyne & Harder, 2011; Coyne et al., 2014); which indicates the need for nurses to adopt an individualized flexible approach so that children can have an active, passive or shared approach as and when they prefer it. Additionally, to be sensitive to differences in participation needs and preferences, nurses need to assess children's preferences on an individual basis using a valid tool. The assessment should not be a one-time event but a process that occurs throughout the course of the child's treatment. This could potentially assist nurses to be sensitive to each child and to address any issues that arise. Nurses could then take time to determine what is important to the children, their values and preferences, and help them sort through the information about their health condition and treatment options to achieve their desired outcome (Gluyas, 2015).

The study pointed out the different roles played by parents as advocates for their children in decisions concerning their care. Because parental support was a key influence on children's participation, they need assistance and guidance on how to involve their child. Parents need to be made aware of their advocacy role and offer guidance on how they can support children's participatory efforts. This is because parents may not be aware of their child's inclusion and active participation, or they may have trouble encouraging children's participation unless they receive permission from the healthcare professionals (Coyne & Gallagher, 2011). Therefore, nurses and other healthcare professionals need to advise and guide parents on how they can support their children's participatory efforts.

This study also identified that most children wished to be fully informed with understandable information concerning their care. Hospital policies and ward guidelines on information sharing need to be developed. Such guidelines should emphasise the importance of giving children sufficient time to communicate and of not prejudging children's capabilities by their age (Coyne & Gallagher, 2011).

3.6.3 Nursing education

The findings of this study have three important implications for education within nursing education. First, the revision of current nursing education seems to be relevant not only for nurses, but also for the majority of the healthcare professionals, especially those in the paediatric ward, considering that their main roles involve children; therefore, they play a central role in facilitating children's participation in decisions. What is evident from these findings is that current healthcare systems are directed by the medical model, which focuses on clinical outcomes and gives less attention to the individual needs and preferences. Therefore, the curriculum for the training of nurses (nursing education) should be revised to ensure that the individuality of the patient, together with their physical and emotional well-being are equally emphasised. The changes within the healthcare system could be initiated by the education system.

Second, inclusion of a course on children's rights in the nursing education syllabus would be beneficial. It is necessary to increase nurses' consciousness of children's rights with more direct training. One of the objectives of this course would be to ensure that the nurses have a sense of awareness of children's rights when dealing with children and are able to encourage and support them. It could also be useful to initiate teaching around how to balance children's rights of participation with the benefits of nursing interventions. It is through such an educational program that the nurses would be updated with knowledge regarding children's rights and the rights for participation and could transfer the informed knowledge to colleagues, children and parents within their clinical practice.

8.4 Recommendations for future research

With regards to the potential limitations related to the methodology, some suggestions for future study have been discussed in Chapter 4 (section 4.14). Considering the additional recommendations for future research in relation to this study, research might be conducted in other geographic areas across Malaysia and involving other types of illnesses to investigate if the findings are reflective of the experiences of children with other illnesses in other contexts.

Given the findings from this study, there is a need for longitudinal research focusing on the decisions process through phases of treatment, relapse, end-of-life, and survivorship, which may produce more substantive findings. Longitudinal research is needed to examine how the participation of children in decisions may vary with time and over the treatment trajectory.

The study pointed out that the child's and the adults' (e.g. parent and nurse) wishes for participation were not shared with regard to decisions in which children should participate. This finding calls for more research to examine and compare children's, parents', and healthcare professionals' perspectives on child participation. Such research is needed because the divergent perspectives between children, parents and healthcare professionals about the meaning and implementation of participation has been found to be the barriers in implementing and improving children's participation in decisions in practices in this current study.

And finally, a research project in developing guidelines for healthcare professionals would also be desirable to encourage the participation of children in decisions regarding their care. The involvement of multifaceted stakeholders (e.g., from community nurses to specialists and from administrators to the policy makers) in the research process is recommended to initiate awareness of the implementation of the new guidelines, hence potentially increasing the adherence to the guidelines.

References

Alderson, P. (1993). *Children's consent to surgery*. Milton Keynes: Open University Press.

Alderson, P. (2000). UN Convention on the Rights of the Child: Some common criticisms and suggested responses. *Child Abuse Review*, *9*(6), 439-443.

Alderson, P. (2007). Competent children? Minors' consent to health care treatment and research. *Social Science & Medicine*, *65*(11), 2272-2283.

Alderson, P., & Goodey, C. (1996). Research with disabled children: How useful is child-centered ethics? *Children & Society*, *10*(2), 106-16.

Alderson, P., & Montgomery, J. (Ed.). (1996). *Health care choices: Making decisions with children* (Vol. 2). Institute for Public Policy Research.

Alderson, P., Sutcliffe, K., & Curtis, K. (2006). Children as partners with adults in their medical care. *Archives of Disease in Childhood*, *91*(4), 300-303.

Allaszewski, A. (2013). Using documents in health research. In J. Allsop & M. Saks (Ed.), *Researching Health: Qualitative, Quantitative and Mixed Methods* (pp. 67), London: Sage.

Ambigapathy, R., Chia, Y. C., & Ng, C. J. (2016). Patient involvement in decisions: A cross-sectional study in a Malaysian primary care clinic. *BMJ Open*, *6*(1), e010063. doi:10.1136/bmjopen-2015-010063

Appleton, J. V., & King, L. (1997). Constructivism: A naturalistic methodology for nursing inquiry. *Advances in Nursing Science*, *20*(2), 13-22.

Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners*, *35*(4), 216-224.

Atkinson, P., Coffey, A., Delamont, S., Lofland, J., & Lofland, L. (Eds.). (2014). *Handbook of ethnography*. London: Sage.

Baggens, C. (2001). What they talk about: Conversations between child health centre nurses and parents. *Journal of Advanced Nursing*, *36*(5), 659-667.

Baird, J., Davies, B., Hinds, P. S., Baggott, C., & Rehm, R. S. (2015). What impact do hospital and unit-based rules have upon patient and family-centered care in the pediatric intensive care unit? *Journal of Pediatric Nursing*, *30*(1), 133-142.

Beale, E. A., Baile, W. F., & Aaron, J. (2005). Silence is not golden: communicating with children dying from cancer. *Journal of Clinical Oncology*, *23*(15), 3629-3631.

Beauchamp, T. L., & Childress, J. F. (2001). *Principles of biomedical ethics*. USA: Oxford University Press.

Beresford, B. A., & Sloper, P. (2003). Chronically ill adolescents' experiences of communicating with doctors: A qualitative study. *Journal of Adolescent Health*, *33*(3), 172-179.

Bjork, M., Nordstrom, B., & Hallstrom, I. (2006). Needs of young children with cancer during their initial hospitalization: An observational study. *Journal of Pediatric Oncology Nursing*, *23*(4), 210-219.

Bricher, G. (2000). Children in the hospital: Issues of power and vulnerability. *Pediatric Nursing*, *26*(3), 277-282.

Brown, K., Mace, S. E., Dietrich, A. M., Knazik, S., & Schamban, N. E. (2008). Patient and family-centred care for pediatric patients in the emergency department. *Canadian Journal of Emergency Medicine*, *10*(01), 38-43.

Bryman, A. (Ed.). (2012). Social research methods. Oxford, England: Oxford University Press.

Butler, A., Copnell, B., & Willetts, G. (2014). Family-centred care in the paediatric intensive care unit: An integrative review of the literature. *Journal of Clinical Nursing*, *23*(15-16), 2086-2100.

Carnevale, F. A., Macdonald, M. E., Bluebond-Langner, M., & McKeever, P. (2008). Using participant observation in pediatric health care settings: Ethical challenges and solutions. *Journal of Child Health Care*, *12*(1), 18-32.

Chao, R., & Tseng, V. (2002). Parenting of Asians. In M.H. Bornstein (series edition), *Handbook of parenting: Social conditions and applied parenting*. (pp. 59-93). Mahwah, New Jersey: Lawrence Erlbaum Associates.

Charmaz, K. (1990). 'Discovering' chronic illness: Using grounded theory. *Social Science & Medicine*, *30*(11), 1161-1172.

Cherney, I. D., & Shing, Y. L. (2008). Children's nurturance and self-determination rights: A cross-cultural perspective. *Journal of Social Issues*, *64*(4), 835-856.

Cherney, I. D., Greteman, A. J., & Travers, B. G. (2008). A cross-cultural view of adults' perceptions of children's rights. *Social Justice Research*, *21*(4), 432-456.

Child Rights Coalition (CRC) Malaysia. (2007). Status report on children's rights in Malaysia. *Kuala Lumpur: Child Rights Coalition Malaysia.* Retrieved March 27, 2016 from http://www.unicef.org/eapro/Report on children rights.pdf

Christensen, P. H. (2004). Children's participation in ethnographic research: Issues of power and representation. *Children & Society*, *18*(2), 165-176.

Christensen, P., & Prout, A. (2002). Working with ethical symmetry in social research with children. *Childhood*, *9*(4), 477-497.

Claflin, C. J., & Barbarin, O. A. (1991). Does "telling" less protect more? Relationships among age, information disclosure, and what children with cancer see and feel. *Journal of Pediatric Psychology*, *16*(2), 169-191

Clarke, S. A., Davies, H., Jenney, M., Glaser, A., & Eiser, C. (2005). Parental communication and children's behaviour following diagnosis of childhood leukaemia. *Psycho-Oncology*, *14*(4), 274-281.

Clarke, Z. (2011). Finding alternatives to restraint: A team of champions in Sheffield, set up to guide service providers on referrals for restraint, has done much to raise awareness of the issues involved. Zara Clarke discusses the progress of the project. *Learning Disability Practice*, *14*(2), 21-23.

Cole, W. M. (2016). Human rights and the Individual: Cross-cultural variation in human rights scores, 1980 to 2010. *Social Forces*, *95*(2), 721-752.

Conway, J., Johnson, B., Edgman-Levitan, S., Schlucter, J., Ford, D., Sodomka, P., & Simmons, L. (2006). Partnering with patients and families to design a patient-and family-centered health care system: A roadmap for the future: A work in progress. *Bethesda, MD: Institute for Family-Centered Care*.

Corlett, J., & Twycross, A. (2006). Negotiation of care by children’s nurses: Lessons from research. *Paediatric Nursing*, *18*(8), 34-37.

Coyne, I. (2006a). Consultation with children in hospital: Children, parents’ and nurses’ perspectives. *Journal of Clinical Nursing*, *15*(1), 61-71.

Coyne, I. (2006b). Children’s experiences of hospitalization. *Journal of Child Health Care, 10*(4), 326-336

Coyne, I. (2008). Children's participation in consultations and decisions at health service level: A review of the literature. *International Journal of Nursing Studies*, *45*(11), 1682-1689.

Coyne, I., Amory, A., Gibson, F., & Kiernan, G. (2016). Information sharing between healthcare professionals, parents and children with cancer: More than a matter of information exchange. *European Journal of Cancer Care*, *25*(1), 141-156.

Coyne, I., Amory, A., Kiernan, G., & Gibson, F. (2014). Children's participation in shared decisions: Children, adolescents, parents and healthcare professionals' perspectives and experiences. *European Journal of Oncology Nursing*, *18*(3), 273-280.

Coyne, I., & Conlon, J. (2007). Children's and young people's views of hospitalization: 'It's a scary place'. *Journal of Children's and Young People's Nursing*, *1*(1), 16-21.

Coyne, I., & Cowley, S. (2007). Challenging the philosophy of partnership with parents: A grounded theory study. *International Journal of Nursing Studies*, *44*(6), 893-904.

Coyne, I., & Gallagher, P. (2011). Participation in communication and decision-making: Children and young people's experiences in a hospital setting. *Journal of Clinical Nursing*, *20*(15-16), 2334-2343.

Coyne, I., & Harder, M. (2011). Children's participation in decisions: Balancing protection with shared decisions using a situational perspective. *Journal of Child Health Care*, *15*(4), 312-319.

Coyne, I., Hayes, E., Gallagher, P., & Regan, G. (2006). Giving children a voice: Investigation of children's experiences of participation in consultation and decisions in Irish hospitals. Retrieved November 28, 2015 from http://www.lenus.ie/hse/handle/10147/45515

Coyne, I., & Kirwan, L. (2012). Ascertaining children's wishes and feelings about hospital life. *Journal of Child Health Care*, *16*(3), 293-304.

Coyne, I., Murphy, M., Costello, T., O'Neill, C., & Donnellan, C. (2013). A survey of nurses' practices and perceptions of family-centered care in Ireland. *Journal of Family Nursing*, *19*(4), 469-488.

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.

Crabtree, B. F., & Miller, W. L. (Eds.). (1999). *Doing qualitative research*. Thousand Oaks, California: Sage.

Curtis, K., Liabo, K., Roberts, H., & Barker, M. (2004). Consulted but not heard: A qualitative study of young people's views of their local health service. *Health Expectations*, *7*(2), 149-156.

Darby, C., & Cardwell, P. (2011). Restraint in the care of children: Colm Darby and Pauline Cardwell review different techniques to restrain and hold young people, and the legal and ethical issues they raise. *Emergency Nurse*, *19*(7), 14-17.

Davis, J., Watson, N. & Cunnigham-Burley, S. 2008. Disabled Children, Ethnography And Unspoken Understandings: The Collaborative Construction Of Diverse Identities. *In:* Christensen, P. & James, A. (Eds.) *Research With Children: Perspectives And Practices*. Oxon: Routledge.

De Civita, M., & Dobkin, P. L. (2004). Pediatric adherence as a multidimensional and dynamic construct, involving a triadic partnership. *Journal of Pediatric Psychology*, *29*(3), 157-169.

Department of Statistics Malaysia. (2010) *Population distribution and basic demographic characteristic report*: Malaysian Government. Retrieved December 19, from https://www.statistics.gov.my/index.php?r=column/ctheme&menu

DeWinter, M., Baerveldt, C., & Kooistra, J. (2002). Enabling children: Participation as a new perspective on child-health promotion. *Child: Care, Health and Development*, *25*(1), 15-23.

Dickens, B. M., & Cook, R. J. (2005). Adolescents and consent to treatment. *International Journal of Gynecology & Obstetrics*, *89*(2), 179-184.

DiMatteo, M. R. (2004). The role of effective communication with children and their families in fostering adherence to pediatric regimens. *Patient Education and Counseling*, *55*(3), 339-344.

Donnelly, J. (2007). The relative universality of human rights. *Human Rights Quarterly*, *29*(2), 281-306.

Donnelly, M., & Kilkelly, U. (2011). Child-friendly healthcare: delivering on the right to be heard. *Medical law review, 19*, 27-54.

Elwyn, G., Edwards, A., & Kinnersley, P. (1999). Shared decisions in primary care: The neglected second half of the consultation. *British Journal of General Practice*, *49*(443), 477-482.

Emerson, R. M., Fretz, R. I. and Shaw, L. L. (Eds.). (2011). *Writing Ethnographic Fieldnotes*. London: The University of Chicago Press.

Eng, T. C., Yaakup, H., Shah, S. A., Jaffar, A., & Omar, K. (2012). Preferences of Malaysian cancer patients in communication of bad news. *Asian Pacific Journal of Cancer Prevention*, *13*(6), 2749-2752.

Erickson, F. (2011). A history of qualitative inquiry in social and educational research. In N. K. Denzin & Y. Lincoln (Eds.), *The Sage handbook of qualitative research* (4th ed.). Thousand Oaks, CA: Sage.

Espezel, H. J., & Canam, C. J. (2003). Parent–nurse interactions: Care of hospitalized children. *Journal of Advanced Nursing*, *44*(1), 34-41.

Fetterman, D. M. (Ed.). (2010). *Ethnography: Step-by-step* (Vol. 17). Thousand Oaks, California: Sage.

Finlay, L. (2002). Negotiating the swamp: the opportunity and challenge of reflexivity in research practice. *Qualitative research*, *2*(2), 209-230.

Finlay, L. (2006). ‘Rigour’,‘ethical integrity’or ‘artistry’? Reflexively reviewing criteria for evaluating qualitative research. *The British Journal of Occupational Therapy*, *69*(7), 319-326.

Finlay, L., & Gough, B. (Eds.). (2003). *Reflexivity: A practical guide for researchers in health and social sciences*. Oxford: Blackwell Publishing.

