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**University of Durham**

**Aspects of paediatric in-patient care: views of  
parents and school aged children**

Olga López de Dicastillo Sáinz de Murieta

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**MSc Thesis**  
Centre for Comparative Public Health  
Supervisor: Dr. Philip Cheung  
2001



28 MAY 2002

# **Aspects of paediatric in-patient care: views of parents and school aged children**

MSc Thesis 2001

Olga López de Dicastillo Sáinz de Murieta

## **Abstract**

The objectives of this project were to investigate the idea of family-centred care from the parents' and children's perspectives, to find out the difference between theory and practice, and to seek parents' views on methods for improving hospital environment and its facilities for children and parents.

This study was conducted in a junior school in County Durham using qualitative and quantitative research methods. The data were obtained via surveying parents and children, interviewing parents whose children had been in hospital and collecting drawings from children.

The facilities for families, parents and children in hospital might have shown some improvement, however there are several aspects that still need to be achieved. Some parents asserted that their basic needs were not being met during their hospital stay with their children. The mothers argued that having a sick child in hospital has an impact on the whole family and hospitals need to give some attention to their concerns. Although many professionals presume that they are working with a family-centred care approach, it is not clear to what extent this concept has been put into practice. The mothers reported the need for adequate communication and negotiation with health professionals to facilitate mutual collaboration and to avoid the anxiety that the participation in care might cause to parents and children.

It has been proposed by some parents that home care could replace hospital-based care. The concern was that support for home care might be inadequate. Mothers in this study also proposed that the practice of home care could be facilitated by having direct communication with named nurses and doctors, using dedicated phone lines. Community nurses have also a part to play in home care. It would be important to consider innovations more proactive to health promotion such as parenting advice about healthy and unhealthy behaviour.

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# Chapter 1 – Introduction

This thesis had its conception when the researcher, working as a nurse, realised that caring for children in hospital engages parents and nurses in a new and fragile enterprise. Why then do the professionals and the health service persist in perpetuating the traditional approach?

In many cases hospitals are designed to make the lives of nurses and doctors easier, rather than to help parents and families in their adaptation to this unknown environment. When a family arrives at the hospital they are usually scared and horrified because their normal world seems threatened. They are in a strange environment, doing those things which they think they have to do or, simply those which they can do.

The well-being of people's family members is essential to each members' health and welfare. Concern over the health of another individual in the family increases anxiety and has negative effects on the well-being of all members (Åstedt-Kurki, Paunonen and Lehti 1997). At the same time, family members have an important influence on the well-being of the child who is in hospital. Having a sick child in hospital causes parents to suffer and to feel vulnerable. If parents are not able to cope with their child's illnesses and hospitalisation they will not be able to help their children, either.

The Convention on the Rights of the Child (1989) stated in its preamble that the family is 'the fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children', and thus, 'it should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community'. The Convention also recognised that the child should grow up in a 'family environment, in an atmosphere of happiness, love and understanding' all of this for the full and harmonious development of the child's personality. If the family is the fundamental



and natural environment for bringing up children, for their appropriate development, why then, during hospitalisations, which are critical events in children's lives, should they be deprived of the protection of their families? Should not parents be the active participants in the care of their children? Permitting parents to stay in hospitals, caring for their children with adequate support from the health professionals, seems to be the best choice when considering children's welfare.

When children are ill at home, they are in familiar surroundings where they can enjoy some degree of freedom. Moreover they are never alone. However, when children stay in hospital innumerable aspects of their daily routine will be affected. Strangers will be in charge of their care. Parents that until then offered them security and protection now seem to be powerless, without any authority over the events that are taking place. Their timetables are different, the food is 'not as good as the one cooked at home' and they have to sleep in a strange bed. The clothes that they have to wear are probably not their own and they do not have their own toys. How do children react when they are deprived of their familiar environment? Their reactions to hospitalisation vary widely. They may react with desperate tears when a stranger approaches to them, but they may also avoid expressing their feelings because they are overwhelmed by fear. It is difficult to predict how a child who is unknown to the health professionals will react towards hospitalisation. Thus, it would be needed to know the child better in order to encourage his or her adaptation. In this sense, who knows the children better than their parents?

It is obvious then, that parents are crucially important in the care of children in hospital. By working together with the health professionals responsible for their child's care, the negative aspects of the hospitalisation will decrease and the benefits will expand. Parents and professionals become partners caring for the child who is ill. This is the philosophy of family-centred care that recognises parents as equal partner with professionals. Parental involvement has been promoted since the publication of The Platt Report (Ministry of Health, 1959), which recommended that there should be a provision of facilities so that the mothers could stay and care for their hospitalised children. Furthermore, parental involvement in hospitals has been reinforced in 1989 by the Children's Act and other publications such as the one implemented by the Department of Health in 1991.

In contrast, not all health professionals' attitude towards parental participation is positive. Some of the health staff recognise the knowledge and abilities of parents, and describe the learning of caring facilities from them (Ford and Turner, 2001). However, other professionals can feel that when parents are actively involved in a child's care, their role is diminished (Darbyshire, 1995).

An additional aspect of parents' involvement in children's care in hospital is that when parents and other family members become involved in the care of a sick child, they can be regarded as clients also (Callery, 1997b; Friedemann, 1989). This means that some of them need care themselves as a consequence of their involvement. Therefore, it is important to question if parents are receiving the care that they need. Are the hospitals offering them the facilities that they would need to care for themselves and consequently for their child properly? Are all the parents' basic needs covered for the duration of their stay? Darbyshire (1994) stated that there was a 'distinct lack of work that asks parents about the nature of this experience of living-in with their hospitalised children'. Polaino-Lorente et al (2000) stated that a lack of experience about how to care for the family in the paediatric wards, and the lack of services for families, has very negative consequences at four levels: parents, children, health professionals and the hospital itself. Firstly, the consequence for parents is that their stress increases when they have a child who is ill. If parents do not receive the adequate support, it would further their stress level affecting ultimately their daily living activities. The higher stress levels may make parents unable to care for their children properly. Then, the children experience the negative consequences of this lack of proper parental care not only in the illness itself but also in its evolution and prognosis. Furthermore, if parents are not able to help their children to adapt to the illness and the hospitalisation, the health professionals will have to make a greater effort when caring for these children. Finally, the negative consequences for hospitals are that their prestige and social consideration depends on parents' and families' opinions about the type of care that was provided. These opinions are later transmitted among the population, creating the social image of that hospital.

The present study seeks to understand both children's experiences of being in hospital and parents opinions about their children being in hospital. Recording parents' experiences of living-in, the study aimed to gather as much information as possible about

the facilities available, the involvement in their children's care and their general opinion regarding hospitals and the health system. It is obviously necessary to determine parents' concerns. This information will be useful in order to help families to promote healthy habits, and also, to design a system of help that will support the family when children become ill. Once all these aspects are considered, it will be possible to care for the family as a whole.

The notion of family-centred care is said to be beneficial, but what do families think about it? Do they think that such care will indeed benefit all the members of the family? Do they want to participate in the care of the children in hospital or in the community? Do they realise the effort that the professionals are making to develop this kind of care? Or conversely, do they think that it is a way of decreasing the extra workload that the nurses and doctors have? It is essential to find the answers to all these questions.

Additionally, it should not be forgotten that within all models of paediatric care, the most important element is the child. There is a tendency from adults to ignore children or be condescending to them. Part of the aim of this project is to develop tools that will help professionals understand the mind-set of children. It cannot be assumed that just because children are of a certain age they are not able to understand about health and illness. Children acquire their understanding from adults explanations, from what they overhear regarding the salience of processes related to these matters in their lives, and also, from other children. Their level of understanding about health and illness depends on the child's stage of cognitive development.

The English psychologist Margaret Donalson (cited in de Winter, Baerveldt and Kooistra, 1999) concluded that children are forced into dependency too frequently in different areas, and so they are denied the necessary experiences that will help them develop their capacities for initiative and responsible action. Therefore, knowing their understanding about being in hospitals, being given medicines and medical procedures, health professionals will be able to develop children's capacities for initiative and responsible action when they are ill and have to go to hospital. However, there are other relevant issues that contradict this idea. Children are supposed to master their lives but the questions are: when can they start to do so?, how far should they be involved in the

decision-making process?, how could their level of responsibility be increased without increasing the stress to extremes that could damage their self esteem and their self confidence?.

Although children's wards and hospitals have changed considerably in the last 20 years, many of the changes have been made according to adults' views and opinions. Recent studies showed that children are treated as *objects* of local welfare-policies (de Winter, Baerveldt and Kooistra 1999). These policies are designed for children and the young people but without involving them. de Winter, Baerveldt and Kooistra claimed that a dialogue should be started with them. This is to treat them as *active subjects* not as objects. Otherwise children learn from a young age that they are not considered as important social subjects, whose opinions and involvement are respected. Hence, children's participation in health subjects ought to be considered as a condition that protects the child's personal development and well-being. This study empowers children, by asking them for their opinions and to describe their experiences.

It is always necessary to check the nature of a child's understanding and feelings of health and illness matters, as well as bearing in mind and working with the cultural assumptions of the family. This awareness creates a healthy balance.

This research proposes several goals. The primary outcome of the research aims to achieve a better understanding of children's conceptions of being in hospital, and their determining factors. It will also give an indication of the idea that parents have about family centred care and their desires to be involved in the hospital care of their children. This information will have implications for nurses and health professionals participating in the development of family care. The research will also serve as a basis for further research into hospital and community health assistance to families.

This report is organised into 9 chapters. The next chapter will describe the bibliography review carried out on different themes: family centred care, hospitalisation, parents' involvement in hospital and children's understanding of health, illness and being in hospital.

Chapter 3 gives a detailed account of the research approach methods employed in this study. To truly understand the context of the research it is necessary to know how the



collection of data and its interpretation has been executed. A brief summary of findings is explained in Chapter 4.

Chapters 5 to 9 present and explore the major themes that arose from participants' interviews as well as from the surveys and drawings. Chapter 5 examines the principles and practice of family-centred care. The chapter provides a description of different aspects of this philosophy of care. Family-centred-care background is also important for understanding the importance of the care of the family when a child is ill in hospital. Parents' opinions on the facilities available for families will also be given in detail.

Chapter 6 focuses on parents' perspectives of hospitals and being involved in their children's care, whereas, Chapter 7 will give voice to children's opinions, feelings and concerns.

Communication is addressed in a separate chapter (Chapter 8) due to its importance in human and professional relationships with parents and children. Chapter 9 undertakes a comparison between home and hospital care, in an attempt to clarify the advantages and disadvantages that both systems of care have, not only for the children but also for their families.

In the final Chapter, the conclusions are offered.

# Chapter 2 – Review of literature

## 2.1. Introduction

Technological advances in health care and the emphasis on wellness have dramatically increased diversity of practice in paediatric nursing. Paediatric nurses can be based in the community (primary care) and in hospitals (secondary care). Inside of the hospital system they can also have several positions. They can work in intensive care units, in wards and in administrative and management positions. In the community they can work in health centres, clients' houses, schools and companies. Additionally, they work in emergency transports, in summer and winter camps and as self-employees. Virtually, they can work anywhere there are children.

The variety of employments requires a variety of educational preparation and experiences. The growing professionalism among paediatric nurses is becoming more evident. Questioning 'the way it has always been done' is critical to the advancement of paediatric nursing practice. Through research nurses will be able to answer their own practice questions. The bulk of nursing research has grown rapidly in recent years. However, nursing research is still in its infancy (Betz, Hunsberger and Wright, 1994).

Published literature from the UK, Canada, USA and Australia was reviewed to identify the knowledge base for the following themes:

- Children's Hospitalisation
  - Preparation for medical procedures
  - Children's point of view
- The historical development of family involvement in paediatrics
  - Nurses' attitudes towards parent participation
  - Parents' views of participation in child care in hospital
  - Integration of relatives
  - Family-centred care
- Children's development
- Understanding children's drawings

## 2.2. Hospitalisation

Hospitalisation has long been recognised as a stressful experience for both children and their parents (Burke et al, 1997; Kauffmann et al, 1998; Kristensson-Hallström and Elander, 1997; Lizasoáin and Polaino, 1992; Mazurek Melnyk, 1994; Ochoa and Polaino, 1999; Ochoa, Reparaz and Polaino, 1997; Polaino, 2000).

John Bowlby and James Robertson were extremely influential in the latter part of the 20th Century. Alsop-Shields and Mohay (2001) have recently discussed their work, theories and their influence on the care of children. Their research was based on the separation of mother and child. Bowlby developed several theories about maternal separation and Robertson's work was more pragmatic. Robertson took Bowlby's evidence and theoretical reasoning and used it to explain his observation of children who were separated from their parents. Using films as a method for collecting data, Robertson was very effective in his campaign to have parents and families accepted in hospital wards. According to Alsop-Shields and Mohay (2001) the work of these two scientists was highly influential in facilitating changes in hospital policies for the care of children in several places around the world: Australia, Europe, USA and Canada. Their work has also led to the development of paediatric nursing models such as 'partnership in care' and 'family-centred care'. In these models the whole family is included as the focal point of care. By implementing this type of care, the emotional trauma of the child decreases.

The British Government set up a parliamentary select committee to investigate conditions in children's ward and hospitals at approximately the same time as Bowlby and Robertson were conducting their research. The resulting document became known as the Platt Report (Ministry of Health, 1959). This document contained 55 recommendations, including allowing parents to stay in hospital with their children, providing accommodation for parents and providing school and recreational play for hospitalised children. Health professionals did not accept the reforms without opposition.

According to Coyne (1995) parent involvement in hospital was later enforced by the Children Act in 1989 and the Department of Health in 1991 (Welfare of children and young people in hospital).

### **2.2.1. Preparation for hospital and medical procedures**

Jocelyn Rodin (1983) studied the usefulness of the children's preparation for hospitalisation and medical procedures, providing empirical data. She claimed that children can be seriously disturbed by a period of hospitalisation, which necessitates parents and health professionals working together to find ways to alleviate children's distress. Although separation from the security of his home and family has been shown to be the major cause of anguish for the child, Rodin (1983) also argued that ignorance of hospitals and what goes on in them is another contributing factor. Preparation for hospital admission requires variation in techniques and management, depending on the child's maturity and the circumstances of the admission. The author reviewed various methods for preparing children for hospital and medical procedures, concluding that the overall effects are beneficial for reducing anxiety. However, she also argued that some of the methods demand a lot of time from professionals who are already busy.

Rodin's idea was that if good medical preparation games were produced, they could be very useful. They should be easy to distribute and attractive to the child. According to Rodin these methods have the advantage of involving parents and teacher who would also learn about some of the medical procedures, and therefore, they would provide the necessary help and support for the child.

When these games were designed, Rodin (1983) undertook two exercises. The first one was undertaken on adults who had experience working with children in hospitals, followed by several organised meetings to find out what a wider range of parents and child-related professionals thought. Rodin created a second questionnaire with the themes that emerged from the meetings. Following this she decided to choose a medical procedure (venepuncture), and study the reactions of children in order to evaluate the effectiveness of the games. She divided children randomly into three groups: (1) children who played with the medical preparation games before the procedure, (2) children who played with the non-medical preparation games before the procedure and (3) children who were not given any games to play with before the procedure. She concluded that children in the first group showed less anxiety during venepuncture than the other groups. Moreover, the effect of the

material was increased if parents told children about the procedure beforehand. The anxiety showed by children was related to the anxiety shown by their parents.

Lansdown (1996) recognised the link between stress reduction amongst children and appropriate preparation for hospital admissions. He suggested preparation should be specific to age, gender and previous medical experiences. He also emphasized the timing when preparation is given. Moreover, Lansdown (1996) defended the necessity for parents to receive appropriate preparation prior to admission as well as the importance of explaining to children why the procedure is taking place.

The benefits of preparing children prior to procedures were also described by Kolk, van Hoof and Fiedeldig Dop (2000). The authors concentrated on three areas, namely preparation elements: local anaesthesia of the skin, provision of sensory and procedural information and involvement of the parents. Prepared children in this study displayed significantly less distress before and during venepuncture than unprepared children, regardless of their gender, ethnical origin, age, injection history, and the mental stress of their parents.

### **2.2.2. Children's point of view**

Not many studies have been carried out on children's views of hospital. Most of the changes that have taken place in the last few decades have been based on the information gathered from adult observers, e.g. parents, nurses and doctors. However, in 1994 a study was carried out in Northern England targeting children specifically. This study was coordinated by The Northern Regional Health Authority and attempted to find out what children think about the paediatric ward, their desires and their priorities for change. Through the Hospital Teaching Service, a short series of interviews was conducted with individual in-patients and a small group of children aged between 4 and 16 years old. The key messages that emerged from the interviews were:

- Children of different ages have different needs
- Poor communication with children can lead to fear, mistrust and a belief in myths

- It is very difficult to keep children with varying levels of severity together in the same ward, for example, recovering children with very ill.
- Children claimed their right to privacy
- The quality of food is very important to children
- Some of the children felt that by staying in the ward they were isolated, thereby losing their freedom
- Adults' wards are inappropriate for children.

After gathering all this information the researcher organised two multi-disciplinary workshops to present children's opinions and facilitate the development of action plans. Children created a leaflet with comments and drawings for distribution to other children expecting to stay in hospital.

## **2.3. Family involvement in the care of children**

Sheldon (1997) concluded that the involvement of parents in the care of their sick children in hospital has positive effects on the children's recovery. It was also suggested that parents are under a great deal of stress when their children are ill not only because of the illness but also because of the medical treatment and the change of role. Participation in care may exacerbate that stress due to a lack of role definition, as well as inadequate information and support about their child's illness, treatment and nursing care.

### **2.3.1. Nurses' attitudes towards parent participation**

Research suggests that nurses' attitude towards parental participation is varied. There is a lack of consensus among nurses about the extent and form of parental involvement.

Johnson and Lindschau (1996) surveyed 62 staff members from several disciplines who were working on four paediatric wards in Australia. Their aim was to identify staff attitudes towards parents' participation in the children's care when they stay in hospital. They concluded that although there have been positive changes in staff's attitudes in a relatively short period of time, the findings show that the attitudes are still quite negative.

Professionals had, for the most part, a neutral attitude towards parental participation in their child's care. They found a higher percentage of professionals with negative attitudes than was the case in previous studies. Health professionals who are married and have children themselves are more sympathetic towards parent participation. The authors also concluded that the sample for this study was too small to draw a firm conclusion, or to make cross-cultural generalisations. However, they posed several questions about paediatric practice: Do attitudes affect practice? The idea of parent participation should be a common practice, why do these negative attitudes still exist? What should be done to support a more positive attitude towards parent participating in the care of their children?

Ford and Turner's (2001) study was based on the nurses' experiences of caring for children with special needs, and their families, in an acute care setting. The authors suggested that feelings of frustration and guilt in nurses could arise from differences between parents' expectations of their child's care needs and nurses' perception of those needs (or nurses' ability to meet parent expectations). Nurses in this study found it difficult to support the individual children in their activities of daily living. They cared for the more immediate needs of children because of the limited time available and because of institutional constraints. Ford and Turner (2001) recommended further investigation into the effects of time and resource constraints in nursing practice.

Darbyshire (1993, 1994) stated that parents and nurses seem to have different understanding in parental participation, both in definition, and in involvement. He also stated that nurses need a deeper understanding of the nature of parent's experiences and how these relate to their own practices, if nurses want to develop a philosophy of care 'based in mutuality and partnership'. He argued that parents have been simply 'helping out the staff' in areas useful for nurses, for example, basic mothering. He further asserts that a 'real involvement' could materialise if mutual relationships are stabilised through negotiation, discussion and dialogue between nurses and parents. He claimed that some nurses prefer not to involve parents in care because they feel their role becomes diminished.

### **2.3.2. Parents' views of participation in child care in hospital**

Coyne's (1995) study discovered the main reasons why parents decided to participate in the care of their children in hospitals. The reasons are: (1) Concern about relinquishing care to strangers, (2) sense of parental duty, (3) concern for consistency of care, and (4) parents' experience of hospitalisation as a child. Parents considered that their presence was necessary in order to relieve the fear of hospitalisation, to provide reassurance for their child and to help in the child's recovery

Coyne (1995) found that there are reasons that enhance parents' participation, but that there are also some factors that could inhibit parents' desire to participate. The factors which enhanced parents' readiness to participate are: (1) having a supportive family network and support from other parents (2) parents' willingness to carry out basic nursing care (bathing feeding, toileting, etc.), and (3) parents knowing they have the expertise.

There were five factors that inhibited parents' participation. Firstly, the feelings of loneliness and inadequate facilities provided for them in hospitals. Secondly, the difficulty in getting information. Emphasis is placed on 'clear, honest and open' communication. Thirdly, the possibility of causing harm to the child or putting the child at risk. Fourthly, some parents are reluctant to undertake what they considered nurses' job. Finally, some parents are unhappy when nurses are not flexible in their behaviour and they encourage parental involvement without negotiation of care with them. Then nurses may coerce parents to take on more responsibility than they are willing to (Coyne, 1995).

Coyne (1995) concluded that parents were willing and highly motivated to participate in paediatric nursing activities pertaining to their children's care. Although parental participation was not without problems, nurses should assess parents' willingness and abilities to be involved in the care of the child, minimizing the disruption to family life and routines.

Callery and Luker (1996) interviewed 24 parents whose children had been discharged from a surgical ward in a children's hospital. These authors wanted to measure parents' satisfaction with child care. They found that parents were often reluctant to express outright criticism from the beginning. The results were that mothers were able to judge the technical quality of their children's care. Parents also indicated their willingness to be with



the children despite the personal and financial cost. The reasons for staying in hospital with their children were both for the emotional well-being of the child and for the parents' own reassurance. Some of the mothers also thought that there were not enough nurses to ensure the care of their children and they felt that they had to stay there to assure their safety and their comfort.

Neill (1996a and 1996b) undertook a study, investigating parent participation in the care of children in hospital. Prior to her main study, Neill carried out an extensive review. She concluded that the findings from several studies were consistent in three aspects: (1) parents want to be involved in the child's basic care; (2) they believe it to be beneficial to the child; and (3) parents want more information related to their child's illness and treatment. Neill also pointed out that there were various arguments for parental participation. The presence of parents is important for the child. Participating parents felt that they were able to continue their parental role. They had the opportunity of accessing more information on the child's progress and this was also better for parents following discharge. Parents also found some benefits for nurses because the involvement of parents in hospital helps nurses with their jobs.

Neill (1996) identified 5 major areas that could inhibit or facilitate parent participation. The first area is the parents' view of the nurse's role. If parents do not see nurses as facilitators of their participation they will not try to participate. The second area is professionals' attitudes. Parents find it difficult to collaborate when professionals have paternalistic attitudes, they give the impression of always being too busy or parents have the feeling of having lost their role. The third is communication. The quality of communication between parents and health professionals will influence parent's participation. The coping mechanisms used by parents during their child's hospitalisation also have a great influence in their participation. The last area is lack of support for parents. Parents in this study found the facilities available to them in the ward environment inadequate. Facilities need to be provided for parents, if they are to be participators in care.

Referring to the aspects of care in which parents want to be involved, Neill stated that parents would like to be involved in those aspects of care basic to the child. Parents

preferred professionals to be in charge of the child's medical care and they wanted to discuss and negotiate the extent of their involvement with professionals.

Kawik (1996) investigated the ways in which parents could be involved in hospital wards by surveying 65 nurses and interviewing 12 parents following their discharge from hospital. Her aim was to determine if parents were able to participate in the care of their hospitalised child and work in partnership with nurses. She discovered that parents were willing to be involved in the child's care, but they experienced difficulties because of the inadequate information they received to help them to do it. She also described that nurses were reluctant to relinquish control of nursing care. Therefore, she ended with the idea that the nurse/parent relationship did not always tend towards an easy partnership.

Kristensson-Hallström, Elander and Malmfors (1997) conducted a study on parents and children undergoing surgery in a day-care unit. The purpose was to assess possible benefits of increasing parental involvement in the care of their children. The authors discovered that parents were well prepared to care for their children. Moreover, children in the intervention group appeared to experience less pain, and fewer children vomited post-operatively than those in the control group. Cleary also found that parents are willing to stay with their hospitalised child in the unit in order to provide care and emotional support (Cleary, 1992)

### **2.3.3. Relatives involvement**

Åstedt-Kurki, Paunonen and Lehti (1997) surveyed 50 family members of adult patients receiving treatment on the acute neurological ward in Finland. The aims of their study were to determine how much time the family members spent in hospital, how they felt the family was supported, if the staff talks with them, the type of help that every family member needs and what kind of experiences family members had in general. They found that family members spent a lot of time with their relatives in hospital. 65% visited the hospital on a daily basis and 68% of the visits had a duration of 1 to 3 hours. An important source of support is keeping family members informed. Only 25% of the relatives saw doctors, only in passing, without having a real opportunity of talking to them. About one third of the family members felt that nursing staff showed an interest in the families' well-

being, and one quarter was told what they could do in hospital. Family members expressed their need for help from nurses and slightly less so from doctors. They conclude that it would be important for nursing staff to facilitate the incorporation of relatives into the process of nursing.

Bluebond-Langner (1996) explored the world of children suffering from chronic life-threatening physical illnesses. She turned her attention to parents and siblings of children with chronic illnesses. She suggested that understanding the impact of the illness lies not only in identifying deficiencies in the lives of those affected, but in appreciating how family members carry on with their lives. Bluebond-Langner (1996) collected information from nine families following an ethnographic approach. She studied the view of the illness, the meaning it has for the family and how parents, healthy siblings and the ill children themselves struggle to contain the intrusion of the disease into their lives. Again, this study reinforces the importance of caring for all the family members.

#### **2.3.4. Family-centred care**

Family-centred care seems to be a central element of children's nursing. However, there is not consensus about its meaning, causing ambiguity and confusion (Coyne, 1996; Hutchfield, 1999; Nethercott, 1993).

There has been in the literature an attempt to clarify concepts such as family-centred care, partnership with parents, parent's involvement and parent participation (Ahmann, 1998; Coyne, 1996; Hutchfield, 1999; Nethercott, 1993; Shelton and Smith Stepanek, 1995). Some of these authors (Coyne, 1996; Hutchfield, 1999; Nethercott, 1993) used the method of concept analysis of some of these terms attempting to increase understanding of them. Coyne (1996) defined concept analysis as

'...method of concept clarification which aims to increase the understanding and facilitate communication about phenomena'

(Coyne, 1996:734)

In 1993, Nethercott attempted to clarify the concept of family-centred care and stated that nurses should fully understand this concept prior to implementation, so that

family needs are met and not just the ward goals. She summarised briefly the origin of family-centred care and defined the terms parental involvement, parental participation and family nursing. She stated that theories of nursing were mainly developed for 'use with children' and not for meeting the specific needs of children and their families. Nethercott claimed that the level of skill of the professional is crucial to implement family-centred care. The nurse should be '*an* expert and not *the* expert' recognising the knowledge and skills of the family in their child's care. She concluded that family-centred care is a major change from traditional paediatric nursing practice.

Nethercott was later criticised by Hutchfield (1999) because although she acknowledged the importance of viewing the family in context and respecting family diversity, she did not give any emphasis to the strength that parents have as having the expertise of their children.

Hutchfield (1999) made a concept analysis of 'family-centred care'. The author reviewed numerous articles and books that were written in the USA and the UK about family-centred care in an attempt to clarify its definition. According to her review the articles published in the USA demonstrated a much clearer conceptualisation of family-centred care.

Hutchfield explained that, in USA, Shelton et al in 1987 marked a new era for the family-centred care developing a framework in collaboration with parents to care for families with children who had special education needs. Their framework had been developed by others to care for chronically and critically ill children, whereas in the UK family-centred care has been developed primarily in the acute hospital setting. Within Shelton et al's context, family-centred care is a philosophy of care where there is a partnership between family and professional, and that promotes normalised patterns of living for the family. However, it is necessary further research to translate this definition of family-centred care into different types of practice because, as they suggested, may not be possible to transfer a framework developed for one setting to another.

The change in the context of the ill children's care resulted in the development of family-centred care in the UK. Children's emotional needs were recognised, and therefore

the presence of parents at the beginning, and their involvement in their children's care later started to be considered as an important factor for the children's well-being in hospital.

Hutchfield (1999) concluded that there are two emerging views of family-centred care. There is an holistic approach of the child and family that is grounded in respect for and co-operation with the family in which the nurse appears as an equal partner and the facilitator of care. There is a more functional and less collaborative view in which the nurse act as a dominant figure in the partnership, deciding the parents' extent of participation and limiting the control of the family of their situation. In both cases, it seems to be clear that the relationship between mothers and health professionals is essential to family-centred care, and thus, nurses require particular knowledge, skills and experience in order to success in the implementation of family-centred care. Hutchfield also found that co-operation, collaboration and negotiated care are not always evident when caring for sick children.

In order to provide a fieldwork element for the process of analysis, Hutchfield (1999) interviewed 24 children's nurses using semi-structured interviews and an unpublished survey, which was undertaken during 1994/1995 on children's nurses. The process resulted in the identification of a lack of clarity related to the consequences of family-centred care. However its antecedents were identified. The attitude of nurses and the provision of adequate resources appeared to be of primary importance. Moreover, being care for by their family should be in the children's best interest. If it is not going to be in the child's best interest to be cared for by the family this model might not be appropriate.

Hutchfield (1999) suggested that further research would be needed to define the positive and negative aspects of family-centred care, how children's nurses should involve parents in the care of their children and how true collaboration and partnership can be achieved.

In 1996, Coyne explored the meaning of parent participation. She wanted to clarify the concept to benefit children and families and to increase the understanding among professionals. Examining British studies from 1969 to 1994, Coyne illustrated how the concept of parent participation has evolved to family-centred care. The studies tended to concentrate on women and their role for child's care, men were mentioned incidentally.

Mothers were allowed to 'room-in' with their children in specially designed units. After that period both mother and father started to be mentioned in the literature, then the expression 'care by parent units' began to emerge. These units allowed parents to stay and participate in their children's care. Then, the importance of other family members were considered and the term parent participation seemed to imply 'family participation' rather than only parents. Parents' participation appeared to be seen as a partnership where the family provides the care with assistance from the nurses. Equality and negotiation are central issues in 'partnership'. Parents and professionals are on equal terms and have mutual respect. More recently, the term family-centred care emerged in the literature. The child was not considered simply as a patient but as a member of a family. The child's care was focused around the children and their families and homelike activities were included in hospital.

Bradley (1996) examined the concept of family-centred care to illustrate the process of nursing knowledge creation. She described in the initial stages a sense of discomfort felt in the nursing practice. Furthermore, parents' pressure and research contributed to change that practice, allowing parents more access to their hospitalised child and caring for their children's basic needs. The consequence is the development of knowledge and practice. Nurses had a better understanding of children's needs and specialised education for paediatric nurses was seen to be important. Then, the research foci changed from exploring stress and dysfunction to family strength and needs. Bradley explained that once the theoretical base has been created, it is necessary to clarify the relationship between theory and practice in order to evaluate the efficacy of knowledge application. This evaluation is necessary to discuss new implications for practice, education and future research.