Fitzgerald, R. M. (2009). Children having a say: A study on children's participation in family law decisions (Doctoral dissertation, Southern Cross University, Lismore, NSW). Retrieved December 12, 2016 from http://epubs.scu.edu.au/cgi/viewcontent.cgi

Forsyth, G. L. (1979). Exploration of empathy in nurse-client interaction. *Advances in Nursing Science, 1*(2), 53-62.

Forsner, M., Jansson, L., & Sørlie, V. (2005). The experience of being ill as narrated by hospitalized children aged 7-10 years with short-term illness. *Journal of Child Health Care*, *9*(2), 153-165.

Franck, T. M. (2001). Are human rights universal. *Foreign Aff.*, *80*, 191.

Franck, L. S., & Callery, P. (2004). Re-thinking family-centred care across the continuum of children's healthcare. *Child: Care, Health and Development*, *30*(3), 265-277.

Franklin, A., & Sloper, P. (2006). Listening and responding? Children’s participation in health care within England. *International journal of Children's Rights*, 13(*1-2*), 11-30.

Franklin, A., & Sloper, P. (2007). *Participation of disabled children and young people in decisions relating to social care*. York: Social Policy Research Unit, University of York.

Gallagher, M. (2009). Data collection and analysis. In Tisdall, K., Davis, J. M., & Gallagher, M. (Eds.), *Researching with children and young people: Research design, methods and analysis*. (pp. 65-127). Washington DC: Sage.

Gastmans, C. (1998). Interpersonal relations in nursing: a philosophical-ethical analysis of the work of Hildegard E. Peplau. *Journal of Advanced Nursing*, *28*(6), 1312-1319.

Gibson, F., Aldiss, S., Horstman, M., Kumpunen, S., & Richardson, A. (2010). Children and young people's experiences of cancer care: A qualitative research study using participatory methods. *International Journal of Nursing Studies*, *47*(11), 1397-1407.

Gill, M. B. (2005). PICU Prometheus: Ethical issues in the treatment of very sick children in paediatric intensive care. *Mortality*, *10*(4), 262-275.

Gluyas, H. (2015). Patient-centred care: Improving healthcare outcomes. *Nursing Standard*, *30*(4), 50-59.

Graham, A., & Fitzgerald, R. (2010). Progressing children’s participation: Exploring the potential of a dialogical turn. *Childhood*, *17*(3), 343-359.

Guba, E.G. and Lincoln, Y.S. (1994). Competing paradigms in qualitative research. In Denzin, N. K. and Lincoln, Y. S, (Eds.), *Handbook of qualitative research*, (pp. 105-117). Thousand Oaks, California: Sage.

Hallström, I., & Elander, G. (2004). Decision-making during hospitalization: Parents’ and children's involvement. *Journal of Clinical Nursing*, *13*(3), 367-375.

Hallström, I., & Elander, G. (2005). Decisions in paediatric care: An overview with reference to nursing care. *Nursing Ethics*, *12*(3), 223-238.

Hammersley, M., & Atkinson, P. (Eds.). (2007). *Ethnography: Principles in practice*. New York: Routledge.

Hart, R. (1992). *Ladder of participation, children's participation: From Tokenism to citizenship*. UNICEF International Child Development Centre, Florence.

Harrington, F. J., & Turner, G. (2001). *Interpreting interpreting: Studies and reflections on sign language interpreting*. Douglas McClean.

Harrison, T. M. (2010). Family-centered pediatric nursing care: State of the science. *Journal of Pediatric Nursing*, *25*(5), 335-343.

Helwig, C. C. (2006). The development of personal autonomy throughout cultures. *Cognitive Development*, *21*(4), 458-473.

Herbert, S. (2000). For ethnography. *Progress in human geography*, *24*(4), 550-568. doi: 10.1191/030913200100189102.

Hermeren. G. (1996). Scale of participation. In Runeson, I., Hallström, I., Elander, G., & Hermerén, G. (2002a). Children's participation in the decisions during hospitalization: An observational study. *Nursing Ethics*, *9*(6), 583-598.

Higman, W., & Shaw, K. (2008). Nurses' understanding about the delivery of family centred care in the neonatal unit. *Journal of Neonatal Nursing*, *14*(6), 193-198.

Hinds, P. S., Oakes, L., Furman, W., Quargnenti, A., Olson, M. S., Foppiano, P., & Srivastava, D. K. (2001). End-of-life decisions by adolescents, parents, and healthcare providers in pediatric oncology: Research to evidence-based practice guidelines. *Cancer Nursing*, *24*(2), 122-134.

Hinds, P. S., Drew, D., Oakes, L. L., Fouladi, M., Spunt, S. L., Church, C., & Furman, W. L. (2005). End-of-life care preferences of pediatric patients with cancer. *Journal of Clinical Oncology*, *23*(36), 9146-9154.

Hofstede, G., & McCrae, R. R. (2004). Personality and culture revisited: Linking traits and dimensions of culture. *Cross-cultural Research*, *38*(1), 52-88.

Holloway, I., & Wheeler, S. (Eds.). (2010). *Qualitative research in nursing and healthcare*. Oxford: John Wiley & Sons.

Hooker, L. (1997). Information needs of teenagers with cancer: Developing a tool to explore the perceptions of patients and professionals. *Journal of Cancer Nursing, 1*(4), 160-168.

Howard, L. M., & Williams, B. A. (2016). A focused ethnography of baccalaureate nursing students who are using motivational interviewing. *Journal of Nursing Scholarship*, *48*(5), 472-481.

Im, E. O. (2008). The Situation-Specific Theory of Pain Experience for Asian American Cancer Patients. *Advances in Nursing Science*, *31*(4), 319-331.

Institute for Family Centered Care. (2005). Family-Centered Care, Questions and Answers. Institute for Family-Centered Care, Bethesda, Maryland. Retrieved March 23, 2016 from http://www.familycenteredcare.org/pdf/fcc_qa.pdf

Jackson, A. C., Stewart, H., O'Toole, M., Tokatlian, N., Enderby, K., Miller, J., & Ashley, D. (2007). Pediatric brain tumor patients: Their parents' perceptions of the hospital experience. *Journal of Pediatric Oncology Nursing, 24*(2), 95-105.

James, A., Jenks, C. & Prout, A., (1998). The sociological child. In James, A., Jenks, C. and Prout, A. (Eds,). *Theorizing childhood*. (pp. 22-34), Cambridge: Polity Press.

Johnson, B. H. (1990). The changing role of families in health care. *Children's Health Care*, *19*(4), 234-241.

Jolley, J., & Shields, L. (2009). The evolution of family-centered care. *Journal of Pediatric Nursing*, *24*(2), 164-170.

Kars, M. C., Duijnstee, M. S., Pool, A., Van Delden, J. J., & Grypdonck, M. H. (2008). Being there: Parenting the child with acute lymphoblastic leukaemia. *Journal of Clinical Nursing*, *17*(12), 1553-1562.

Kars, M. C., Grypdonck, M. H., & Van Delden, J. J. (2011). Being a parent of a child with cancer throughout the end-of-life course. *Oncology Nursing Forum, 38*(4), E260-E271.

Keshavarz, S., & Baharudin, R. (2009). Parenting style in a collectivist culture of Malaysia. *European Journal of Social Sciences*, *10*(1), 66-73.

Kelsey, J., Abelson-Mitchell, N., & Skirton, H. (2007). Perceptions of young people about decisions in the acute healthcare environment. *Nursing Children and Young People*, *19*(6), 14.

Kelly, M., Jones, S., Wilson, V., & Lewis, P. (2012). How children's rights are constructed in family-centred care: A review of the literature. *Journal of Child Health Care*, *16*(2), 190-205.

Kilkelly, U., & Donnelly, M. (2006). *The child's right to be heard in the healthcare setting: Perspectives of children, parents and health professionals*. Office of the Minister for Children.

Kilkelly, U., & Donnelly, M. (2011). Participation in healthcare: the views and experiences of children and young people. *The International Journal of Children's Rights*, *19*(1), 107-125.

Kirby, P., Lanyon, C., Cronin, K., & Sinclair, R. (2003). Building a culture of participation: Involving children and young people in policy, service planning, delivery and evaluation: Handbook. Retrieved January 12, 2015 from http://dera.ioe.ac.uk/17522/1/Handbook%20-%20Building%20a%20Culture%20of%20Participation.pdf

Kirk, S. (2007). Methodological and ethical issues in conducting qualitative research with children and young people: A literature review. *International Journal of Nursing, 44*(7), 1250-1260.

Kling, Z. (1995). The Malay family: Beliefs and realities. *Journal of Comparative Family Studies, 26*(1), 43-66.

Knoblauch, H. (2005). Focused Ethnography [30 paragraphs]. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, *6*(3), Art. 44. Retrieved February 23, 2014 from http://nbn-resolving.de/urn:nbn:de:0114-fqs0503440

Kralik, D., Visentin, K., & Van Loon, A. (2006). Transition: A literature review. *Journal Of Advanced Nursing*, *55*(3), 320-329.

Kreicbergs, U., Valdimarsdóttir, U., Onelöv, E., Henter, J. I., & Steineck, G. (2004). Talking about death with children who have severe malignant disease. *New England Journal of Medicine*, *351*(12), 1175-1186.

Krishnan, U. D. (2004). *Parent-adolescent conflict and adolescent functioning in a collectivist, ethnically heterogenous culture: Malaysia* (Doctoral dissertation, The Ohio State University).

Lambert, V., Glacken, M., & McCarron, M. (2008). 'Visible-ness': The nature of communication for children admitted to a specialist children's hospital in the Republic of Ireland. *Journal of Clinical Nursing*, *17*(23), 3092-3102.

Lambert, V., Glacken, M., & McCarron, M. (2011). Communication between children and health professionals in a child hospital setting: A Child Transitional Communication Model. *Journal of Advanced Nursing*, *67*(3), 569-582.

Lambert, V. (2012). 1 Theoretical foundations of communication. *Communication Skills for Children's Nurses*, 1. Retrieved January 20, 2016 from http://www.mheducation.co.uk/openup/chapters/9780335242863.pdf

Lansdown, G. (Ed.). (1995). *Taking Part: Children's participation in decisions* (Vol. 1). London: Institute for Public Policy Research.

Lansdown, G. (2001). *Promoting children's participation in democratic decisions* (No. innins01/9). Retrieved June 12, 2015 from https://www.unicef-irc.org/publications/pdf/insight6.pdf

Lansdown, G. (2010). The realisation of children's participation rights. In Percy-Smith, B. & Thomas, N. (Eds.), *A handbook of children and young people's participation: Perspectives from theory and practice* (pp. 11-23). London: Routledge.

Lansdown, G. (2014). 25 Years of UNCRC: Lessons learned in children's Participation. *Canadian Journal of Children's Rights, 1*(1), 172-190.

Lapine, A., Wang-Cheng, R., Goldstein, M., Nooney, A., Lamb, G., & Derse, A. R. (2001). When cultures clash: Physician, patient, and family wishes in truth disclosure for dying patients. *Journal of Palliative Medicine*, *4*(4), 475-480.

Larsson, I. E., Sahlsten, M. J., Segesten, K., & Plos, K. A. (2011). Patients' perceptions of barriers for participation in nursing care. *Scandinavian Journal of Caring Sciences*, *25*(3), 575-582.

Le Poire, B. A. (Ed.). (2006). *Family communication: Nurturing and control in a changing world*. Thousand Oaks: Sage.

Lee, P. (2007). What does partnership in care mean for children's nurses? *Journal of Clinical Nursing*, *16*(3), 518-526.

Lee, Y. K., Low, W. Y., Lee, P. Y., & Ng, C. J. (2015). Factors influencing decision-making role preferences: A qualitative study of Malaysian patients with type 2 diabetes during insulin initiation. *International journal of nursing practice*, *21*(S2), 125-131.

Liben, S., Papadatou, D., & Wolfe, J. (2008). Paediatric palliative care: Challenges and emerging ideas. *The Lancet*, *371*(9615), 852-864.

Lim, G. C. C. (2002). Overview of cancer in Malaysia. *Japanese Journal of Clinical Oncology*, *32*(1), S37-S42.

Lin, T. E., & Lian, T. C. (2011). Relationship between perceived parenting styles and coping capability among Malaysian secondary school students. In *Proceedings of International Conference on Social Sciences in Singapore*. Retrieved May 05, 2016 from http://www.ipedr.com/vol5/no1/5-H00032.pdf

Lincoln, Y. S. & Guba, E. G. (2000). Paradigmatic controversies contradictions, and emerging confluences. In: N. K. Denzin& Y. S. Lincoln (Eds). Handbook of

Qualitative Research,2nd edn. (pp. 136–188). Thousand Oaks, CA: Sage Publicati-ions, Inc.

Lindeke, L., Nakai, M., & Johnson, L. (2006). Capturing children's voices for quality improvement. *MCN: The American Journal of Maternal/Child Nursing*, *31*(5), 290-295.

Littlechild, B. (2000). Children's rights to be heard in child protection processes law, policy and practice in England and Wales. *Child Abuse Review*, *9*(6), 403-415.

Lowes, L. (1996). Paediatric nursing and children's autonomy. *Journal of Clinical Nursing*, *5*(6), 367-372.

Lundy, L. (2007). 'Voice'is not enough: Conceptualising Article 12 of the United Nations Convention on the Rights of the Child. *British Educational Research Journal*, *33*(6), 927-942.

MacKay, L. J., & Gregory, D. (2011). Exploring family-centered care among pediatric oncology nurses. *Journal of Pediatric Oncology Nursing*, *28*(1), 43-52.

Mah, H. C., Muthupalaniappen, L., & Chong, W. W. (2016). Perceived involvement and preferences in shared decisions among patients with hypertension. *Family Practice, 33*(3), 296-301.

Malaysia Nursing Board (2015) Nursing Board Malaysia Code of Professional Conduct for Nurses. Retrieved June 13, 2016 from http://nursing.moh.gov.my/about-us/midwives-board /

Mason, J. (2002). *Qualitative Researching.* London: Sage.

Martens, F., De Loof, S., & Idrissi, S. H. (2008). Parental participation in care in the pediatric intensive care unit. *Pediatric Intensive Care Nursing*, *9*(1), 11-15.

Mason, J., & Bolzan, N. (2009). Questioning understandings of children's participation. In Percy-Smith, B. & Thomas, N. (Eds.), *A Handbook of children and young people's participation*, (pp. 125-132). London: Routledge.

Matsuoka, M., & Narama, M. (2012). Parents' thoughts and perceptions on hearing that their child has incurable cancer. *Journal of Palliative Medicine*, *15*(3), 340-346.

Mayall, B. (2000) Conversations with children: working with generational issues. In Christensen, P. & James, A (Eds) *Research with children: perspectives and practices*. (pp. 120-135). New York: Falmer Press.

Mayall, B. (Ed.). (2002). *Towards a sociology for childhood: Thinking from children's lives*. Open University Press.

Mayall, B. (2012). An afterword: Some reflections on a seminar series. *Children's Geographies*, *10*(3), 347-355.

Mays, N., & Pope, C. (1995). Qualitative research: Observational methods in health care settings. *British Medical Journal*, *311*(6998), 182-184.

McCabe, M. A. (1996). Involving children and adolescents in medical decisions: Developmental and clinical considerations. *Journal of Pediatric Psychology*, *21*(4), 505-516.

McCrum, S., & Bernal, P. (1994). *Interviewing children: A training pack for journalists*. Buckfastleigh: Children’s Voices.

McNeish, D. (1999). Promoting participation for children and young people: Some key questions for health and social welfare organisations. *Journal of Social Work Practice*, *13*(2), 191-203.

Merriam, S. B. (Ed.). (2009). *Qualitative Research: A Guide to Design and Implementation*. USA: John Wiley & Sons.

Meleis, A. I. (Ed.). (2010). *Transitions theory: Middle range and situation specific theories in nursing research and practice*. New York: Springer Publishing Company.

Meleis, A. I., Sawyer, L. M., Im, E. O., Messias, D. K. H., & Schumacher, K. (2000). Experiencing transitions: an emerging middle-range theory. *Advances in Nursing Science*, *23*(1), 12-28.

Migone, M., Mc Nicholas, F., & Lennon, R. (2008). Are we following the European charter? Children, parents and staff perceptions. *Child: Care, Health and Development*, *34*(4), 409-417.

Mikkelsen, G., & Frederiksen, K. (2011). Family-centred care of children in hospital: A concept analysis. *Journal of Advanced Nursing*, *67*(5), 1152-1162.

Miles, M. B., & Huberman, A. M. (Eds.). (1994). *Qualitative data analysis: A sourcebook.* Beverly Hills: Sage.

Miller, S. (2001). Facilitating decisions in young people. *Paediatric Nursing*, *13*(5), 31.

Ministry of Health Malaysia. (2012). *Paediatric Services Operational Policy*. Medical Development Department: Ministry of Health Malaysia. Retrieved February 16, 2015 from http://www.moh.gov.my/index.php/PediatricServicesOperationalPolicy.pdf

Ministry of Health Malaysia (2013) *Midwives Board Malaysia: The code of professional conduct and practice of a midwife*, Retrieved February 10, 2016 from http://www.moh.gov.my/index.php/pages/view/1202

Mohd, A., & Kadir, N. A. (2012). Protection of children in Malaysia through foster care legislation and policy. *International Journal of Social Sciences and Humanity Studies*, *4*(1), 63-72.

Moore, L., & Kirk, S. (2010). A literature review of children's and young people's participation in decisions relating to health care. *Journal of Clinical Nursing*, *19*(15-16), 2215-2225.

Moore, P. M., Wilkinson, S. S., & Rivera Mercado, S. (2004). Communication skills training for health care professionals working with cancer patients, their families and/or carers. *Cochrane Database System Review*, *2*, 1-21.

Morrow, V. (Ed.). (2009). *The ethic of social research with children and families in young lives: Practical experiences*. Oxford: Young Lives.

Morrow, V., & Richards, M. (1996). The ethics of social research with children: An overview. *Children & society*, *10*(2), 90-105.

Moyle, W. (2003). Nurse–patient relationship: A dichotomy of expectations. *International Journal of Mental Health Nursing*, *12*(2), 103-109.

Murphy-Berman, V., Levesque, H. L., & Berman, J. J. (1996). UN Convention on the Rights of the Child: A cross-cultural view. *American Psychologist*, *51*(12), 1257.

Name of the hospital. (2010). *Patient and Family Rights Policy*.

Nalasami, P. R., Bakar, S. H. A., Yusoff, J. Z., Wahab, H. A., Omar, N., & Islam, M. R. (2015). Implementation of child rights in the children's homes in Malaysia. *Asian Social Work and Policy Review*, *9*(3), 232-244.

Neale, B. (2002). Dialogues with children: Children, divorce and citizenship. *Childhood*, *9*(4), 455-475.

Neale, B., & Flowerdew, J. (2007). New structures, new agency: The dynamics of child-parent relationships after divorce. *International Journal of Children’s Rights*, *15*(1), 25.

Newton, M. S. (2000). Family-centered care: Current realities in parent participation. *Pediatric Nursing*, *26*(2), 164.

Ngadimon, I. W., Islahudin, F., Hatah, E., Shah, N. M., & Makmor-Bakry, M. (2015). Antibiotic and shared decisions preferences among adolescents in Malaysia. *Patient Preference and Adherence*, *9*, 665-673.

Ng, C. J., Lee, P. Y., Lee, Y. K., Chew, B. H., Engkasan, J. P., Irmi, Z. I., ... & Tong, S. F. (2013). An overview of patient involvement in healthcare decisions: A situational analysis of the Malaysian context. *BMC Health Services Research*, *13*(1), 1-7.

Noh, C. H. C., Yusooff, F., & Hasim, M. S. (2013). Communication Patterns of Malay Families in Terengganu, Malaysia. *Procedia-Social and Behavioral Sciences*, *102*, 635-642.

Odigwe, C. (2004). Children say they are not involved enough in their treatment. *British Medical Journal*, *328*(7440), 600.

O'haire, S. E., & Blackford, J. C. (2005). Nurses' moral agency in negotiating parental participation in care. *International Journal of Nursing Practice*, *11*(6), 250-256.

Orb, A., Eisenhauer, L., & Wynaden, D. (2001). Ethics in qualitative research. *Journal of Nursing Scholarship*, *33*(1), 93-96.

Ow, R. (2003). Burden of care and childhood cancer: Experiences of parents in an Asian context. *Health & Social Work*, *28*(3), 232-240.

Ozcan, C. T., Oflaz, F., & Sutcu Cicek, H. (2010). Empathy: The effects of undergraduate nursing education in Turkey. *International Nursing Review*, *57*(4), 493-499.

Pang, M. C. (1999). Protective truthfulness: The Chinese way of safeguarding patients in informed treatment decisions. *Journal of Medical Ethics*, *25*(3), 247-253.

Parahoo, K. (Ed.). (2006). *Nursing Research: Principles, Process and Issues.* Wales: Palgrave Macmillan.

Peart, N., & Holdaway, D. (2000). Ethical guidelines: Health research with children. *New Zealand Bioethics, 1*(1), 3-9.

Pelander, T., & Leino-Kilpi, H. (2010). Children's best and worst experiences during hospitalisation. *Scandinavian Journal of Caring Sciences*, *24*(4), 726-733.

Peplau, H. E. (1987). Interpersonal constructs for nursing practice. *Nurse Education Today*, *7*(5), 201-208.

Peplau, H. E. (1992). Interpersonal relations: A theoretical framework for application in nursing practice. *Nursing science quarterly*, *5*(1), 13-18.

Peplau, H. E. (1997). Peplau's theory of interpersonal relations. *Nursing Science Quarterly*, *10*(4), 162-167.

Petersen, M. F., Cohen, J., & Parsons, V. (2004). Family-centered care: Do we practice what we preach? *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, *33*(4), 421-427.

Phipps, E., True, G., Harris, D., Chong, U., Tester, W., Chavin, S. I., & Braitman, L. E. (2003). Approaching the end of life: attitudes, preferences, and behaviors of African-American and white patients and their family caregivers. *Journal of Clinical Oncology*, *21*(3), 549-554.

Polit, D. F., & Beck C. T. (Eds.). (2006). *Essentials of nursing research: Methods, appraisal, and utilization* (Vol. 1). Lippincott Williams & Wilkins.

Prout, A., & James, A. (Eds.). (1997). *Constructing and reconstructing childhood: Contemporary issues in the sociological study of childhood*. New York: Falmer Press.

Punch, S. (2002). Research with Children – the same or different from research with adult? *Childhood*, *9*(3), 321-341.

Punch, S. (2004). Scrambling through the Ethnographic Forest: Commentary on the research process. In V. Lewis, M. Kellett, C. Robinson, S. Fraser, & S. Ding (Eds.). *The Reality of Research with Children and Young People.* (pp. 135). London: Sage.

Punch, S. 2009. Case Study: Researching Childhoods in Rural Bolivia. *In:* Tisdall, E. K. M., Davis, J. & Gallagher, M. (Eds.) *Researching with Children & Young People. Research Design, Methods and Analysis*. London: Sage.

Raitt, F. (2007). Hearing children in family law proceedings: Can judges make a difference? *Child and Family Law Quarterly*, *19*, 204.

Rao, N., McHale, J. P., & Pearson, E. (2003). Links between socialization goals and child-rearing practices in Chinese and Indian mothers. *Infant and Child Development*, *12*(5), 475-492.

Raval, H. (2003). Therapists' experiences of working with language interpreters. *International Journal of Mental Health*, *32*(2), 6-31.

Rindstedt, C., & Aronsson, K. (2012). Children's intent participation in a pediatric community of practice. *Mind, Culture, and Activity, 19*(4), 325-341.

Ritchie, J., Lewis, J., & Elam, G. (2003). Designing and Selecting Samples. In Ritchie, J., & Lewis, J. (Eds.), *Qualitative Research Practice: A guide for Social Science Students and Researchers.* (pp.111-146). Los Angeles: Sage Publications.

Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (Eds.). (2013). *Qualitative research practice: A guide for social science students and researchers*. London: Sage.

Rogoff, B., Paradise, R., Arauz, R. M., Correa-Chávez, M., & Angelillo, C. (2003). First hand learning through intent participation. *Annual Review of Psychology, 54*(1), 175-203.

Roper, J. M., & Shapira, J. (Ed.). (2000). *Ethnography in nursing research: Methods in nursing research.* Thousand Oaks: Sage.

Ross, L. F. (1997). Health care decisions by children is it in their best interest? *Hastings Center Report*, *27*(6), 41-46.

Royal College of Nursing. (2010) Maximising nursing skill in caring for children. Retrieved June 13, 2017 from file://chss.datastore.ed.ac.uk/chss/hiss/users/Desktop/Royal%20of%20paediatrics-2010.pdf

Ruhe, K. M., Badarau, D. O., Brazzola, P., Hengartner, H., Elger, B. S., & Wangmo, T. (2015). Participation in pediatric oncology: Views of child and adolescent patients. *Psycho-Oncology, 25*(9), 1036-1042.

Runeson, I., Elander, G., Hermeren, G., & Kristensson-Hallstrom, I. (2000). Children's consent to treatment: Using a scale to assess degree of self-determination. *Pediatric Nursing*, *26*(5), 455-458.

Runeson, I., Enskär, K., Elander, G., & Hermerén, G. (2001). Professionals' perceptions of children's participation in decisions in healthcare. *Journal of Clinical Nursing*, *10*(1), 70-78.

Runeson, I., Hallström, I., Elander, G., & Hermerén, G. (2002a). Children's participation in the decisions during hospitalization: An observational study. *Nursing Ethics*, *9*(6), 583-598.

Runeson, I., Hallström, I., Elander, G., & Hermerén, G. (2002b). Children's needs during hospitalization: An observational study of hospitalized boys. *International Journal of Nursing Practice*, *8*(3), 158-166.

Runeson, I., Mårtenson, E., & Enskär, K. (2007). Children's knowledge and degree of participation in decisions when undergoing a clinical diagnostic procedure. *Pediatric Nursing*, *33*(6), 505.

Sala, M.J. (2002). *The conflict between collectivism and individualism in adolescent development: Asian Indian female decisions in regard to cultural normative behaviour*. (Doctoral dissertation, Loyola University, Chicago). Retrieved April 12, 2016 from ProQuest Thesis.

Savage, E., & Callery, P. (2007). Clinic consultations with children and parents on the dietary management of cystic fibrosis. *Social Science & Medicine*, *64*(2), 363-374.

Sayed Abdul Rahman, S.M. (2000). "Child Protection -The Malaysian Perspective". Proceeding of the Fifth National Conference on Child Abuse and Neglect: Child protection - current status, future direction. Kuala Lumpur: Malaysian Association for the Protection of Children (MAPC). (pp. 5-IO).

Schalkers, I., Parsons, C. S., Bunders, J. F., & Dedding, C. (2016). Health professionals' perspectives on children's and young people's participation in health care: A qualitative multihospital study. *Journal of Clinical Nursing*, *25*(7-8), 1035-1044.

Scott, J. T., Harmsen, M., Prictor, M. J., Sowden, A. J., & Watt, I. (2003). Interventions for improving communication with children and adolescents about their cancer. *The Cochrane Library*.

Shapiro, J. (2008). Walking a mile in their patients' shoes: empathy and othering in medical students' education. *Philosophy, Ethics, and Humanities in Medicine, 3*(1), 1.

Shelton, T. L., Jeppson, E. S. & Johnson, B. H. (1987). *Family-centered care for children with special health care needs*. Association for the Care of Children's Health, 3615 Wisconsin Ave., NW, Washington, DC 20016.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, *22*(2), 63-75.

Shier, H. (2001). Pathways to participation: openings, opportunities and obligations. *Children & Society*, *15*(2), 107-117.

Shields, L. (2001). A review of the literature from developed and developing countries relating to the effects of hospitalization on children and parents. *International Nursing Review*, *48*(1), 29-37.

Shields, L. (2010). Questioning family-centred care. *Journal of Clinical Nursing*, *19*(17-18), 2629-2638.

Shields, L., & Nixon, J. (2004). Hospital care of children in four countries. *Journal of Advanced Nursing*, *45*(5), 475-486.

Shields, L., Pratt, J., & Hunter, J. (2006). Family centred care: A review of qualitative studies. *Journal of clinical nursing*, *15*(10), 1317-1323.

Shields, L., Kristensson-Hallström, I., Kristjansdottir, G., & Hunter, J. (2003). Who owns the child in hospital? A preliminary discussion. *Journal of Advanced Nursing*, *41*(3), 213-222.

Sixsmith, J., Boneham, M., & Goldring, J. E. (2003). Accessing the community: Gaining insider perspectives from the outside. *Qualitative Health Research*, *13*(4), 578-589.

Sinclair, R. (2004). Participation in practice: Making it meaningful, effective and sustainable. *Children & Society*, *18*(2), 106-118.

Sjöberg, C., Amhliden, H., Nygren, J. M., Arvidsson, S., & Svedberg, P. (2015). The perspective of children on factors influencing their participation in perioperative care. *Journal of Clinical Nursing*, *24*(19-20), 2945-2953.

Smith, A. B. (2002). Interpreting and supporting participation rights: Contributions from sociocultural theory. *The International Journal of Children's Rights*, *10*(1), 73-88.

Smith, A. B. (2007). Children and young people's participation rights in education. *The International Journal of Children's Rights*, *15*(1), 147-164.

Snethen, J. A., Broome, M. E., Knafl, K., Deatrick, J. A., & Angst, D. B. (2006). Family patterns of decision-making in pediatric clinical trials. *Research in Nursing & Health*, *29*(3), 223-232.

Soderback, M., Coyne, I., & Harder, M. (2011). The importance of including both a child perspective and the child's perspective within health care settings to provide truly child-centred care. *Journal of Child Health Care, 15*(2), 99-106.

Spyrou, S. (2011). The limits of children's voices: From authenticity to critical, reflexive representation. *Childhood*, *18*(2), 151-165.

Stake, R. (2000). 'Case study'. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 436). Newbury Park, CA: Sage.

Surbone, A. (2008). Cultural aspects of communication in cancer care. *Supportive Care in Cancer*, *16*(3), 235-240.

Tates, K., Elbers, E., Meeuwesen, L., & Bensing, J. (2002). Doctor–parent–child relationships: A ‘pas de trois’. *Patient Education and Counselling*, *48*(1), 5-14.

Taylor, N., Tapp, P., & Henaghan, M. (2007). Respecting children's participation in family law proceedings. *International Journal of Children’s Rights*, *15*(1), 61.

Temple, B., & Young, A. (2004). Qualitative research and translation dilemmas. *Qualitative Research*, *4*(2), 161-178.

Terry, L., & Campbell, A. (2001). Are we listening to children's views about their treatment? *British Journal of Nursing*, *10*(6), 384-390.

Thomas, N. (2007). Towards a theory of children's participation. *International Journal of Childrens Rights*, *15*(2), 199.

Thomas, N. (2012). Love, rights and solidarity: Studying children’s participation using Honneth’s theory of recognition. *Childhood*, *19*(4), 453-466

Tiedeman, M. E., & Lookinland, S. (2004). Traditional models of care delivery: What have we learned? *Journal of Nursing Administration, 34*(6), 291-297.

Tieffenberg, J. A., Wood, E. I., Alonso, A., Tossutti, M. S., & Vicente, M. F. (2000). A randomized field trial of ACINDES: A child-centered training model for children with chronic illnesses (asthma and epilepsy). *Journal of Urban Health*, *77*(2), 280-297.

Tisdall, E.K.M. (2011) ‘Taking forward children and young people’s participation’, In Hill, M., Head, G., Lockyer, A., Reid, B. and Taylor, R. (Eds.), *Integrated working in children’s services*, Harlow: Pearson.

Tisdall, E. K. M., & Davis, J. (2004). Making a difference? Bringing children's and young people's views into policy-making. *Children & Society*, *18*(2), 131-142.

Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, *48*(4), 388-396.

Trollvik, A., Ringsberg, K. C., & Silén, C. (2013). Children's experiences of a participation approach to asthma education. *Journal of Clinical Nursing*, *22*(7-8), 996-1004.

Tse, C. Y., Chong, A., & Fok, S. Y. (2003). Breaking bad news: A Chinese perspective. *Palliative Medicine*, *17*(4), 339-343.

Tuckett, A. G. (2004). Truth-telling in clinical practice and the arguments for and against: a review of the literature. *Nursing Ethics*, *11*(5), 500-513.

Tudge, J., & Hogan, D. (2005). An ecological approach to observations of children’s everyday lives. In Greene, S. & Hogan, D. (Eds.), *Researching Children’s Experience, Approaches and Methods*. (pp. 102-122). London: Sage.