Ahmann (1988) stated that implementing family-centred care requires a 'change of philosophy, attitude and practice. She explained that in practice there is a conflict between aspects of family-centred care and more traditional models. Ahmann gave an overview of several prevalent models of care: the medical model, the child-focused model, the family-focused model and the family-centred model of care. She explained that the understanding of these models is important to identify the interference of them with family-centred practices. The medical model is focused on diagnosis and treatment and it is the responsibility of the professional to carry out these functions. In this model there is nearly

no acknowledgement of the central role of the family. In the child-focused model professionals lead the assessment but they take into account the needs that they perceive the child to have. The family is seen as an accessory to care. In the family-focused model, although the family members' needs are considered, the professionals tend to take a dominant role. According to Ahmann, in the family-centred care model professionals recognise the central role of the family in the child's life. They also recognise family strength and capabilities, inviting them to participate actively taking into account their preferences and limitations. This requires sharing information openly between families and health professionals.

Betz, Hunsberger and Wright (1994) in a textbook entitled 'Family-Centered Nursing Care of Children' had as its basic premise that the child is best understood and cared for within the context of the family.

## **2.4. Children development**

Piaget's theory of cognitive development has heavily influenced a great part of the literature on children's conceptualisation of health and illness. Piaget's theory has been thoroughly debated, but it has been practically unchallenged in terms of children's illness concepts (Yoos, 1994). Piaget's developmental theory is based on biological maturation, believing that all humans go through stages at differing speeds, dependent on the individual's environment. He assumed that development is an inherent, unalterable, evolutionary process with different developmental phases or stages (Maier, 1969).

Lansdown (1996) drew attention to the fact that it is difficult to ascertain the level of understanding that children have about health and illness. Lansdown also made a differentiation between healthy children's and sick children's ideas about illness.

Brewster (1982) investigated the relationship between cognitive development and children's understanding of 'cause of illness', 'intent of medical procedures' and 'role of the medical staff'. She took a sample of 50 children between the ages of 5 and 12 years old who were chronically ill, hospitalised children. Five cognitive tasks were administered to

each child. All tasks were based on Piaget's work. The author concluded that children's understanding of illness is determined by cognitive and emotional maturation.

According to Brewster (1982) prior to giving information, it is necessary for it to be gathered. Explanations must take the child's conception of the cause of his illness and the reason for treatment into account and guide him/her through the ideas that are new to him/her. She also pointed out that if egocentric thought (the child believe that he/she had done something wrong to cause the illness) serves a defensive need, the staff should be careful not to break down defences unless one is sure that more desirable concepts will occur. Some people choose to blame themselves rather than admit that illness may be cause by mere chance and that nothing can be done to control it. Guilt may serve as a defence against helplessness.

Bibace and Walsh (1980) and Perrin and Gerrity (1981) studied the development of children's concept of illness in the light of Piaget's theory. The former authors, concluded that knowing what children of different ages understand about illness would enable health professionals to develop meaningful ways of explaining illness and to reassure children, for the development of health education strategies and to provide some degree of control over the illness.

Helen Rushford (1996) stated that the theory related to children's concepts of illness and its practical application are both crucial components of a child health nursing curriculum. She claimed that most papers about children's conceptualisation of health and illness are published in psychology medical journals, so the findings of these studies are not being used to inform nursing practice. In 1999, Rushford made a review of the literature on how children's conceptualisation of health and illness develops. Most of the studies were influenced by the work of Piaget. However, more contemporary theorists refute Piaget's theory suggesting that children are able to understand more complex concepts about illness than what was previously thought. She cited Carey and Vygotsky as alternative developmental theories.

Siegal and Peterson (1999) made an important addition to the literature on children's concepts of health, illness and their internal bodies. The first chapter describes children's conceptualisation about biology and health. Different themes, such as children's



understanding of the physician's role and the competence to consent medical and psychotherapeutic treatment, are also considered.

## **2.5. Understanding children's drawings**

In several studies the need for asking children directly about their experiences is suggested (Hart and Chesson, 1998; Strachan, 1993). However, the need for developing sensitive and reliable instruments is also suggested.

An activity such as drawing, which appears to be so natural and spontaneous, can provide an insight into a child's general and basic nature (Cox, 1992). Drawings have been used in the past not only to diagnose and evaluate the child, but also to provide a way for the child to communicate issues, feelings, emotions, fears, and other experiences, as well as to explore, invent and problem solve through self expression (Malchiody 1998). The study of children's drawings is not new. In the late 1970s, for instance, Jacqueline Goodnow (1977) enumerated several reasons for having an interest in studying children's drawings. Firstly, drawings are indications of more general phenomena of human life. Thus, a better understanding of the drawings will result in a better understanding of children and development in general. Secondly, drawings can tell us something not only about children but also about the nature of thought and problem solving among children and adults. A third reason is that a great deal of thinking and communication takes place visually.

Accessing children's ideas is easy in practice. All one needs are drawings that simply take a few minutes to create and all the materials needed are paper and a few coloured pencils. However, drawings provide rich sources of information. Kübler-Ross (1981) used drawings as a means of communicating with terminally ill children. Furth (1988) expanded this technique with people that are not dying, but who nevertheless are helped through spontaneous drawings to express what is within their unconscious mind. This method is very effective with young children, whose capacity for abstract verbal expression is not yet fully developed and thus are most open to the symbolic means of communication represented by spontaneous drawings. Important unconscious psychic contents are conveyed in drawings. If this unconscious content is deciphered it provides information about the individual. Furthermore, drawings can apply to others as well,

especially to the members of the children's family (Furth, 1988). According to Malchiody (1998) children integrate their internal perceptions with their external experiences of the world through art. Therefore, art contributes to their self-discovery and to their relationships with people, environment, and even society.

Some recent studies have used drawings as an effective method for data collection from children. Hart and Chesson (1998) described how adults: parents and health staff, are usually the ones who provide information about children. However, they also highlighted that adult's perceptions of children's responses are not always a reflection of the child's feelings and needs, and therefore seeking children's views is important for the individual child. They claimed that children should be consulted directly. For that reason they suggested different effective methods of collecting data from children. It was their contention that the information obtained from a child's drawings might not be obtained by any other methods. According to these authors drawings have two main advantages. First, emotions repressed from children's conscious minds are often expressed in their drawings in a non-threatening way. Second, drawings inform not only of the psychological condition of the patient but also about the somatic. Additionally, Hart and Chesson (1998) stated that drawing interpretation is a rational way of gaining insight based on firm research. When interpreting children's drawings, account has to be taken of the child's age, stage of emotional and cognitive development, and their level of understanding

Sartain, Clarke and Heyman (2000) argued that children should be considered as active users of health care services and therefore, it is necessary to ask directly about their views and perspectives. Their research was focused on the search for the child's perceptions about their illness and health care experiences. Sartain, Clarke and Heyman (2000) interviewed children from 4 to 14 years old with chronic illness following their discharge from hospital. The interviews were augmented with a drawing technique, which provided a focal point for the interview and helped the researcher establish a rapport with every child. The authors concluded that the use of children's drawings was a successful data collection technique. They also stated that giving children a voice is important to know how children react to hospitalisation.

Sartain et al (2001) undertook a study aiming to compare 40 families experiences of hospital and home care for acute illness in children. Parents and children were interviewed separately. The ages of the children varied from 5 to 12 years old. Children were given the option whether or not to draw. Two themes could be chosen: 'being in hospital' or 'being at home'. During the interviews, the questions were initially focused on children's drawings in order to ease them into the interview situation, exploring any emergent themes from the drawings. Later the interview focused on the 'nicest' and the 'worst' things about hospital and home care. Again, this study reinforces the importance of listening to the views of users and carers to improve the quality of health care systems.

Tamm and Prellwitz (2001) aimed to examine the feelings among pre-school children and schoolchildren towards physically handicapped children using wheelchairs. Forty-eight children aged from 6 to 8 years old took part in the study, which combined drawing, interviews and a self-assessment scale. The children who took part in this study provided a wide range of information concerning their attitudes, ideas and impressions about children with disabilities. Moreover, children were conscious of the physical obstacles that are presented in the surrounding environment resulting in the disabled child becoming isolated from other children. This study is another example of how children's views can be gathered when using appropriate methods during the data collection stage.

# Chapter 3 - Methodology

## 3.1. Introduction

The objectives of this project were to investigate the idea of family-centred care from the parents' and children's perspectives; to find parents' experience of child care in hospital and the differences between theory and practice; to seek parents' views on methods for improving hospital environment and facilities for children and parents.

The subject of family-centred care is extremely complex. It involves asking sensitive questions about the parents' experience of their children's hospitalisation. Quantitative methods are not considered appropriate for this type of research where part of the research is concerned with people's feelings and emotions and children's perceptions about hospital and hospital experience. Qualitative techniques such as interview and focus groups are considered more appropriate. As discussed in previous chapter; methods used by Kübler-Ross (1981), Furth (1988) or Goodnow (1977) among others can also be used in this research to investigate what children think about hospital and about health professionals in general, and what children think about specific medical procedures such as injections or surgical operations.

The theme of children's involvement in decisions has become prominent in recent years. Article 12 of the United Nations Convention on the Rights of the Child has had some impact on the thinking about demands for children to 'have a say' (Thomas and O'Kane, 2000). The Article 12 said as follows:

'States 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.**  
**Convention on the Rights of the Child. United Nations**

Other professional groups, such as social workers, also recognised the importance of asking children about matters related to them. For instance, Thomas and O'kane (2000) stated that children are generally not listened to with the same attention that adults expect to receive. In addition, the concern about their safety tends

to reduce children's autonomy. Frequently opinions of children have not been considered because they have been seen as having insufficient understanding of the general issues, or because they have lacked the competence to cope with what the process involved. Therefore, the information was provided by their families (parents principally) and health professionals who were implicated in their care.

In order to take into account children's wishes and feelings, it is important to have an open-minded commitment to listening to what children have to say about the subjects they want to talk about, and in the ways in which they want to express themselves. Adults have a tendency to ignore children, or talk down to them. In addition, health professionals have a tendency to use technical language which may not be understood by children. Further consideration should be given to the language development of the children. The art of listening can be perfected through experience. It is more difficult to develop new tools which can allow the researcher to enter into the mind-set of children. The area, into which this research falls, is 'hospital experience': what might cause distress to the subjects studied. Taking into account these factors, the tools designed for this project had to be enjoyable from the children's point of view and yet searching. Both of these are very important aspects of the research methodology.

The tools developed in this study will be used to explore what healthy children think about "*being in hospital*" and "*being away from home, from school, from friends and from familiar surroundings*". Separating sick children from their parents and familiar environs has been shown to have detrimental psychological effects, such as emotional trauma and increased anxiety. Being in hospital also implies a change in environment including a change of routine, food, timetables and familiar objects, any of which might be upsetting for children. Therefore, it is important to understand their opinions and feelings when they go to see the doctor or they have to stay in hospital (in the context of being ill). It is also important to find out from children, both with or without previous hospital experience, how they feel about being in hospital, what their worries are, and how hospitals can be made more friendly. Seeking their views, wishes and worries, a plan could be designed to reduce the psychological trauma linked to the experiences of being ill in hospital.

### **3.2. Available methods used in this project**

Quantitative research may be defined as an objective, value free and systematic process in which numerical data are manipulated and analysed statistically (Cormack, 1996).

Qualitative research focuses on people's life histories or everyday behaviour (Silverman, 2001) or people's understandings of the world (Pope and Mays, 1999). Thus, qualitative research concentrates on more subjective narrative materials and the use of words, instead of numbers as quantitative research does. In this study it was very important to gain detailed information about parents' and children's feelings, opinions and experiences of being in hospital.

Instead of considering quantitative and qualitative research as methodological opposites, each is used in this investigation to complement the other. Qualitative research is useful to 'validate' data obtained from quantitative research and sometimes providing a different perspective on the same social phenomena (Bryman, 1988; Pope and Mays, 1999). Qualitative methods might enable the research to get at the affective domains where quantitative methods cannot.

The questionnaires (quantitative method) were followed by the interviews (qualitative method) in order to clarify and complete the initially obtained information. Conversely, qualitative studies could be used as a preliminary approach to quantitative research (Bryman, 1988), which is the case of the children questionnaire. This questionnaire was designed after having several workshops with groups of children and finding out what their worries and concerns were. The use of both approaches within the same study provides a richer and deeper understanding of the phenomenon being studied (Cormack, 1996).

#### **3.2.1. Surveys**

Surveys are a method of social research, and questionnaires are the most widely used survey data collection technique. In this project questionnaires were chosen as a tool that permitted access to a relatively large number of individuals with the least possible cost (Burns, 2000). Questionnaires as a method of data collection have limitations but they can be overcome partly with a careful design and pilot

testing (de Vaus, 1994). Two different questionnaires were used during this research. One of them was designed for the parents and the other for the children.

### **3.2.2. Interviews Versus Focus Groups**

Several quantitative studies in the past have used structured questionnaires. These questionnaires were largely developed from a professional understanding rather than from the parents' point of view. Therefore, it was not possible to establish if the information collected explored issues that really mattered to families or if it was a result of what professionals believed to be of importance (Neill, 2000). Hence, in order to avoid this bias, there was an obvious need for having another method that would be useful to interpret the survey findings (this means to 'triangulate' the obtained data) and to complete the information collected from the questionnaires. Following this a dilemma between using focus groups or interviews arose.

According to Barbour & Kitzinger (1999) focus groups are a method of exploring people's experiences, opinions, wishes and concerns. It is especially useful for allowing participants to create their own questions, frames and concepts, and for finding out their priorities in their own vocabulary. Discussion groups are more useful for examining how such knowledge is used in social interaction than for considering what the content of that knowledge is (Barbour & Kitzinger, 1999). Focus groups are considered suited to the study of attitudes and experiences on specific topics.

An interview is a 'verbal interchange' used by the interviewer with the aim of obtaining information and discovering the interviewee's beliefs and opinions (Burns, 2000). Interviews are classified in three types: unstructured (or open-ended), semi-structured (or focused) and structured.

Having considered the relative merits of interview, focus group techniques and practicalities, it was decided to interview parents instead of organising focus groups for several reasons. Firstly, it was not possible to organise focus group with parents because of various practical constraints. For example, it was not possible to find a time when all parents could be present. Furthermore, it was difficult to find a room where the discussions could take part. Thirdly, some research has shown that it was only in interviews that some respondents gave voice to their discomfort, upset and meaning (Barbour & Kitzinger, 1999). The researcher believes that some parents

would feel more confident sharing information in private interviews rather than participating in focus group. Additionally, with this method there was more time to explore deeply some of the responses that parents gave in the questionnaires.

### **3.2.3. Using drawings as a data collection tool in child research**

As described in the review of literature, drawings have been used in the past not only to diagnose or evaluate the child, but also to provide a way for the child to communicate issues, feelings, emotions, fears, and other experiences, as well as to explore, invent and problem solve through self expression (Malchiody, 1998). It has been said that a great deal of thinking and communication takes place visually, therefore, it was felt that this method was appropriate.

Drawing if used effectively can help young children, especially those whose capacity for abstract verbal expression is not yet fully developed and thus are most open to the symbolic means of communication by means of spontaneous drawings. According to Malchiody (1998) children integrate their internal perceptions with their external experiences of the world through art. Therefore, art contributes to their self-discovery and to their relationships with people, environment, and even society.

Referring to the drawings content, the children were asked to produce their drawings *impromptu* (Furth, 1988) which means drawings are executed on request, on the spur of the moment, without preparation (by contrast, *spontaneous* drawings are done by individuals on their own because they wanted and not because they were asked to do so). In this study several topics were selected for the children, namely: their experiences in hospital (if they had some) or how they imagine a hospital and the type of work that health professionals (in this case nurses) are developing there. Some professionals believe that assigned topics are less useful than children-generated topics. Furth (1988) maintained that “only spontaneous drawings could contain unconscious material”. However, he realised that the unconscious not only reveals itself using spontaneous drawings but is also manifested in pictorial elements and motifs.



### **3.3. Piloting research instruments**

Since a number of new instruments were intended for this study, it was important to pre-test them prior to main data collection.

Parents' questionnaires were piloted in order to eliminate ambiguous questions and to ensure the questionnaire provided the answers needed. The pilot study in this case aimed to examine whether the wording of each question was clear, to study how the respondent interpreted the questions, and to ensure that the range of responses given was sufficient. When possible, a pilot study should be carried out with a small sample group that has the same inclusion criteria as the group that will be included in the main study (de Vaus, 1994; Reid and Boore, 1987).

The intention of the children's pilot stage was to ensure children find methods used for data collection are user-friendly and enable them to express their concerns. Therefore, there were four objectives in the children's pilot study:

- i. Getting to know the school system and the methodologies that are used to teach children. Moreover, it was important to identify the health themes that were included in their curriculum in order to be familiar with them.
- ii. Establishing trust and finding the best way of communicating with children.
- iii. Investigating methods for main data collection.
- iv. Identifying themes with children for the purpose of main data collection.

#### **3.3.1. Questionnaires**

##### **a. Parents' questionnaire**

The questionnaires were structured with forced choice questions but they also had open-ended questions to achieve a better understanding of parents' perceptions since in these questions every participant can formulate their own answers.

The total number of questions was 31, and some of these contained a set of filter (Bowling, 1997) or contingency (de Vaus, 1994) questions depending on the answer given. Filter questions which did not apply to some respondents were clearly labelled,

and respondents were directed to the next appropriate question. This increased the number of items up to 40. The use of filter questions is very useful as it assures that questions are relevant to each participant (de Vaus, 1994). Six of the items were open-ended questions, which aimed to offer respondents an opportunity to discuss issues and personal concerns in their own words. The other items were closed questions with structured answers. 15 of them offered two possible answers ("yes/no") and asked for clarification with the aim of having a more complete view of the parents' feelings and a better understanding of them. Finally, there were 19 questions that had several options to tick, offering the possibility of adding new options.

This type of questionnaire design attempted to overcome the different disadvantages of each sort of question. For example, it is well known that answers linked with closed questions are pre-determined by the researcher and can create false opinions if the options are not broad enough. However, according to de Vaus (1994) these questions are quicker to answer and this is very important when questionnaires are long or the participant's motivation is low. de Vaus (1994) also stated that although open-ended questions are more difficult to analyse and time consuming, they are more appropriate for obtaining general ideas of the phenomenon and giving participants the opportunity to answer in their own words.

Five different sections can easily be differentiated in this questionnaire (See Appendix A). The section on personal and social characteristics provides the necessary data for identifying possible associations between responses and differences in age, gender and socio-economic status. These data were assessed at the end of the questionnaire because relevant bibliography suggests that sensitive questions such as occupation or age should not be addressed at the beginning of the questionnaires, and that it is better to start asking easy questions that tend to motivate participants (de Vaus, 1994). The other four sections contained a variety of question formats in order to ensure that the questionnaire remained interesting.

Taking into account the fact that participants would answer these questionnaires at home, it was important to be aware of the risks of non-response. Also taken into consideration was the fact that parents' motivation might not be optimal. Thus, the format of these questionnaires was simplified and their length reduced in an attempt to address this potential problem.

The pilot study was carried out in December 2000. Questionnaires were distributed to 50 employees in a nursery school. The response rate of the pilot study was 10%. In addition, the play ladies working in this nursery and the teachers working in Chester-le-Street Junior School were also asked to give their perspective about the questionnaire.

The questionnaire did not present any major problem. There were no particular questions, which got a high non-response rate. Most of them were properly answered. Participants correctly followed filter questions (Bowling, 1997) and when they were asked for comments, the obtained responses were also high. (See final questionnaire in Appendix D). However, some minor issues were identified and the questionnaire was amended as follows:

- The general structure of the questionnaire was modified by being printed out on both sides of the sheet (instead of one side of the sheet) with the aim of decreasing the number of sheets used.
- The section on 'socio-demographic' questions was modified at the Head Teacher's advice:
  - The question about marital status was eliminated because she considered that it could be a sensitive question and might decrease the response.
  - The occupation was specified as optional for the same reason.
  - The postcode was eliminated with the idea of reassuring the confidentiality.
- Question 4 was reworded since responses showed that it was not clear enough for the participants. It asked 'Can you imagine what it is like to be a patient in a children's ward?' and it was reworded as 'How do you think a patient in a children's ward feels?'
- One of the items in question 21 was also modified because parents showed their uncertainty about what it was referring to. The item was 'Parenting' and the new term was 'Parenting advice'.
- Another item on 'giving rectal medicine' were removed because the head teacher thought that it was inappropriate.

## **b. Designing children's questionnaire.**

The questionnaire for the children was designed based on the results derived from activities undertaken described in section 3.3.2. In order to establish clearer and more specific information three themes were chosen:

- *"Being examined by doctors"*: Examining by doctors is one of the first few procedures which children in hospital will experience. Depending on the nature of the child's illness, the same procedure may be carried out every day or repeated many times during the day. Therefore, this was considered a relevant topic to choose.
- *"Being given injections"*: This theme arose from the pilot testing study. Any time they were talking about hospital, being ill, etc., one of the most general concerns was about being given injections.
- *"Being given medicines"*: All the professionals that have worked with children know the difficulties that sometimes occur when the children are asked to take medicines. It is important to reduce children's stress towards medication. By knowing how the children feel about having medicines, health professionals would be able to reduce stress by providing a better adaptability to the treatment.

The total number of questions was 28. One of these questions contained a filter question and three of them were divided in two parts. This made a total of 32 items. Five of these items were open-ended questions. The other items were closed questions with different options to tick. 23 of them offered two possible answers ("yes/no"). Finally, there were 4 questions that had several options to tick.

The design of the questionnaire for children had to combine style and contents in order to get a friendly 'tool' that the children were able to complete. With this purpose it was printed using colours. Moreover, pictorial elements were incorporated to attract children's attention, thereby facilitating their understanding (Appendix G). La Greca (1990) suggests cartoon drawings generate interest in general.

It has been previously explained that closed questions can create false opinion if the options are not properly broad. However, it has been proven that it is better to avoid the use of complex questions with a wide variety of options when directing questions at children. Several authors expressed (Chomsky (1969), Ervin (1964),

Landau (1982) and Smith (1926), all cited by La Greca, 1990) that some changes in syntax and semantics continue to occur during the elementary school years. Hence, it is very important when designing a questionnaire for children to use a language suitable to children's vocabulary and reading abilities.

Initially, the questionnaire was designed with the idea of carrying out some interviews with the children once the data had been analysed. The interviews were going to take place in an effort to clarify the answers that the children gave within the questionnaires. After discussing this issue with the head-teacher it was decided to abandon the intended interviews in order to protect the children from possible psychological trauma.

### **3.3.2. Working with children in health and hospital issues**

The research tools were piloted at Chester-Le-Street Junior School. The school was chosen due to previous association between the head teacher and the Centre for Health Studies as well as because of the school's interest in health matters. This school is a Church of England Voluntary Controlled School situated in Hilda Park Estate, which is on the outskirts of Chester-Le-Street, in the north of County Durham. The school was opened in January 1969 and was the first semi-open plan school built in the area.

The school is organised into 8 mixed ability classes. They are grouped into year groups. Usually children in each group are equally distributed into classes; for example, there are two classes in each of Year 3 (aged 7-8), Year 4 (aged 8-9), Year 5 (aged 9-10) and Year 6 (aged 10-11).

The following programme of action was adopted after an initial meeting with the head teacher of the school. The idea of having a 'Spanish Club' at lunchtime would be regarded by the school as an extra-curricular activity that was free for those who decided to participate. It would be welcomed by parents. More importantly from the researcher's point of view it was a means of getting to know the school and the children. It would enable the researcher to understand the language that children use and to explore ways of discussing more complex issues relating to health and illness.

Every teacher offered the children in his or her class the possibility of joining the 'Spanish Club'. The children were enthusiastic about the club. The number of

volunteers was high, and thus, the teachers chose those who would take part in this activity. The result was 4 groups, one from each year. Two of these groups had ten children each and the other two had twelve with an equal proportion of boys and girls in each group. Later a fifth group of 12 children joined the club due to the interest that the children showed in learning Spanish.

Five workshops took place within the Spanish Club at Chester-le-Street (See Appendix E for more information about Spanish Club). The themes chosen were (i) food, (ii) sports, (iii) professions and (iv) the family. Each session was divided into 2 parts: in the first 10-15 minutes the main aim was teaching Spanish, and the last 15 minutes were used to collect data about general issues in health and lifestyle connected with the weekly theme. The workshops were designed with the same structure for all the age groups, but in fact, they were changing depending on the participation, collaboration and abilities that the children showed. Firstly, the method used was group discussion, trying to get information from the group. Other methods were used during the following two weeks: drawing and writing. The aim of the writing activity was to know their writing ability and how far they are able to describe a situation that they had previously experienced. Likewise, as it has been described before, drawings are very effective means of communication with young children, whose capacity for abstract verbal expression is not yet fully developed.

The methods of collecting data were not just chosen because of their utility for obtaining information from children. They needed to fit with the children's academic curriculum, trying to continue in a similar sense to the development of their curricular skills (those are verbal communication, writing exercises and drawing ability).

Some limitations were identified during the piloting process:

- First of all, the time of day in which the sessions took part. It was just after lunchtime, following a tight morning schedule. They finished classes at 12, and then they had lunch. The Spanish Club was from 12:30 to 13:00 after which they had their regular classes. The time used for the Spanish Club clashed with their scheduled rest period after lunch. This was the reason why some of the children gave up the Club. However, it was the only time slot that was available.

- Another limitation was the room in which the work with the children took place. The library was allocated by the head-teacher. The problem is that the school is an open plan school and the library is a thoroughfare. Constant interruptions were experienced and children were distracted.
- As the researcher had no previous experience of teaching primary school children it was not easy to manage them, especially those who tended to misbehave.

However, researching with children had positive aspects as well. Children always tend to tell the truth and do their best if they feel that somebody is concerned about them. Sometimes adults overprotect them thinking that they will not be able to understand some situations or to respond to questions. Children collaborated explaining what they felt without fear.

### **3.4. Sample**

#### **3.4.1. Parents' questionnaire**

There were 132 questionnaires distributed. The teachers oversaw the distribution of the questionnaires. They gave them to the children, who were in charge of giving the questionnaires to the parents. The children would also be responsible for bringing them back upon completion. The total number of questionnaires returned was 88.

#### **3.4.2. Interviews with parents**

Invitation to 30 parents consented to being interviewed at the survey stage was sent by the head-teacher. Only those parents whose children had been in hospital at least once were included. 10 parents were selected.

#### **3.4.3. Children's questionnaire**

School-age children were chosen as the focus of this research because according to the literature (Betz et al, 1994; Maier, 1969) children between the ages of 7 and 11 are far more skilful with language than younger children. They are more likely to say what they think without inhibition. La Greca (1990) stated basic

linguistic skills are acquired between one and five years of age. During primary school there is a refinement of these basic skills, and thus, the communication with the researcher was enabled.

Written permission was obtained from parents by the head teacher for the selected children. From the 88 parents that brought the questionnaire back, there were 68 that gave their authorization. 55 out of 68 completed the questionnaire.

#### **3.4.4. Children's drawings**

56 children were asked during the 'Spanish Club' if they would like to draw. Two of them refused the invitation to draw because they preferred to go to the playground. A total of 54 took part in this part of the project.

### **3.5. Main data collection**

#### **3.5.1. Parents' questionnaires**

Every questionnaire had an identification number in order to assure the anonymity, as well as an introductory paragraph that explained the aims of the questionnaire (See Appendix C). The sheet guaranteed the anonymity of the participants and the confidentiality of the data. Moreover, every questionnaire had an introductory letter written by the head teacher of Chester-le-Street Junior School (See Appendix B). The head teacher thought that parents would be more co-operative if the school were to distribute the questionnaires for the researcher, thereby showing the approbation of the school and asking the parents for their voluntary participation.

#### **3.5.2. Interviews with parents**

Ten parents were interviewed individually using the semi-structure interviewing technique. The purpose of the interviews was to find out what parents thought about their experience of having their child/children in hospital. The conversation was free following, thus allowing the parents talk about their personal situations and what mattered to them. An interview guide was developed. This was done without fixed ordering or fixed wording of questions. However, the interview was guided by the researcher in order to be sure that the crucial points of the study were not omitted.



Burns asserts that semi-structure interviews 'permits greater flexibility than the close-ended type and permits a more valid response from the informants' perception of reality' (Burns, 2000: 424).

The contents of the interview were extrapolated from the results of the questionnaire survey and the issues requiring discussion were:

- Collaboration between health professionals and parents
- Parents feelings and opinions about the hospitalisation
- Children's feelings and opinions about the hospitalisation
- Parents expectations of health professionals
- Caring for the family while staying in hospital
- Support received from the Health System

The purpose of the interview was explained to each parent before starting. They were also told that they could freely withdraw from the interview at any time. Initially, a broad-brush question was asked: 'Could you talk about the experience of your child being in hospital?'. Then, more in-depth questions were asked as time went on and as opportunities arose.

It was decided that all the interviews, with the permission of the parents, would be recorded, as it would allow the researcher to take an active part in the discussion. However, sometimes non-verbal activities were registered, as they were useful in the data interpretation. All the interviews were transcribed verbatim in order to facilitate their analysis.

Literature explains that the location for an interview ought to be governed by the principle of naturalism. This is in an environment which might be a natural one for the informant (Sapsford & Abbott, 1998). In this study the choices were limited. The interviews took place either in the school or in the informant's own house. Seven of the interviews took place in the school and three were held at the participants' homes. Interviews that took place in the school presented several problems, due to the fact that they were allocated in the teachers' common room, being sometimes interrupted by teacher traffic. Neither did parents feel entirely comfortable in the common room. Private homes proved to be the best location. Parents felt really secure and relaxed, resulting in a more fluent conversation.

### **3.5.3. Children's questionnaire**

The questionnaires were distributed to the teachers, who gave them to the children, in February 2001. They took the questionnaires to their homes because in this way parents could examine the type of questions that were asked. The questionnaires had an introductory letter for the parents (See Appendix F) explaining once more the aim of the research, asking them not to fill out the questionnaire and not to interfere in their children answers. Their right not to take part in this activity was explained. The children's questionnaires were returned to the school upon completion.

### **3.5.4. Process of obtaining data from drawing**

The researcher always stayed with them while they were drawing, avoiding interrupting them in the process and in some cases keeping notes of what they were saying.

It is note worthy to describe the materials used during this activity. Firstly, the paper was standard white typing. The size was A4. According to Furth (1988) if the paper is too large it is difficult for a child to handle, and if it is too small, a child's manual dexterity may not be developed enough to express his or her ideas within such limited space. Therefore, A4 was used. The children could choose the direction in which they wanted to draw, either horizontally or vertically. Furthermore, they were supplied with sufficient drawing materials. Standard coloured pencils and felt pens were made available, as well as graphite pencils and erasers. They freely chose the material that they preferred to use.