United Nation, (1989). *Convention on the Rights of the Child*. New York, United Nations. Retrieved September 20, 2014 from http://digitalcommons.ilr.cornell.edu/child

UNCRC. (2007). Concluding Observations of the Committee on the Rights of the Child: Malaysia, CRC/C/MYS/CO/1. Retrieved January 12, 2017 from http://www.refworld.org/docid/468912822.html

UNICEF, Malaysia (2017). *CRC in Malaysia*. Retrieved June 26, 2016 from https://www.unicef.org/malaysia/children_crc-in-malaysia.html

Uprichard, E. (2008). Children as ‘being and becomings’: Children, childhood and temporality. *Children & Society*, *22*(4), 303-313.

Vaknin, O., & Zisk-Rony, R. Y. (2010). Including children in medical decisions and treatments: Perceptions and practices of healthcare providers. *Child: Care, Health and Development*, *37*(4), 533-539.

Varma, S., Jenkins, T., & Wendler, D. (2008). How do children and parents make decisions about pediatric clinical research? *Journal of Pediatric Hematology/Oncology*, *30*(11), 823-828.

Vis, S. A., Strandbu, A., Holtan, A., & Thomas, N. (2011). Participation and health: A research review of child participation in planning and decision-making. *Child & Family Social Work*, *16*(3), 325-335.

Voon, S. J., & Pearson, E. (2011). Understanding early childhood socialisation in immigrant families: Malaysian-Chinese parents' perceptions on the importance of ethnic identity and cultural maintenance. *International Research in Early Childhood Education, 2*(1), 30-44.

Wassmer, E., Minnaar, G., Aal, N. A., Atkinson, M., Gupta, E., Yuen, S., & Rylance, G. (2004). How do paediatricians communicate with children and parents? *Acta Paediatrica, 93*(11), 1501-1506.

Watanabe, A., Nunes, T., & de Abreu, G. (2014). Japanese parents’ perception of disclosing the diagnosis of cancer to their children. *Clinical Child Psychology and Psychiatry*, *19*(1), 125-138.

Whitney, S. N., Ethier, A. M., Fruge, E., Berg, S., McCullough, L. B., & Hockenberry, M. (2006). Decisions in pediatric oncology: Who should take the lead? The decisional priority in pediatric oncology model. *Journal of Clinical Oncology*, *24*(1), 160-165.

Whitty-Rogers, J., Alex, M., MacDonald, C., Gallant, D. P., & Austin, W. (2009). Working with children in end-of-life decisions. *Nursing Ethics*, *16*(6), 743-758.

Wilson, M. E., Megel, M. E., Enenbach, L., & Carlson, K. L. (2010). The voices of children: stories about hospitalization. *Journal of Pediatric Health Care, 24*(2), 95-102.

Winskel, H., Salehuddin, K., & Stanbury, J. (2013). Developmental milestone expectations, parenting styles and self-construal in Malaysian and Australian caregivers. *Kajian Malaysia*, *31*(1), 19-35.

Woodgate, R. L., & Degner, L. F. (2002). Expectations and beliefs about children's cancer symptoms: Perspectives of children with cancer and their families. *Oncology Nursing Forum, 30*(3), 479-491.

Wolcott, H. F. (1992). Posturing in qualitative inquiry. *The handbook of qualitative research in education*, 3-52.

Young, B., Dixon-Woods, M., Windridge, K. C., & Heney, D. (2003). Managing communication with young people who have a potentially life threatening chronic illness: Qualitative study of patients and parents. *BMJ*, *326*(7384), 305-309.

Young, B., Moffett, J. K., Jackson, D., & McNulty, A. (2006). Decision-making in community-based paediatric physiotherapy: A qualitative study of children, parents and practitioners. *Health & Social Care in The Community*, *14*(2), 116-124.

Zainudin, T. N. A. T., & Rahim, A. A. (2013). Child patient and consent to medical treatment in Malaysia: A legal perspective. *Journal of Global Peace and Conflict*, *1*(1), 41-48.

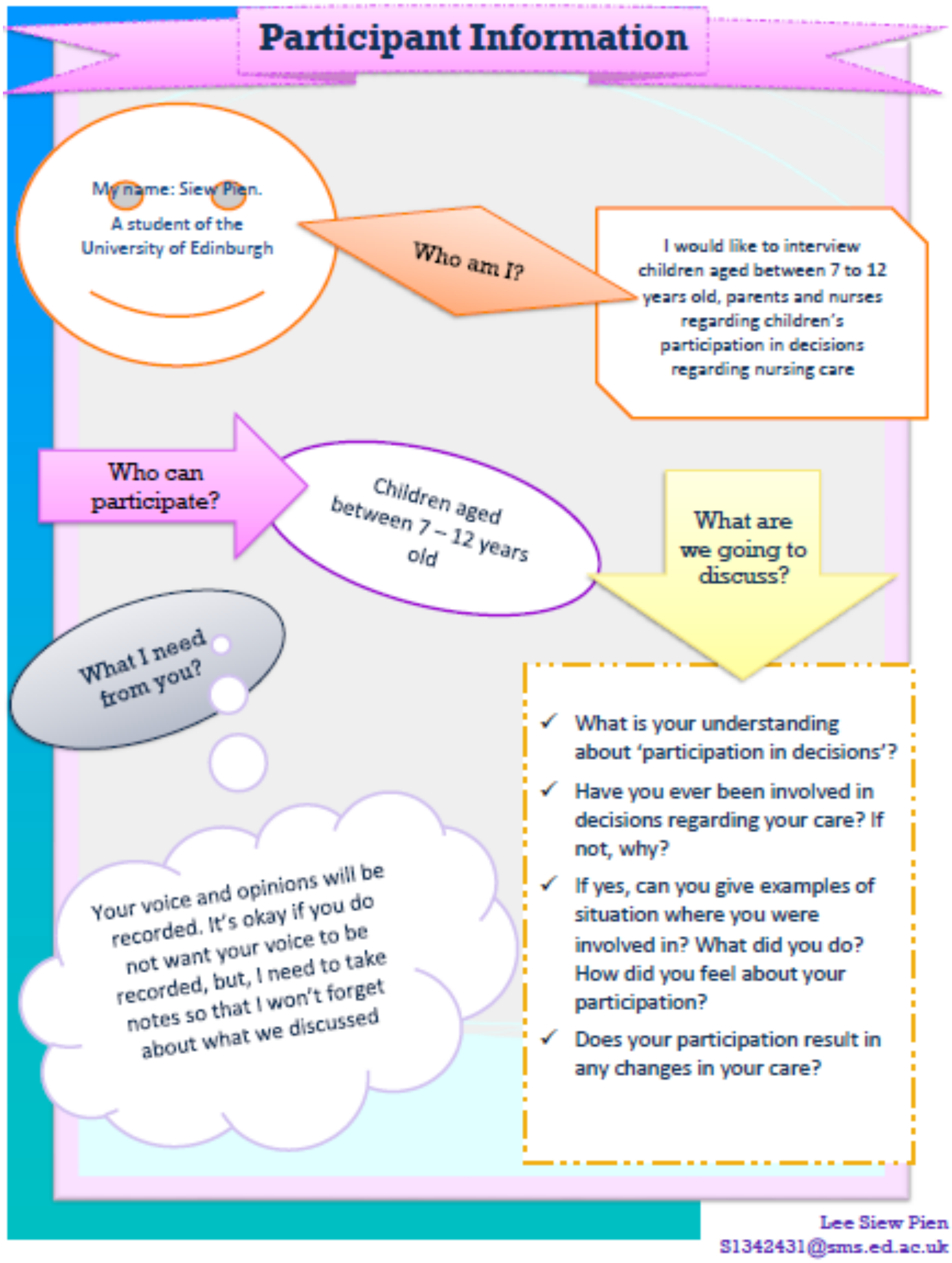
Zwaanswijk, M., Tates, K., van Dulmen, S., Hoogerbrugge, P. M., Kamps, W. A., & Bensing, J. M. (2007). Young patients', parents', and survivors' communication preferences in paediatric oncology: Results of online focus groups. *BMC Pediatrics*, *7*(1), 35.

Zwaanswijk, M., Tates, K., van Dulmen, S., Hoogerbrugge, P. M., Kamps, W. A., Beishuizen, A., & Bensing, J. M. (2011). Communicating with child patients in pediatric oncology consultations: A vignette study on child patients', parents', and survivors' communication preferences. *Psycho-Oncology*, *20*(3), 269-277.

Appendices

Appendix 1 – Participant information sheet for children

i) English version



Participant Information

My name: Siew Pien.
A student of the University of Edinburgh

Who am I?

I would like to interview children aged between 7 to 12 years old, parents and nurses regarding children's participation in decisions regarding nursing care

Who can participate?

Children aged between 7 – 12 years old

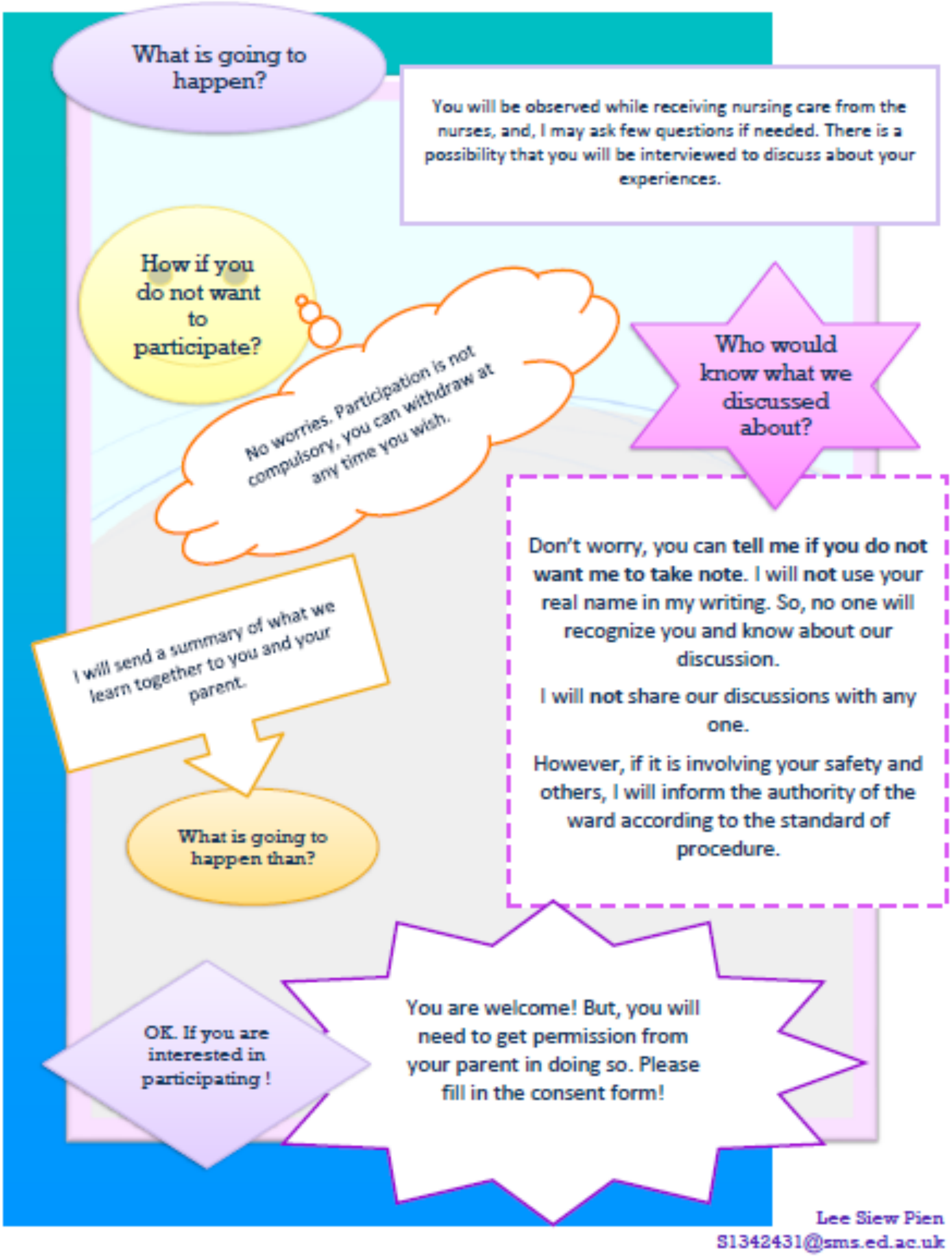
What are we going to discuss?

- ✓ What is your understanding about 'participation in decisions'?
- ✓ Have you ever been involved in decisions regarding your care? If not, why?
- ✓ If yes, can you give examples of situation where you were involved in? What did you do? How did you feel about your participation?
- ✓ Does your participation result in any changes in your care?

What I need from you?

Your voice and opinions will be recorded. It's okay if you do not want your voice to be recorded, but, I need to take notes so that I won't forget about what we discussed

Lee Siew Pien
S1342431@sms.ed.ac.uk



What is going to happen?

You will be observed while receiving nursing care from the nurses, and, I may ask few questions if needed. There is a possibility that you will be interviewed to discuss about your experiences.

How if you do not want to participate?

No worries. Participation is not compulsory, you can withdraw at any time you wish.

Who would know what we discussed about?

Don't worry, you can **tell me if you do not want me to take note**. I will **not** use your real name in my writing. So, no one will recognize you and know about our discussion.

I will **not** share our discussions with any one.

However, if it is involving your safety and others, I will inform the authority of the ward according to the standard of procedure.

I will send a summary of what we learn together to you and your parent.

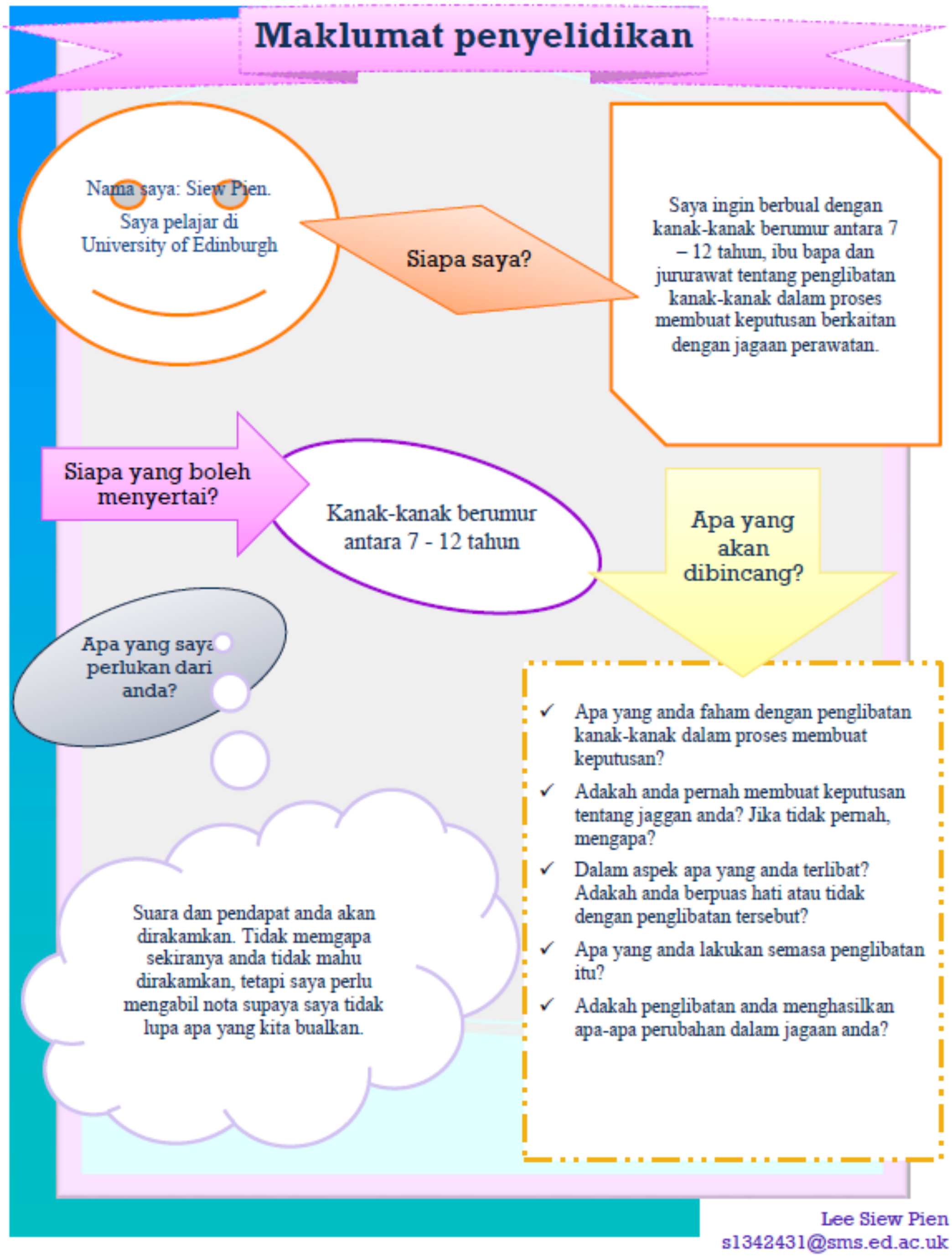
What is going to happen than?