The verbal directions given to the children by the researcher for drawing were 'I'm a nurse. I work in a hospital with children. I would like all of you to think about me working in the hospital helping children who are ill. Could you draw something about that?'. One of the criticisms may be that the products from the children may be biased towards the idea of a 'nurse' or it may be biased towards the researcher. Children may be personalising the researcher when producing their drawings. However, children needed a prompt and it was necessary in order to get them involved and to have a sort of identification with the topic selected. Some of the children did not know what to draw, but they were allowed time to think for

themselves after the initial suggestion. If they seemed lost then a specific suggestion was given such as 'Have you ever been in hospital? Could you draw what happened when you were there?'

When collecting drawings children were asked to put their names and their class group, in an effort to ensure an accurate interpretation.

Although it is very important to give the children ample time to draw during the 'Spanish Club', time allocated was limited to 30 minutes and the children had to return to their school routine promptly. As a result, some drawings were incomplete. Therefore, some important details could be missing from some pictures.

### **3.6. Data analysis**

#### **3.6.1. Questionnaire**

Since this study included quantitative and qualitative data, different modes of analysis were necessary. A total of 129 variables were coded in the parents' questionnaire and 31 in the children's questionnaire. Content analysis of the qualitative data was undertaken (Miller and Dingwall, 1997). Descriptive statistics were used mainly for the quantitative part of the study. Moreover, comparative analysis with non-parametric tests was utilized (Reid and Boore, 1987). Chi-squared analysis or Fisher exact test were used in analysis that entailed comparisons of proportions in order to establish any significant differences between the data. SPSS for windows version 10 was the statistical package used for the analysis of the surveys.

#### **3.6.2. Interviews**

The interviews were analysed using 'Content Analysis'. According to Bauer and Gaskell (2000) content analysis is 'a technique for making inferences from a focal text to its social context in an objectified manner'. They use the term 'objectified' referring to methodical and organized procedure that can be reproduced at any time. Content analysis is a useful indicator of worldviews, values, attitudes, opinions, prejudices and stereotypes and, consequently, the comparison of different communities (Bauer and Gaskell, 2000). Although content analysis could have some

weakness, it was chosen because it is a systematic and public method that uses raw data as it naturally occurs. It can also deal with large amount of data. When using content analysis, the researcher goes beyond what is said and infers the meaning of something (Morse, 1994). This analysis requires intensive labour.

The transcriptions were studied carefully, noting recurring themes. These themes were coded and classified into 7 categories: facilities for parents, facilities for children, procedures inducing anxiety, health professionals, information-communication, participation in the child's care, and home versus hospital. An experienced researcher helped with the development of the categories and the association between them. Quotes will be used in the following chapters to represent the range of responses.

### **3.6.3. Drawings**

In this study, 42 drawings were analysed by the researcher. It is recognised that there is a danger of interpreting children's work from the adult perspective, as an adult, one cannot possibly understand what children think. There are numerous aspects that one should consider and there are no fixed rules for interpreting images. Indeed, it is difficult and almost impossible to read other people's thinking unless what they mean is expressed verbally. Malchiody (1998) stated that adults sometimes wrongly react to children's drawings because it is difficult for adults 'to see children's drawing with anything but their adult eyes'. She also advised using a phenomenological approach in order to avoid imposing an adult standard on children's work and making assumptions about content and meaning (Malchiody, 1998). This phenomenological point of view is based on being open to the several meanings that drawings could have, paying attention to the context where drawings are created, and trying to perceive the children's world view. Therefore, the study of the drawing should be done from many perspectives.

However, Furth (1988) states that 'hearing with the eyes is a formidable task, but it is, in fact, the person who approaches picture analysis with apprehension who will most probably succeed in it'. Furth assures that there is only one rule for pictures interpretation and that is 'to know that one does not know'. The same idea was expressed by Malchiody (1998) who declares that the first step in working with

children's drawing is 'taking a stance of 'not knowing''. She also argued that in deciphering drawings, there are no completely erroneous theories; rather all of them contribute to understanding children's work. Besides, simple explanations of drawings are not always possible because many elements and experiences come together in children's creative work.

The drawings were grouped under various themes in an effort to complete the information about what children think of being in hospital. It was an analysis of content more than an interpretive approach, which is a very difficult task for a beginner researcher.

### **3.7. Reliability and validity**

There are limitations with the tools used in this research even though they have been piloted and shown to have yielded the data required for the research. Exploring health and illness through drawing is a relatively new field. Inevitably there will be mistakes made by the researcher because she is a novice in this field.

The validity of an instrument is the extent to which it measures what it is supposed to measure. In other words, validity gives information about how well an instrument measures the area of interest, its empirical indicators or previous theories (Burns, 2000).

In this case, in an attempt to enhance the validity of the instrument, different strategies were followed. Questionnaires were designed specially for the study according to the specific objectives determined. In addition to this, an exhaustive literature review guided the construction of questions, and an expert researcher reviewed the questionnaires. Another technique to improve internal validity is 'triangulation'. Triangulation consists of the use of two or more methods of data collection to find out whether they corroborate one to another (Burns, 2000; Silverman, 2001). Interviews were used to triangulate the data from the questionnaires.

Reliability of a tool is the grade of consistency with which this tool measures the aspects that it is supposed to be measuring (Polit and Hungler, 1991). Dependability, stability, consistency and accuracy are synonyms of reliability (Burns 2000). In other words, reliability is ensured when it is used in different sites with

similar characteristics, and the results are similar. In this case, the reliability of this instrument has not been properly tested due to time restraints and the availability of only one researcher. The pilot work was carried out in an attempt to enhance the reliability of this instrument and an expert researcher supervised the research process.

### **3.8. Ethical issues and access**

It is crucial not to cause unnecessary distress to parents and children. Therefore, every effort was made to minimise any psychological, emotional or physical risks associated with the study (Polit and Hungler, 1991).

Permission was sought from the school governors via the head teacher prior to the commencement of the project. Written consent was sought from parents for their permission to allow their children to take part in the Spanish Club and the research project.

At the beginning of each parent interview, explanations were given to the parents and they were also informed that they could terminate the discussion during the process without needing to give any explanation. Moreover they were reassured that their privacy would be respected.

Every questionnaire, the interviews, the drawings and the consent were coded in order to ensure the anonymity and confidentiality. Throughout the period of data collection, data was stored in a closed drawer in the researcher's study and nobody, except the researcher and the supervisor, had access to them.

# Chapter 4 - Findings

## 4.1. Introduction

The results obtained from the responses of parents and children as they related to the study aims, provided both qualitative and quantitative data useful for the exploration of families' and children's experiences in hospital.

### Response rates

132 parents were involved in the questionnaire survey. A total of 88 questionnaires were returned. The response rate was 67%. One of them was discarded because the questionnaire was returned uncompleted. Children's questionnaire response rate was higher, 81% (See Table 4.1).

**Table 4.1. Sample, participation and response rate**

<b>Methods</b>	<b>Sample</b>	<b>Participation</b>	<b>Response rate</b>
Parents' questionnaire	132	88	67%
Children's questionnaire	68	55	81%

30 parents met the inclusion criteria to take part in the interview. In the end only 10 were able to take part. It was the end of the term and all the interviews had to take place within one week. Some of the parents could not come because of work commitments. Mothers and fathers were both invited to participate but only mothers attended.

The drawings, as it has been previously explained, were created during the Spanish sessions. All 56 children took part in this exercise but only 42 drawings were usable.

## 4.2. Sample characteristics

### 4.2.1. Socio-demography

#### a. Parent's Survey

The demographic characteristics of the sample are summarised in Table 4.2.

**Table 4.2. Socio-demographic characteristics of parents in questionnaires and interviews**

Characteristic:	Survey Frequency (%)	Interviews Frequency (%)
<b>Gender</b>		
Female	76 (97%)	10 (100%)
Male	2 (3%)	0
<b>Age</b>		
25-29	6 (8%)	0
30-35	31 (38%)	3 (30%)
36-40	26 (32%)	4 (40%)
>40	18 (22%)	3 (30%)
<b>Number of children:</b>		
1	10 (12%)	0
2	52 (64%)	8 (80%)
3	16 (20%)	2 (20%)
4	3 (4%)	0
<b>Employment status</b>		
Full time	18 (22%)	2 (20%)
Part time	39 (48%)	4 (40%)
Self-employed	3 (4%)	1 (10%)
Unemployed	10 (11%)	0
Economically inactive	11 (15%)	3 (30%)
<b>Occupation</b>		
I Professional	6 (9%)	0
II Managerial and Technical	14 (20%)	2 (22%)
III <sub>n</sub> Skilled non-manual	19 (28%)	3 (34%)
III <sub>m</sub> Skilled manual	3 (4%)	0
IV Partly skilled manual	4 (6%)	0
V Unskilled manual	4 (6%)	1(11%)
Housewife	10(14%)	2(22%)
Civil servant without more explanation	9 (13%)	1(11%)

Although both fathers and mothers were encouraged to complete the questionnaire, the sample consisted primary of women (97%), which appears to be consistent with a Neill's (2000, p. 823) findings, in that mothers were the main providers of data and fathers formed only a very small proportion of the samples.

As shown in table 4.2 the ages of these mothers were classified within four divisions. Most of the parents (70%) were between 30 and 40 years old. Approximately, 8 % were



between 25 and 29 years of age and 22% of them were over 40 years old. They had a mean of 2.5 (SD±0.67) children with a minimum of 1 and a maximum of 4. The average age of their children was 8 years old (SD±3, 1-18). Most of them (60%) were between 7 and 11 years old.

48% of the parents work part time. 22% have a full time job and 4% are self-employed. The unemployment rate in this group of parents is 11%, and 15% are economically inactive. If the sample is separated by gender we can observe that 100% of male individuals work full time while the females work mostly part time (49%) however, 20% work full time. Comparing this with the census of 1991 we can notice that the numbers of mother that work part time in this sample is higher than in the female group described in this census (49% in the sample versus 22% in Chester-le-Street census). Conversely, the number of full time working women is lower (16% less in the research group). The percentage of females who are economically inactive (35% in the census and 15% in the sample) is also lower. The unemployment rate is nearly double among the individuals in the sample compared with the total of females in the Chester-le-Street census (11% and 4% respectively).

The valid answers concerning occupation were classified into the Standard Occupational Classification as follows:

- I Professional occupations (doctor, engineer, lawyer, etc.)
- II Managerial and Technical occupations (nurses, teacher, etc.)
- III In Skilled occupations non-manual (nurse assistant, secretary, shop assistant, etc.)
- III m Skilled occupations manual (carpenter, butcher, etc.)
- V Partly skilled occupations (drivers, postman, etc)
- V Unskilled occupations (cleaner, labourer, etc)

(Office of Population Censuses and Surveys, 1995)

The researcher decided to create 2 additional categories: housewife and civil servant. Due to the fact that most of the individuals in the sample were women, it was important to know the number of them that stayed at home and could spend more time taking care

of their children. The 'civil servant' category was created because a number of parents that provided an answer to the occupation question failed to give adequate information in order to classify them more specifically.

Those parents occupied in managerial and technical or non-manual positions constituted 20% and 28% respectively. The percentage of individuals in professional occupations was 9%. 14% considered that their occupation was housewife and 13% were working as civil servants.

#### **b. Interviews**

Although both fathers and mothers were invited to the interviews, only mothers responded to the call to participate in the interview, a point consistent with the questionnaire. The percentages are quite similar to the ones obtained from the questionnaires (See table 4.2). The women were mainly between 30 and 40 years old (70%), and 30% were above 40. They had an average of 2.2 (SD±0.42) children with a minimum of 2 and a maximum of 3. The subjects interviewed had similar employment characteristics to the sample from the survey, except for the group of 'economically inactive'. This group had a rate two times greater than in the mothers interviewed (30% versus 15% in the questionnaire). Moreover, the rate of self-employed was also higher in the mothers who came to the interview (10% versus 4%). The difference in percentages (higher proportion of mothers 'economically inactive' and 'self-employed') might be due to the fact that mothers who are in these groups can more easily organise their timetable in order to be able to come to the interviews. Their occupations are mainly in the sector of 'managerial and technical' (22%) and in the sector 'skilled non-manual' (34%). Approximately, 22% are housewives.

#### **4.2.2. Previous experiences in hospitals**

##### **Number of children in hospital, number of hospital admissions and length of hospitalisation**

The parents who took part in this study had had their children in several hospitals in the North East of England (Durham, Newcastle and Sunderland).

It was relevant for this study to have information about the previous experiences that parents had in hospitals. The first section of the questionnaire was designed to meet this aim. Most of the parents (88.5%) had been in hospital themselves and almost all the parents (97.5%) had been in hospitals as visitors. Moreover, 73.6% of parents had visited a paediatric ward. A total of 55 parents (63%) had had their children in hospital.

The respondents of the survey who had spent some time in a hospital had an average of 1.6 (SD±0.65) children. The mothers interviewed had a similar average 1.40 (SD±0.52). There also was no significant difference in admission rates between the survey cohort and the interview cohort. (2.32 (SD±1.17) for subjects in the survey and 2.60 (SD±1.35) for those interviews). The main differences were found in the average of length of hospital stay which was longer in the children of the interviewed mothers (7.8 days (SD±12.6) versus 4.1 (SD±4.5)) (see Table 4.3).

**Table 4.3. Number of children in hospital, number of hospital admissions and length of hospitalisation**

	Survey Mean(SD)	Interviews Mean(SD)
Number of children in hospital	1.6 (SD±0.65)	1.40 (SD±0.52)
Number of hospital admissions	2.32 (SD±1.17)	2.60 (SD±1.35)
Length of hospitalisation (days)	4.1 (SD±4.5)	7.8 (SD±12.6)

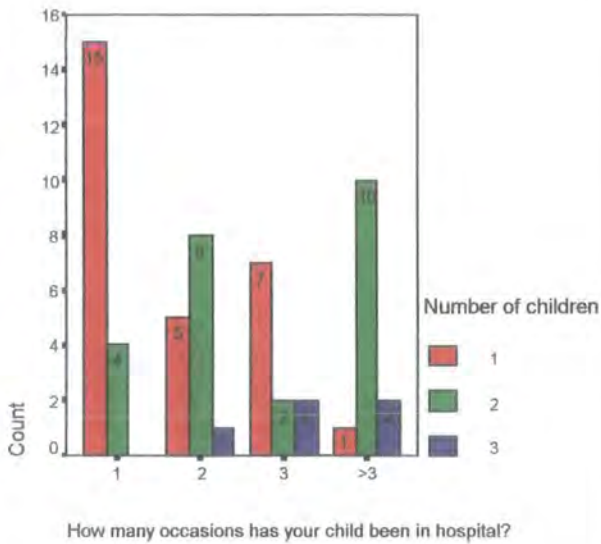
As can be observed in Table 4.4, nearly 27% of the survey respondents had just one child hospitalised and on only one occasion. This percentage is similar to that of the interviewees (30%). The most important difference between the subjects in the questionnaire cohort and the interview cohort is that mothers interviewed had two children in hospital which is three times higher than that in the questionnaire cohort (40% versus 18%). 14% of the parents that replied to the questionnaire had two children having admitted to hospital twice. 21% of them had one child that was hospitalised on two or three occasions versus 30% for the mothers that took part in the interview cohort. The remaining 20% had a varied number of children in hospital with different number of hospital admissions (see figures 4.1 for more data).

**Table 4.4: Number of children in hospital compared with the times that they went in**

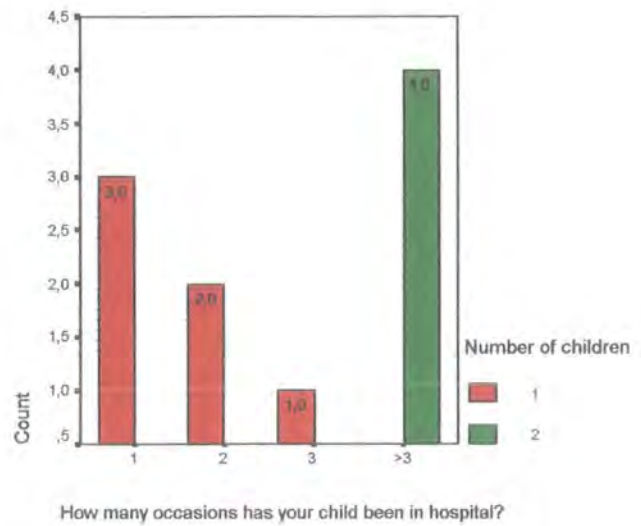
	Survey (%)	Interviews (%)
One child on one occasion	27	30
One child on two or three occasions	21	30
Two children on two occasions	14	0
Two children in hospital more than three times	18	40
Other	20	0

**Figure 4.1: Number of children in hospital compared with the times that they went in.**

**Figure 4.1.1 Survey Respondents.**



**Figure 4.1.1 Mothers Interviewed**



### Reasons for hospitalisation

55 parents gave a total of 76 reasons for the hospitalisation of their children. The reasons for being admitted to hospital were categorized according to the International Classification of Diseases Revision 9 (ICD9) (See table 4.5). One of the categories - 'Pregnancy/ childbirth/ puerperium'- was not used because it was inappropriate for this group of children. 5 parents (6.6%) did not specify the reason for their children's hospitalisation.

The reasons for staying in hospital also varied broadly. The most common reasons were 'infection and parasitic diseases' (26.7% in the interviewed mothers and 14.5% in the questionnaire), 'Musculoskeletal/connective tissues' (13.3% for the interviewed

mothers and 14.5% in the questionnaire) and ‘Nervous system/ Sense organ diseases’ (13.3% for the interviewed mothers and 11.8% in the questionnaire), ‘digestive system disease’ (6.7% for the interviewed mothers and 17.1% in the questionnaire) and ‘respiratory system disease (6.7% for the interviewed mothers and 10.5% in the questionnaire (According to the *International Classification of Diseases*. See table 4.5).

**Table 4.5: Motives for staying in hospital classified according to the International Classification of Diseases.**

	Survey		Interviews	
	Frequency	%	Frequency	%
Infectious/parasitic diseases	11	14.5	4	26.7
Neoplasms	1	1.3	-	-
Endocrine/nutrition/metabolic diseases	2	2.6	-	-
Nervous system/ Sense organ diseases	9	11.8	2	13.3
Circulatory system disease	1	1.3	1	6.7
Respiratory system disease	8	10.5	1	6.7
Digestive system disease	13	17.1	1	6.7
Genitourinary system diseases	1	1.3	1	6.7
Skin/subcutaneous tissue diseases	3	3.9	-	-
Musculoskeletal/connective tissues	11	14.5	2	13.3
Congenital anomalies	1	1.3	1	6.7
Symptoms/signs/ill defined conditions	7	9.2	-	-
Injury and poisoning	3	3.9	1	6.7
No specified	5	6.6	1	6.7
Total	76	100.0	15	100.0

### **Interviewees and the hospitalization of their children**

Table 4.6 summarizes the data referring to the number of children hospitalised, the number and length of hospitalisations, the reason for being hospitalised and the seriousness according to the parents’ opinion. The reasons for hospital stay were classified according to the ICD9 in Table 4.5. Furthermore, in order to provide more exact information, Table 4.6 includes the description of the diseases, using the same expressions that the mother employed.

Table 4.6: Summary of number of children hospitalised per family, number and length of hospitalisation, reasons and seriousness.

Parent	Number of children hospitalised	Number of hospitalisations	Longest hospitalisation (Number of days)	Diseases	Seriousness
1	1	1	5	Meningitis	Very Serious
2	2	More than 3	5	Viral infection + Croup, Measles.	Serious
5	2	More than 3	14	Heart operations. Diabetes. Rotavirus. Blockage in stomach. Perforated Ear Drum Repaired	Gravely ill
7	2	More than 3	3	Asthmatic, requiring hospital treatment	Fairly serious
9	1	1	1	Check pressure behind eyes due to family history of glaucoma	Routine admission
10	1	1	1	Exploratory	Routine admission
11	1	2	3	Broken elbow, Food poisoning.	Fairly serious
12	1	2	4	Suspected Perthes Disease	Routine admission
13	1	3	10	Quinzy	Very serious
14	2	More than 3	42	Kidney transplant	Gravely ill

The mothers interviewed in this study had heterogeneous characteristics and this fact was useful for the collection of information from parents with different types of experiences in hospital.

### Seriousness of the illnesses

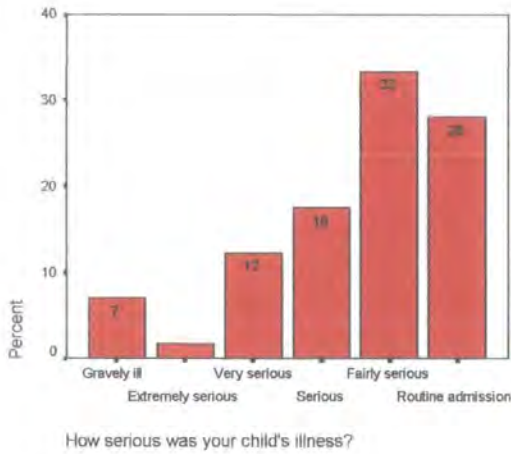
When asking parents about the seriousness of the illnesses, 64% considered that their children were seriously ill. However, they described several degrees of severity: 'fairly serious' (33%), 'serious' (17%), 'very serious' (12%) or 'extremely serious' (2%). 7% of the children were 'Gravely ill'. 28% of the hospitalisations were due to 'routine admissions' (See Figure 4.2.1). Compared to the mothers that took part in the interviews, similar percentages were found: 30% were 'routine admissions' and in 50% of the cases the child was considered seriously ill. The differences appear in the degree of seriousness. Mothers interviewed seem to have had more children 'very serious' (20%) or 'gravely ill' (20%) than the questionnaires' sample (See Figure 4.2.2). It could be possible that the



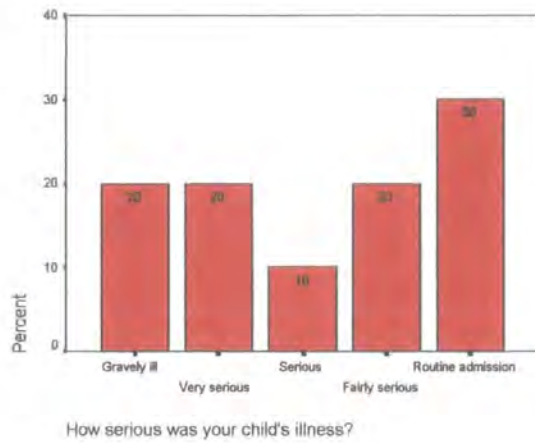
mothers who decided to participate in the interviews were the ones with a considerable amount of experience in hospital and they had something to contribute to this study. This is a very important point as the information obtained is based on personal experiences of parents. However, the information obtained is not biased toward serious illnesses, as 3 out of 10 were 'routine admission'.

**Figure 4.2: Classification of the seriousness of the illnesses**

**Figure 4.2.1. Survey**



**Figure 4.2.2. Interviews**



### 4.3. Parents' impression of the facilities in children's wards

Parents were asked about their impression of the facilities in the paediatric wards. This was an open-ended question and a total of 99 responses were classified into five categories: 'General impressions about facilities' (39%), 'Hygiene' (6%), 'Ambience' (15%), 'Facilities' (26%), 'Health professionals' (14%) and 'Others' (14%) (See Table 4.7). 29% of parents had the 'general impression' that the paediatric wards were good, varying between 'very good' (18%), 'good' (8%) and 'fairly good' (3%). 3% considered that children units were simply adequate and 7% of the parents thought that the wards were inadequate classifying them as 'old-fashioned' (6%) or 'poor' (1%). Hence, the experience is divided.

Referring to 'hygiene', 3% stated that the units were 'clean' versus 1% that thought that they were 'dirty'. There was 2% who expressed that the wards were 'tidy'.

Concerning 'ambience', 9% made positive comments, expressing that these paediatric wards were 'comfortable' (4%) and 'relaxed' (1%), 'cheerful, lovely and pleasant' (3%) and 'child friendly' (1%). 6% of the parents thought that the wards were 'gloomy, uninviting and daunting'.

7% of parents described the 'facilities' as 'excellent' and 'very good'. 3% thought that the services were 'good' specifying that the 'play room was well equipped' (1%) and 2% said that there were 'toys available for all ages'. Another 2% thought that the facilities were 'fairly good' with one of the parents explaining that 'it was ok if not staying for very long'. The word 'basic' was used by 4% and finally there were 10% that made unfavourable comments about the facilities. These comments were: there were not enough facilities, there were not many rooms where parents could stay overnight with their children, the play area was not very well equipped (nothing for older children, some of the toys were rather old, play area could be bigger and have more activities to help children to play), the ward was not well designed and, finally, there was no privacy.

One of the parents admitted that she could not remember how the facilities were.

**Table 4.7: Parents' impression of the facilities in children's ward**

PARENTS' IMPRESSIONS OF THE FACILITIES IN CHILDREN'S WARD		
General impression about facilities (39%)	Good (29%)	Very good (18%) Good (8%) Fairly good (3%)
	Adequate (3%)	
	Inadequate (7%)	Old fashioned (6%) Poor (1%)
Hygiene (6%)	Clean (3%) Tidy (2%) Dirty (1%)	
Ambience (15%)	Positive comments (9%)	Comfortable (4%) Relaxed (1%) Cheerful-lovely-pleasant (3%) Child friendly (1%)
	Gloomy, uninviting and daunting (6%)	
Facilities (26%)	Very good (7%) Good (3%) Fairly good (2%) Basic (4%) Unfavourable comments (10%)	
Others (14%) Such as opinion about nurses and other members of the staff		



## **Ambience**

The researcher was concerned with 2 specific areas, namely, the general environment and ward decoration. Parents were asked to describe how a ward should be decorated. 47% thought that the 'colour scheme' was very important. Approximately, 30% responded that the wards should be bright, and 24% specified that they should be colourful. It is also significant that 8% of parents considered that the ward should vary its decoration, using themes according to the age of the children, the time of the year (for example, Christmas, Eastern or Halloween) and also including 'theme orientated rooms which children can relate to'.

12% of the parents also gave importance to the 'Ambience'. From this 12%, 5% suggested that the paediatric units should be 'Friendly'. The idea of having a ward as similar as possible to the home environment was indicated by 2% of the parents. The remaining 5% used adjectives such as: calm, clean, fresh, modern, secure, not all clinical, not formal, more like a nursery or school.

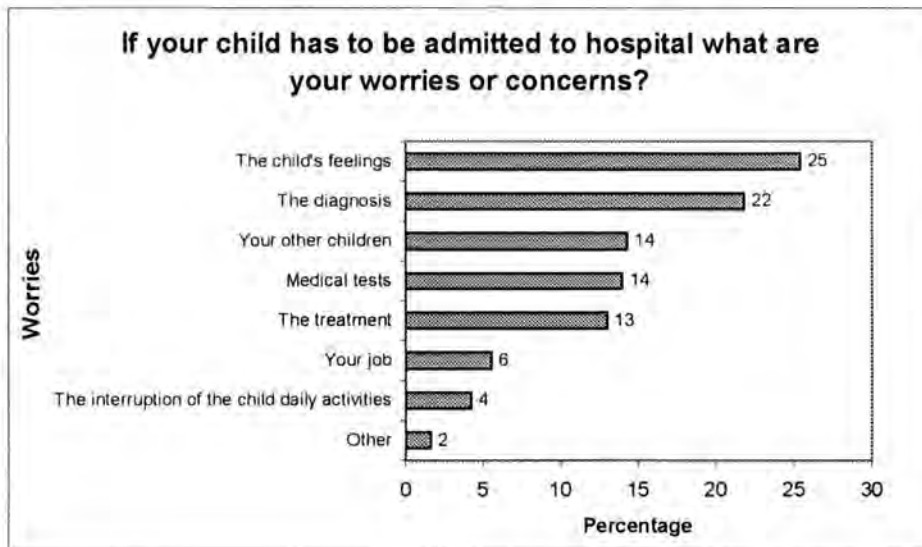
23% thought that all the paraphernalia like pictures, posters, carpets, curtains, borders, bedding, children art work, soft furniture, mobiles hanging from the ceiling were important. A child friendly design was essential for 2% of the respondents.

Parents' opinions about the facilities available in hospitals will be discussed further in the following chapters.

### **4.4. Parents' worries and Children's feelings.**

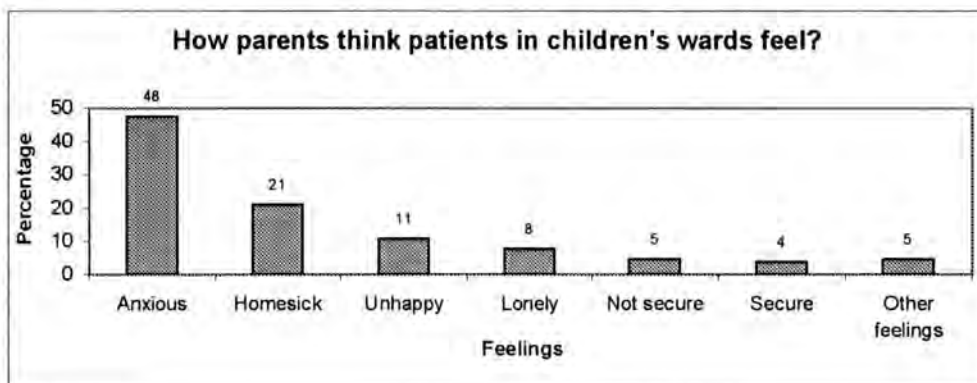
When children have to stay in hospital their parents are worried about their children's feelings (25%) and the diagnosis (22%). They also showed concern about other children in the family (14%), the medical tests (14%) and the treatment (13%) that was going to be necessary during the hospitalisation. 4% were worried about the interruption of the child's daily activities. 6% expressed that they were worried about their jobs (See Figure 4.3). Under the subheading of 'others' (approximately 2%) were grouped parents' opinions about aspects such as prognosis, loss of sleep for children and parents and the risk of having other infections.

**Figure 4.3. Parents' worries and concerns**



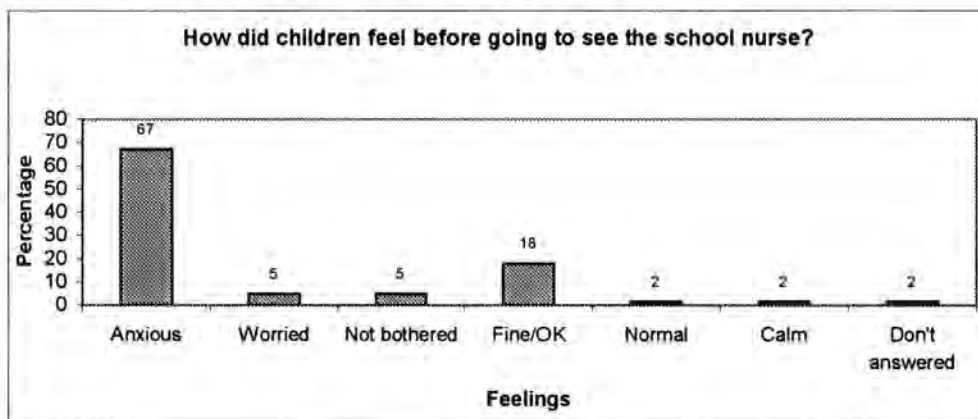
Because parents are worried about their children's feelings it became necessary to have them explain why this concern exists, and how children feel in a paediatric ward from the parents' point of view. As is shown in Figure 4.4, parents think that their children are principally anxious (48%, being 25% nervous and 23 frightened), homesick (21%) and unhappy (11%). There were not a statistically significant difference between the responses provided by parents who had been in hospital with their children and those that had not been staying in.

**Figure 4.4. Children's feelings from parents' point of view**



In the children's questionnaires children were asked how they felt before going to see the school nurse and before having the injections against meningitis. Not all the children who took part in this study had been in hospital before, therefore, they could not be asked how they felt while they stayed in hospital. This question was open-ended and the responses were grouped under subheadings (see Figure 4.5). Most of the children (67%) said that they were anxious (stating that they were nervous and frightened (34% and a 33% respectively)). 5% also stated that they were worried. Another 5% asserted that they were not bothered and 8% that they were 'OK' or 'Fine'. Finally, some of them expressed that they were normal (2%) or calm (2%).

**Figure 4.5. Children feelings before seeing the school nurse**



#### **4.5. Other findings**

One of the themes that arose from the data was 'communication', and how adequate was the provision of information during the time in hospital. Three different approaches will be described: communication between health professionals and children, between health professionals and parents, and between parents and children. Parents and Children made clear the need for proper channels of communication during the entire hospitalisation.

51% of the questionnaire respondents would prefer their children to be cared at home. Out of 51% of these parents, a small number of parents (2%) specified that they wanted to care for their children at home; 1% preferred some limited help from nurses; and 1% emphasized that they would prefer not to have any help when caring for their children.

## Chapter 5 – Family-Centred Care

### 5.1. Introduction

Family-centred care is a philosophy (Coyne, 1996, Bradley 1996, Ahmann 1998) of care that has emerged in response to the changed health care needs of infants and children. Many professionals (Hylton 1990; Åstedt-Kurki, Hopia and Vuori, 1999) agree with the idea that the respect for families and the involvement of them in the care of their children are indicators of quality in paediatric care.

There are several reasons why health professionals should concentrate on the family. First, the family is the primary source of many of the social beliefs and information on health issues. Individuals will usually ask opinions of other family members before seeking outside help, therefore, the family is an important starting point for health care. Second, individuals experience a number of major life events such as marriages, giving birth, death and bereavement, etc., and these can be associated with increased levels of illness. Third, a physical illness, while distressing to the individual, may provide a useful function when the whole family is considered. In the community, health professionals usually recommend a treatment that is then provided by the patient or other family members and the family may support or sabotage the treatment. Moreover, an individual is likely to change unhealthy behaviour only with the encouragement and support of his/her family. Hence, the intervention of the family becomes crucial when the objective of the nursing work is the promotion of health and the prevention of illnesses. In these situations, family beliefs and interventions are more important than the welfare assistance. The health professionals cannot change some models of behaviour, which could damage the individual's health, if the family do not support the proposed recommendations.

On the other hand, it is important to consider the effects of the child's illness on the rest of the family as well. The reactions of families to children's illnesses or disabilities are different. Childhood illness has been considered as a potential area of stress for parents by many authors (Darbyshire, 1994; Eiser, 1993; Polaino-Lorente, 2000). Byrne and Hunsberger (1994) stated that when the family is experiencing stressful situations, namely the illness of a child, significant reactions occur such as problems with communication,

lack of role clarity and the appearance of conflicts. Each member of a family has a role to fulfil. The other members of the family rely on that person to fulfil his or her role. The clarity of roles contributes to the effective functioning of the family.

Family response to the illness of the child depends on the perceived severity of the illness, the support available to the family and to the individual child, and siblings and parental coping responses to the illness (Byrne and Hunsberger, 1994). In the literature, mothers have received more attention compared with fathers and another family members in relation to how they respond to their children illness (Eiser, 1993), how they make decisions regarding health care (Gross and Howard, 2001) and how they cope with childhood illness (Swallow and Jacoby, 2001).

When hospitalisation is required, parents feel uncertain and confuse, not only because they do not know what they can do for their child who is ill, but also because they are not sure about their parenting role inside the hospital (Darbyshire, 1994). Parents at home are the ones who 'know best' in matters concerning to their child. However, when parents stay in hospital the health professionals are the ones who 'know best' and parents find themselves trying to get information from others and negotiating permission to participate in the most basic areas of the child's care. This situation contributes to increase parents' anxiety.

This chapter will attempt to clarify the meaning of the term 'family-centred care'. Firstly, it will define the concept of family and the importance of the family in health sciences. Secondly, it will define concepts such as 'parental involvement', 'parental participation', 'partnership with parents' and 'family nursing' in order to aid in the understanding of this model of care. Then, it will briefly explained how to implement family-centred care and the eight key elements that contribute to its definition. It will consider the consequences that the development of this model brings with it. The application of this kind of care provides a major level of quality to nurses' work and an improvement in the level of health of children and family. The last section will provide the data discussion emerged from the interviews carried out with parents.

## **5.2. What does this study mean when using the term 'Family'?**

Family and kinship are very important aspects of human society. The family is a social organization of peoples that is an essential element worldwide. Nonetheless, both the organization of the family unit and the structure of kinship relations vary through time and depending on the societies concerned.

Western society has been characterized by a great diversity of family organization. This diversity is the consequence of the different geographical characteristics, occupational activities, social class structures, and whether the family has a rural or urban base. Historically, there were considerable differences between different regions of Europe and even between different areas in the same country. In addition, religious and ethnic groups have had influence over family configuration.

In the 21<sup>st</sup> Century, it is controversial to precisely define the term 'family'. Cultural, subcultural, religious, and class differences create a variety of forms within the family, and this variety cannot be overestimated. For the purposes of this research, and due to the fact that this thesis cannot be dedicated to the multiple definitions of this term, when the word 'family' is used it will be referring to the 'nuclear family'. According to the 'Encyclopaedia Britannica' the nuclear, or conjugal, family is defined as 'the basic unit of family organization in virtually every society. It is generally defined as a married couple and its children (including adopted and foster children, as well as the couple's natural children)'. However, in whatever way the family is defined, all the members of the family are usually affected by the presence of a child who is ill.

The initial idea was to collect information about the type of families that were going to participate in the study. However, this was not possible, in part because the head teacher of the School thought that it would be inappropriate to include such questions in the questionnaire. Moreover, as it was described in the chapter on methodology the inclusion of some questions could reduce the number of respondents and could also cause '*reactivity*'. This means that people tend to give answers that will represent them as respectable and socially conforming, giving a false impression about the real situation (Sapsford and Abbott, 1998).

The 1991 Census County Report was reviewed with the intention of having a clearer idea about the characteristics of the families that live in Chester-le-street. The Census described that there was a total of 640 households with one family and with dependent child(ren). 81% of them were 'married couples', 5% were 'cohabiting couples' and 14% were 'lone parents'. Therefore, it was assumed that the families that took part in the research are consistent with these statistics. It is important to take into account that the school was a religious school, which could influence the type of families that bring their children to study in this centre.

### 5.3. Clarification of concepts

As it has been said before, there is no consensus about the meaning of family-centred care, and there exists ambiguity and confusion although it seems to be a central element of paediatric nursing (Bradley, 1996; Coyne, 1996; Hutchfield, 1999; Nethercott, 1993).

Several authors (Coyne, 1996; Friedmann, 1989; Hutchfield, 1999; Nethercott, 1993; Neill, 1996) used different terms when talking about families and their inclusion in the child's care. Some of these terms are described below:

- Parental involvement (Hutchfield, 1999; Nethercott, 1993). The nurse exercises control over the family involvement. Parents are respected as constant in the child's life and as owner of the knowledge about their children. The diversity of family life is accepted as well. On the other hand, in studying the relationship between nurses and parents, it can be observed that they are both seen as strangers but they have an open and honest communication. The nurse's role is to give nursing care, helping parents to give normal care and being an advocate for the family. The nurse remains the expert who controls the family's involvement and participation, delegating tasks. Nurses view themselves as professionals who 'know best'.
- Parental participation (Coyne, 1996; Nethercott, 1993, Kristensson-Hallström, 1999): this concept incorporates the characteristics of parental involvement but it is

based in a more collaborative relationship. The participation in care is negotiated and voluntary. The strengths of family are acknowledged. The focus remains on the tasks done in a hospital environment. Parents learn more complex aspects of caring for their children and provide the care regardless of any reluctance on their part. According to Nethercott (1993) nurses assume rather than assess.

Neill (1996a) and Kawik (1996) adapted a Brownlea's (1987) definition of participation that says as follows:

'Parents getting involved or being allowed to become involved in a decision-making process or the delivery of care, or the evaluation of care, or even simply to become one of a number of people consulted on their child's care'

Neill, 1996a:34

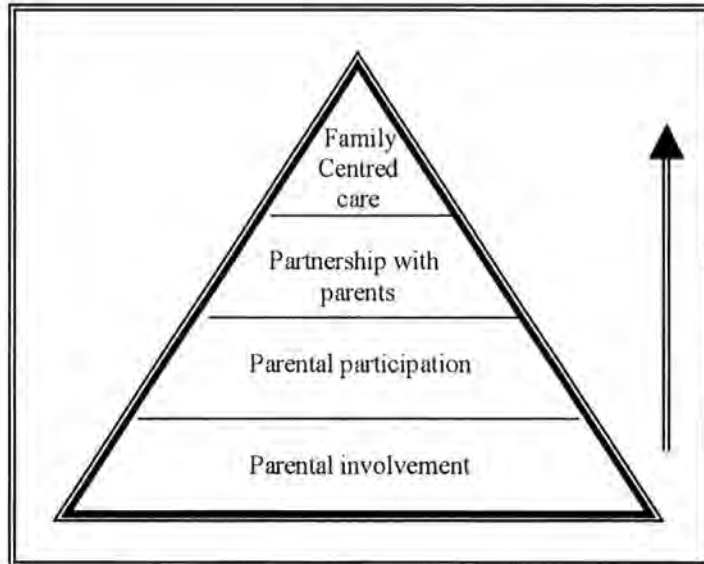
Neill (1996) stated that by this definition, parents are given the choice of their level of participation, and the need of negotiation between parents and professionals is recognised. Moreover, it contemplates temporal variations in parents' desired degree of participation.

- Partnership with parents (Hutchfield, 1999; Taylor, 1996, Stower, 1992): the family and the nurse have equal status and are equally concerned with family well-being. Parents are empowered to give care and they are considered primary caregivers. Nurses are supporters, advisors and facilitators in this process.

There have been some authors such as Pike (cited in Coyne, 1996) who saw involvement and participation as synonymous. According to Hutchfield (1999), there seems to exist a hierarchical relationship between these three terms (parental involvement, parental participation and partnership with parents) described above and family-centred care, as it is described in the diagram 5.1.



**Diagram 5.1. Hierarchical relationship between parental involvement, parental participation, partnership with parents and family-centred care.**



'Family nursing' is another concept that offers a different view of caring for families by nurses. Friedemann (1989) described that it is practised on three levels. Moreover, she stated that the nurse who practices on a higher level is also involved in the lower levels. The three levels are:

- **The individual:** The family is seen in the context of the individual. One individual is the client and the other individuals are subsystems who have a supportive function, helping the client to make changes. The nurse teaches parents to care for themselves and counsels them in coping with their child's illness. The goal at this level is the personal well-being of all the individuals in the family.
- **The interpersonal:** This consists of two or more individual systems depending on the number of family members interacting with each other at a given time. The nurse acts as a moderator by intervening with the family interaction system. The goal is mutual understanding and support among family members.

- **The family system:** This is the nursing of the whole family. It is a difficult concept that still lacks consensus according to Friedemann (1989). The goal consists of change in the family systems as a whole, and increased harmony between systems and subsystems, as well as between system and environment. The nurse specialist negotiates with the family for an approach with the family, which is adapted to the family's needs. The plan needs to be consistent with the general strategies the family uses in daily coping.

The terms described in this section are employed interchangeably and indiscriminately in the literature, probably due to the lack of a clear definition of what family-centred care involves. According to Nethercott (1993) the concepts of parental involvement, parental participation and family nursing differ from that of family-centred care. Coyne (1996) and Hutchfield (1999) stated that the concept of family-centred care is the result of the evolution of the concept 'parental involvement' to 'parental participation', and then to 'partnership', which is the stage before the family-centred care (See diagram 5.1).

Additionally, it is important to consider that family-centred care has an evolutionary nature. This means that this concept is neither static nor definitely closed. It will continue changing with the changing needs of children, and with social evolution. For instance, due to the fact that there is a change in emphasis from institutional to community care, the concept of family-centred care seems to provide a strong conceptual foundation for the enhancement of care for the child in the community.

Recognizing that the terms 'parental involvement' and 'parental participation' have different connotations, this thesis will employ them interchangeably. The reason for doing this is that the terms are not used in the following chapters as systems of care for children. Rather, they are employed to mean that parents should take part in the care of their children, in the decision making process and in every aspect related with the well-being of the child and the family.

#### **5.4. Implementing family-centred nursing**

A key to the family-centred care is that professionals recognise the central role of the family in the child's life (Casey, 1988). It is important to add that not only are the problems and needs identified, but also family strengths and capabilities. This information is used to design a plan of care in better detail. In this plan the family is invited to participate actively in the assessment, planning, implementation and evaluation of care, to the extent they choose. The plan requires a process of openly sharing information between families and professionals (Ahmann 1998). Parents' knowledge and need for training must be taken into account.

In order to explain family-centred care, Tumbull and Summers (cited in Ahmann 1998), use an analogy with the Copernican Revolution. Copernicus was a Polish astronomer who demonstrated that the sun not the earth, was at the centre of the universe. In this sense the family is considered the centre of the universe and the service delivery system is one of the many planets revolving around it. If the health systems were the centre of the universe instead of the family, the family would always be circulating around the system. This would imply that the system is more important than the family itself. However, using the Copernican image, we can conclude that the family has to be the most important element, i.e. the centre of universe within the health care system.

According to the findings of this study this is not happening within the actual hospital system. The current situation of allowing parents to stay in hospitals but not to assist in care is inappropriate. Although parents are allowed to stay in hospital close to the child's bed, they are not being included in the care of their children and neither are they being offered the necessary resources to care for themselves.

#### **5.5. Elements of family-centred care**

Shelton et al (cited in Hutchfield, 1999), in 1987, developed a framework in collaboration with parents to care for families with children having special education needs in the USA. They defined eight key elements of family centred care, developing a brief

description of them. In 1994, these elements were re-examined (Shelton and Smith Stepanek, 1995) in order to clarify them. The eight elements are:

- Incorporating into policy and practice the recognition that the family is a constant in a child's life, while the service systems and support personnel within those systems fluctuate.
- Facilitation of family/professional collaboration at all levels of hospital, home and community care (care of an individual child; program development, implementation, evaluation and evolution; policy information).
- Exchanging complete and unbiased information between families and professionals in a supportive manner at all times.
- Incorporating into policy and practice the recognition and honouring of cultural diversity, strengths, and individuality within and across all families, including ethnic, racial, spiritual, social, economic, educational and geography diversity.
- Recognising and respecting different methods of coping and implementing comprehensive policies and programmes that provide developmental, educational, emotional, environmental, and financial supports to meet the diverse needs of families.
- Encouraging and facilitating family-to-family support and networking.
- Ensuring that hospital, home and community service and support systems for children needing specialised health and developmental care and their families are flexible, accessible and comprehensive in responding to diverse family-identified needs.
- Appreciating families as families and children as children, recognising that they possess a wide range of strengths, concerns, emotions, and aspirations beyond their need for specialised health and developmental services and support.

*Shelton and Smith Stepanek, 1995:363*

From these aspects the idea of holistic family-centred care, which takes care of the child and the family can be observed. Hence nurses cover all family members' needs but

always emphasise the family strengths and capabilities. However, there is a lack of studies on how these elements will be translated into practise.

## **5.6. Consequences**

At this stage the consequences seem to be based on the assumption that both children and family will benefit from the family-centred approach. However, the information obtained from some research (Kay 1996b, Hutchfield 1999, Darbyshire,1994) in which the parents have to take care of children reveals that sometimes caring for their sick children is very stressful for parents. Hutchfield (1999) suggests that some families might not benefit from this approach for several reasons. For example, parents do not have enough knowledge to deal with the stress that the situation causes which makes them unable to act properly. Therefore, new research could help to identify those families in which the application of this work system could cause more damage than benefits.

Moreover, little or no thought has been given to a pragmatic approach towards family-centred care. There are only theoretical issues about family-centred care in the articles consulted and sometimes research which only explain the opinions of nurses and students. In contrast, there is a lack of information about how the professionals can implement this system of care in their everyday work. In fact, there are only recommendations about very few aspects such as communication skills. Keeping meaningful communication is considered an essential element on which to base the family-centred care. Therefore, it is very important to dedicate adequate time for communication with the family in order to facilitate the teaching and supportive role of the nurse. It is for this reason that children's nurses need particular knowledge, skills and experience, in order to implement family-centred care.

Few would argue the many benefits of the family-centred care. These benefits can be classified into three groups: the first is the benefit for children's health and developmental outcomes, better prevention of illness and promotion of health. The second is the benefit for the family, family empowerment, parental skills and emotional well being, parental view of service's effectiveness, parental sense of control over their child's care and

ability to provide quality home care. The last group of benefits is for nurses, and these benefits involve efficient and effective use of resources, ability to provide quality home care working to the mutual satisfaction of parents and the professionals.

All these benefits could be increased if a system to provide this kind of care were developed. Although sometimes the use of this term seems idealistic because it needs a more practical approach, it is necessary to first make the concept itself clear because there is a high level of confusion pertaining to it. And thus, it is necessary to clarify its meaning in order to improve the implementation of this model of care by nurses.

In conclusion, the development of this model of care can be observed. The care of children has moved from care by the family in the home, to care by the professionals in hospitals and now to care at home and in the hospital by family and health professionals (Coyne, 1996). The changes have been motivated not only by nurses who are willing to share the care and the decision making with parents, but also by parents because they wanted to become involved in their child's care.

The benefits that families and children can obtain with this approach of care are clear. Moreover, it enhances the quality of nurses' work and nurses receive greater satisfaction. The reason for the higher satisfaction is that their actions have an aim and a clear purpose inside the care plan and they do not only perform isolated acts. However, the provision of this care requires that nurses have very good training during their studies and acquire particular knowledge, skills and experiences. Family centred care appraisal and the realisation of new clinical research will help the implementation of this model of care, giving a more practical approach.

### **5.7. Family care: Summary of data emerging from the interviews**

Several questions arise when dealing with children who are ill and their families. Firstly, it is essential to know the influence that the child's illness has on the family. Secondly, families could react in very different ways; therefore their possible reaction should be taken into account. Sometimes, the family does not have the knowledge or the ability to cope with the illness, consequently, other family members might experience

disorders in their own health. If this is the case, can we help the family, and through the family help the child who is ill? Is the health system in general, and hospitals in particular, actually providing the care that the family needs? The following paragraph summarises what mothers think about the facilities that parents and siblings found when they stayed in hospital.

As Callery (1997) stated, it is important to have programmes and plans for the care of families rather than just care of the children. A consequence of the parents' involvement in their children's care is that those parents need support to provide this care. Taking care of parents should be part of the health professionals' work.

All the mothers interviewed agreed that the care of the family is needed when staying in hospital. They argued that an ill child has an impact on the whole family. The entire family suffers and is affected. Therefore health professionals should pay attention to the effect that the illness and the hospitalisation have in the rest of the members of the family (Mother 5, Mother 14). The concept of family-centred care becomes more significant when dealing with long term or chronic illnesses.

There are two aspects to consider in the involvement of the family:

- The hospital should provide facilities to the family to stay in hospital, and thus, a quasi-family atmosphere is created for the children, which reduces the feeling of an unknown situation and the number of strange people around them.
- The hospital should have a responsibility to take care of the other family members, providing them with all the necessary elements to make their lives easier during the hospitalisation: justifications for parents to present in their work proving that they have a child in hospital, open visits, care of the siblings, etc.

'...but if it was going to be a long term... a long term situation in those cases yes I would be torn. Because yes, I want to be with Daniel for example in hospital but I would understand that my other child would... be missing me because I wasn't at home. So, I suppose in an ideal situation I would like us all to be together. But I mean, they wouldn't allow Kieran to stay with me in hospital because obviously he would miss his brother if his brother wasn't there. So, in an ideal situation I would like as all to be together but I don't know how that could be accommodated.'

Mother 7

## Siblings

Bluebond-Langner (1996) showed how the attitudes of healthy siblings towards chronic illness are influenced by what they experienced within the family. In addition, the ways healthy children cope with brothers' and sisters' illness are dependent on the way their parents cope with the care required by the ill children in the family. The healthy siblings' view also makes a progression from the initial diagnosis through the following months and years as in the case of chronic illnesses, to the hospitalisation with advanced and terminal stages of the disease. She described that siblings often find it difficult to engage in open communication. Bluebond-Langner (1996) emphasised that it is necessary to preserve the family members' need to maintain everyday life and relationships while giving parents and siblings permission to discuss feelings necessary for a sense of well-being.

The care of the other siblings at home is a concern to the 50% of the interviewed mothers. Parents are torn between staying in the hospital with the child who is ill or returning to their homes to look after other siblings.

'...It was a bit, yes we wanted to go home for Scott, but I wanted to be here as well. It was hard, working away, you want to be in wards. So, I came home and spent the Saturday night with Scott. Eh, then on the Sunday night his dad came home and I spent the night with him the next day. So, we had two turns.

Mother 5

'... when you are away you are worried all the time, worried about the others.'

Mother 12

Some of the problems are solved when both parents can manage to be involved, with one at home and the other in hospital. However, that is not always possible because they have some commitment with their jobs that are very difficult to rearrange. Most of the times other family members (nearly in a 70%, according to the questionnaire) are the ones that provide support to the parents, and take responsibility of the care of the children that are at home.

'My mother looks after him, my mother stays in my house with him but when they said on the Saturday that only one parent could stay on the Saturday night.'

Mother 5

'Well I obviously I have my husband to take him or my mum ...'

Mother 7



‘Just my husband that helped a lot and parents...’

Mother 12

However, relatives cannot always dedicate time to stay with the siblings or to go to the hospital and allow the parents to have a rest.

‘Parents and husband but they have to take any time off work ..., which is often very difficult.’

Mother 12

‘Well if I could arrange it: yes. But with elderly parents, you can’t always arrange it.’

Mother 14

When parents cannot find the support of other family members, the search for someone to take care of the siblings becomes another source of anxiety as well as time consuming.

‘It puts extra pressure on you trying to find people to look after your other child while you are in hospital with one child. So, you know, I’ve gotta try and juggle things about... childcare, things like that.’

Mother 7

In these situations the health system could supply hospitals with playrooms or rooms where the siblings could stay if needed. There are some hospitals where this sort of care is provided for siblings; conversely, in other hospitals siblings have to stay in the same room as the child who is ill. It could be of interest to also have different activities according to the ages of the children.

‘... they have two separate playrooms, most of them, one for younger children, eh... jigsaws, lego, stuff like that... but if you’ve got an older child coming in visiting, they’ve got playstation games, computers, PCs, in another playroom, so they do accommodate, or vice versa, if your older one’s in the play room for your younger child, they do accommodate. And they’ll allow them there for most of the day, anyway. So, it’s not too bad. I mean you do get to see your other child...’

‘He came to visit Steven when he was in Sunderland, and he was quite happy, there was a playroom there, he went off into the playroom’

Mother 5

‘No they weren’t sort of... that you had to stay in a room. They were actually in the ward, you know, like sitting next to the bed, you know and things like that.’

Mother 10

Family members need to be provided with enough information and support to cope with the illness of another family member. Parents need to support their other healthy children. Likewise, siblings need to benefit from constant parent participation and support in activities (Betz, Hunsberger and Wright, 1994). Once more, communication between parents and siblings becomes important. Moreover, nurses can help directly and indirectly with the siblings of the child who is ill. They can help parents anticipate the illness’ prognosis in order to help them to prepare the siblings to cope with their brother or sister’s illness. Health professionals can also interact directly with them.

The siblings’ knowledge and the understanding about illnesses should be taken into consideration. Siblings become really involved when the illness that the child presents is a chronic one. In this case, some of the children have a very active role that helps both the parents and the sibling who is ill

‘...they don’t say ‘we don’t want them here’, they welcome them in to the ward, and because, I think a lot of them now, erm... think if your other child’s there, it’s bringing the poorly one...it’s helping them ‘cause they want to be up and about playing with the other child as well, you know, so it’s helping them recover. They encourage the family to come and spend the day, they don’t mind. It is unlimited visiting time. So... Steven’s quite enjoyed coming to visit Scott at some point, you know? ‘Ach, I’ll go and visit Scott again today ‘cause they’ve got a playstation game in there that I haven’t got’ you know? So he quite enjoys coming.’

Mother 5

‘I think it is good he needs to have the family around. And the other members of the family needs to come in and see specially if they’re round about the same ages the child that is in hospital. The other family members need to be in, they need to see him because other ways they think ah!... that something dreadfully wrong... Yeah, I think it is a good thing that they can have so many people in.’

Mother 11

The involvement of the siblings has to be considered, always having in mind that they sometimes may experience stress or acts of frustration, anger, fear, jealousy or resentment (Betz, Hunsberger and Wright, 1994). These siblings' responses are linked to their stage of development, the communication and support patterns inside of the family, and each individual personality. Therefore, it is important to individualise the degree of involvement that they are able to adopt and the type of care that they need.

'Well, some of them... to me... they tend to get in the way, I mean, obviously the child who was ill was getting all the attention of the nurses and the parents and you think these children again left out you could see the jealousy, you know, coming through from these children, you know there was some with temper tantrums you know, creating, you know, they just need some time out and that sort of thing. You can see the nurse... I think it is too much for the nurses as well to cope with the ill child. They try to attend the sick child and they have got these other, you know, 2 or 3 children squabbling in the corner. It is quite disrupting for them... that'

Mother 10

The visits of the sibling to the hospital have positive effects described by the mothers:

- For children who are ill:
  - o Receiving visits of people who are familiar for them provides a sense of normality
  - o Taking their mind off the situation while playing with their siblings
  - o Siblings help to recover
- For the health professionals:
  - o They have the opportunity to know how the family is dealing with the illness and to evaluate how it is coping with the illnesses
- For the family:
  - o Parents can stay with their other children also
  - o Spending the day together, families find it easier
  - o Siblings need to know what is happening with their sibling because otherwise they can have a wrong image of the entire situation.

However, one mother (Mother 10) described that having the other brothers or sisters in hospital could have negative effects for the child who is ill and for the health care professional. According to her the ill child could be 'fed up' because of the visits due to the fact that they 'probably just need to concentrate on getting themselves better'. Moreover, they need 'a rest period from their brothers and sisters' and 'time for themselves to recover'. Equally, health care professionals have so much work that it is difficult for them to cope with the siblings.

'You can see the nurse... I think it is too much for the nurses as well to cope with the ill child. They try to attend the sick child and they have got these other, you know, 2 or 3 children squabbling in the corner. It is quite disrupting for them... that'

Mother 10

From the mothers' point of view professionals have different attitudes towards the visits. Their attitude varies from 'encouraging the visits' to 'not minding or not saying no to visitors'. Visits have effects on the child who is ill. Most of the mothers think that they are useful because they help children to recover, taking their mind off their time in hospital, and thus, making their stay in hospital more acceptable. Moreover, it is through visits that parents get some rest and have a break from caring for their children. Mothers agreed that visiting time should be unlimited and open to all.

# **Chapter 6 – Parents’ experiences of hospital care**

## **6.1. Introduction**

Parents’ participation has been widely described in literature on children hospitalisation (Callery and Smith 1991; Callery and Luker, 1996; Callery, 1997b; Cleary, 1992; Coyne, 1995; Darbyshire, 1993; Darbyshire, 1994; Darbyshire, 1995; Johnson and Lindschau, 1996; Kawik, 1996; Neill, 1996a; Neill, 1996b; Sheldon, 1997). Health professionals should be aware of parents’ emotional and physical needs and provide the support necessary for avoidance of adverse effects that their children’s hospitalisation could cause to them. It is essential to ensure the well-being of parents and family in order to ensure the child’s safety and welfare as it will be explained in this chapter.

## **6.2. Parents looking after their children in hospital**

Polaino (2000) stated that having a child with physical or psychological disabilities, not only long term but also temporary ones, augments the risk of disruption within the normal function of the family. Moreover, parents’ and children’s distress associated with hospitalisation is widely acknowledged (Burke et al, 1997; Kauffmann et al, 1998; Kristensson-Hallström and Elander, 1997; Lizasoáin and Polaino, 1992; Mazurek Melnyk, 1994; Ochoa and Polaino, 1999; Ochoa, Reparaz and Polaino, 1997; Polaino, 2000). However, this distress and the problems associated with hospitalisation will be different among children with chronic or disabling conditions and among healthy children with single hospitalisation (Burke et al, 1997)

Parents expressed that being in hospital with a child who is ill makes them feel tired and worried. Not only are they living through a distressing experience (child illness, treatment and prognosis, unpleasant procedures are performed on their children, etc.), but also, they stated that there is a lack of hospital facilities that would help them to cope better with the situation. Referring to the time that they spent in hospital, parents gave a number of explanations that were grouped under four subheadings:

- Physical exhaustion: four parents used expressions like 'I was so tired', 'It is very tiring', 'It was hard to be there all the time' and words like 'exhausting'.
- Being tied down: 'You can't do your own thing', 'you are sitting around waiting', 'I really didn't have a lot of time' stated three parents.
- Preference to stay with the child: (two parents) Although they expressed that they did not have enough time for themselves, they also declared that they would prefer to be with the children every moment during the hospitalisation and to avoid leaving them alone, forgetting even their own personal needs. They found it more stressful to go out of the ward than to stay in with the child who is ill. They asserted 'I couldn't rest', 'I had to be with her [the child]', 'I wouldn't have left her', 'I wouldn't like to leave her', 'I was so worried about her', 'I would prefer to stay there', 'You want to be with them all the time', 'You don't want to be at home', 'You don't want to go', 'You can't go because you are too tired'
- Wanting a break: three parents agreed that a rest is needed. They needed a break to go out of the ward, to have fresh air or go for a walk. 'Daily nurse coming in to stay half an hour to give me a breath, a break', 'I would like a break', 'perhaps somebody coming for a couple of hours', 'I would like to have a bit of fresh air, a bit of a walk, change of scene', 'You also need a break for a few minutes'.