OK. If you are interested in participating !

You are welcome! But, you will need to get permission from your parent in doing so. Please fill in the consent form!

Lee Siew Pien
S1342431@sms.ed.ac.uk

ii) Malay version



Maklumat penyelidikan

Nama saya: Siew Pien.
Saya pelajar di
University of Edinburgh

Siapa saya?

Saya ingin berbual dengan kanak-kanak berumur antara 7 – 12 tahun, ibu bapa dan jururawat tentang penglibatan kanak-kanak dalam proses membuat keputusan berkaitan dengan jagaan perawatan.

Siapa yang boleh menyertai?

Kanak-kanak berumur antara 7 - 12 tahun

Apa yang akan dibincang?

Apa yang saya perlukan dari anda?

- ✓ Apa yang anda faham dengan penglibatan kanak-kanak dalam proses membuat keputusan?
- ✓ Adakah anda pernah membuat keputusan tentang jaggan anda? Jika tidak pernah, mengapa?
- ✓ Dalam aspek apa yang anda terlibat? Adakah anda berpuas hati atau tidak dengan penglibatan tersebut?
- ✓ Apa yang anda lakukan semasa penglibatan itu?
- ✓ Adakah penglibatan anda menghasilkan apa-apa perubahan dalam jagaan anda?

Suara dan pendapat anda akan dirakamkan. Tidak memgapa sekiranya anda tidak mahu dirakamkan, tetapi saya perlu mengabil nota supaya saya tidak lupa apa yang kita bualkan.

Lee Siew Pien
s1342431@sms.ed.ac.uk

Apa yang akan berlaku?

Anda akan diperhatikan semasa anda menerima rawatan daripada jururawat dan jika perlu, saya akan bertanyakan beberapa soalan semasa pemerhatian. Kemungkinan anda akan ditemuramah di dalam ward untuk membincangkan pengalaman anda semasa berada di hosiptal.

Bagaimana jika saya tidak menyertai?

Tidak mengapa. Peyertaan adalah tidak wajib, anda boleh tarik diri pada bila-bila masa sahaja.

Siapa akan tahu apa yang kita akan bincangkan?

Jangan bimbang, **anda boleh beritahu saya sekirnya anda tidak mahu saya membuat catatan**. Saya **tidak** akan menggunakan nama sebenar anda. Jadi tiada orang akan tahu apa yang kita bincangkan.

Saya **tidak** akan kongsi pembincangan kita dengan orang lain.

Bagaimanpun, sekiranya keadaan memerlukan seperti melibatkan keselamatan anda dan orang lain, saya akan membeitahu pihak yang berwajib dan mengikut tatacar yang disediakan.

Saya akan menghantar ringkasan laporan tentang apa yg kita pelajari bersama kepada anda dan penjaga.

Apa yang akan berlaku seterusnya?

OK. Saya nak sertai!

Anda dialu-alukan! Tetapi anda mesti mendapat kebenaran daripada ibu atau bapa atau penjaga anda. Sila isikan borang kebenaran yang deberikan !

Lee Siew Pien
s1342431@sms.ed.ac.uk

Appendix 2 – Participant information sheet for parents

i) English version

Participant Information for Parent

THE UNIVERSITY OF EDINBURGHSCHOOL
of HEALTH in SOCIAL SCIENCE
DOOR WAY 6, MEDICAL QUAD
TEVIOT PLACE, EDINBURGH
EH8 9AG

Telephone: +6 019 368 0605
Email: L.Siew-Pien@sms.ed.ac.uk

Research Topic
Understanding Children's Participation in Decisions about Their Care in a Malaysia Context.

Name of Researcher
Lee Siew Pien

Introduction

I am inviting you to take part in a research project. However, before you make a decision to participate I would like you to understand what it involves and why I am undertaking it. Please read the information leaflet thoroughly. Part one of the leaflet details the purpose of the project and what happens if you take part.

My name is Lee Siew Pien, a nurse. I am conducting a research to gather information that will help us to improve paediatric nursing care provision in Malaysia. In addition, I will use the information to write my dissertation as a requirement to get my degree at the University of Edinburgh. My supervisors are: Dr Elaine Haycock-Stuart and Prof Kay Tisdall. The title of the study is:

Understanding Children's Participation in Decisions about Their Care in a Malaysia Context.

Children who have been diagnosed with leukaemia need to cope with many changes after the initial diagnosis. They need to undergo several cycles of treatment, often require long periods of hospitalization on a frequent basis, which may impair the child's health's outcome. Participation of children with leukaemia in the decisions is extremely important as the participation affect the outcome of the children's health. Nevertheless, little is known about how children experience in the decisions. The purpose of the research is to explore participation of children with leukaemia in the decisions about their care in a Malaysia context. It is considered that a better understanding of how children participate in the decisions will help to improve care of children during their hospitalization.

The study is a qualitative case study to be conducted in a tertiary and secondary hospital setting. The study will involve parent of a child currently diagnosed with leukaemia and receiving care in the oncology haematology unit. You have been identified as one of the potential participants because your child is currently admitted and receiving care in the unit.

The study

If you decide to participate in the study, you will be observed as your child received care from the nurses in the unit. During the observation period, I will occasionally be speaking into a digital recorder a low voice. At you convenient time following the observations, I will ask you to reflect on the care your child received from the nurse. I will interview you to discuss your experience during the participation of your child in the decisions about his/her care. With permission, a recording will be taken of the observations and the conversation, but is only because I need an accurate record of the issues I observe and what we discuss.

Confidentiality

Please be assured of your privacy and confidentiality, all data obtained from you will be securely maintained in locked cupboard, and no name will be attached to the folders containing your data. Your information will be identified numerically and not by name. The results of the study may be published in midwifery journals, but participants or hospitals will not be identified in the publication. In addition, once I have analysed the transcripts, I will destroy the recording. Anything you tell me will be treated confidentially.

Possible Risks and Benefits of the Study

There are no perceived risks to you, the children under your care and their parent. However, the interviews involve in-depth probing of your thoughts and behaviours. In case you are not happy with the interview process, you may choose to withdraw from participating. In addition, an independent nurse will be available to provide counselling and guidance and this process may help you reflect on your practice.

There are no direct benefits to you from participating in the study. The findings from the research may help to improve participation of children in the decisions.

Participation in the study

Participation in the study and consent to have your interview digitally recorded is entirely voluntary you may decide not to participate or not without stating the reasons. If you believe my presence affects your care provision, feel free to stop the process of data collection.
If you want to contact me or my supervisors for further information regarding any aspects of this study on the following numbers and addresses:

Name	Telephone	Physical and Email Address
Dr Elaine Haycock-Stuart	+447 (0131 6)50 8442	University of Edinburgh. School of Health in Social Sciences, The Medical School, Teviot Place, Edinburgh. EH8 9AG e.a.haycock-stuart@ed.ac.uk
Prof. Kay Tisdal	+44 (0) 131 65 1 1560	University of Edinburgh. The Graduate School of Social and Political Science Chrystal Macmillan Building 15a George Square Edinburgh EH8 9LD K.Tisdal@ed.ac.uk
Lee Siew Pien	+6019 368 0605	International Islamic University Malaysia (IIUM), Kuantan, Pahang L.Siew-Pien@sms.ed.ac.uk

Finally, thank you for your interest and for taking time to read through this invitation. If you are willing to participate I would like to ask you to read through and sign the 2 consent forms, one for you and one for my records. Please keep this information for future use.

ii) Malay version

MAKLUMAT PENYERTAAN

(IBU BAPA / PENJAGA)

THE UNIVERSITY OF EDINBURGH
SCHOOL of HEALTH in SOCIAL SCIENCE
DOOR WAY 6, MEDICAL QUAD
TEVIOT PLACE, EDINBURGH
EH8 9AG
Telephone: +6 018 290 3706
Email: L.Siew-Pien@sms.ed.ac.uk

Tajuk Kaji Selidik

Memahami Penyertaan Kanak-Kanak Dalam Membuat Keputusan
Tentang Penjagaan Mereka Dalam Konteks Malaysia

Nama Penyelidik

Lee Siew Pien

Pengenalan

Saya mempelawa anda untuk mengambil bahagian di dalam satu projek kaji selidik. Sebelum membuat keputusan untuk menyertainya, anda perlu memahami apa yang terlibat dan kenapa saya mengambil tugas ini. Sila baca maklumat penyertaan in dengan teliti. Bahagian pertama menerangkan tujuan projek ini dan apa yang akan berlaku sekiranya anda mengambil bahagian.

Nama saya Lee Siew Pien, seorang jururawat dan pelajar kedoktoran (PhD) Kejururawatan, University of Edinburgh, United Kingdom. Saya menjalankan satu kaji selidik untuk mengumpul maklumat yang akan membantu kita memperbaiki penjagaan perawatan kanak-kanak di Malaysia. Tambahan pula saya akan menggunakan maklumat ini untuk menulis tesis sebagai sebahagian dari keperluan untuk mendapatkan ijazah di Universiti Edinburgh. Penyelia saya ialah Dr. Elaine Haycock-Stuart dan Prof. Dr. Kay Tisdall. Tajuk kaji selidik ini ialah Memahami Penyertaan Kanak-Kanak Dalam Membuat Keputusan Tentang Penjagaan Mereka Dalam Konteks Malaysia.

Kanak-kanak yang disahkan menghidapi penyakit leukemia perlu berdepan dengan banyak perubahan dalam hidup mereka. Mereka perlu menjalani beberapa pusingan rawatan, yang memerlukan jangka masa hospitalisasi yang panjang dan kerap. Ini mungkin akan menjejaskan taraf kesihatan dan kehidupan mereka. Kajian telah membuktikan bahawa penglibatan kanak-kanak dalam perbincangan dan membuat keputusan akan meningkatkan kefahaman mengenai kesihatan mereka, menigkatkan kerjasama, meningkatkan kepuasan hati dan sekali gus akan meningkatkan taraf kehidupan mereka.

Walau bagaimanapun, pengetahuan mengenai pnglibatan kanak-kanak dalam membuat keputusan di Malaysia adalah terhad. Oleh sebab itu, kaji selidik ini akan dijalankan bertujuan menerokai penyertaan kanak-kanak leukemia dalam proses membuat keputusan tentang penjagaan mereka dalam konteks Malaysia. Kefahaman ini akan membantu memperbaiki dan meningkatkan kualiti penjagaan mereka semasa menjalani rawatan di hospital.

Kaji selidik ini yang akan dijalankan di Institut Pediatirk Hospital Kuala Lumpur and akan melibatkan ibu bapa atau penjaga yang menjaga anak mereka yang mengidapi penyakit leukaemia di KK3. Anda secara langsung terlibat dalam penjagaan anak yang menghidap leukemia. Oleh sebab itu, anda adalah diperlawa untuk menyertai kaji selidik ini.

Kaji Selidik

Kalau anda membuat keputusan untuk mengambil bahagian dalam kaji selidik ini, anda dianggap sebagai amat prihatin kepada kanak-kanak leukemia di unit ini. Kaji selidik ini akan melibatkan pemerhatian dan temubual. Dalam jangkamasa pemerhatian, saya akan sekali sekala akan bercakap ke dalam rakaman digital dengan suara perlahan. Pada masa yang sesuai saya akan meminta anda memberi maklum balas tentang penjagaan yang diterima oleh anak anda.Saya juga akan menemubual anda untuk berbincang tentang penglibatan anak anda dalam proses membuat keputusan tentang penjagaan mereka. Dengan persetujuan anda, sesi temubual akan dirakamkan, ini semata-mata kerana saya perlukan rekod yang tepat semasa pemerhatian dan apa yang kita bincang.

Kesulitan Maklumat

Segala maklumat akan dirahsiakan; segala maklumat atau data yang diperolehi daripada anda akan diletak di dalam almari yang berkunci dan tiada nama dikepilkan pada fail-fail berkenaan. Maklumat anda akan dikenalpasti melalui nombor bukannya nama anda. Keputusan kaji selidik mungkin akan diterbitkan di dalam journal tetapi nama peserta atau hospital tidak dinyatakan. Tambahan pula, setelah saya membuat analisis, saya akan musnahkan segala rekod. Segala maklumat yang anda berikan kepada saya adalah sulit.

Kemungkinan Risiko dan Manfaat daripada Kaji Selidik Ini

Kaji selidik ini boleh dianggap tidak berisiko kepada anda, anak di bawah jagaan anda serta jururawat yang menberi penjagaan rawatan. Seandainya anda tidak senang/gembira dengan proses temubual, anda boleh memilih untuk menarik diri dari mengambil bahagian pada bila-bila masa.

Tiada manfaat secara langsung kepada anda dengan menyertai kaji selidik ini. Penemuan atau hasil daripada kaji selidik ini akan membantu memperbaiki penglibatan kanak-kanak dalam pembincangan mengenai jagaan perawatan dan proses membuat keputusan semasa menerima rawatan di hospital. Secara tidak langsung, ini akan meningkat taraf kualti penjagaan perawatan and hidup kanak-kanak leukaemia terutamanya semasa menerima jagaan perawatan di hospital.

Penyertaan Dalam Kaji Selidik

Penyertaan di dalam kaji selidik ini dan persetujuan untuk ditemubual dan akan dirakam secara digital adalah secara sukarela. Anda boleh memilih untuk tidak mengambil bahagian tanpa memberi apa-apa alasan. Sekiranya anda percaya bahawa kehadiran saya akan memberi kesan kepada bahagian penjagaan anda, anda boleh memberhentikan proses temubual dan pemerhatian yang saya jalakan. Sekiranya anda ingin menghubungi saya atau penyelia saya untuk mendapat keterangan lanjut mengenai apa-apa aspek dalam kaji selidik ini sila berbuat demikian di alamat email dan nombor telefon berikut:-

Nama	No. Telefon	Email
Dr Elaine Haycock-Stuart	+447 (0131 6)50 8442	University of Edinburgh. School of Health in Social Sciences, e.a.haycock-stuart@ed.ac.uk
Prof. Kay Tisdal	+44 (0) 131 65 1 1560	University of Edinburgh. The Graduate School of Social and Political Science K.Tisdal@ed.ac.uk
Lee Siew Pien	+6 018 2903 706	International Islamic University Malaysia (IIUM), Kuantan, Pahang. L.Siew-Pien@sms.ed.ac.uk

Akhir kata, saya mengucapkan berbanyak terima kasih di atas kesudian anda dan mengambil masa membaca surat jemputan ini. Jikalau anda bersedia untuk mengambil bahagian, saya memohon agar anda membaca dengan teliti dan tandatangan 2 borang persetujuan, satu salinan untuk anda dan satu salinan untuk simpanan saya. Sila simpan maklumat ini untuk kegunaan masa hadapan.

Appendix 3 – Participant information sheet for nurses

i) English version

Participant Information for Nurses

THE UNIVERSITY OF EDINBURGHSCHOOL
of HEALTH in SOCIAL SCIENCE
DOOR WAY 6, MEDICAL QUAD
TEVIOT PLACE, EDINBURGH
EH8 9AG

Telephone: +6 019 368 0605
Email: L.Siew-Pien@sms.ed.ac.uk

Research Topic
Understanding Children's Participation in Decisions about Their Care in a Malaysia Context.

Name of Researcher
Lee Siew Pien

Introduction

I am inviting you to take part in a research project. However, before you make a decision to participate I would like you to understand what it involves and why I am undertaking it. Please read the information leaflet thoroughly. Part one of the leaflet details the purpose of the project and what happens if you take part.