### **6.2.1. Parents' participation in the child's care**

Parents want to be included in the care of their hospitalised children. According to the questionnaire 98% of the parents would be ready to help to look after their own children in hospital. The reasons parents gave (in the questionnaire) for caring for their children personally in hospital were grouped into several subheadings. These were, security and love towards their children (71%), release staff time (13%), continuity in the child's care and normality (each with 5%) and reassurance from parents' point of view (2%).

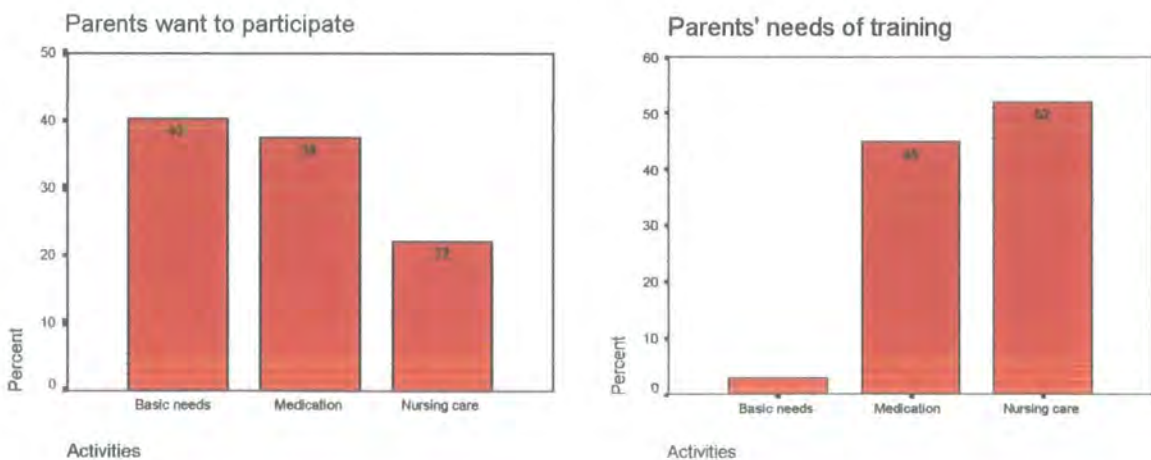
49% would like to participate in all the activities offered (taking care of the basic needs, giving medication and nursing care) in which the child is involved. Studying the activities separately, 37% would like to help when administering medicines and 40% when

the activities to be done are in relation to the basic needs of the children (bathing, feeding, toileting, atec.). 22% would like to participate in the nurses' activities, e.g. taking temperature, pulse rate, blood pressure, helping with wound care, doing chest physiotherapy (See Figure 6.1). Neill (1996a) recognized that parents are more desiring to participate in 'basic care' than in 'medical care'. Furthermore, parents in Coyne's (1995) study were reluctant to do activities that they considered the nurses' responsibilities. However, Chester-le-Street parents contradict Coyne's findings. Evidence in this study suggests that most of the parents are keen to help with the children's basic needs (40%) but high percentages of parents are also willing to help in the other activities, agreeing that they would need training for some activities (79%), mainly for the administration of medicines (45%) and for nurses' activities (52%). Only 3% reported the need for training in the care of their children's basic needs. One of the mothers interviewed related in these words the need for training:

'but I think if he had to receive treatment at home I would like the staff to take time to show me how to do it but obviously I would like them to be confident in my ability as well before I would to go in to take sole responsibility too far. (...) I don't know, maybe change bandages and things like that, you know, and clean rooms. I think that would be helpful if the parent could do it but obviously the medical staff would have to be confident that we knew what we were doing before hand.'

Mother 7

Figures 6.1: Parents participation and training needs.



Parents' desires to be involved in most of the aspects of their child's care were not always reflected in their experiences. This is consistent with other studies (Neill, 1996b). The activities in which most interviewed mothers participated during their children's hospitalisation were mostly in relation to the basic needs of the children: feeding, washing, bathing, making them comfortable, changing bed-linens, dressing, etc. Further, parents wanted the responsibility of keeping their children entertained.

**Parent:** I was there really. I did the things like feeding and making him comfortable and stuff like that

**Interviewer:** So, you didn't feel like they kept you away?

**Parent:** NO, no they wanted... I think, it was because he was in a room all by him self it was good for them to have me there... eh... I was really just there to, to watch him, I guess. There were not a lot of things to do really.'

'... I think a lot of parents would rather be there anyway to do the general things like washing and feeding. I think that most parents would not mind that.'

#### Mother 1

'They have very little to do with her really, I mean, I do everything so I mean I washed her, bathed her or whatever was needed obviously because I was there all the time. So, eh... and she was only a little, she might be younger than 18 months, so I cannot really say that there was more than that. They weren't nasty with her but they didn't have much to do with her.'

**Interviewer:** Do you think they welcomed your help?

**Parent:** I think it was expected, really, because I was there and I was sleeping over night I think it was expected.'

#### Mother 2

'... So, he did all night he wet the bed about 5-6 times and I had to change the bed, I think, with him lying there all the night, you know...'

'I was responsible to take him into the playroom. Keep him amused. Read him books. I had to do it, everything.'

#### Mother 3

'I think you could only help in a sort of a ... how can I say it? A sort of menial, run of the mill jobs, I mean, I wouldn't consider myself qualified to administer an injection to a child. I mean, I think if a child has a wound I think I would be able to dress the wound. I should, hope so, because I've got a first aid certificate. You know what I mean? but I wouldn't... I think I would feel uncomfortable giving a child an injection because it's not something I



have done before eh... I think it would depend very much on... when you talk about help, on what sort of help you are talking about, you know? - If it's just like changing a bed or helping with food or dressings or maybe just spending time with the child, but I think if it actually comes down to the medical treatment that would have to be left to the professionals.'

Mother 9

Mother 9 (above) expressed that some activities, such as medical treatment, have to be left to the professional and she did not even consider the possibility of participating in them. However, some of the parents showed an interest in being more involved in the medical treatment, but always under the appropriate supervision.

'I think I would have felt more involved if I could have given him his medicine or helped with the nebulizer because I was just feeling a little bit of a spare part, you know, just sitting there and not wanting to get in their way but not wanting to appear that you are not interested because obviously you are. So, yes I think administering the medication would have been a help for me as long as somebody was making sure I was doing the correct thing. Just to feel that I was helping I think.'

Mother 7

As we have seen above some parents want to participate in the child's care, carrying on with activities that they are accustomed to doing at home, other parents want to go further helping in the administration of medicines and in nurses' activities. However, it is important not to generalise and assume that all of them have the knowledge or the ability to participate in everything.

There were also three mothers who thought that their involvement in the care was adequate. They explained that there were no more activities in which they could help (Mothers 1, 9 and 10). Moreover, one mother expressed that she was encouraged to do as much for her daughter as she could, showing her approval for such encouragement. Nevertheless, she was referring to activities relating to the basic needs of the child:

'... and I was encouraged to do as much for Lindsay as I could, but you would do that for your child anyway. You know, like bathing and feeding them, 'cause she couldn't feed very well, and drinking and stuff - she couldn't drink very well. But, it was good.'

Mother 13

Two mothers related that if they would not be allowed to help in the care of their children (when they considered themselves able to participate in those activities) they would be upset (Mothers 2, 10 and 11). Probably this discomfort in the parents would also be reflected in the children as described by Mother 10. Thereby, the parents' participation would be of psychological benefit to the child.

**Interviewer:** If they had not allowed you to come into the theatre?

**Parent:** I think that would have put me in a difficult position. I don't... I mean, If I had been upset I think it would have reflected on the child as well. He probably would say something like 'I don't want to go in here', you know, 'without mum's there'. Especially being so young. Five is quite young really to be left.'

Mother 10

We can observe that the willingness to be involved varies among parents. It is also important to discuss the limit of this involvement. As parents suggested, health professionals and parents should work out a compromise about the limits of parental involvement (Mother 10 and 11) always acknowledging that each parent is different, and being careful not to generalise about the activities they are able to do. In some situations parents can do nothing, and it is better for them to leave the professionals to do their job, for two main reasons:

- The professionals know how to cope with some problematic circumstances
- The professionals are the ones who have medical knowledge, they are the specialists

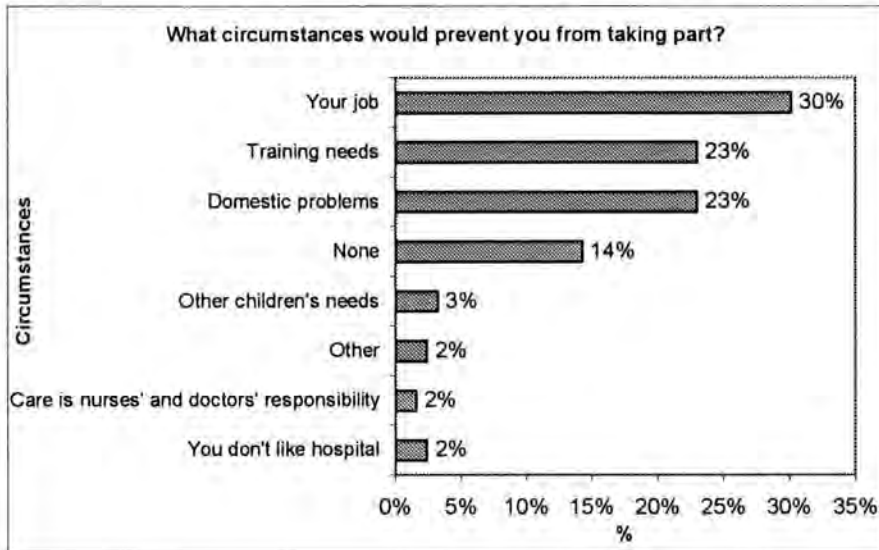
'I just stood back and let them get on with it, 'cause, I suppose, they're the professionals, and they know how to cope with panic attacks. Because at first I started laughing because I thought Lindsay was just being silly, you know? She kept saying 'oh mam, I'm going funny!' and I started laughing and went 'oh, sure you've always been funny!' You know, and making, like, a joke of it. And it started getting where she was shaking and stuff, so I thought 'ooh, there's something wrong here!', so I just shouted at the nurses and they came straight in, and just took over - they were really great. (...) It's best to just let them get on with it... they're the specialists.'

Mother 13

### 6.2.2. Reasons that could prevent parents from taking part in hospital activities

Parents described that the main reasons for not participating in their children's care (see Figure 6.2) would be work commitments (30%), domestic problems and training needs (with equal percentage of 23%). 14% of the parents assured that there is not any circumstance that could stop their participation in their children's care.

Figure 6.2: Circumstances that would prevent parents of taking part in their children's care



Moreover, 79% of the parents said that they would not be able to help on a regular basis. Of the 21% of the parents that said they would help on a regular basis, 47% could spare 1 or 2 hours per day, 30% stated that they would be there all the time necessary, 17% could help for 3 or 4 hours and 6% could spend less than 1 hour.

### 6.2.3. Advantages of parents' involvement in their children care

The mothers interviewed described the many advantages that come out from parents' participation. These advantages are not only for parents but also for children and health professionals:

- For parents:
  - They would feel that they have more control of the situation. 60% of the parents addressed, in the questionnaire, said that they were not in control

during the hospitalisation of their children. According to Neill (1996b), when children require hospitalisation, parents often feel a loss of control because they have been unable to help their child by their own efforts. When parents are involved in their children's care the feeling of a lack of control can be alleviated:

'I was doing him all anyway. You know, so, I mean they were all really good. And I think as long as the parents feel that they have got some control in things that are explained to them and they understand what is going on. I think people feel, parents do feel happier'

Mother 11

- They feel that they are helpful caring for the children, and thus their satisfaction increases:

'Did I want to be involved? I think yes. I think I would have felt more involved if I could have given him his medicine or helped with the nebulizer because I was just feeling a little like a spare part, you know, just sitting there and no wanted to get in their way but not wanting to appear that you are not interested because obviously you are. So, yes I think administering the medication would have been a help for me as long as somebody was making sure I was doing the correct thing. Just to feel that I was helping I think.'

Mother 7

- They are more autonomous but always knowing that the nurses would be available if needed.

'I knew they were there if I needed them which I was happy with..., I didn't want a sort of... around all the time. I was happy with that.'

Mother 10

- They can continue carrying on with activities that they used to do at their homes, for instance bathing. This allows the parent and the child to continue with some routines previously done in their homes, making the scenario less unfamiliar.

'I normally bathe Sophie so why shouldn't I carry on bathing her while she is in hospital. I mean that's fine with me. That's what I would like to do anyway...'

Mother 2

- For children: Most hospitalised children need their parents' presence and participation for support and help with the ability to cope with difficult situations (Kristensson-Hallström, 1999)

- Children are happy with their parents' caring for them.

'cause either one of them would create [a fuss] if I couldn't stay with them. They wouldn't be happy. They wouldn't be happy at all. And I think the nurses would regret saying what they'd said! : 'We've got our hands full here!'

Mother 5

'Because I think that would help the children if the parents were helping treat'

Mother 7

- There are fewer strangers taking care of the child.

'There is no way I would want somebody else in the room while she was getting washed. Eh... I wouldn't ... I don't think I would have allowed anybody to be there and bathe her. I wouldn't have allowed the nurses, would you? (...) So it's better to have the parents there.'

Mother 13

- For health professionals: There are two sides. Firstly, they should spend more time giving information to parents in order to involve them in their care. Secondly, nurses also profit. Parents will know what they have to do, how to do it and when they need to ask for professional advice. An example of the former follows:

'As I say everybody was running around... sort of... they seem to have something else to do, so, I think if they try to stop and show me... how to administrate the medication that would have been another job for the nurses that they probably could have done without. So, I don't think they would have been welcome all the time'

Mother 7

The latter:

'I saw to all his basic needs and cares because we had a separate toilet just for Mathew... The nurses, as long as they are happy, I think the staff as long as they are happy that the

parent is competent to carry out the needs of the child they are quite happy just to stand back and let the parents check the, you know, do all the basic care of the child.'

Mother 11

#### **6.2.4. Parents as cheap labour in hospital**

The purpose of including parents in the child's care is not to decrease the health professionals' work. Parents should not be used as 'cheap labour' in hospital or in the health system. Some parents wondered in the interviews if, without their help, their children would have the proper attention. Three of the mothers showed fear of their children being neglected if they did not participate in their children's care:

'... because he hadn't had an operation or he hadn't had any thing really serious they don't tend to bother with you too much. But If I was there I would say 'yes I want my child bathed' so I would have to bathe him.'

Mother 3

'...I don't think if the parents weren't there I don't think they would get a bath. They don't take it upon themselves to bath.'

Mother 5

'Because they have got more time to do what they are paid to do and that's to nurse. I mean it's good in one respect. It means that I have to do the bed and then the washing and make sure they brush their teeth and they can't be with the child they can't be there every minute of the day they have got other things to do. So, they don't know if they're eating. They don't know if they're drinking enough. That sort of thing. And some things they've got to leave to us and they did that with me.'

Mother 13

The descriptions given by these three mothers correspond to the opinions of mothers interviewed by Callery and Luker in 1996. They found that mothers believed that there were not enough nurses to ensure the care of their children, and thus, they had to stay with their children in order to assure their safety and comfort.

If parents have the feeling that they are being used as substitutes for health professional staff they will distrust the health system. In that case, the relationship between parents, doctors and nurses will deteriorate and misunderstandings and conflicts will start to appear.

### **6.3. Facilities available for parents in hospitals**

The hospitalisation of children requires a great adaptation from parents. This is a very demanding task both physically and mentally. Parents' distress could be decreased by improving the hospital facilities. Moreover, if the facilities available for parents were adequate they would feel encouraged to stay in hospital and care for their children. This idea was reinforced by Coyne (1995). In her study parents expressed dissatisfaction with the facilities provided for them and she argued that it was reason enough to discourage parents to stay. During the interviews, Chester-le-Street mothers made some objections on three main themes: sleeping, catering and washing facilities.

#### **6.3.1. Sleeping facilities**

It has been reported that sleep loss for parents when staying in hospital with their hospitalised children has led to a sense of fatigue and contributed to their mental stress (Kristensson-Hallström and Elander, 1997).

During the interviews, two mothers complained that they did not have proper sleep while they were in hospital. This is due mainly to two factors:

- They are not supplied with a proper bed
- The environment and the system of continuous work in hospitals: Hospitals are not quiet places where someone could rest without noise and interruption.

Simply by supplying parents with a proper bed and reducing the noise, they could be helped to have a proper rest. This could be solved with individual rooms in which child and family could have a little more privacy.

#### **6.3.2. Catering facilities**

In this section a diversity of experiences were registered:

- Three parents who stayed with their children during lunch time showed their satisfaction (7, 10, 13)

- Four parents (1, 2, 5, 14) did not have the assurance of food supply. They preferred not having meals over leaving the hospital.
- The voucher system (described by three parents) seems a possible alternative but it could be better if they could choose to have the meals in the room with the child according to parents' preferences.

In these interviews we can observe that it is not routine practice to offer facilities to parents. Rather, facilities were supplied when nurses responded to immediate needs presented by parents. The health professionals are the ones who respond to the immediate demands of parents when these facilities are not available inside the health system. Thus, the health professionals' relationships with parents are dominated by unpredictability (because it will depend on the professionals who are working at that moment, in terms of their willingness to help the parents in addition to their routine labour). For instance, mother 5 could sleep in a spare bed '...but we had to up and dress before the day staff arrived', mother 10, talking about meals said, 'I don't think that happens normally. The parents have to go down to the restaurant but I didn't want to leave him' and finally mother 14 stated, 'It didn't always happen. It depended on who was serving the meals'. Therefore, parents cannot be assured of having their basic needs covered in every situation.

Giving some parents the freedom to cater for themselves in hospital would ease the problem of meals not being provided routinely. In this way parents could please themselves when needed. Some parents described how they had the option of using kitchen facilities and preparing their own food inside the hospital. Having kitchen facilities would save parents the time and the effort of going to another place. This would reduce the need for visitors arriving to supply parents with meals that are not provided by the hospital.

### **6.3.3. Washing facilities**

What would one feel like after three days in a very warm environment in hospital with the same clothes and for the whole duration?

Only one mother stated that there were showers for parents (Mother 7). Two of the mothers described that they had to go back home to have a shower (Mother 2 and 7).



Another mother said that she was not sure if there were showers, but she used to have a bath after she bathed her daughter.

It would be convenient for the parents if the hospital would provide washing facilities in the ward area. They could have a shower there without being in a hurry to go back to their houses and return to hospital every time that they needed to have a shower.

Another important issue is the provision of laundry facilities. If parents are going to stay there for a long time, having laundry facilities would reduce the need to go out to wash their clothes, or to depend on somebody else to do the laundry for them.

A report of a UK survey about children's services in acute health care provision (Royal College of Paediatric Nurse Managers' Forum, 1999) notes that whilst some Trusts provide excellent parent facilities, including the provision of meals in the ward or free tea and toast at breakfast time, many still provide only very basic provision. Parents have to share the same toilets and washing facilities with the children on the ward. One mother said that she considered it difficult (Mother 1), awful and dreadful to have to cope with the facilities if she would have to stay in hospital for a long term.

At this point, it should be said, it is not only important to have a number of facilities for parents but also to explain all the details for using the facilities, including where they are, and how and when they can be used. Three parents (Mother 1, 5 and 13) did not even know the variety of ancillary staff that was available during the hospitalisation.

#### **6.4. Facilities available for children from parent's point of view**

We cannot forget that children are the protagonists during their hospitalisation. Burke et al (1997) described that healthy children who have a single, brief experience of being hospitalised present a small set of stressors (the number of stressors is higher when considering children with chronic and disabled conditions). The stressors are:

- Fear of the unknown
- Separation from parents
- Painful or intrusive events

The stressors reported for parents of children with chronic and disabled conditions differ in families, and over time within families (Burke et al, 1997). There are four main groups of stressors:

- Maintaining often idiosyncratic procedures and routines related to the child's condition
- Maintaining the child's often complex activities of daily living
- Communicating with multiple health care professionals
- Maintaining family life routines during repeated and extended hospitalisations

A similar approach can be observed in the work of Bluebond-Langner (1996). She found that parents feel devastated upon hearing the diagnosis of a chronic illness, their lives changed as a result of the diagnosis and they were also frightened of the prognosis. She tried to understand the day-to-day rituals and stresses of living with cystic fibrosis. This author discussed how difficult it was for some parents to learn certain procedures and to administrate some medication. However, parents in her study soon understood the complexities of the illness and its daily regimen of treatment. The families involved in her study developed an extensive awareness of treatments, research and transplants, and medical jargon was commonly used. Parents also described the constant juggling that is necessary to establish routine treatment-related tasks and medical appointments with all the family's other priorities. Moreover, she found that parents try to balance the needs of other family members while caring for the ill child.

In the present study, of the 10 mothers interviewed almost half of their children had been hospitalised for an average length of three days. In addition, 60% of the children of those mothers interviewed (n=10) had been hospitalised three times. Thus, we can observe how parents described some factors in relation to the former three stressors.

**a) Fear of the unknown:**

Working as a paediatric nurse it was not unexpected to find situations in which children arrived in hospital for the first time, without even knowing the purpose of their 'visit'. They arrived thinking that they were going on holiday or for a trip when they were really going to have a tonsillectomy. Once there, they found

themselves in an entirely different environment from what they expected, and surrounded by many strange people who were carrying out procedures that were not as pleasant as the supposed 'holiday'. Always, in these cases, children were scared of every movement that was made inside the hospital. When somebody simply knocked on the door, they were watchful about what was going to happen. Although nowadays, most of the children know the reasons they need to be in hospital and, more or less, the treatment that they are supposed to receive, the fear of the unknown is still present. The ambience, the procedures and the health professionals themselves constitute a myriad of unfamiliar elements that children have to face. It seems obvious that the more unknown a situation is, the more likely it will be to cause anxiety. The following parents' comments show that this feeling of 'fear of the unknown' was present in at least three children.

'She was scared of the unknown. I mean, not that you wanted to go through it, but if she had been through it a few times before then she probably wouldn't have been this frightened because she would know. She is frightened of the unknown and frightened of strangers.'

Mother 9

'He was a little bit frightened at first with it, having a mask over his face but as soon as he got used to that, he was sort of recharged his batteries.'

Mother 7

'It is a fear of the unknown'

Mother 11

One mother described how some hospitals invite families to visit the ward prior to being admitted (when admission is planned) in order to reduce the anxiety experienced by children (and also parents) that have never been in hospital before.

'Prior to Daryl being admitted... we were sent a letter inviting us to go there for a visit.'

Mother 10

#### **b) Separation from parents:**

Separation from parents has been widely described in times past in the bibliography about hospitals and children (Alsop-Shields and Mohay, 2001; Cleary, 1992; Rodin, 1983; Lansdown, 1996). The British child psychiatrist John Bowlby in

1944 (cited in Alsop-Shields and Mohay, 2001) concluded that the separations from the mother for extensive intervals of time could be the origin of 'affectionless character'. According to Bowlby, children form an attachment to their mothers, and once this bond is created, children try to maintain it. If separation occurs for any length of time they become anxious, especially if they are under perceived threat. Another British author, James Robertson, influenced by Bowlby's work, and after experiencing his own child's admission to hospital, decided to focus his research on the separation of mother and child due to hospital admission (Alsop-Shields and Mohay, 2001). These two authors, among others, described the stages through which children pass when separated from their parents. However, their theories show some contradictions, the former being more theoretical and the latter more pragmatic.

During the interviews mothers explained how their children were better if parents were allowed to stay with them. Children in these cases were less distressed and their adaptation to the hospitalisation was made easier.

'It wasn't distressing... I think if I have had to leave them alone then it would have been a different matter. I think they would have been upset. But because I was there, I think it was just like a new playroom for him'

Mother 7

'Perhaps it might be better if a parent was there before'

'She thinks as much as her parents are there... it's just like a sense of ... she was just scared'

Mother 9

'I was allowed to stay with him all the time...' 'That made it a lot easier for him'

'That made everything a lot easier emotionally'

Mother 10

### c) Painful or intrusive events:

Children in hospitals often go through procedures that cause them fear and emotional distress. For instance, needles are universally feared, or at least disliked, especially by children. The importance of the prevention of this distress for medical procedures is generally acknowledged, particularly for when the procedures are painful or frightening. Sometimes the medical procedures can hurt and confuse

them, especially if they do not understand the purpose. Thus, communication with children (adapted to the child's level of intellectual ability) is one of the keystones when children stay in hospital. The context in which the medical practice occurs is also important. Olds outlined, in 1978, (cited in Rodin, 1983) that children are usually unable to dissociate the medical procedures from a setting which is not child-friendly and sometimes even frightening.

Some examples of how mothers and children viewed medical procedures during the hospitalisation are quoted below:

'They were trying to take blood from him and they didn't get it the first time and Dan got really worked up... He is frightened of hospital and he is frightened of having blood taken again.'

Mother 2

'She was so hysterical she'd pulled the needle out of her arm and then blood was coming out'

'I don't want to do this. It is hurting mammy'

'As soon as they put the needle in she just started screaming her head off'

Mother 9

'It's the needle business that he is absolutely terrified of.'

Mother 10

'They had problems finding her veins to put the canula in, ... and they tried 5 times'

'... they wrapped her arms...'

'... They didn't have time to wait for the cream'

Mother 13

## **6.5. Parents' impressions of health professionals**

Neill (1996b) found in her study about parental participation that some professionals' attitudes inhibited parents' participation. In this research 95% of the parents surveyed described their relationships with the health professionals as 'satisfactory'. However, the mothers interviewed described how they would like to improve their relationships with the health professionals when they stay in hospital with a child who is ill. Parents' expectations of nurses and doctors were summarised in an attempt to describe the ideal type of professionals that should be working with children in hospital.

It is reasonable to support the notion that parents want qualified professionals to care for their children. Therefore, knowledgeable doctors and nurses are the first requirement in order to give children and their families the best attention. According to the opinion of the interviewed parents, the health professionals should be entirely dedicated to their job and never leave parents alone when they need qualified professional support. Mother 5 described her experience in several hospitals as follows:

‘Absolutely brilliant. It’s like if you’ve known them forever. When we go in, ‘Hospital 1’ is like first name terms straight all the way. So approachable, it is unbelievable. I found in ‘Hospital 1’ they were more approachable, and more... hard working, and more ...what word am I looking for... I can’t think of the word but ... I have been in ‘Hospital 2’ a lot and because it is not as serious in illness so whatever they... tend... I think because I’m there looking after him. It’s my job. They don’t come in body that much, you’re left to get on whether on your own short of things’

In another part of the interview the same mother related how they were ‘abandoned’ on their own in one of the hospitalisations:

‘...It’s a bit dull sometimes because you are left for a long time, just recently Stephen was in ‘Hospital 3’... just after Christmas, for ...eh, he had a perforated eardrum and he had to have it operated on, a skin graft I mean, he, it’s just a few weeks down the line since he’s had it, and...he was in day surgery they decided that he would have to stay over night. There wasn’t enough staff on the ward we were on, on the day surgery ward. So, we had to be moved across the hospital to another ward. And, they ...might as well not have been there. We never saw a nurse from walkin’ in to walkin’ out the next morning. We didn’t, the only a time a nurse approached us was the morning before we were ready to come home, to change Stephen’s dressings []. Apart from that we might as well not have been in there.’

‘We saw one doctor on the Thursday morning to discharge us and that was it. That was an awful experience that was the worst experience I had of hospital, neglecting.’

Parents realise that nursing staff has a high workload and wards are understaffed in many cases. However, they also described how other nurses simply didn’t do their jobs.

‘Now they (nurses) were quite happy because we were there because they could get on with their nattering. Other nurses are pleased if you help because they want to get on with their jobs, you know it’s different hospitals you go in there and see some of them from start and the shift to finish in their shift they never stop. And they’ll say to you ‘Oh! The juice is such and such. If Stephen wants a drink, can you just get him a drink? Because we are busy’, you know. Or they say the juice is there while you’re sitting here and that way you can just help yourself, you know. You can tell

the nurses that are dedicated and they're thankful for your help because they are busy; but you can tell the ones who will be thankful you're there so they can put their feet up, sort of thing.'

Mother 5

Parents would like nurses to have time to 'chat' with the child and the family. Sometimes, nurses are so busy that they just go to the room when they have something practical to do, and spending some time talking with the family is considered as a waste of time. However, this idea of 'waste of time' is a misconception as it should be the duty of the nurse to chat with children and their parents. Nurses should make time, as part of their routine, to go to the room and talk to the family in order to know more about what the families needs and concerns. It is important not to give the outward impression that they are in a hurry and that they do not have time to talk and listen to these concerns. One mother narrated her experience with nurses and doctors:

'That particular time we didn't have much contact with them especially not the doctors... (...) The nurses? Yes, we did see the nurses but usually only when Sophie needed something done. She needed the temperature taken. They came in and took the temperature and then they chatted to you and that was fine but they wouldn't just come in just to say how things were, just when there was something to be done...'

Mother 2

Nurses and doctors should be friendly and show their approachability and availability with a reassuring attitude towards the child and the family. Furthermore, it is especially important in a children's ward for professionals to be patient, calm, and also careful of the manner and tone that they use to speak to the children. They should possess the ability to cope with the physical, psychological and emotional demands of the children, as well as being persuasive, to children involved in caring for themselves. Mother 13 described her satisfaction with the health professionals in the following words:

'...The doctors were always very helpful, approachable. The nurses were really friendly. Lindsay was really at ease - they were all really nice to her as well. You know - they'd talk to her rather than talk to me, they would speak to her and tell her what was going on, and then let me know as well.'

Mother 13

They should be informative and make the parents feel involved in the care of their children. Nevertheless, they have to take control when needed. Finally, they should always

be sincere, and always tell the truth. One mother described some of the previous aspects of her child's hospital experience with these words:

'... for thirteen years now or more, there's still one nurse, one sister at the hospital, who would never lie to you, would always know the correct thing to do, whom I trust, absolutely, and I would make sure that I speak to her. I think, you know, the hospitals, they have to gain either the patient's or the parent's trust: they have to work so hard to do that in the first place. And then once they have everyone's trust, it's easy after that. It's just, obviously, they have to prove their worth in the first place, for the parents to have their trust.

'Well, they make sure that the parents are well aware that they can do their job perfectly. No mistakes.'

Mother 14

Trust emerges as an important aspect. The professionals should achieve the parents' trust, but they should also believe in parents' abilities and knowledge. This is a bi-directional relationship, caused by the fact that health professionals have the medical knowledge and parents know their child better than anyone else. Thus, all the information given by the parents must be seriously considered. '*I felt like nobody was taking me seriously*' related mother 7.

One interviewed mother commented how giving parents some control over some events and helping them to understand the situation made parents feel better:

'... so, I mean, they were all really good. And I think as long as the parents feel that they have got some control in things that are explained to them and they understand what is going on. I think people feel... parents do feel happier.'