My name is Lee Siew Pien, a nurse. I am conducting a research to gather information that will help us to improve paediatric nursing care provision in Malaysia. In addition, I will use the information to write my dissertation as a requirement to get my degree at the University of Edinburgh. My supervisors are: Dr Elaine Haycock-Stuart and Prof Kay Tisdall. The title of the study is:

Understanding Children's Participation in Decisions about Their Care in a Malaysia Context.

Children who have been diagnosed with leukaemia need to cope with many changes after the initial diagnosis. They need to undergo several cycles of treatment, often require long periods of hospitalization on a frequent basis, which may impair the child's health's outcome. Participation of children with leukaemia in the decisions is extremely important as the participation affect the outcome of the children's health. Nevertheless, little is known about how children experience in the decisions. The purpose of the research is to explore participation of children with leukaemia in the decisions about their care in a Malaysia context. It is considered that a better understanding of how children participate in the decisions will help to improve care of children during their hospitalization.

The study is a qualitative case study to be conducted in a tertiary and secondary hospital setting. The study will involve nurses currently practice in the oncology haematology unit, children who diagnosed with leukemia and their parent. You have been identified as one of the potential participants because you are currently working in the oncology and haematology unit and you are involved in the care of children with leukaemia.

The study

If you decide to participate in the study, you will be observed as you care for children with leukaemia in the unit. During the observation period, I will occasionally be speaking into a digital recorder a low voice. At you convenient time following the observations, I will ask you to reflect on the care you provided to the children. I will interview you to discuss the involvement of children with leukaemia in decisions about their care. With permission, a recording will be taken of the observations and the conversation, but is only because I need an accurate record of the issues I observe and what we discuss.

Confidentiality

Please be assured of your privacy and confidentiality, all data obtained from you will be securely maintained in locked cupboard, and no name will be attached to the folders containing your data. Your information will be identified numerically and not by name. The results of the study may be published in midwifery journals, but participants or hospitals will not be identified in the publication. In addition, once I have analysed the transcripts, I will destroy the recording. Anything you tell me will be treated confidentially.

Possible Risks and Benefits of the Study

There are no perceived risks to you, the children under your care and their parent. However, the interviews involve in-depth probing of your thoughts and behaviours. In case you are not happy with the interview process, you may choose to withdraw from participating. In addition, an independent nurse will be available to provide counselling and guidance and this process may help you reflect on your practice.

There are no direct benefits to you from participating in the study. The findings from the research may help to improve participation of children in the decisions.

Participation in the study

Participation in the study and consent to have your interview digitally recorded is entirely voluntary you may decide not to participate or not without stating the reasons. If you believe my presence affects your care provision, feel free to stop the process of data collection.

If you want to contact me or my supervisors for further information regarding any aspects of this study on the following numbers and addresses:

Name	**Telephone**	**Physical and Email Address**
Dr Elaine Haycock-Stuart	+447 (0131 6)50 8442	University of Edinburgh. School of Health in Social Sciences, The Medical School, Teviot Place, Edinburgh. EH8 9AG e.a.haycock-stuart@ed.ac.uk
Prof. Kay Tisdall	+44 (0) 131 65 1 1560	University of Edinburgh. The Graduate School of Social and Political Science Chrystal Macmillan Building 15a George Square Edinburgh EH8 9LD K.Tisdal@ed.ac.uk
Lee Siew Pien	+6 019 368 0605	International Islamic University Malaysia (IIUM), Kuantan, Pahang L.Siew-Pien@sms.ed.ac.uk

Finally, thank you for your interest and for taking time to read through this invitation. If you are willing to participate I would like to ask you to read through and sign the 2 consent forms, one for you and one for my records. Please keep this information for future use.

ii) Malay version

MAKLUMAT PENYERTAAN
(JURURAWAT)

THE UNIVERSITY OF EDINBURGH
SCHOOL of HEALTH in SOCIAL SCIENCE
DOOR WAY 6, MEDICAL QUAD
TEVIOT PLACE, EDINBURGH
EH8 9AG
Telephone: +6 018 290 3706
Email: L.Siew-Pien@sms.ed.ac.uk

Tajuk Kaji Selidik

Memahami Penyertaan Kanak-Kanak Dalam Membuat Keputusan
Tentang Penjagaan Mereka Dalam Konteks Malaysia

Nama Penyelidik

Lee Siew Pien

Pengenalan

Saya mempelawa anda untuk mengambil bahagian di dalam satu projek kaji selidik. Walau bagaimanapun sebelum membuat keputusan untuk menyertainya, anda perlu memahami apa yang terlibat dan kenapa saya mengambil tugas ini. Sila baca maklumat penyertaan in dengan teliti. Bahagian pertama menerangkan tujuan projek ini dan apa yang akan berlaku sekiranya anda mengambil bahagian.

Nama saya Lee Siew Pien, seorang jururawat dan pelajar kedoktoran (PhD) Kejururawatan, University of Edinburgh, United Kingdom. Saya menjalankan satu kaji selidik untuk mengumpul maklumat yang akan membantu kita memperbaiki penjagaan perawatan kanak-kanak di Malaysia. Tambahan pula saya akan menggunakan maklumat ini untuk menulis tesis sebagai sebahagian dari keperluan untuk mendapatkan ijazah di Universiti Edinburgh. Penyelia saya ialah Dr. Elaine Haycock-Stuart dan Prof. Dr. Kay Tisdall. Tajuk kaji selidik ini ialah Memahami Penyertaan Kanak-Kanak Dalam Membuat Keputusan Tentang Penjagaan Mereka Dalam Konteks Malaysia.

Kanak-kanak yang disahkan menghidapi penyakit leukemia perlu berdepan dengan banyak perubahan dalam hidup mereka. Mereka perlu menjalani beberapa pusingan rawatan, yang memerlukan jangka masa hospitalisasi yang panjang dan kerap. Ini mungkin akan menjejaskan taraf kesihatan dan kehidupan mereka. Kajian telah membuktikan bahawa penglibatan kanak-kanak dalam perbincangan dan membuat keputusan akan meningkatkan kefahaman mengenai kesihatan mereka, menigkatkan kerjasama, meningkatkan kepuasan hati dan sekali gus akan meningkatkan taraf kehidupan mereka.

Walau bagaimanapun, pengetahuan mengenai pnglibatan kanak-kanak dalam membuat keputusan di Malaysia adalah terhad. Oleh sebab itu, kaji selidik ini akan dijalankan bertujuan menerokai penyertaan kanak-kanak leukemia dalam proses membuat keputusan tentang penjagaan mereka dalam konteks Malaysia. Kefahaman ini akan membantu memperbaiki dan meningkatkan kualiti penjagaan mereka semasa menjalani rawatan di hospital.

Kaji selidik ini yang akan dijalankan di Institut Pediatirk Hospital Kuala Lumpur and akan melibatkan jururawat yang memberi jagaan perawatan kepada kanak-kanak yang mengidapi penyakit leukaemia di KK3. Anda secara langsung terlibat dalam penjagaan kanak-kanak yang menghidap leukemia. Oleh sebab itu, anda adalah diperlawa untuk menyertai kaji selidik ini.

Kaji Selidik

Kalau anda membuat keputusan untuk mengambil bahagian dalam kaji selidik ini, anda dianggap sebagai amat prihatin kepada kanak-kanak leukemia di unit ini. Kaji selidik ini akan melibatkan pemerhatian dan temubual. Dalam jangkamasa pemerhatian, saya akan sekali sekala akan bercakap ke dalam rakaman digital dengan suara perlahan. Pada masa yang sesuai saya akan meminta anda memberi maklum balas tentang penjagaan yang diterima oleh anak anda. Saya juga akan menemubual anda untuk berbincang tentang penglibatan anak anda dalam proses membuat keputusan tentang penjagaan mereka. Dengan persetujuan anda, sesi temubual akan dirakamkan, ini semata-mata kerana saya perlukan rekod yang tepat semasa pemerhatian dan apa yang kita bincang.

Kesulitan Maklumat

Segala maklumat akan dirahsiakan; segala maklumat atau data yang diperolehi daripada anda akan diletak di dalam almari yang berkunci dan tiada nama dikepilkan pada fail-fail berkenaan. Maklumat anda akan dikenalpasti melalui nombor bukannya nama anda. Keputusan kaji selidik mungkin akan diterbitkan di dalam journal tetapi nama peserta atau hospital tidak dinyatakan. Tambahan pula, setelah saya membuat analisis, saya akan musnahkan segala rekod. Segala maklumat yang anda berikan kepada saya adalah sulit.

Kemungkinan Risiko dan Manfaat daripada Kaji Selidik Ini

Kaji selidik ini boleh dianggap tidak berisiko kepada anda, kanak-kanak di bawah jagaan anda serta ibubapa mereka. Seandainya anda tidak senang/gembira dengan proses temubual, anda boleh memilih untuk menarik diri dari mengambil bahagian.

Tiada manfaat secara langsung kepada anda dengan menyertai kaji selidik ini. Penemuan atau hasil daripada kaji selidik ini akan membantu memperbaiki penglibatan kanak-kanak dalam pembincangan mengenai jagaan perawatan dan proses membuat keputusan semasa menerima rawatan di hospital. Secara tidak langsung, ini akan meningkat taraf kualti penjagaan perawatan and hidup kanak-kanak leukaemia terutamanya semasa menerima jagaan perawatan di hospital.

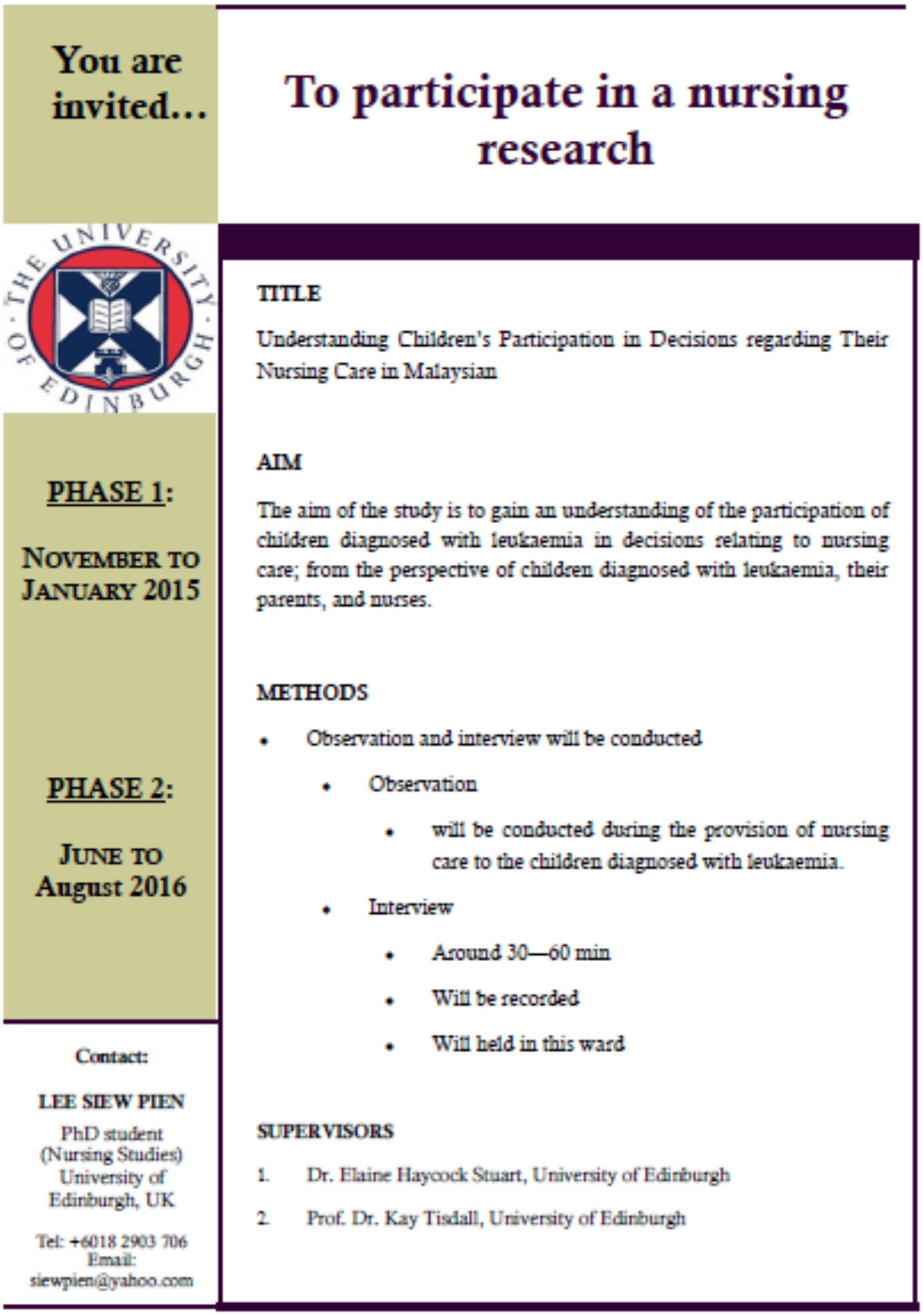
Penyertaan Dalam Kaji Selidik

Penyertaan di dalam kaji selidik ini dan persetujuan untuk ditemubual dan akan dirakam secara digital adalah secara sukarela. Anda boleh memilih untuk tidak mengambil bahagian tanpa memberi apa-apa alasan. Sekiranya anda percaya bahawa kehadiran saya akan memberi kesan kepada bahagian penjagaan anda, anda boleh memberhentikan proses temubual dan pemerhatian yang saya jalakan. Sekiranya anda ingin menghubungi saya atau penyelia saya untuk mendapat keterangan lanjut mengenai apa-apa aspek dalam kaji selidik ini sila berbuat demikian di alamat email dan nombor telefon berikut:-

Nama	No. Telefon	Email
Dr Elaine Haycock-Stuart	+447 (0131 6)50 8442	University of Edinburgh. School of Health in Social Sciences, e.a.haycock-stuart@ed.ac.uk
Prof. Kay Tisdal	+44 (0) 131 65 1 1560	University of Edinburgh. The Graduate School of Social and Political Science K.Tisdal@ed.ac.uk
Lee Siew Pien	+6 019 368 0605	International Islamic University Malaysia (IIUM), Kuantan, Pahang. L.Siew-Pien@sms.ed.ac.uk

Akhir kata, saya mengucapkan berbanyak terima kasih di atas kesudian anda dan mengambil masa membaca surat jemputan ini. Jikalau anda bersedia untuk mengambil bahagian, saya memohon agar anda membaca dengan teliti dan tandatangan 2 borang persetujuan, satu salinan untuk anda dan satu salinan untuk simpanan saya. Sila simpan maklumat ini untuk keguanaan masa hadapan.

Appendix 4 – Flyer for nurses



You are invited…

To participate in a nursing research

PHASE 1:

NOVEMBER TO JANUARY 2015

PHASE 2:

JUNE TO August 2016

Contact:

LEE SIEW PIEN
PhD student
(Nursing Studies)
University of
Edinburgh, UK

Tel: +6018 2903 706
Email:
siewpien@yahoo.com

TITLE

Understanding Children's Participation in Decisions regarding Their Nursing Care in Malaysian

AIM

The aim of the study is to gain an understanding of the participation of children diagnosed with leukaemia in decisions relating to nursing care; from the perspective of children diagnosed with leukaemia, their parents, and nurses.

METHODS

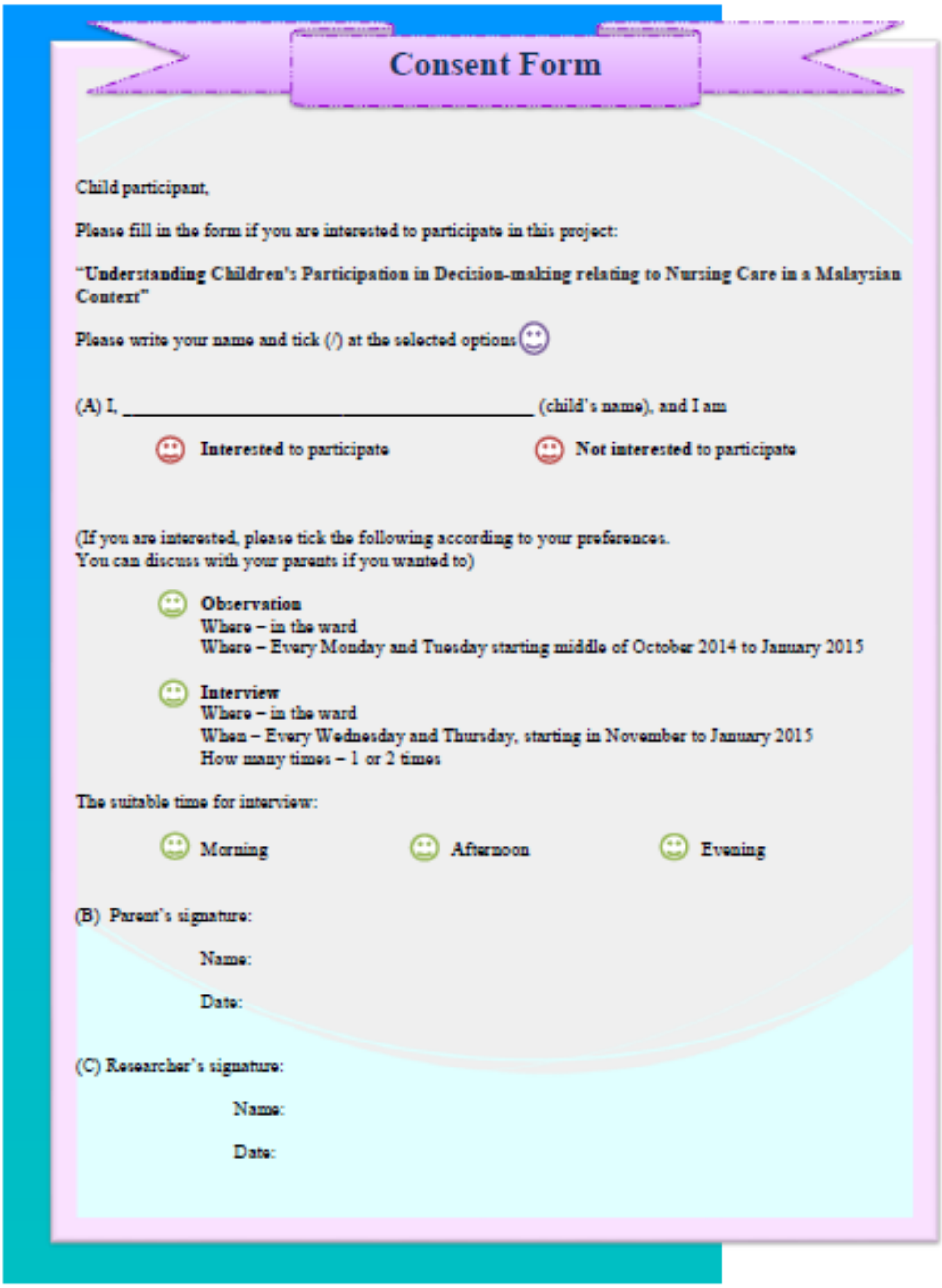
- Observation and interview will be conducted
    - Observation
        - will be conducted during the provision of nursing care to the children diagnosed with leukaemia.
    - Interview
        - Around 30—60 min
        - Will be recorded
        - Will held in this ward

SUPERVISORS

1. Dr. Elaine Haycock Stuart, University of Edinburgh
2. Prof. Dr. Kay Tisdall, University of Edinburgh

Appendix 5 – Informed consent form (for children)

i) English version



Consent Form

Child participant,

Please fill in the form if you are interested to participate in this project:

"Understanding Children's Participation in Decision-making relating to Nursing Care in a Malaysian Context"

Please write your name and tick (/) at the selected options ☺

(A) I, ______________________________________ (child's name), and I am

☺ **Interested** to participate ☺ **Not interested** to participate

(If you are interested, please tick the following according to your preferences.
You can discuss with your parents if you wanted to)

☺ **Observation**
Where – in the ward
Where – Every Monday and Tuesday starting middle of October 2014 to January 2015

☺ **Interview**
Where – in the ward
When – Every Wednesday and Thursday, starting in November to January 2015
How many times – 1 or 2 times

The suitable time for interview:

☺ Morning ☺ Afternoon ☺ Evening

(B) Parent's signature:

Name:

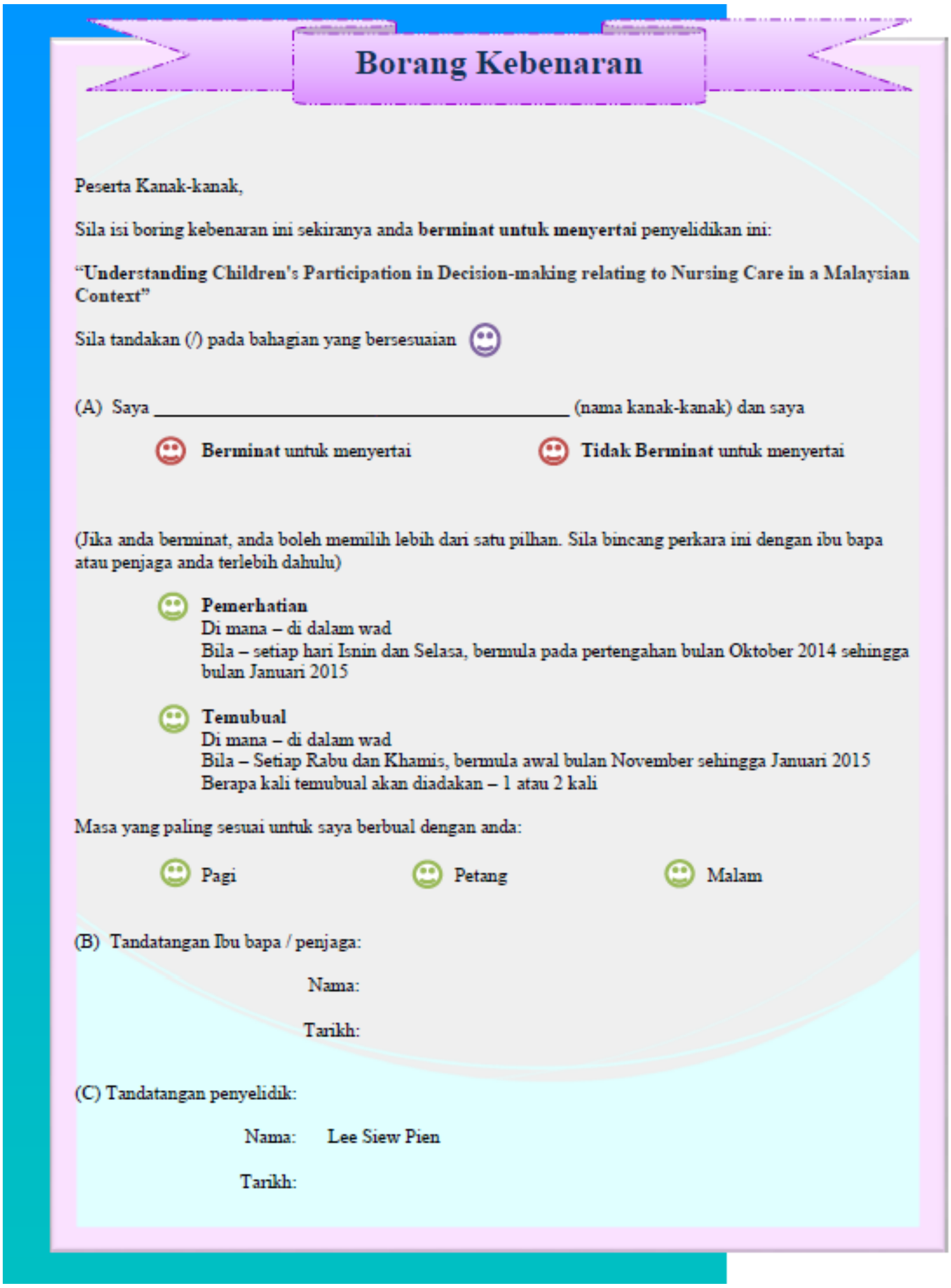
Date:

(C) Researcher's signature:

Name:

Date:

ii) Malay version



Borang Kebenaran

Peserta Kanak-kanak,

Sila isi boring kebenaran ini sekiranya anda **berminat untuk menyertai** penyelidikan ini:

"Understanding Children's Participation in Decision-making relating to Nursing Care in a Malaysian Context"

Sila tandakan (/) pada bahagian yang bersesuaian ☺

(A) Saya ________________________________ (nama kanak-kanak) dan saya

☺ **Berminat** untuk menyertai ☺ **Tidak Berminat** untuk menyertai

(Jika anda berminat, anda boleh memilih lebih dari satu pilhan. Sila bincang perkara ini dengan ibu bapa atau penjaga anda terlebih dahulu)

☺ **Pemerhatian**
Di mana – di dalam wad
Bila – setiap hari Isnin dan Selasa, bermula pada pertengahan bulan Oktober 2014 sehingga bulan Januari 2015

☺ **Temubual**
Di mana – di dalam wad
Bila – Setiap Rabu dan Khamis, bermula awal bulan November sehingga Januari 2015
Berapa kali temubual akan diadakan – 1 atau 2 kali

Masa yang paling sesuai untuk saya berbual dengan anda:

☺ Pagi ☺ Petang ☺ Malam

(B) Tandatangan Ibu bapa / penjaga:

Nama:

Tarikh:

(C) Tandatangan penyelidik:

Nama: Lee Siew Pien

Tarikh:

Appendix 6 – Informed consent form for parents and nurses

i) English version

CONSENT FORM

THE UNIVERSITY OF EDINBURGH
SCHOOL of HEALTH in SOCIAL SCIENCE
DOORWAY 6, MEDICAL QUAD
TEVIOT PLACE, EDINBURGH
EH8 9AG

Research Topic

Understanding Children's Participation in Decisions about Their Care in a Malaysia Context.

Name of Researcher

Lee Siew Pien

I AGREE WITH THE FOLLOWING STATEMENTS:

1. I know that it is up to me whether or not I want to take part in this study project.
2. I would like to confirm that I have read and understood the participant information leaflet. I have been given chance to consider the information and ask questions about the project and have them answered to my satisfaction.
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reasons.
4. I understand that the interviews will be recorded unless I object.
5. I understand that the observations and interviews will be utilized for academic purposes and findings may be published in journals but anonymity will be maintained.
6. I also understand that there are no direct benefits from participating in the study. I am not being rewarded financially or otherwise for my participation.

7. All the procedures have been explained, I had a chance to discuss the study and ask questions.

8. I have received a copy of this consent form to keep for future reference.

I GIVE MY FULL CONSENT BY SIGNING THIS FORM TO PARTICIPATE IN THE RESEARCH

Print your name in BLOCK CAPITALS:

I ____, hereby consent to participate in the research project on Understanding Children's Participation in Decisions about Their Care in a Malaysia Context.

Signature ______________________________ Date___________________________

Investigator name: _______________________________

Signature ______________________________ Date ____________________________

ii) Malay version

BORANG PERSETUJUAN

THE UNIVERSITY OF EDINBURGH
SCHOOL of HEALTH in SOCIAL SCIENCE
DOORWAY 6, MEDICAL QUAD
TEVIOT PLACE, EDINBURGH
EH8 9AG

Tajuk Penyelidikan

Penyertaan Kanak-Kanak Di Dalam Proses Membuat Keputusan
Tentang Penjagaan Mereka, Dalam Kontek Malaysia.

Nama Penyelidik

Lee Siew Pien

SAYA BERSETUJU DENGAN KENYATAAN BERIKUT:

- ✓ Saya tahu bahawa terpulang kepada saya dan anak saya samada hendak mengambil bahagian atau tidak dalam projek kaji selidik ini.
- ✓ Saya mengesahkan bahawa saya dan anak saya telah membaca dan memahami maklumat penyertaan yang diberikan oleh penyelidik. Saya dan anak telah diberi peluang untuk meneliti maklumat dan bertanya soalan tentang projek ini dan menjawabnya secara selesa.
- ✓ Saya memahami bahawa penyertaan anak saya adalah secara sukarela dan anak saya bebas untuk menarik diri pada bila-bila masa tanpa memberi sebarang alasan.
- ✓ Saya memahami bahawa temubual akan direkod melainkan saya dan anak menentang.
- ✓ Saya memahami bahawa pemerhatian dan temubual akan digunakan untuk tujuan akademik dan penemuan ini mungkin diterbitkan di dalam journal tetapi kerahsiaan nama dikekalkan.
- ✓ Saya memahami bahawa tiada sebarang manfaat secara langsung daripada penyertaan di dalam kaji selidik ini. Anak saya tidak diberi ganjaran kewangan atau apa-apa bentuk sekalipun di dalam kaji selidik ini.

- ✓ Semua tatacara telah dijelaskan, dan saya dan anak mempunyai peluang untuk berbincang tentang kaji selidik dan bertanya soalan dengan penyelidik.
- ✓ Saya telah menerima satu salinan borang persetujuan ini untuk disimpan demi rujukan masa hadapan.
- ✓

SAYA MEMBERI SOKONGAN SEPENUHNYA DENGAN MENANDATANGANI BORANG KAJI SELIDIK INI.

Tulis nama anda dengan menggunakan **HURUF BESAR**

Saya,………………………….., dengan ini bersetuju untuk mengambil bahagian di dalam kaji selidik yang bertajuk: Memahami Penyertaan Kanak-Kanak Di Dalam Membuat Keputusan Tentang Penjagaan Mereka Dalam Kontek Malaysia.

Tanda tangan……………….........

Tarikh……………….....................

Nama Penyelidik:…………………

Tanda tangan………………..……..

Tarikh…………….........................

Appendix 7 – Observation checklist

Observation checklist

Pre observation comments:

Location of observation: Date:

Description of Activity:

[This is for describing what happened during the day as accurately as I can. I take a ‘who, what, when, where, why, how’ approach and try to stick to ‘facts’ to create a verbal snapshot of what happened. This includes noting direct quotes and snippets of conversations].

Reflections:

[I reflect on the day’s experiences, writing about how I might have influenced events, what went wrong (and what I could do differently next time), and how I feel about the process].

Emerging Questions/Analyses:

[Here I note questions I might ask, potential lines of inquiry, and theories that might be useful. This is where I start to do some analytical work].

Future Action:

[This is a ‘to-do’ list of actions. I usually include a timeframe alongside each point].

OBSERVATION GUIDE

Location of observation					
Observation Time					
Person being present: ☐ Children ☐ Nurse ☐ Parent ☐ Others:					
Description of situation					
Levels of Participation	1	2	3	4	5

Description / Characteristic of Participation	Yes	No
Information was conveyed to the child	☐	☐
Different alternatives were offered	☐	☐
Children were given opportunity to think and ask questions	☐	☐
Children were asked for their views on what is planned	☐	☐

What decision was made	
Who made the decision	
Reaction to the decision	
Children	
Parent	
Nurses	

Are the decision reconsidered?	Yes	No

Interaction between children, parent and nurse in the situation

Children's Action	
Parent's Action	
Nurse's Action	

Appendix 8 – Interview guide

Field Note (Interview)

Pre interview comments:

Location of Interview: Date:

Description of environment:

Non-verbal behaviour (e.g. tone of voice, posture, facial expressions, eye movements, forcefulness of speech, body movement, and hand gestures)

Content of interview (e.g. use of key words, topics, focus, exact words, or phrases that stand out)

Researcher impressions (e.g. discomfort of participant with certain topics, emotional responses to people, event or objects)

Analysis (e.g. researcher's questions, tentative hunches, trends in data, and emerging patterns)

Technological problems (e.g. lost 5 minutes when tape turned)

Post-interview comments:

Individual Interview (CHILDREN)

Introduction and warm up

Welcome child to the interview room and offer her a seat.

The researcher introduces herself.

Explain to the participant the purpose of the interview session. Review the Participant Information sheet together and give her a copy to go though it carefully once again.

After reading through the information leaflet, review the consent form with the participants and answer any questions or queries. If he/she agrees with everything obtain consent by letting parent sign 2 consent forms and give one copy to the parent, and keep safe the other copy.

Interview

The purpose of the questions was to explore children experience in decisions relating to nursing care

[Recall the situation seen during the observation and discuss with the child]

Can you explain in detail regarding your situation?

What happen during that time?

How do you participate in the discussion?

What decision has been made? By whom?

Do you able to influence the decisions?

Do you want to be involved in the discussion? Why?

Does the nurse ask your opinion/permission before they decisions regarding your own nursing care?

Have your involvement resulted in any changes to the nursing care provide?

Yes – could you please tell the changes, NO – why?

The purpose of this question was to identify the child's preferred role while participating in decisions.