Mother 11

### **Health professionals' attitudes towards parents' participation:**

- **Do nurses and doctors welcome parents' help?**

As described by Neill (1996b) some professionals have a paternalistic attitude and impose their own views and solutions on others, without considering the opinion of the child or the family. Johnson and Lindschau (1996) found in their study that the majority of professionals have a neutral attitude towards parents who are participating in their children's care. However, they also found negative attitudes towards parents' participation,



and none of the participants in their study strongly accepted the idea of parents' participation during the hospitalisation. Darbyshire (1995) detected that professionals can feel that their role is diminished when parents are actively involved in a child's care.

Parents in this study were asked in the questionnaire if they thought that nurses and doctors would welcome their help. 91% thought that the nurses and doctors would welcome their help; however, 5% considered that the help of parents would be unwelcome. 4% were uncertain.

Most of the parents who thought that health professionals would welcome their help believed that it was due to 'overwork' in paediatric wards (54%). These parents believed that by helping in the ward the workload would be reduced and that was the main reason that health professionals would welcome their help. Some expressions used were: 'Because the staff is so busy', 'Doctors and nurses are over worked and any help from parents makes it easier for staff and child', 'They are so short staffed', 'To relieve pressure when the ward is busy', 'Nurses and doctors worked extremely hard and worked long hours', 'To allow them to complete paperwork and care for other children whose parents may not be available', 'If parent could look after their children's general care then doctors and nurses could concentrate solely on health care'. Moreover, during the interviews some of the parents explained that their participation in the wards would help with the problem of 'overwork':

But obviously it reduces their work a lot so they can do something else if they've got mums in there looking after their children

Mother 2

**Interviewer:** Do you think that nurses and doctors would welcome your help?

**Parent:** I think so. Sometimes, they might be short-staffed, mightn't they? - in the hospital ward. And I would have thought that if they were busy, and as a mum, you're there... and it's perhaps meal times, and the child's not eating, then if the mum is there. Do you know what I mean?

Mother 9

**Interviewer:** Do the nurses invite you to participate?

**Parent:** Oh yes, yes. Because they are kept busy with other children, whose parents aren't there. So if they can have parents who are going to be there...of course, it's better for them

to have parents to look after their own children. And it gives the nurses more free time to see to other children whose parents can't be there.

Mother 14

7% of the parents believed that their participation in the care was welcomed for providing some personal security for the child. For example, parents said that it was going to be 'less frightening and more comfortable for the child' and also to 'help children to settle and be less afraid. One of the mothers interviewed also said:

'I would think that I'm there to do that not because they are short staffed just because it would be better for them [the children]'

Mother 1

Although some parents answered that their help would be welcome, in their comments such welcome was 'conditional' (39%) to different factors. Firstly, it would depend on the health professionals and their willingness to accept help. Secondly, one mother explained in the questionnaire that it would rely on 'how forward thinking the manager of the ward was'. Parents' attitudes and their willingness to participate was another different factor that plays an important role.

During the interviews one of the mothers (Mother 7) related how she felt that her help was unwanted:

**Interviewer:** Did they invite you to help?

**Parent:** No I wasn't. It was just the nurses came to give medicine. That was it. No, I just have to sit down. It wasn't something that I really thought about at the time but with hindsight I think I would have liked to be more involved but you're just trying... you realise that the staff are very busy, you see, you just try to keep out of their way really, you know you just don't want to get under anybody's feet, so... I think because they are always under so much pressure to get everybody seen to ... but yes I think I would have liked to have helped.

- **Are parents and children's opinions respected by health professionals?**

Parents were asked in the questionnaire if they thought that nurses and doctors respected parents' and children's opinions (See Table 6.1). Most of them (75-77%) concluded that they respect their opinion only 'sometimes'. Approximately 20% of the parents thought that their children and their own opinions were 'always' respected by nurses and doctors. There were, some small percentages of parents (this is not a reason to consider these indicators less important) who stated that doctors never respect child's opinions (2%) and or parents' opinions (1%). 1% of the parents felt that nurses do not pay attention to parents' opinions at all.

Parents strongly believed that 78% of the doctors and 65% of the nurses expect parents to accept professionals' advice. 88% stated that doctors, nurses and parents have to share responsibilities in taking care of the child, and 84% stated that doctors, nurses and parents should share responsibility for decision-making. Therefore, caring for the child in hospital should be a shared responsibility between doctors, nurses and parents, with a careful avoidance of the paternalistic attitudes that health professionals often adopt.

**Table 6.1. Are parents' and children's opinion respected?**

	<b>Always (%)</b>	<b>Sometimes (%)</b>	<b>Never (%)</b>	<b>Don't Know (%)</b>
<b>Doctors respect child's opinions.</b>	18	76	2	4
<b>Nurses respect child's opinions.</b>	20	76	-	4
<b>Doctors respect parents' opinions.</b>	19	77	1	3
<b>Nurses respect parents' opinions.</b>	22	75	1	2
<b>Doctors expect parents to accept professionals' advice.</b>	78	20	1	1
<b>Nurses expect parents to accept professionals' advice.</b>	65	31	1	3
<b>Doctors, nurses and parents have to share responsibilities in taking care of the child.</b>	88	12	-	-
<b>Doctors, nurses and parents have to share responsibilities in making decisions.</b>	84	15	-	1

## 6.6. Procedures induced anxiety

Professionally, health staff have the responsibility of ensuring that medical procedures are carried out as effectively as possible. However, caring for a child during medical procedures presents a challenge: help not only for children but also for their parents, throughout the procedure.

When parents care for their children during unpleasant procedures efficiency and detachment are required. However, parents are not like the other workers in hospital who have been socialized into roles, which enable them to maintain detachment as well as concern. Thus, caring for the child during medical procedures might contribute to increasing the distress amongst parents.

Parents' presence during procedures increases the sense of security for the child and is correlated with lower levels of distress in their children (Brennan, 1994), but inadequate research has been carried out to determine how well parents are able to cope with painful procedures being performed on their children (Sheldom, 1997). If parents are involved to help with medical and nursing procedures, parental stress levels may be increased. The increment of the parental stress level may affect their satisfaction with the care provided. Furthermore, it may affect the well-being of the child, increasing the child's anxiety during the procedures (Sheldom, 1997). Then, the relevance of the presence of parents depends on the specific behaviour the parent displays (Kolk, van Hoof and Fiedeldij Dop, 2000)

There is evidence to suggest in the study that if the parents are involved in procedural activities, due to their status, they are unable to cope with the emotional stress of seeing their child being treated or being sick. The mothers that participated in the interviews described how they lived through some of the medical procedures:

- Some of them with fright and anxiety, using various expressions:
  - o 'You are a bit frightened' (Mother 2)
  - o 'I came out of the theatre and burst into tears (...) Sometimes it is worse for the parents (...) You are on edge; you are trying not to be on edge because you don't want your child to be on edge. That's the hardest part(...) I was panicking (...) That was a bit scary (...) ' (Mother 9)
  
- Others related that it was a traumatic experience:
  - o 'It was a bit traumatic as a parent' (Mother 9)

- 'I must admit it is traumatic (...) It is very traumatic' (Mother 11)
- Feelings of desolation were also present in some of the mothers interviewed:
  - 'I was absolutely heart broken' (Mother 11)
  - 'He used to be sick a lot and that was awful (...) I used to tube feed him and within seconds he used to be sick. That was the worst time' (Mother 14)
- Others showed hesitation regarding the provided care:
  - 'I wanted to say stop (...) It was a disaster really' 'I think some parent would see that child in distress and say 'No that is enough. You are stopping' but I think others would let them do anything because they would think that they know best. I think that really depends on the parents. And I really wish I had said 'stop, you are not doing any more' but I didn't, never mind. Next time.' (Mother 2)
  - They had problems finding her veins. They tried 5 times. So, she had like... the way in there they wrap her arms, you know' (Mother 13)
  - ... the nurses felt... they told me just to leave the cushions and let her come out of it in her own time. I found that quite hard, because all I wanted to do was pick her up and cuddle her. (Mother 9)
  - You don't know what is going on at the end of the corridor (Mother 11)

These explanations of emotions are consistent with Callery's (1997a) work. He also found that parents could be distressed when their own child was in pain or undergoing unpleasant investigation.

Nevertheless, parents realised that being present in some of the procedures even though stress causing, was helpful for the child. Consequently, parents feel better because they know what is happening during the procedures and because they see that their children are less anxious when they are present. What seems to be happening to some extent is that parental involvement reduces parents' anxieties because the children's anxiety also decreases.

'I was there when they gave him the injection ... and I was allowed to meet him at the end ... I felt a lot better'

'I think that made it a lot easier for him and of course being there virtually as he came round, you know, I mean, the nurse was obviously the first that he saw but I was also there. That made everything a lot easier, emotionally'

Mother 10

'I must admit it is traumatic but it is actually better going into the anaesthetic room and at least you can see'

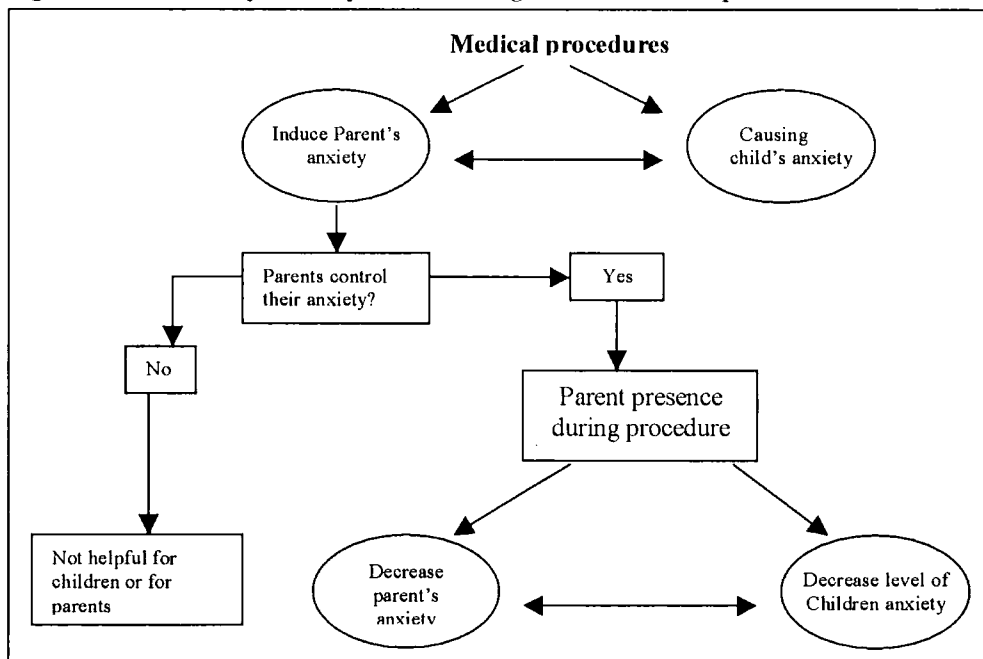
Mother 11

'I prefer to be there... to see what is going on'

Mother 12

If parents' presence during procedures is correlated with lower levels of distress in their children and conversely children's lower levels of anxiety help parents to decrease their anxiety (see above), then the result of parents' involvement during medical procedures is mutually beneficial. However, if parents reach high levels of anxiety they might not contribute positively during the procedure. Consequently, it might better be for them not to take part in that procedure, in order to avoid negative effects for their children and for themselves (see Figure 6.3). But parents can be given a choice, i.e. to take part and to withdraw from stressful situations if they cannot cope.

**Figure 6.3: Effects of parents' presence during children medical procedures**



In the light of the evidence in this study parents should not be compelled to take part in medical and nursing procedures routinely. Parents' inclusion in procedures should not be

done systematically. Their opinion of, and desire for, participation must be respected if positive effects are going to be achieved. As mother 11 related:

'It has got to be the parents' individual choice. Parents mustn't feel that they are being pushed into anything that they don't want to do. That is where the communication comes in. The nurse and staff have got to see, talk to the parents and find out what they want to do. If they don't want to go into the anaesthetic room they shouldn't be made to feel that they have to go in. If that's what they want. I mean, communication, you know, that is the essential to everything, isn't it. And if you don't communicate between all the parties it's eh... that is where the problems are going to arise.

Mother 11

The statement above, by Mother 11, emphasises the importance of communication between parents and health professionals. This theme is thoroughly addressed in Chapter 8.

Brennan's review (1994) showed that although there is a recognition of parents' potential contribution to child care in hospital, parents are often unprepared for this role. Therefore, it is important to design interventional programmes that inform parents about how they may be involved in the procedures in order to help them to assist their children to cope with those medical procedures.

In order to reduce parents' distress it could be useful to explain the possible reactions that the child may have when a procedure is being carried out. Parents also need to be told the procedures will be executed, and about their purpose. If they are previously made aware of this information, parents would not be so surprised by the children's behaviour. As stated by Mazurek (1994), if parents know what changes in the behaviour may occur, their anxiety levels would decrease and the participation in their children care would increase. Besides, if explanations about the procedure and its purpose are provided, parents will understand its importance, even if it means that the child will suffer during the procedure. Moreover, when working with children, it is the health professionals' responsibility to evaluate as to whether the tests or treatments are really necessary, or if they could be postponed and planned for a more appropriate time.

Positive outcomes for both parents and children will be obtained if parents are taught stress reduction techniques and they have an active role in helping their children to cope with the procedures.

It is necessary to take into account every detail at the preparatory stage, during the procedure and after it. As the most familiar caregivers, parents provided some ideas about how procedures could be less traumatic for their children:

'One thing was we were in a lovely little room with him were there were a little bedroom. He could go to bed or watch the tele. They took him out of that into a clinical room to take blood, which is a big thing anyway, for a child. He goes into this room and he saw all this medical cabinets everywhere, medical equipment and the lady with a trolley in the middle of this room. I think it would have been better if they just took blood in the bedroom while he was watching TV where he wouldn't have been stressed. I wouldn't have been stressed. And they might have got the blood the first time. And also, I think there were 2 nurses and 1 doctor and then there was me and the there was my husband and there was Sophie the sister who wanted to come in and see what was happening. Eh, there was just too many of us in there and I think both of the nurses in there were holding his arms and holding, trying to hold him still and I was holding him and then the doctors spoke to him, with the needle... and it was a disaster really. So, I think that probably less people in there. Eh, and not to move him, just to do it in the bedroom where he was used to being surrounded it would have been better.'

Mother 2

Parents know their children best and thus, health professionals working with children cannot keep parents apart and ignore their concerns relating to medical procedures. By asking parents' advice and providing them with adequate information, parents' involvement in their children's care can become a reality.





# **Chapter 7 - Perceptions of hospitals and illness by children**

## **7.1. Introduction**

Nowadays, there exists a growing belief that children have the right to be involved in their health care management. This includes their involvement in the consent for treatment, giving children voices in the decision-making process surrounding their care, and giving them the opportunity to be active participants both in their health care and in the education that they receive. However, deciding how much children are able to understand is not simple, and therefore it is essential for the paediatric health care practitioners to explore children's knowledge, beliefs and ability to understand health and illness concepts.

Firstly some points of Piaget's theory of cognitive development will be briefly summarised. Following from this, the children's view of health professionals, hospitals, medicines and medical procedures will be explained. What can be done to reduce children's distress during hospitalisations and the important role of play has at any stage of children's lives will also be described.

## **7.2. Piaget's theory of cognitive development**

Piaget's theory of cognitive development has heavily influenced a great part of the literature about children's conceptualisation of health and illness. Piaget's theories have been thoroughly debated, but have been practically unchallenged in terms of children's illness concepts (Yoos, 1994). Piaget's developmental theory is based on biological maturation, believing that all humans go through maturation stages but at different speeds, dependent on environmental factors. He assumed that development is an inherent, unalterable, evolutionary process with different developmental phases or stages (Maier, 1969).

Piaget maintains there are five traditional stages:

1. The sensorio-motor phase (0-2 years)
2. The preconceptual phase (2-4 years)
3. The phase of intuitive thought (4-7 years)
4. The phase of concrete operations (7-11 years)
5. The phase of formal operations (11- on)

According to this model, the children that took part in this research would be included in the phase of **concrete operations**. At this stage children are not longer egocentric, as they are able to consider events from different perspectives (Green, 1991). During the middle school years, children achieve the concepts of conservation and reversibility. Operational thought refers to their mental capacity to order and relate experience to an organized whole. However, in the concrete operations phase children cannot perform mental operation unless they can perceive their inner logicity. At this stage children move from an inductive to a deductive mode of thinking and from a world of mythology to a world of science. They also understand the value of rules, and base their judgement on reason. In accordance with Piaget, language follows a developmental continuum from verbal expression to verbal exchange. Furthermore, the structure of language assumes significance and also becomes a part of the thinking and communication process. Notions of animism continue (objects with spontaneous movement are considered to be alive) but it is later in this phase when physical and natural explanations contribute to more realistic understanding. Loss of animism obliges children to face the concept of death and to use a biological interpretation of all life near them (Maier, 1969).

Several studies (Hergenrather & Rabinowitz, 1991) put forward that young children have a more accurate knowledge of the causes, consequences, and treatment of illness than most previous studies suggested. Moreover, after studying nurses' knowledge of how children view health and illness, Rushforth (1996) suggested that beliefs about children's cognitive immaturity might be denying them an explanation about their treatment which they would be able to understand.

Rushforth (1996) also proposed that the limited knowledge and misunderstanding that children may have could be due to poor or partial information received. Piaget is being challenged by this statement because children seem to be able to develop sophisticated levels of understanding about aspects of their anatomy, health and illness if they receive appropriate information. Nevertheless, as Bibace and Walsh (1980) contemplated the clinical usefulness of Piagetian theory is to alert health professionals to children's immature understanding in order to promote empathy with their irrational fears, and thus, contribute more effectively to the prevention and treatment of illness. Therefore, effective communication with children will help children to better understand health and illness related issues and will enable them to make informed choices and to be lively participants in their care (Rushforth, 1996). It is essential for health professionals that work with children to embrace both the theory pertaining to children's concepts of health and illness and its practical application, in order to provide suitable information according to children's ages, levels of knowledge and previous experiences.

Strachan (1993) in a study about 'emotional responses to paediatric hospitalisation highlights the need to ask children directly about their experiences. Moreover, other studies cited in Docherty & Sandelowski (1999) concluded that children are the best sources of information about themselves. One of the aims of this research was to give children a chance to talk about health and illness in order to obtain information directly from them.

Children probably do not have a full understanding about biology and health; however, this does not suggest they are not able to learn about these subjects.

### **7.3. Children understanding of biology, health and illness.**

Knowledge of biology in children is minimal, thus they cannot provide detailed biological explanations. As they grow older and they are exposed to the media, schools, peers and social activities they are able to understand more complex matters related to health and the causes, the transmission and treatment of illness.

Harkins (1994) explained that children define 'health' as the absence of illness. The understanding of illness is easier than the understanding of health. Healthy children can identify with needles or feelings such as pain. Illness causes disruption in daily activities that are central for the child. Moreover it is more threatening to their well-being. There may be two other reasons for children's poorly developed concept of health. First, children tend not to receive reinforcement for health behaviours, whereas they receive extra attention for illness symptoms. Second, the information that children receive comes from different sources (family, school, media and peers) and sometimes this information is contradictory.

According to Piaget children believe in '*immanent justice*'. This is the idea that 'nature herself will punish misdeeds' (Flavell, 1963). Transgressors against adult authority will be castigated because adults are so powerful that they can enlist inanimate objects to punish the disobedient. This is a line of research expressed in Piaget's work. In medical literature (Kister and Patterson, 1980), it has long been reported that paediatric patients may report feelings of guilt about their illnesses. However, other more recent studies (Hergenrather and Rabinowitz, 1991; Siegal, 1988) have concluded that misbehaviour as a cause of illness was rare, and that children have more knowledge of contagion and contamination than was previously estimated.

Bibace and Walsh (1980) explained (in light of Piaget's theory) that children in the Concrete-Logical stage (between 7 and 11 years old) give explanations of illness centred in *Contamination* and *Internalisation*. In relation to the former, the child is able to distinguish between the causes of illness and the manner in which it is detrimental. Persons, objects or external action, which are 'bad or harmful' for the body, are seen as the causes of illness. The child, after being in physical contact with the cause, becomes ill because he or she has been contaminated. Older children use Internalisation in the Concrete-Logical stage. Although illness may be caused by external causes, it is located inside of the body. The external cause is linked to the internal effect of illness through a process of internalisation such as swallowing or inhaling (Bibace and Walsh, 1980).

Helping children to understand the causes of illness could help them to cope with the illnesses and alleviate some of the fears and guilt they experience when they are ill.

Kalish (1996) found in a study made with pre-schoolers that judgement of requiring medication, having fever and being unhealthy were attributes of illness. One explanation, according to Kalish (1996), could be that children think of illness in terms of socio/behavioural theory in which illness is related to feelings (fever) and appropriate responses (taking medicines). It could also be possible that children often incorporate typical characteristics into concepts as if they were definitive.

Experience can also play an important role in relation to concepts of illness. Jenney and Campbell (1997) suggested that illness is a learning experience for children and that developmental changes in the concept of illness may be the result of experience. Kleiber and Harper (1999) in a review of preparation methods for medical procedures concluded that it is probably the quality of the child's experiences that matter, and not the quantity. They found in their review that the quality of the previous medical experience had an effect on the child's behaviour and was cause of distress.

Having a knowledge of what children comprehend can assist professionals in dealing with children who are ill. Fears and worries that may be considered as irrational can be understood and thus health professionals can better explain the situation to the children, while also giving proper support to their parents.

## **7.4. Children's understanding of health professionals role**

### **7.4.1. The physician role**

How children, especially young ones, see the physician's role has not been previously explored. However there are some studies available about how children understand adult authority and role-association. For children, social position and authority are linked to age. From 4 to 9 years children believe that their parents possess epistemic authority, i.e. 'they know best'. Very young children chose knowledge attributes as those which legitimated authority. Middle-childhood children rely on the idea that authority involves knowledge and social position (Laupa, 1991). Middle childhood children differ from young children and adolescents. The former chose knowledge attributes to legitimate authority and the latter two chose social position. Taking into account Laupa statements

(1991), the responses to the physician's role during the interview and the examination may be different, varying these perceptions according to the children's age. According to Herbst et al (1999) what children report in the context of a medical examination depends not only on the role and authority of the physician but also upon their own social role as a patient and, of course, the doctor-patient relationship.

Herbst et al (1999) also asked children about what they perceived as the doctor's job. Most of the children in his study mentioned the use of medical equipment or procedures, for instance, the use of stethoscopes and giving immunisations. They also gave some conceptual descriptions about what doctors do. When healthy children were asked, health maintenance was also included in several children's descriptions. In the research done in Chester-Le-Street children were not asked directly about what they think a doctor's job is but about what they liked most and least about going to the doctor. The responses given were consistent with Herbst's research. Some examples about allusion to the use of medical equipment and procedures are 'he [the doctor] looks in my ear', 'listen to my chest', 'they [doctors] look in my mouth', 'you get injections' and 'examining you'. Referring to the conceptual descriptions children used expressions such as 'they give me something to make me better', 'he [the doctor] will make me better', 'the doctor is going to make you better with medicines', 'you get treatment to make you better'. Concerning health maintenance one of the children said, 'I like when he tells you that you are going to be OK'

### **What children like most and least about going to the doctor**

That they will 'get better' is what children like most (33%) about going to the doctor (See Figure 7.1). They used the following expressions: 'He (the doctor) makes you better', 'They (doctors) make you feel better', or 'Thinking that he (the doctor) is going to make you better with medicines'. 13% of the children stated that they most liked playing with the toys that are in the waiting room. 'Child friendly doctors' were the responses of 7% of the children. In smaller percentages they also liked: to receive rewards (stickers, sweets, etc) at the end of the visit (5%), being examined (5%), feeling secure (because of doctor's knowledge) (4%), and when the doctors talk to them (4%). A very significant percentage (20%) of the children do not like anything about going to the doctor.

**Figure 7.1: What children like most about going to the doctor**

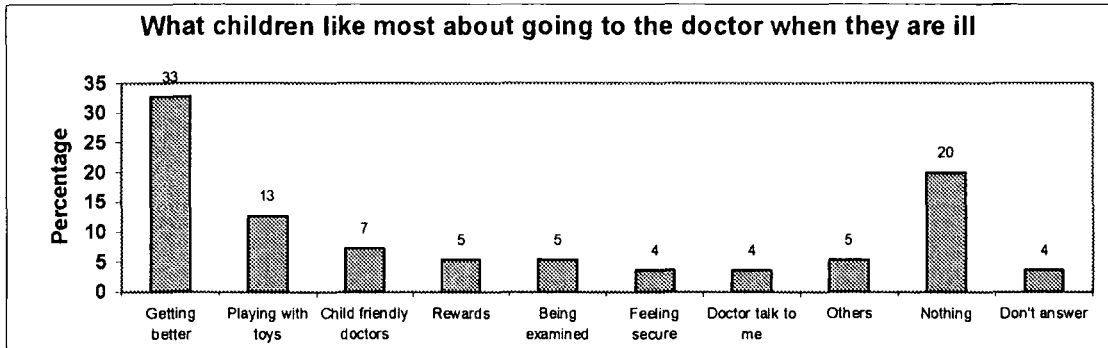
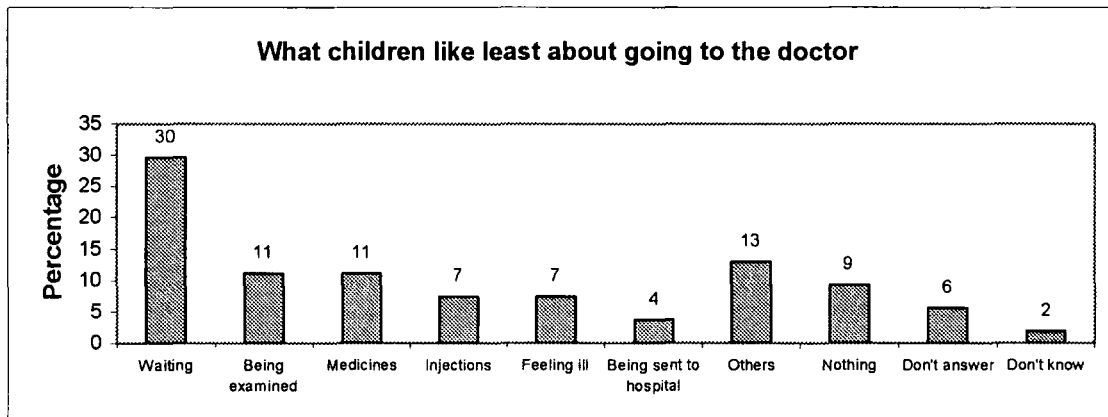


Figure 7.2 indicates what children dislike most. 30% of the children stated that they dislike waiting for long periods of time, 11% said they disliked being examined and having to take the medicines prescribed, feeling ill and being given injections (7% each) and being sent to hospital (4%).

It is relevant to add some of the responses that were included inside the section of 'others'. Children said that they don't like 'when doctor talks about things that I [the child] don't understand', 'If he [the doctor] says something serious' and 'In case he [the doctor] hurts me'. 9% asserted that they do not mind going to the doctors.

**Figure 7.2: What children like least about going to the doctor**



As it was described in the chapter on methodology, the examination by doctors is the first contact that children have when they arrive at the hospital. It is the most common activity because the doctor examines them in order to make a diagnosis, and such an examination will be repeated on various occasions (daily or even several times per day). Children also related spontaneously about what they either like or dislike when being

examined by doctors. For example, 93% of the children said that they don't mind the doctor using a stethoscope to listen to their chest or abdomen, similarly they do not mind when the doctor examines their mouths (87%) and their ears (91%).

24% of the children are bothered when doctors examine their abdomen by palpation. Why this was the case was not clarified within the questionnaire. There are at least three possible reasons for this. Firstly, when children's abdomens are being examined they have to lie down. Lying down, children could feel less secure seeing the figure of the adults in the room from a different perspective, and thus, could become more frightened. Secondly, before doing an examination doctors usually wash their hands and sometimes their hands are not very warm before touching the child's abdomen. It could also be possible that the procedure is painful when the abdomen is tender as in the case of acute appendicitis.

#### **7.4.2. The nurse role**

##### **Image of the nurses**

Shelly (aged 7) and Katy (aged 10) (Drawings 9 and 18) drew a nurse. In Shelly's drawing the nurse appears complete, and in Katy's only the nurses' head has been drawn.

In the children's drawings not only clothes or uniforms that nurses wear are seem to be important, but kindness and approachability are equally relevant. Smiles are always appreciated. The nurse was drawn by Shelly (Drawing 9) with arms extended, being ready to take care of the children.

Campbell et al (2000) concluded that an equilibrium is needed in the children's nurses' uniforms between presenting a professional authority figure, providing security for families and showing approachability. Participants in this research suggested that the image of the nurses should be a friendly one and this would be connected with issues of approachability.

Several issues arise when talking about paediatric nurses' uniforms. It is important to find a functional uniform that makes nurses feel comfortable, permitting them proper mobility. They must also be easy to clean. However, this 'practical uniform' will be the image and the symbol of the hospital. Therefore, it has to respond to children's and parents'



expectations of approachable and friendly nurses who are also knowledgeable and self-confident.

### **Nursing activities**

A variety of activities were drawn or described by children. Five children drew the nurse simply 'Standing' close to the patient's bed (drawings 3, 6, 12, 16 and 24).

Two more children produced a drawing showing the nurse helping children who are on crutches (drawing 17 and 25). Julie (aged 11) drew a girl who had a broken leg with a plaster splint resting on a board. We can observe that the girl is now better but she had previously been in bed and probably using the wheel chair. This drawing includes 'edging'. The bed is only partially drawn in the picture; there is a part that has gone off the paper. According to Furth (1988) edging 'consist of a figure or object along the edge of the paper that often even goes off the paper, so that it is only partially drawn in the picture'. This is a method of getting involved partially but not being fully committed (Furth, 1988). Possibly, the girl was partially recovered from her illness. What might be shown is that she is trying with the help of the nurse to recover and continue the healing of a fracture without having to go back to bed.

One child drew the nurse holding hands with a child (drawing 4). Nurses with their arms extended were drawn by four children (drawings 4, 5, 9 and 15). According to Furth (1988), when arms are in extension they could easily reach other figures in the picture that are close to them. So, the nurse is wanted by the children.

In drawings 7 and 10 we can observe that the nurses are shown to be carrying or looking at the treatment charts. Drawing 11 shows that the nurse is carrying a tray with several utensils. It seems that drawings produced by these children were based on their personal experience and match precisely what nurses do in reality.

In another drawing (see 23) the nurse is reading a book to a child. Rachel aged 11 (drawing 27) drew the nurse giving an object to a patient (it could be some medicine in a small glass). Playing table games with a child also appears in one drawing (drawing 26). The child that made this drawing said *'the nurse is playing with this boy who is going to get*

*an operation the next day*'. And finally, the Nurse was put in a playroom by Aida, aged 11 (Drawing 22).