How do you prefer to involve in discussion and decisions about your care in the ward.

Individual Interview (PARENT/GUARDIAN)

<u>Introduction and warm up</u>

Welcome the parent to the interview room and offer her a seat

The researcher introduces herself.

Explain to the participant the purpose of the interview session. Review the Participant Information Leaflet together and give her a copy to go though it carefully once again.

After reading through the information leaflet, review the consent form with the parent and answer any questions or queries. If she agrees with everything obtain consent by letting her sign 2 consent forms and give one copy to the parent, and keep safe the other copy.

Interview

The purpose of this question was to explore the understanding of parent regarding the participation of children in decisions relating to nursing care.

Can you tell, what is your understanding of the involvement of children in the communication and decisions relating their nursing care?

The purpose of the questions was to explore children experience in decisions relating to nursing care.

What does children's participation in decisions means to you?

Have your child ever involve in the discussion and decisions regarding their own nursing care? If yes, how many in the last 12 months?

What aspect of decisions dose your child involved in?

Probe:

Please give example of the situation where your child involved.

How does your child participate in decisions?

Probe:

What he/she do during the involvement?

Has the involvement of your child resulted in any changes to the nursing care provide?

Yes – could you please tell the changes, NO – why do you think?

The purpose of this question was to identify the factors influencing participation of children in the decisions in relation to nursing care.

What problems did you experience when taking care for your child?

Probe:

The situation that make you difficult [your child's personal condition; the treatment; hospitalization; your understanding of the child's illness; support from healthcare professional]

What is easy about caring for children with leukaemia?

Can you describe situation where your child were OR were not allowed to participation in the discussion and decisions about their care?

What factors were seen as reason for promoting your child's participation?

What factors were thought to restrict your child's participation?

The purpose of this question was to identify the support given by nurses/parent to the children in decisions relating to nursing care.

Personally, would you support your child to be involved in discussion and decisions?

If there was one thing you could tell me about your actions to encourage your child to participate in discussion and decisions, what would that one thing be?

Do you think you provide enough/good support to your child?

Are there any better ways to be given for better children's participation?

What are your suggestions for how children with leukaemia would better participate in the decisions?

Individual Interview (NURSES)

Introduction and warm up

Welcome the nurse to the interview room and offer her a seat

The researcher introduces herself.

Explain to the participant the purpose of the interview session. Review the Participant Information Leaflet together and give her a copy to go though it carefully once again.

After reading through the information leaflet, review the consent form with the nurse and answer any questions or queries. If she agrees with everything obtain consent by letting her sign 2 consent forms and give one copy to the nurse, and keep safe the other copy.

Interview

The purpose of the interview was to gather additional demographic information about the participants.

Can you tell me:

How did you come to this unit

How would you describe oncological and haematology unit

The purpose of this question was to explore the understanding of nurses regarding the participation of children in decisions relating to nursing care.

Can you tell, what is your understanding of the involvement of children in the communication and decisions relating their nursing care?

The purpose of the questions was to explore children experience in decisions relating to nursing care

What does children's participation in decisions means to you?

Have you ever involve children in decisions regarding their own nursing care? If yes, how many in the last 12 months?

What is the age range of children involved?

What aspect of decisions are children involved in?

Probe: please example of the situation where children are involved.

How does the child participate in decisions?

Probe: what do the child do during the involvement?

Has the involvement of children resulted in any changes to the nursing care provide?

Yes – could you please tell the changes, NO – why?

The purpose of this question was to identify the factors influencing participation of children in the decisions in relation to nursing care.

What problems did you experience when caring for children with leukaemia? Probe: The tasks that make the actions difficult, what is easy about caring for children with leukaemia?

Can you describe situation where children were or were not allowed to participation in the decisions about their care?

What factors were seen as reason for promoting the child's participation?

What factors were thought to restrict the child's participation?

How did your knowledge, skills and experience influence your decisions to involve children in decisions regarding their care?

The purpose of this question was to identify the support given by nurses to the children in decisions relating to nursing care.

Personally, would you support the children in the decisions?

If there was one thing you could tell me about the nurses interventions to encourage children participate in decisions relating to nursing care, what would that one thing be?

Will you share with me the kind of thing you do in your practice in this setting to encourage children participate in discussion and decisions relating to their nursing care?

Probe:

Who do you involve in these interventions?

How do you communicate these interventions? (communicate between and among the nurses) – {change of shift report, records, notes on calendar, notes to each other, phones calls}

Where did you get guidance from to help with your decisions when caring for the children to be involved in decisions?

Do you think you provide enough/good support to the child

Are there any better ways to be given for better children's participation?

Do your organization offer support to facilitate children involve in decisions? Probe: give example.

Suggestions

What are your suggestions for how children would better participate in the decisions

In your opinion, what additional support might be useful for caring of children with leukaemia?

Appendix 9 – Profile of child participants

No	Pseudo-name	Age	Gender	Race	Diagnoses	Been Diagnosed	Times of admission
1	Alexis	11	Boy	Malay	CML	4m	9
2	Adela	12	Girl	Chinese	CML	8m	7
3	Ruby	8	Girl	Malay	ALL	Newly diagnosed	1
4	Vince	7	Boy	Malay	ALL	3y 8m	19
5	Phoebe	8	Girl	Malay	ALL	3y	15
6	Edna	10	Girl	India	ALL	Newly diagnosed	3
7	Noah	9	Boy	Malay	ALL	3m	6
8	Ray	9	Boy	India	ALL	Newly diagnosed	1
9	Dane	10	Boy	Malay	AML	2y 2m	12
10	Abbie	12	Girl	Malay	ALL	Newly diagnosed	1
11	George	12	Boy	Malay	AML	Newly diagnosed	1
12	Kate	12	Girl	Chinese	ALL	2y	9
13	Eva	11	Girl	Malay	AML	Newly diagnosed	4
14	Jane	7	Girl	Malay	ALL	4m	6
15	Nita	10	Girl	Malay	ALL	Newly diagnosed	1
16	Ralph	7	Boy	Malay	ALL	Newly diagnosed	1
17	Elbert	7	Boy	Malay	ALL	1m	3
18	Dale	8	Boy	Malay	ALL	3m	3
19	Amanda	8	Girl	Malay	ALL	1y 4m	7
20	Tina	11	Girl	Chinese	ALL	Newly diagnosed	1
21	Bob	8	Boy	Malay	CML	Newly diagnosed	1

Appendix 10 – Profile of parent participants

No	Pseudo-name	Child	Relationship with child	Age	Race	Educational Background	Employment	Number of children
1	Jenny	Alexis	Mother	39	Malay	Diploma	Secretary	2
2	Zana	Adela	Mother	39	Chinese	Secondary	Housewife	4
3	Jess	George	Mother	39	Malay	Diploma	Teacher	6
4	Damia	Ruby	Mother	54	Malay	Primary school	housewife	3
5	Eddy	Vince	Father	42	Malay	Secondary	Businessman	2
6	Teri	Phoebe	Mother	45	Malay	Degree	Teacher	4
7	Vicky	Edna	Mother	36	India	Secondary	Factory worker	4
8	Christ	Noah	Cousin	22	Malay	Secondary	unemployed	0
9	Rachel	Ray	Mother	35	India	Secondary	housewife	4
10	Olive	Dane	Mother	42	Malay	Degree	business	3
11	Chloe	Abbie	Mother	38	Malay	Degree	Teacher	2
12	Beth	Kate	Mother	41	Chinese	Secondary	housewife	2
13	Blake	Eva	Father	45	Malay	Secondary	Businessman	3
14	Maria	Jane	Mother	40	Malay	Degree	Teacher	4
15	Nancy	Ralph	Mother	38	Malay	Secondary	Housewife	3
16	Rena	Nita	Mother	37	Malay	Secondary	housewife	3
17	Ezra	Elbert	Mother	32	Malay	Diploma	Midwife	2
18	Alice	Dale	Mother	45	Malay	Secondary	Housewife	6
19	Becky	Amanda	Mother	43	Malay	Secondary	Housewife	4
20	Vina	Tina	Mother	38	Chinese	Secondary	Businesswoman	3
21	Rita	Bob	Mother	36	Malay	Degree	Teacher	2

Appendix 11 – Profile of nurse participants

No	Pseudo-name	Age	Race	Marital Status	Number of Child	Educational Background	Nursing Experience (years)	Experience in the Unit (years)
1	Nora	38	Malay	Married	4	Oncology	15	15
2	Vina	36	Malay	Married	2	Oncology	13	13
3	Alina	32	Malay	Married	2	Oncology	8	8
4	Alison	27	Malay	Married	1	Nursing	5	4
5	Laura	25	Malay	Married	1	Nursing	4	3
6	Amelia	27	Malay	Single	0	Oncology	7	6
7	Alma	25	Malay	Married	1	Nursing	4	3
8	Amber	26	Malay	Married	2	Nursing	5	5
9	Bella	24	Malay	Single	0	Nursing	3	2
10	Mabel	33	Malay	Married	1	Oncology	6	5
11	Maya	25	Malay	Single	0	Nursing	3	3
12	Camila	28	Malay	Married	2	Nursing	4	2.5
13	Hilda	21	Malay	Single	0	Nursing	1	1
14	Ann	24	India	Single	0	Nursing	3	2
15	Irene	22	Malay	Single	0	Nursing	1	1
16	Cara	23	Malay	Single	0	Nursing	1	1
17	Gail	22	Malay	Single	0	Nursing	1	1
18	Selena	22	Malay	Single	0	Nursing	1.5	1.5
19	Vivian	21	India	Single	0	Nursing	1	1

Appendix 12 – Ethical approval from the Section of Nursing Studies Ethics Research Panel

SCHOOL OF HEALTH IN SOCIAL SCIENCE
The University of Edinburgh
Doorway 6
Medical Quad
Teviot Place
Edinburgh
EH8 9AG

E-mail: K.Melia@ed.ac.uk
Telephone: 0131 650 3893
Fax 0131 650 3891

Siew Pien Lee
Doctoral Researcher in Nursing Studies
School of Health in Social Science
Medical School
Teviot Place
Edinburgh
EH8 9AG

Date: 13 November 2014

Dear Siew Pien

APPLICATION FOR LEVEL 2/3 APPROVAL

Project Title:
UNDERSTANDING CHILDREN PARTICIPATION IN DECISION MAKING IN A MALAYSIAN CONTEXT

Thank you for submitting the above research project for review by the Section of Nursing Studies Ethics Research Panel.

I can confirm that the submission has been independently reviewed and was approved on 6 November 2014.

Should there be any change to the research protocol, it is important that you alert us to this as this may necessitate further review.

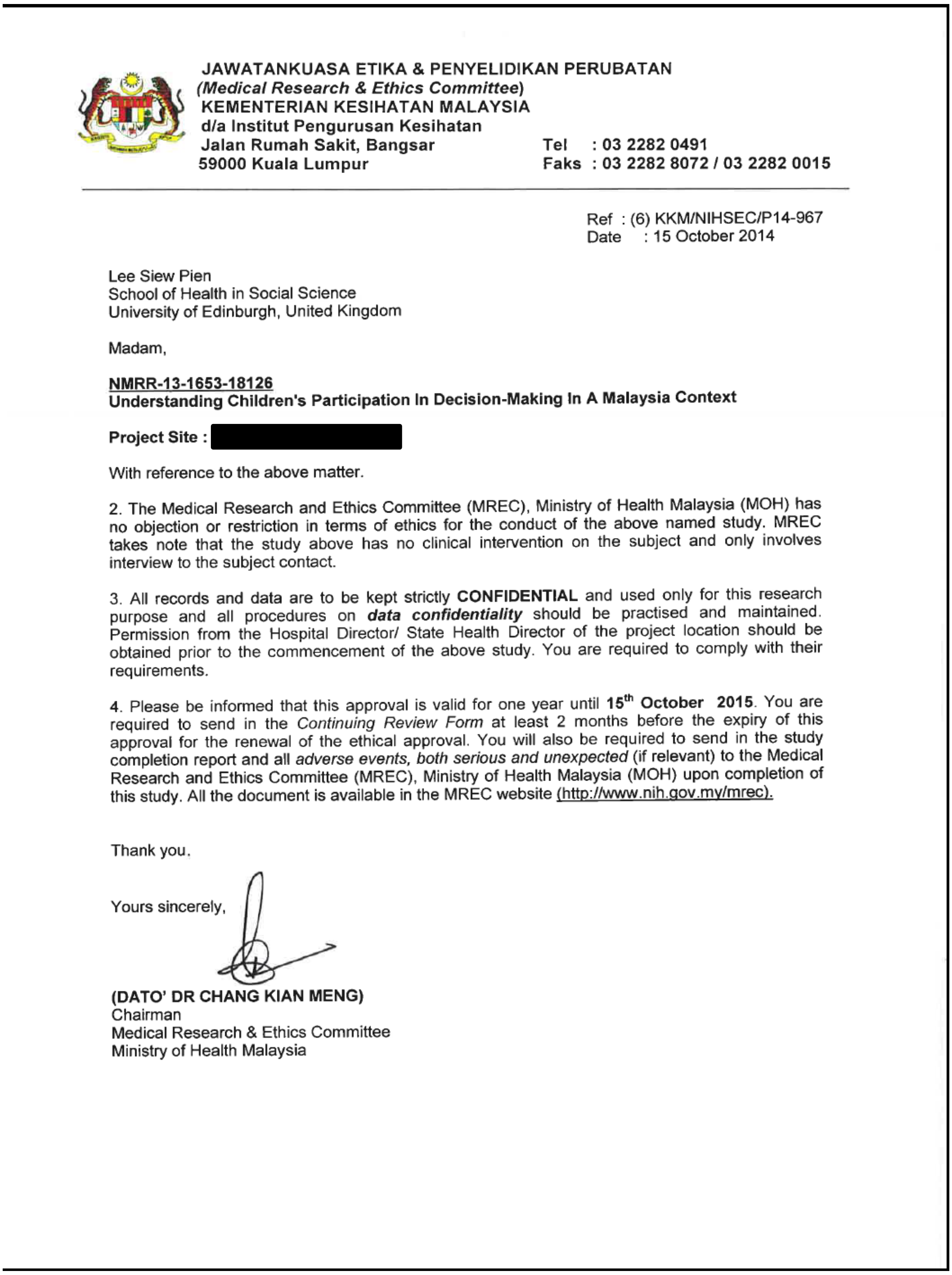
Yours sincerely

M. Jane Richards

M Jane Richards

On behalf of
Kath M Melia
Professor of Nursing Studies

Appendix 13 – Ethical approval from Medical Research and Ethics Committee (MREC)



JAWATANKUASA ETIKA & PENYELIDIKAN PERUBATAN
(Medical Research & Ethics Committee)
KEMENTERIAN KESIHATAN MALAYSIA
d/a Institut Pengurusan Kesihatan
Jalan Rumah Sakit, Bangsar
59000 Kuala Lumpur

Tel : 03 2282 0491
Faks : 03 2282 8072 / 03 2282 0015

Ref : (6) KKM/NIHSEC/P14-967
Date : 15 October 2014

Lee Siew Pien
School of Health in Social Science
University of Edinburgh, United Kingdom

Madam,

NMRR-13-1653-18126
Understanding Children's Participation In Decision-Making In A Malaysia Context

Project Site : [redacted]

With reference to the above matter.

2. The Medical Research and Ethics Committee (MREC), Ministry of Health Malaysia (MOH) has no objection or restriction in terms of ethics for the conduct of the above named study. MREC takes note that the study above has no clinical intervention on the subject and only involves interview to the subject contact.

3. All records and data are to be kept strictly **CONFIDENTIAL** and used only for this research purpose and all procedures on ***data confidentiality*** should be practised and maintained. Permission from the Hospital Director/ State Health Director of the project location should be obtained prior to the commencement of the above study. You are required to comply with their requirements.

4. Please be informed that this approval is valid for one year until **15th October 2015**. You are required to send in the *Continuing Review Form* at least 2 months before the expiry of this approval for the renewal of the ethical approval. You will also be required to send in the study completion report and all *adverse events, both serious and unexpected* (if relevant) to the Medical Research and Ethics Committee (MREC), Ministry of Health Malaysia (MOH) upon completion of this study. All the document is available in the MREC website (http://www.nih.gov.my/mrec).

Thank you.

Yours sincerely,

(DATO' DR CHANG KIAN MENG)
Chairman
Medical Research & Ethics Committee
Ministry of Health Malaysia