## 7.5. Medicines

Valerie, aged 8, related: *'I think nurses help people in hospital because they want people to get better and they want people to live. So, they give people medicine.'*

Pamela (aged 9) said *'Nurses work in hospital. A nurse works there to help people when they are ill and to make people better. To make people better you can give them tablets and you can give them medicine.'*

Children were asked in the questionnaire about the medicine that they usually took for a 'sore throat'. The reason for selecting this particular question was that in cognitive-developmental studies, 'illness' in general (according to Rosch's theory of categorization, cited in Yoos, 1994) is a category situated in a high level (in Rosch's words is a 'superordinate' category), and the literature shows that these types of categories are difficult for children to learn. It is better to select a disease at a 'basic' level, in which concepts are more salient to young children (Yoos, 1994), so that they will be able to provide more information about it. Furthermore, most of the children have had a 'sore throat' at some time in their lives, and thus, they could provide information from their life experiences.

Most of the children (69%) took 'syrup' when they had a sore throat and 24% took pills. 45% of the children did not like the taste of the medicine that they had (See Figure 7.3). However, they assured (96%) that they would still take the medicine even if they do not like the taste because they knew it would help them to get better. When asked about which medicine they do not like the majority said they dislike capsules mostly (61%), 23% said that they did not like pills and 10% stated that they do not like syrup either (See Figure 7.4). 29% of the children considered having to take medicines is a nuisance.

Figure 7.3: Medicines that children took

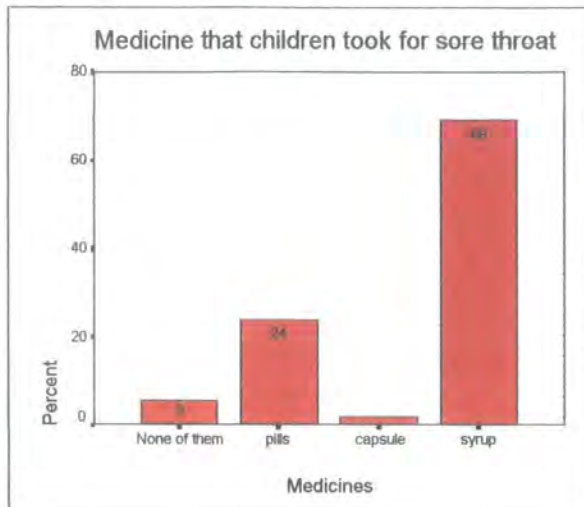
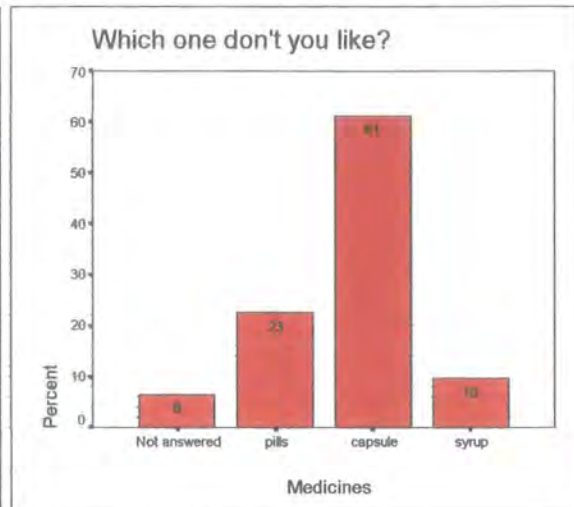


Figure 7.4: Medicines that children dislike



## 7.6. Hospital paraphernalia

By understanding more about children's thinking, fears and reaction to hospitalisation and procedures involved in their care, health professionals will be able to implement new interventions in their clinical practice. The hospital provides a mixture of experience: the child is confined to a bedroom, entirely different from the one that he or she has at home; there are also some adjacent areas that are also totally unfamiliar. Children usually have to visit some other areas inside the huge hospital. They have to undergo medical procedures that are unpleasant and unfamiliar. Misunderstanding, fears and fantasies are often manifested in evident upset behaviour during the procedures. Children feel powerless and most of the time they have no privacy (Cleary, 1992). Furthermore, they have to adapt to hospital routines.

Children were asked, how they felt when they were in hospital. They had three different symbols (☺ ☹ ☠) from which they had to choose. 45% selected the intermediate one (☹). The 'smiling face' (☺) was selected by 18% of the children, and lastly, an 11% selected the 'turned down mouth' (☠), a sad face.

### 7.6.1. Arrival to the hospital

Drawings were the principal source of information about hospitals. Two of the drawings made reference to the transport used for bringing children to hospital. Pamela (aged 9) (see drawing 14) drew an ambulance. The ambulance is yellow and appears to be more like a bus than a proper ambulance because there is space for several people in it. It seems to be very important how children arrive in hospital and how they are received in the emergency unit. Their first contact with the system and the health professional may make them feel insecure and mistrust hospitals. Joe (aged 8), when talking about his drawing, commented, *'A child is injured by a car crash or ill. So, somebody rings the ambulance and they bring the child to hospital'*

### 7.6.2. Hospital Façade

Two pictures (see drawings 1 and 2) were of the 'Hospital Façade'. A 7 years old child's picture represents a hospital in which there are a number of people (patients, sick children) who are pursuing various activities, socialising and making friends. A child is in bed at one end. There is also a child sitting in a chair who appears to be crying. Why is the child crying? Tom said *'He is crying because he is going to have an operation. He is going to be all right because they will put him into sleep'*. He could also be crying because there does not appear to be anyone with him. He is alone. Cleary (1992) explained that children's happiness while they are in hospital depends more on whether they are lonely or have company.

In Wiley's drawing (Aged 7) the word hospital appears to be relatively prominent in the picture. The exterior of the hospital is colourless and drab, dull and boring to look at. It appears that there are people looking out from some squares which suggest possible windows of the hospital

How a hospital looks from the outside it is also important. Children's first impressions on their arrival could condition their thoughts and feelings towards hospitals in the future.

### 7.6.3. Hospital environment

Olds (cited in Rodin, 1983) stated that the physical environment of the paediatric ward is extremely important. According to her, 'an unfamiliar institution setting' augments pain, discomfort and illness. It is difficult for children to dissociate hospital or wards, medical procedures and other unattractive and frightening circumstances such as being taken to operating theatre or having to stay in bed. Olds also considered that in a comfortable environment the child's anxiety would be ameliorated and children would co-operate more with the examination, the procedures and treatment.

In the drawings of Sheila, Cassie, Gabrielle and Rebecca, the hospital environment is highlighted. Sheila (aged 10), in drawing 15, has drawn a colourful and bright ward. It could be an example of how a children's unit should be decorated. The bed appears to occupy a dominant position in the drawing. She has drawn a small table with different utensils on it, and one of them appears to be a syringe. That means things 'are done' to children in hospital which are unpleasant and painful. Children might link all the procedures as those performed while they are confined to bed.

Brenda and Eva, aged 7 (drawings 6 and 7), Sylvia, Joe and Valery aged 8 (drawings 10, 11, 12), Sheila and Alice, aged 10 (drawings 15, 16), and Gabrielle, aged 11 (drawing 24) drew big beds in the centre of their pictures with the child lying on it and the nurse close to the bed of the patient. Probably, having to stay in bed is one of the issues that worry children. Bed confinement may have dominated the life of some of these children or their siblings, parents or close relations. Staying in bed for a long time is a nuisance to most of the children, who prefer to be playing or are busy with activities to do. Alice (aged 10) assured, '*I was never happy when I stayed in hospital. Nothing fun to do*'.

Consistent in the drawings are nurses who are always close to the child's bed and always smiling.

The colour is also important in the furniture and in the walls in the drawing made by Cassie, aged 10 (drawing 17). It may be relevant to introduce ornaments as flowers or flowerpots with bright colours in the wards. This may help them to sometimes forget that they are in a hospital.

Gabrielle (aged 11) has drawn a colourful room (see drawing 24). This room is more reminiscent of a home environment than of a hospital setting. The nurse is also dressed like an ordinary person, more like her mother, and not like a nurse in uniform.

The ward is brightly coloured in Rebecca's drawing (aged 11, see drawing 27). Furthermore, the child has the opportunity to play with toys and some books that are placed on the bed. The beds in Rebecca's drawing are smaller than those used in real hospitals. Probably she would like to have a bed similar to the one that she has at home. It might also mean that the bed becomes less significant as shown in Sheila's drawing (drawing 15) as Rebecca has almost or partially recovered.

### 7.7. Children in a paediatric wards

There are 5 people in picture number 3 (drawn by Andy, aged 7), which represents a hospital ward for sick children. The nurse is dressed in yellow. There is also a child that appears to be sitting on something that could be a wheelchair. The child seems to have his leg splinted with a plaster. There are two other children that are placed in beds. These 3 children look as if they are not very happy. Andy drew them with turned down mouths. As indicated by Lewis and Greene (1983), a turned-down mouth is a clear sign of anxiety. The fourth child is standing up. He seems to have a problem with his arm, which is in a plaster. In this case a smile can be observed on his face, as well as on the nurse's face. It might be assumed that Andy does not like situations in which his mobility is affected because of his broken leg and his necessitated bed-rest. However, it seems not to bother him much as long as he can be mobile.

Lyn (aged 7, see picture 4) drew 4 figures, three of them are children and the last one is a nurse. It appears that a child with a broken leg in a wheelchair is arriving at hospital. Soon after his arrival, he is placed in bed. Once more it comes into view that the child who is in the wheelchair and the one who is lying have sad faces (turned down mouths); however, the nurse and the other child are smiling. This picture and the one made by Andy might show that children pass through different emotional stages before recovering their previous well-being (initially unhappy and after that recovering the smiles in their faces).

Sarah (Aged 7, see picture 5) drew a very peculiar children's ward. The initial impression of this picture was distressing. Looking at the children's faces one can observe that they are sad or disappointed. The nurse is the only one who is smiling in the picture. The ward seems to be situated near the sea as denoted by the dolphin and the background, which might be the sea under a cloudy sky. There might be different stages of illness in it. There are two different levels in the picture, the upper and the lower level, which seem to be connected:

- The first stage is the one where the child is lying on bed. The cloud that is above her is important. It may symbolize that she is having health problems.
- Both the dolphin and the nurse are in the centre of the picture. It might be that the nurse is identified with the dolphin. The nurse's arms are extended as though she could reach the children to take care of them. The child might consider that with the help of the nurse, sickness will be cured. The nurse is the only one smiling, and usually dolphins represent joy. It would seem that the trajectory of the dolphin is also important. The movement of the dolphin flows from the first stage toward the last. It is in the last part that the children are slightly better, though they are still ill.
- The sun is starting to shine in the third stage. There are still clouds but it seems that after the intervention of the nurse the children are starting to feel slightly better. Lewis and Greene (1983) stated that the presence of sun in the pictures is linked with dependency factors. They stated that the more often the sun is included the greater the child's reliance on advice and guidance from adults. Thus, according to the drawing it might seem that Sarah is confident that she will recover under the care and guidance of the nurse.

The nurse appears as somebody necessary to care for the children when they have to stay in hospital. When Sarah finished her picture she was asked about her drawing:

'How are the children feeling in your picture?'

*'Sad because they are ill.'*

'What is the nurse doing?'

*'Making them better.'*

## **7.8. Medical Procedures**

According to Brennan (1994) the primary fear for children who are ill or in hospital is the 'fear of bodily distortion, mutilation or annihilation. She stated 'Getting hurt', 'sharp things' and 'getting a shot' as some of the most frequent fears of children. These remarks are consistent with the present study because, as it will be seen in the following sections, injections and surgical operations are procedures that worry children most.

### **7.8.1. Injections**

The injection is the predominant image in Denise's picture (aged 9) (drawing 13). Injections seem to be one of the procedures that most worries Denise. Sheila, aged 10 (drawing 15) drew a room, in which there appears to be a trolley that contains different utensils. One of them seems to be a syringe. Injections are again present when talking about hospitals and illnesses, showing the concern that they cause in children. Joe (aged 8, drawing 11) put the nurse in a central position in his drawing, with an injection and a thermometer inside of a tray.

With the purpose of having more information about children's beliefs in relation to injection, they were asked about the last injection that they had received in the school. The injection given was a meningitis vaccine. The questionnaire was distributed 3 weeks after the vaccination. They were asked if the injection hurt and in 74% of the cases replied it did not. 65% assured that they did not have a sore spot for a long time after the injection, and, 64% of the children stated that they forgot about the injection quickly. When asked how they would react if they needed an injection again in the future, 93% replied that they would be less worried. Experience seems to be important to the reduction of anxiety in the case of being given injections. 58% of the children said that the nurse did not comfort them after the injection was given. This could be a point for nurses to consider in the future.

### **7.8.2. Surgical Operations**

Significant differences emerge between the drawings made by girls and the ones painted by boys aged 11. All the males (drawings 19, 20 and 21) have drawn operating



theatres. These pictures are different from the others drawn by the female children. Moreover, we can observe in all of them the presence of blood. It could be possible that one of the boys had started to draw something and the others were influenced by this drawing. Nevertheless, children usually have operation-related experiences in hospital, hence, a possible reason for drawing on this theme. It is also possible that different gender roles could have had some sort of influence. The boys might not be receiving the same exposure or influence as the girls, since they may have different toys, games, and access to comics or books that could have more violent contents.

The drawings give a very detailed picture of the elements that we can find in an operating theatre. Displayed are monitors, lamps, trolleys with material for surgical procedures, etc. Every doctor is dressed in green and is wearing surgical masks and something that could be rubber gloves. Scalpels and blood are also present.

### **7.9. Reducing children's stress.**

Mothers provided some ideas about how the stressors could be reduced. Three parents described how important it was for their children to be with the parents in the ward all the time (7, 9, 10).

It seems relevant to give information to the children without frightening them in order to reduce stress. It is essential not to start the procedure directly, but to keep the child informed about what is going to happen. The information given should be appropriate to the age, knowledge and previous experience of the child.

'Well, Lindsay was about 10 when it happened so, obviously they didn't want to frighten her, so they told her thing that, you know, you just going to take a swallow and the sort, the little... They explained how she would feel and what it would feel like. When the test was getting done and why they were doing it and they said 'is that ok with you?' And Lindsay said 'well...e...'. They said 'it is not going to hurt' And she was all right. They put her [cream], which is a good thing. They don't just dive in there with needles and staff. Even when they were trying the canula they explained 'We need to find a nice vein' and they didn't go in the first time they said 'It is very important that you stay still because if you move we would not be able to find it' and that sort of thing.'

Mother 13

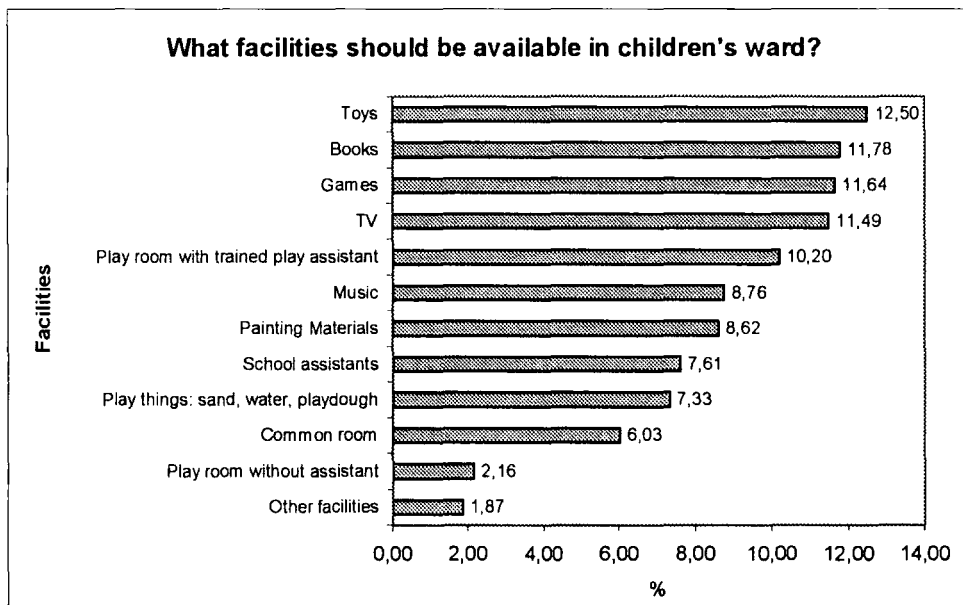
Every procedure should be done while reassuring the child, explaining the procedures to him or her and making the scene funny as though it were a kind of game.

‘They knew set up and they had the cream on and then they put the canula in she didn’t feel it. She didn’t even know that it’d gone in. She was telling them about singing and staff like this and they were asking questions, you know, and they went ‘right that you go’ and then she said ‘Oh that is in already’ And when she looked it was in her arm so she didn’t even feel it. She didn’t even know that they’d put it in, so...’

Mother 13

When asking parents about the facilities that should be available in a children’s ward, close to 12% considered that there should be toys, books, games and televisions. Parents also said other facilities should be available such as music (9%), painting materials (9%) and other playing things such as sand, water, play-dough, etc. (7%). 10% of the parents thought that there should be a playroom with a trained play assistant, and moreover, nearly 8% declared that a school assistant should be accessible in paediatric’ wards. Finally, 6% said that a common room should also be available.

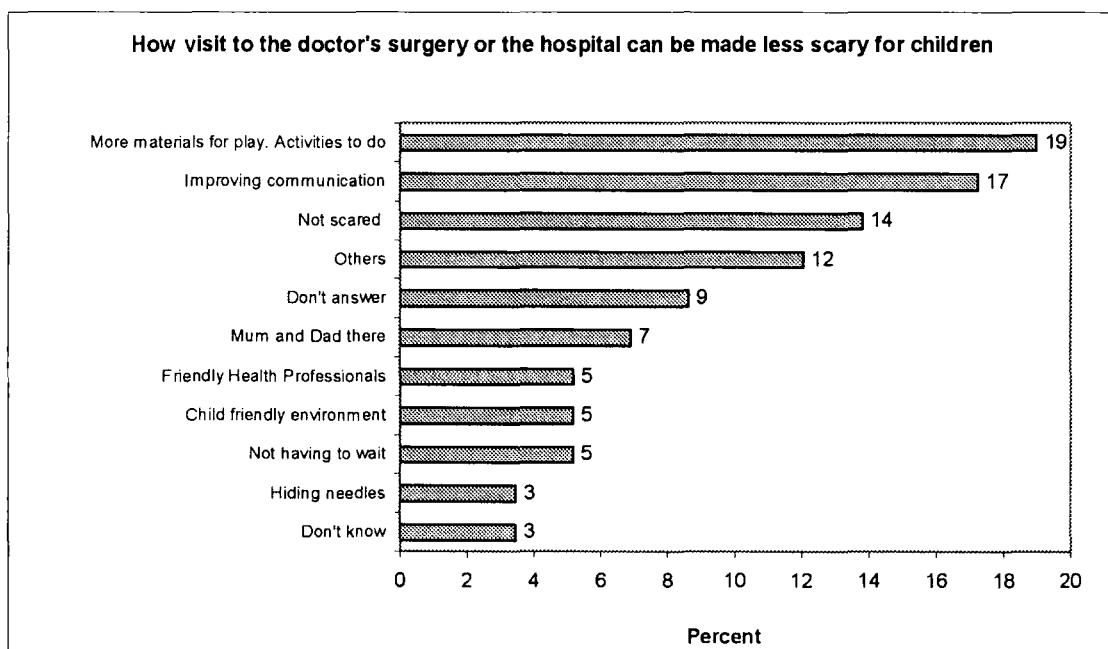
Figure 7.5. Facilities that should be available in a children’s ward



Children were asked in the questionnaire how they thought a visit to the doctors’ surgery or the hospital could be made less scary for them. From the children’s point of view, they would like to have more materials such as toys, books, computers, videos and televisions and more activities to do (19%). 17% of children also felt that the

communication should improve, with expressions such as ‘knowing where you are going’, ‘if the doctor talk to me directly’, ‘If I knew what I was in for’, ‘My mum and dad talk to me and reassure me’, ‘If they told me before what they are going to do’, ‘Talking to me more’. Moreover, they want their mothers and fathers to be present with them so as to feel less scared (7%). They would prefer not to wait for long periods of time (5%) and also, it would be helpful for them to be in a friendly environment (5%) with ‘nice and friendly’ health professionals (5%). They would also prefer to avoid the use of needles (3%) and they advise the health professionals ‘to hide all the injections and scissors and all the sharp stuff’ because they are scared of them. 12% of the children gave variety of responses. One child explained ‘I said to my self that it will not hurt and it didn’t’, another said that he would like ‘to bring a special toy’. One more stated ‘the medicine could be nicer’ and finally another declared that he would like to be ‘given stickers’.

**Figure 7.6: Making the visit to the doctor’s surgery or the hospital less scary for children**



### **Innovations**

An example of creativity was provided by Jeremy (Aged 7). After finishing his drawing (number 8), he said *‘The children in the ward can drive to the theatre when they*

*are going to have an operation. It is quite funny*'. Jeremy suggested a way of self-propelling or toy riding to the operating theatre.

A patient is usually conveyed from the ward to the operating theatre on a trolley, with the patient lying down and being pushed by a porter accompanied by a nurse. However, Jeremy described in his drawing another creative way of moving paediatric patients inside of the hospital. When caring for children every aspect is important. In this picture, for example, driving oneself to the operation theatre is an enjoyable experience. It helps the child temporarily forget about the operation.

If children have a pleasant experience it will be less traumatic. They would be more able to accept the situation and may even enjoy it, e.g. the situation described by Jeremy. Playing or having some distracting activities would make them forget for a while that they are in hospital.

#### **7.10. Toys and playroom**

Play is considered the 'food and drink of mental growth' and it is essential for a child's well-being and development (Lansdown, 1996). The term 'play therapy' is one used by psychotherapists. This therapy is a tool to help in the diagnosis and treatment of emotionally disturbed children. However, the use of play as therapy also helps distressed or potentially distressed children to cope with their fears and to handle the events that they are experiencing (Chambers, 1993). Chambers (1993) declared that the use of play as a therapy helps children to reduce anxiety when they are in hospital and to clarify misunderstandings or doubts that children could have. It cannot be forgotten that play helps to provide normality to children who are in an unfamiliar environment.

Three different theorists (among others) the Psychoanalytic Theory of Erik Erikson, the Cognitive Theory of Jean Piaget and the Learning Theory of Robert Sears have their own theories about 'Play'. Erik Erikson, for instance, considers play as one of the major ego functions. According to Erikson, play deals with life experience, which the child attempts to repeat, to master or to negate in order to organize his or her inner world in relation to his or her outer world. Play also involves self-teaching and self-healing (Maier,

1965). Piaget saw play as a means by which children assimilate information (Flavell, 1963) and it is an essential part of the evolution of intelligence (Maier, 1965). Sears stated that play provides a chance for the child to explore the structure of his or her immediate universe by 'trial and error'. Exploration of the world is made through play. At the same time, through adequate play activity, children can express their joys, or frustrations and anger (Maier, 1965). Therefore, if play is so important for continuing a normal development trajectory and for serving as a normalizing activity (Lansdown, 1996) that detracts from the strange experience (hospitalisation) and makes it a familiar one, what are hospitals offering to facilitate play in paediatric wards?

According to children's drawings there are several types of toys that could help children in their play when they stay in hospital. They drew some soft toys such as teddy bears (Sarah aged 7, drawing 5 and Rebecca aged 11, drawing 27) and a doll (Julie aged 11, drawing 25). Having some familiar toys, children might feel better. Lesley, aged 11, (drawing 26) also drew a nurse playing board games with the child. Playing and spending as much time as possible with children would be helpful to make them feel more secure and relaxed. Games help them not to be worried about the impending operations or procedures they must experience during their hospitalisation. Rebecca (aged 11, drawing 27) drew some books. Aida presented a playroom. 'The playroom, and the doll is on the drip' is how Aida (aged 11) entitled her drawing (22). The only person that she drew was the nurse. The other characters that appear in the pictures are dolls. Although she made the drawing in the playroom, nobody was playing. There were just some scattered toys across the floor.

The doll that is in the corner has a 'drip' and she cannot move from that place. It is as though she could not get a toy because she is bound to the fluid-therapy. It may indicate that according to Aida's point of view, when someone has a 'drip' he or she is condemned to stay without playing. Cleary (1992) related how a girl aged 9, that took part in her research, was on a drip. For two days her life was imprisoned by the drip. Only when she was liberated did she start to talk to the other children. She also described how other children in the ward were playing and 'rushing' about until they had to be bound to a drip. Toys are especially necessary for children that might not read, and are confined to and need to be attached to apparatus.

# Chapter 8 - Communication

## 8.1. Introduction

One can easily realise when working in a paediatric ward how important it is to maintain a good rapport with children and their families. Communication plays an essential role; it is central not only for conveying information but also for transmitting feelings and emotions. How many times is a mother looking forward to having just a few words with health professionals responsible for her child's care? How often are children too shy or so scared he or she does not dare to ask questions about what is going on?

Rodin (1983) stated that through communication, hospital personnel can help children to understand medical procedures. Improved understanding will facilitate the relationship between the child, the parents and the staff. Another author, Burr (in the foreword written for Claire's book (1992)) argued that poor communication can be 'disastrous' not only in clinical terms but also by the relationship with parents who may feel that they are not trusted. This chapter will discuss how communication functions at three levels:

- Health professionals and children.
- Health professionals and parents.
- Parents and children.

## 8.2. Communication between health professionals and children

Even if children are not directly involved in the decision-making process when talking about their treatment, they are nonetheless still part of the process. According to Lansdown (1996) one of the reasons for encouraging communication with children is helping them to reduce their anxiety. When working as a paediatric nurse, the researcher had worked with children younger than 10 years old suffering from cancer, who asked every morning for the results of their blood test: 'has the level of my erythrocytes increased

today?' Children with chronic illness or with a background of frequent hospitalisation use even medical jargon when talking about their situation. However, the question is to know how much do they understand what they are saying or are they simply repeating what they hear every day from their parents and doctors.

Communication with children has many imperfections but speaking to children at their level of understanding is considered most important. The keys to successful communication between adults and children are (Brennan,1994):

- Being honest and direct
- Encouraging children to verbalise feelings and concerns
- Taking into account that some children could be more upset if too many explanations are given
- Keeping an empathetic interaction, which includes acknowledgement of the children's distress, reinforcement of the children's cooperative behaviour and the use of soft, comforting sounds.
- Avoiding the use of certain words that can evoke fantastical conceptualisation in the child's mind ('cut', 'shot', 'put to sleep'), using more benign words. Explanation of the sentences that children could not understand would also be important.

Children were asked several questions with the purpose of knowing how they see the communication with the health professionals. Firstly, they were asked if doctors talk directly to them. 71% of the children affirmed that doctors do talk to them. However, this question could be misunderstood without further explanation. When it was formulated, it was done so with the aim of knowing the extent to which doctors provide information to children and if children feel that they receive enough explanation about their situation. Children, nevertheless, could have replied that doctors talk to them, considering, for example, 'greetings' when they arrive to the doctors' surgery. The validity of the question is not assured.

Children were also asked about the understanding of what doctors tell to them. 44% of them do not understand what doctors say to them. Children also assured that they would

not ask question (45%) if they did not understand what the doctors say. Therefore, when working with children it cannot be assumed that they understand what doctors tell them. Moreover, building up trust in the child is an essential requirement to get children's self-expression in a hospital environment.

In some of the open-ended questions children made clear their need for having good channels of communication. Children's responses were related to this issue when they were asked about how the visit to the doctors' surgery or the hospital could be made less scary. 17% of the children gave answers suggesting a better communication. They used the following statements: 'explaining things in words that children can understand', 'if the doctor talk to me directly', 'going a few times and knowing where you are going', 'if I knew what I was in for', 'if they tell me before what they are going to do' or 'talking to me more'.

At the same time, some parents expressed (during the interviews) that children should be included in all the information processes. They showed their satisfaction when the children were provided with information that was easy to understand and when the health professionals adapted to the age of every child. Further, some of them related the fact that they would like the health professionals to give information to the children reinforcing the channels of communication. For example, one mother (13) said:

'I think that keeping the parents informed of what is going on and keeping the children themselves informed is important'

Mother 13

Misconceptions will be avoided if clear information is provided to children. In the absence of suitable information children will imaginatively construct their own answers. Therefore, it is important to clearly respond to children's questions about medical equipment and treatments (McGrath and Huff, 2001). However, as Brewster (1982) stated, before giving information it is important to gather it. The explanations given must take the child's conceptions into account, introducing new ideas gradually and softly in order to help the child's comprehension. Although having suitable information will help children to understand and cooperate with the treatment, it doesn't mean that all well-informed children will cope well with their illnesses. It is indispensable to take other factors into



account such as personality, severity of the illness and most importantly, how the family copes with difficulties. Some children may be more upset by explanations and do better with only the essential information for the procedure.

Through play, communication with children could be facilitated and trust from children towards health professionals could be encouraged. Children may simply use a drawing to express their anxiety, their fears and communicate with adults through their art. Further, children verbalize their thought more freely when they engage in play activity with an adult whom they trust (Chambers, 1993; Landsdown, 1996).

### **8.3. Communication between health professionals and parents**

The provision of information seems to be crucial. The question is, 'how should the information be provided?' First of all, professionals' attitudes are essential. As Shields (2001) stated, parental anxiety can be alleviated by communicative and understanding staff. They should show their availability and their desire to share information with parents. Verbal and written information are important because one reinforces the other. More importantly, the interaction with the family will be more effective, letting the parents know at every stage what is happening, giving information gradually but continuously, and explaining so that the parents understand. However, it is essential not to provide too much information because that could frighten and stress the parents for no obvious reason.

The sharing of information should be sensitive to parents' concerns, beliefs and needs (Kai, 1996). Most of the parents do not have medical knowledge so they cannot be active members in some aspects of the care of their children. Nevertheless, it does not mean that they are not able to understand what is happening, or are unable to take part in some decisions, with the provision of some proper information. Every parent is different and has a different background. Hence, the explanations given should be personal and adapted to every individual.

Parents should be given information. When knowing what is going to happen during the procedure the parents are not surprised by their children's reactions and they can cope better with the situation. Therefore, through giving information, the fear of the unknown

would be decreased, and parents could cope better with helping their children when they need to have some painful or intrusive experiences. This is consistent with Mazurek's study (1994), which found that mothers who received information about the effect of child behaviour or the parental role participated more in their children's care than mothers who did not receive the information.

However, as it has been said at the beginning of the chapter, communication is not only useful for providing accurate information to parents. Communication also requires listening to what parents have to say. Health staff should show that they are receptive to parents' opinions, worries and concerns.

### **Doctors know best versus Parents know best: Implications for communication.**

Cultural factors are taken in account when the statement 'doctor knows best' is used. Although in the questionnaire just 17 % of the parents related that 'Doctor knows best always' and 81% expressed that 'Doctor knows best sometimes', we can observe in the interviews that 3 parents out of 10 assure that 'Doctor knows best'. The use of this statement implicates two different meanings. Firstly, the hospital ward provides a context in which health professionals have a more powerful position than parents (Callery, 1991). Some doctors show their stronger position by making parents feel that their opinion or concerns are not taken into account due to the fact that they do not have sufficient medical knowledge to participate in problem solving or in the decision-making process. However, in other interviews this assertion is used to express that parents trust doctors because they are professionals who know how to treat their patients and solve the problems that could arise.

The former meaning is manifested with expressions such as:

'...because it's a doctor some people are frightened or intimidated by that and they don't think ... I think some parents probably don't ... don't ask questions'

Mother 1

'I think some parents would see that the child in distress and say 'No, that is. You are stopping' but I think others would let them do anything because they would think that

they know best. I think that really depends on the parents. And I really wish I have said 'stop, you are not doing any more' but I didn't, never mind. Next time.'

Mother 2

'Doctors sort of know best and do it without consulting anyway'

'Doctors know best... I mean, I'm not a doctor'

'All right, yes you know best, you do it'

Mother 5

'I do not have medical knowledge'

'I suppose doctors do expect you to take what they say'

Mother 7

**The latter meaning appears clearly in expressions like:**

'They didn't want us trailing him through to hospital for a year, two years, after the operation, you know?- They said a sort of 'after six months you needn't bring him back anymore'. He is fine... So, leave it to the professionals!'

Mother 5

'What a doctor would advise to us it is probably what I would follow, in fact without doubts.'

'I do not think I will query a doctor. I would take the impression that 'doctor knows best''

'I would put my faith in the doctor'

Mother 7

'They are the experts they know what to do'

Mother 12

Nevertheless, parents showed that their opinion should be respected because parents 'know what is best for the child as a parent' (Mother 7). They would like to be consulted and to be able to discuss with the doctor:

'They never consulted with me and said, you know, this time they did and I had some control over the situation, yeah, definitely'

'He values your opinion. He sits and listen to what you have to say'

Mother 5

‘Doctor should take more time out to speak to people because I definitely found that was helpful.’

‘The doctor came back after he had finished all his cases to discuss things and let me know exactly what I needed to do.’

‘It is definitely more helpful to discuss’

Mother 7

‘I’m more aware of what my own child needs to what a stranger doctor and nurses could be’

Mother 10

‘Your opinion is always respected if they don’t agree with your opinions they would talk things through and they’ll come with some compromise with things’

‘It is a question of discussing and talking and then coming to a compromise between the staff and your self and the doctors basically’

Mother 11

‘They always told me what was happening, told me what they were going to do, and they said... ‘is that ok?’ and I said ‘yes, whatever is best for her’ you know. They always ask my ‘not my opinion’ but a ‘not advice really’ but they always included me in things. I always felt part of it not just stuck outside.’

Mother 13

‘...consultants, doctors and nurses always thought that you were only the mother, so, what did you know? Always, nearly always. And the truth is –who knows their child better than the mother? So that really made me sick of the hospital situation, if they are not going to listen to the mother’

‘You think that doctors know best but... we should pay more attention to our instinct’

Mother 14

Parents want and need to have information about medical and nursing care, not only about their child’s diagnosis, treatment and prognosis, but also about what parents are expected to do and general information about being in hospital. They gave different important reasons for being informed:

- a. Information makes parents competent and help them in caring for their children. In one mother’s words (mother 7):

- i. 'I think the more information you have about the child, about the illness, about what medication, what treatment he is going to receive... the more competent you can be'
- ii. 'Because when the situation arises you don't know really anything about it. We are not nurses. We are not doctors. We don't know the outcomes of things. And I think the more information you can get the better'

b. By having information, one can participate in the making decisions process. As mother 11 said:

- i. 'The staff is there to make sure that parents know and can make decisions on that.'

c. When parents do not have enough information, it increases their concerns and their anxiety. This statement is supported by mother 13:

- i. 'I was worried thinking 'oh, what's wrong?' at that time they cannot give you any information...'
- ii. 'I was worried because I didn't know what to do for her'

d. Information helps parents to cope with the situation and progress in a satisfactory way. According to mother 14:

- i. 'Parents need to know the whole truth. No matter how terrible. They need to know so they can work it out'

e. Knowing general information about where things are and what could or could not be done in the ward, they would adapt better to the hospitalisation and to their role inside of the hospital system. Mother 1 described her experience in the following lines:

- i. '... tour around... where the kitchen is ... just general things like that, that maybe would have helped me to feel that I was welcome to go around.'
- ii. 'I felt a little bit, bit bad of going out of the room sometimes'

Some of the parents expressed that they only got enough information when they made enquires. But what would have happened had they not asked? It could be important for parents not only to be given information but also to be given the chance to ask questions in case that they do not understand something or they would like to have more information.

It is essential that parents do not feel intimidated and that health professionals seem accessible and friendly. If the health professionals do not have this friendly attitude and are not empathetic towards parents, parents will think that they are an inconvenience or a nuisance when they ask questions. If there is not a clear channel of communication, misunderstandings and distrust will arise. However, according to Callery (1991) 'nurses control information whereas the parent is uncertain and dependent on others for information'. Because of this nurses, and of course doctors, should not wait for the parents to ask questions to solve their doubts, but should anticipate the parents' hesitations and give them information that will be useful to improve their adaptation to the hospital and to the illness of the child.

Similarly, it is important to check if the information that has been given has been fully understood, so as not to leave the family unaided, having failed to solve the doubts or misunderstanding that could exist.

The questionnaire exhibited that in 79% of the cases the parents tended to think that the information that they received was sufficient. That means that 21% of the parents considered the information was insufficient. Although they complain about the information being insufficient, 95% of the parents assured that this information was enough to look after their child and 97% stated that they understood the information received.

When parents were asked in the questionnaire whether they would have wanted to have more information, 26% of the respondents claimed that they would have liked more information on treatment and 16% would have wanted to know more about the child's progress.

Furthermore, parents were asked if they would like doctors and nurses to share all the information about the prognosis of the child's illness even when there was an uncertainty about the outcomes. 98% said all the information should be shared. The reasons given for this response were grouped under seven main subheadings: right of parents to know (24%), want to know the truth (24%), enabling them to prepare for the future (24%), help to make decisions (9%), relieve worries (6%), help with child questions (4%) and allow work with professionals (4%). 5% of the answers were allocated under the subheading 'others' because of the impossibility of including them in any other category.

The reasons that 2% of the parents argued against being informed in case of uncertainty were 'because they may cause worry when there is no need' and 'it should be optional some parents may prefer to be left in the dark'. Kai (1996) questioned whether the sharing of uncertainty in decision making by a doctor would facilitate parents' education and understanding or create further difficulty. Doubts about sharing uncertainty arise because doctors and nurses might be wary of causing parents unnecessary anxiety. However, parents have the right to know all information concerning their children's treatment and prognosis. Furthermore, according to the parents involved in this study the dilemma seems to be solved. Parents prefer being informed even if the outcome is uncertain.

### Parents' Feelings

Parent's who had been in hospital were asked to select from a range of statements those which corresponded with their feelings during their child's hospitalisation. The responses are summarised in Table 8.1. 28% of the parents were 'satisfied with the information and support that they received from doctors and nurses', 18% declared themselves 'secure because they were confident about the health professionals' activity and knowledge' and 17% were 'satisfied with the doctor and nurses, who were always readily accessible'.

On the other hand, 7% stated that they were 'worried about bothering their doctor with questions and doubts' and 6% were 'frustrated because nurses and doctors offered insufficient information'. 10 % felt 'worried because you did not know how to help their child inside the hospital system' and 7% thought they were 'unable to protect their child from potential harm'

**Table 8.1: Parents' feeling when they stayed in hospital with their children**

Parents' Feelings	Percentages
Satisfied with the information and support that you received from your doctor and nurses.	28 %
Secure because you were confident about the health professionals' activity and knowledge.	18 %
Satisfied with the doctor and nurses who were always readily accessible.	17 %
Worried because you did not know how to help your child inside the hospital system.	10 %
Unable to protect your child from potential harm.	7 %
Worried about bothering your doctor with questions and asking your doubts.	7 %
Frustrated because nurses and doctors offered insufficient information.	6 %
Others	7 %

Parents were asked in the questionnaire if they felt that they were in control of the situation when their children were in hospital. 60% of the parents replied that they were not in control. The motives argued for not being in control of the situation were grouped under seven categories: 'no information given' (32%), 'therapy beyond parents' control' (16%), 'did not know what to expect' (12%), 'Strange- hospital surroundings' (12%), 'no control over illness' (8%), 'too upset' (8%) and 'child was upset by routine' (4%). Some of the comments made by parents within the category of 'no information given' were:

'Because you only saw the doctor once a day for a couple of minutes'

'Not always kept fully informed'

'Doctors gave limited information when they had some'

'More available 'bodies' to ask would be better. Sometimes nurses are too busy'

'They only tell you what they think you need to know'

The idea that parents are not being given enough information or at least appropriate information is reinforced by parents again in this question, and also consistent with other studies (Neill, 2000). The lack of information argued by 32% of the subjects appears to be the cause for parents not to control the situation during their children's hospitalisation. The findings emphasise the importance of acknowledging and addressing parents' feelings of loss of control in order to design proper interventions. For instance, by stimulating parents' participation in their children's care, parents' sense of control might increase.

#### **8.4. Communication between parents and children**

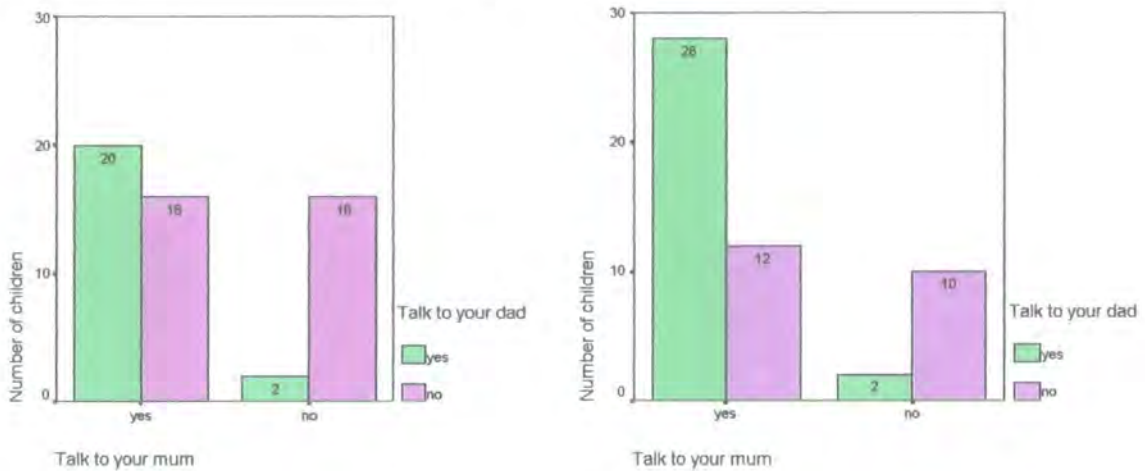
Two children (out of 55) assured that being in hospital or visiting the doctors' surgery is not frightening for them because 'my mum talks about it a lot' or because 'my mum and dad always talk to me and reassure me'. However, what should one tell the child when preparing him or her for hospitalisation, investigation, treatment or surgery? How can parents do it in the best way?

Within the questionnaire two very simple questions were asked in an attempt to gain a very broad idea about the kind of communication existing between children and parents. Children were asked if they talked to their parents and siblings about their feelings before



and after being given the injection (Meningitis C) in the school. The results were that 20 children out of 55 (36%) talked before the injection with both parents. There were 16 children (29%) that did not talk to their parents at all. Two children (4%) talked about their feelings just with their fathers, whereas 16 children (29%) discussed it only with their mothers (p=0.006) (See Figure 8.1).

**Figure 8.1. Number of children talking to their parents before (left figure) and after (right figure) being given the injection**



The percentages do not vary significantly in the responses after the injections. Most of the children (51%) talked to both parents about it, 21% talked to their mothers and 4% just to their fathers. 18% did not talk to either of their parents. 6% did not answer this question at all.

When asking about their siblings most of the children did not talk to them about the injection before (72%) or after (64%).

The percentage of children that did not talk at all to their parents (29% before having the injection and 18% after it) is important. Several reasons for this could exist, but these would be merely speculation because the answers within the questionnaire did not provide more data. An explanation might be that parents did talk to their children but did not remember the conversation. Perhaps, parents felt it more convenient to avoid the issue, thinking that talking about the injection might provoke anxiety in the child. Nevertheless, it

is not enough to only consider the reasons of this lack of communication between children and parents. It is also important to consider the consequences. Where or from whom are these children going to get the necessary information about issues as important for them as medical treatment, health promotion and vaccination, among others? How are children going to be able to cope effectively with the events if they don't have enough information?

Parents may be the most suitable people to give explanation to children because they know their children best. Nevertheless, they firstly need a clear comprehension of the circumstances before they can transmit this information to their children. There could be some parents that are not willing or simply do not know how to establish an effective communication with their children.

On balance it can be observed that if parents and children do talk about illness, simple or complicated procedures, then there is a role for them to play in the family-centred paediatric model of care.

# Chapter 9 – Home versus Hospital

## 9.1. Introduction

'Paediatric home care' is the provision of skilled care and support services to a child in his or her place of residence (Maurano, 1994). Home care is a form of care that brings care and responsibility, within a safe medical practice to the family. This concept of caring for sick children at home is not new. Families throughout history have been the primary caregivers and have traditionally cared for the ill members in the home. Nevertheless, since the early 1980s, home care has expanded to include the care of very ill children in the home. This change in the location and delivery of health care services to children and family has had a profound effect on paediatric health care practices (Maurano, 1994). Home care is supposed to facilitate a normal family function. Whereas the hospital setting is illness-oriented, the home setting focuses on normalisation. Meeting the needs of the child and of the family means facilitating normal family function.

The idea of home care has been applied in several countries, such as United States, England, or Australia. The models of these three countries present similarities and differences. However, a combination of them may prove to be more convenient.

The term 'home care' or 'home health care' is commonly used in American literature (Maurano, 1994). In the United States 'home care' has been developed in response to several social factors. In particular, paediatric home care has been shaped by the need to reduce costs, by increasing consumer demands for quality services and by technological developments (Maurano, 1994). Paediatric institutions and private paediatricians are the agencies involved in home care, resulting in substantial saving to health care institutions. The responsibility of the home care is shared between the health professionals in hospital and the health professionals who will be responsible for the care of the children at home in co-operation with the children's family.

Sartain et al (2001) defined 'hospital at home' as a way of delivering medical and nursing care in a patient's own home as an alternative to hospital admission. This term is used mainly in British articles (Coast et al, 1998; Jones et al, 1999; Richards et al, 1998;

Wilson et al, 1999; Shepperd et al, 1998a; Shepperd et al, 1998b; Shepperd and Iliffe, 2000). In England there are two models for paediatric home care. One of them is the community model and the other is the hospital outreach model (While and Dyson, 2000). The first one is linked to primary health and the second to the hospital service. While and Dyson (2000) expressed that the hospital outreach model permits nurses to maintain their therapeutic knowledge and skills more easily, whereas the community model permits nurses to be informed and connected to community networks and changes in local services for children. There are also some differences within the provision of care. The hospital outreach employs more highly educated staff with a referral pattern centred upon the hospital paediatric services. In contrast, the community model is community focused and its referral patterns are centred in primary health, providing more extensive hours of service.

A recent Australian article (Sherring, 2000) used the term 'Extended Paediatric Service' referring to the care that is conducted at home as part of the care services offered by the paediatric ward of the local general hospital. This kind of care was developed as a flexible and innovative extension of the principles of 'hospital in the home' programmes, which were designated to care for the children with long-term acute care needs in their own homes. Linking this service with the ward, parents can have continuous 24-hours access to staff who are familiar with all the aspects of their children's care. The purpose of these programmes was to decrease the stress and trauma caused by hospitalisation, decreasing the social and economic cost of families related to repeat hospital visits and reducing the cost of accurate care hospital services in that Australian area. The stress is decreased by spending more 'non-treatment' time in the child's own environment rather than in the strange environment of the hospital.

Children are in a familiar surrounding at home, the range of freedom is wider and they are never alone. If the child has to stay in hospital, deprived of this surrounding, how would he or she feel? On the other hand, the decision of caring for the children at home cannot be made without taking into account the parent's opinion. Parents need to trust themselves, their children and the health care professionals, to receive the education that is needed to care for their children and to be empowered. They have to be confident with their own physical and emotional ability to manage the child's care at home.

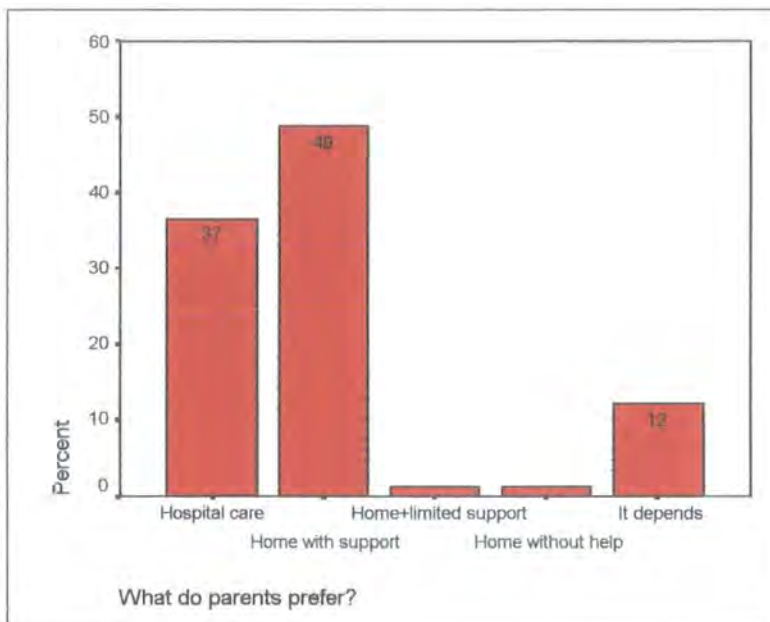
Home care can provide an alternative to hospital care in two ways, facilitating an early discharge from hospital or avoiding admission.

This chapter will discuss the possibility of caring for the children who are ill at home, describing the preferences of the mothers interviewed and the type of services that they thought they would need. Lastly, some economical aspects about the matter will be considered.

## 9.2. Parent's preferences

Parents were asked which they would prefer hospital or home care if or when their children required regular medication and nursing care (see Figure 9.1). An analysis of the questionnaire shows, 51% of the parents would prefer their children to be cared for at home, 36% preferred their child to stay in hospital and 13% said that it would depend on circumstances. 2% of the 51% said that wanted to care for their children at home and they also emphasized that they would prefer not to have any help when caring for their children (1%) or simply have 'limited access to nursing help' (1%).

**Figure 9.1: Parents' preferences when the child requires regular medication and nursing care**



The reasons given for preferring to have children in hospital were the 'expertise' to deal with illnesses and that the hospital is 'appropriately equipped'. The reasons argued to stay at home are that it is better for the child to stay in the home environment; the child is happier, less anxious, more supported and more comfortable; it causes minimal disruption to the family unit and the child's prospects of recovery are better. These reasons are more or less consistent with research undertaken by Sartain (2001). In her study the parents gave reasons such as increased comfort, more freedom, more time with nursing staff on a one to one basis, continuity of normal life, less financial cost, and a perception that children recover better at home. The difference is that in her study there were a higher percentage of parents, i.e. 90% showing preference for home care compared with 51% in the present study. In an attempt to justify the difference in percentages, it was assessed if a relationship exists between having a previous stay in hospital and the actual preference for home care. The association between these two variables was not significant. However, the sample is not large enough to say that no relationship exists. If we analyse this result in combination with the interviews, an association between them seems to appear. The mothers with greater experiences in hospital preferred home care.

Guidance and support of the family by health care professionals are integral to the concept of home care. During the interviews some of the parents showed their interest in caring for their children at home but always with external support:

- Nurses coming one or two times per day:

'Yeah, so if he was to be nursed at home then I would expect a morning visit and an afternoon visit, yeah.'

Mother 1

'... I would think if they needed nursing care everyday they probably send a district nurse every day and I would be quite happy with that. Because I happen to know the district nurse, personally (laughs)'

Mother 9

'A daily nurse coming in, you know, to stay half an hour. Probably just to give me a breather, you know, a break, that's the word.'

Mother 10

'Erm... probably the community nurses or somebody to come here and help.'

Mother 13

- Having a contact telephone number:

'I had quite good support at home and I had the telephone number for the ward as well, so no, again because of his condition I think I got a lot of support...'

Mother 1

'I think perhaps just a contact telephone number so you can phone somebody and you'd know that somebody is going to be there'

Mother 2

'... as long as I had someone that I could contact if any questions arose...'

Mother 7

'When ever you go out of hospital they all gave you a contact number of the ward and a contact person to speak to over the next couple of days if you have any problems'

Mother 11

- Having the possibility of taking the child quickly to get immediate treatment if needed and 'open access' to hospitals:

'You can take the child somewhere very quickly and you are going to get immediate treatment'

Mother 2

'If I was really worried about some stuff, somebody who can come around quickly...and help...'

Mother 12

'... If he was ever to be taken poorly - seriously poorly - I have open access to hospital. I don't have to ring my GP and say 'is it all right if I take Scott?' I can just bundle him in the car and straight to the hospital. Cut the middleman out, sort of thing. Because he's diabetic, I can just whip him straight through to the hospital, no questions asked, you know?'

Mother 5

'...it's what we call open access. If you have any problems when you go home during the first couple of days, if you have a major problem you pick the phone up and say 'this is my problem. Can you give me some advice?' and they take contact until everything is sorted out. It is really good.'

Mother 11

Mothers expressed that children are happier in their own home, in their own environment, in a familiar surrounding and 'get well more quickly in their natural surrounding' (mother 14).

'I think perhaps more children to stop at home to be looked after and just go in hospital when they really, really need to. (...) I think it is important to keep the child in their familiar environment as much as you can.'

Mother 2

'...as opposed to being in hospital... I think the children are happier in their own home, aren't they, well everybody is'

Mother 9

'I think they do realise that children are better off in the home environment rather than in the hospital environment'

Mother 11

Mothers in this study agree in principle that the idea of home-based paediatric care is better for the whole family. For example, some of the mothers said: 'it's better for the rest of the family to be at home', 'the family can keep some of their usual routines and it is easier to take care of other siblings', 'you can't live a normal life' when you have a child in hospital. However, there are practical implications for such an ideal model of care. It assumes that mothers have sufficient knowledge to care for the child especially when complications occur. It assumes also that the health service can provide the necessary support and nursing services for children suffering from different types of illnesses. The following case study highlights the anxiety that a mother had to go through when nursing her child at home without any support.

'When Scott was a baby, he was poorly a lot. He vomited a lot. He didn't put a lot of weight on and he was always poorly. I spent a lot of my time at home up tight, worrying about the weight loss but I always felt once I got him in the hospital he was in the right place. It took some of the burden off me and I used to think, well. They know what they are doing. They'll make him better sort of thing, you know. It took some of the burden off of me at home because at home you are alone. Eh... Well, Not alone I have got my husband but I mean he is at his work all day and I'm sort of sitting there anxious, thinking oh he's vomited again and look at how much weight he's lost, he's sleeping a lot. He shouldn't be sleeping. What do I want to do? Should I give him another drink...? So, when you get into hospital that is not far away from here because he did need the professionals and they'll know if should have another drink now. They should know if he is sleeping too much, or, he shouldn't be like that or his temperature is high or whatever, you know. I always feel better knowing that they are in good hands. For all the



nurses do take a back seat because I'm there I can always get up out of my chair and go and report to them, they're always there if I want them. The way I feel: it's nice to know they're there when you need them.'

Mother 5

It was suggested by some authors (Shepperd and Iliffe, 2000) that 'hospital at home' services increase patients' satisfaction compared with hospital care. However, it seems that the carers could not think the same because some disadvantages could be present when taking care of the patients at home. One of the mothers related that sometimes at home 'you wouldn't necessarily get all the help' (Mother 12).

'It would depend what was the matter, wouldn't it? If ... eh what type of equipment they needed, and whether they just pop in for five minutes or whether they stay hours so. Because if you'd be at home you wouldn't necessary get all the help. You wouldn't get somebody to do the shopping and meals and... what everybody else you probably, I want to do or I wouldn't be able to concentrate on the poorly child, don't you?'

Mother 12

The same mother (12) also said 'So you wouldn't feel as if you were alone on your own really then'. It is important for parents not to be 'abandoned' by the health system and to be caused more anxiety. One of the mothers interviewed described her experience as follows:

'And the local GP had misdiagnosed her three times, and wouldn't give her medication or anything. Which is why it got to the seriousness that it was, and she was rushed into hospital and what have you. Near the end, she had to have medication at certain times of the day, and they said 'at this point, she can go home, but you've got to be extremely - you know, if anything... if you're not sure of anything... you've got to bring her back in. If something goes wrong, you've got to bring her back in quick.' And, erm, he says, 'but...' and then the specialist came round, and he said 'I think I'd prefer her in hospital' and I went: 'well, I think I would as well, with it being so serious, I would be frightened in case I can't get her here quick enough.' And he went 'yeah, it's better to have her in hospital, and we'll give her the medication and wait until it's totally over with, then send her out.' Because the local, I don't know what you call them, 'house doctors' or something - not the specialists, not the consultant, the normal doctors that come round, they were saying 'oh she's fine to go home', but she hadn't had anything to eat for about ten days - not a bite passed her mouth for ten days - because she couldn't swallow. She could hardly drink. She was dehydrated and stuff, and I wasn't happy with her coming home because

she hadn't eaten, because she couldn't drink. She could barely swallow her medicine - it had to be put in intravenous. And they were going to let me do it at home, intravenous, and I went 'no! no!' I wasn't happy with ...doing it that way, you know? So they just said 'oh no, we'll just keep her in'.

**I: At home would you be the one who had to give the medication intravenous?**

P: They would leave the... it's a canula. They would leave that in her arm and I just have put it into her arm. Eh... that I wasn't kind on doing... no!!!

**I: You don't have the help of the community nurses in that case?**

P: No they were going to leave me on my own. So... (laughs) NO! I'd rather have her in hospital if there was a nurse who was going to come out and do it then fine but it was 6 o'clock set to have it 6 o'clock in the morning and 4 o'clock in the afternoon and then midnight. Eh... It was at 10 o'clock that I was supported anyway, and then I just didn't think I could, I could do it properly.'

Mother 13

It is important before deciding what type of care a family should receive to be sure that parents can cope with the situation if the ill child is at home. Thus, health professionals should provide the support and the information necessary to help parents to care for the child who is ill.

Mothers also ask for more community nurses for children (mother 9, 11 and 13) who would be able to give the necessary support when children stay ill at home. And thus, more procedures could be done at home keeping children in their own environment.

'if they need to do investigations and things, you know, they can come and doing them at the house. Why does the child have to go in a hospital into the day unit? You know, some of them yes, like X rays they have to be done in hospital but there are a lot of thing that could be done at home with the child in her own environment. For example, blood they can come and take the blood from the child at home.'

Mother 2

### **9.3. Services after hospital discharge**

Most of the parents (93%) thought that in the short term after hospital discharge, it was 'very important' (79%) or 'important' (14%) to have 'telephone communication with the ward'. A similar percentage of the mothers asserted that a telephone line with a named ward nurse (88%) or a named doctor (79%) is also 'very important' (54% for nurses and 41% for doctors) or 'important' (34% for nurses and 38% for doctors). The idea of home visits by a ward person was considered less important or not important at all (for 31% of the parents). 'Home visits by parent self-help groups' was also supposed not to be important for 49% of the mothers, or simply 'fairly important' for 30%. Parents' opinions about 'private home care service' and 'private education service at home' vary, the former being slightly less important than the latter.

### **9.4. Economical aspects**

From the economic point of view it would appear that home care does not produce cost saving. Some studies argued that an increase in cost for some groups of patients has been observed (Shepperd et al, 1998b). There are other trials that stated that it is cheaper to stay at home (Coast et al, 1998; Jones, 1999) especially when the relatives accepted this sort of care by themselves (Shepperd and Iliffe, 2000). Therefore, it is important to highlight that parents should be informed of the different possibilities in the care of their children, looking for their agreement when home care is decided.

The change of hospital schemes to home care involves changing the patients from the secondary to the primary sector. Thus, the community health care services should be ready to receive an influx of children and families. In this sense, mothers interviewed were right when asking more community nurses to care for their children at home. For the sake of balance, there should be an increase of resources coming from the community health care. This could bring together a shift of the costs to primary and community care. Another consideration is the cost that having a child at home can present to families. In some occasions one of the parents may relinquish gainful employment to stay at home and care

for the child. Other times, parents may necessitate extra expenses to relieve parents of the burdens of continuous care for an ill child.

On the other hand, the hospital at home scheme resulted in fewer days of care than did hospital admission (Wilson, 1999). Therefore, the Health System would reduce costs from hospital beds and could redirect part of the expenditure designated for hospital care to the care of children at home and to help the families in this scheme of care.

## Conclusion

The objectives of this project were to investigate the idea of family-centred care from the parents' and children's perspectives, to find out the difference between theory and practice, and to seek parents' views on ways of improving hospital environment and facilities for children and parents.

Although the facilities available in hospitals for families, parents and children have improved in recent years there are several aspects that still need to be achieved. Some interviewed parents expressed how their basic needs were not being covered during their hospital stay with their children. They continue to express their willingness to participate in their children's care. They claimed that they would like to participate not only in parenting the child, but also in providing medical and nursing care. At the same time, parents agree that training would be necessary for the realisation of some of the activities.

Participation during medical procedures can also induce parental anxiety. Paediatric nursing has a broad field for exploration concerning this matter. The first necessity would be the creation of programmes to make parents' involvement in their children's care a reality. In future research it would be useful to explore whether parents' participation is always possible, the limits of this participation, and the positive and negative consequences that parents' involvement could have for children and families. It is necessary to examine what sorts of effects the giving of explanations to parents about how to perform procedures would have, their utilities, and possible reactions from the children. It would also be convenient to give details to parents about what is generally expected from them when they are in hospital caring for the ill child, and what facilities are available to them.

Sometimes the participation of parents is assumed, especially in activities that are helpful for the health professionals who are too busy to perform them. This participation in

care is far removed from the family-centred care's philosophy, where parents' involvement has to be negotiated with them.

Although many professionals in hospital environment presume that they are working with a family-centred care approach, it is not so clear that they are enhancing the participation of the families with their attitudes.

This research also emphasised the importance of listening to children's opinion of aspects that concern them. Adults may have different attitudes towards listening to children's voices. Some adults may have a paternalistic attitude in order to protect children, acting in what seems to be the best way for them, but without listening to them. Other adults may simply have little interest in what children have to say. And there are some others who are concerned about children's views but without the knowledge or the ability to obtain information from them.

It has also been argued that children do not have the capability or the understanding to participate in the decision-making process. Hence, children's opinions, if asked, were ignored and parents and health professionals spoke for them. However, unless children's perceptions are known, health professionals will not be able to respond to their needs, and therefore improvements in their care will not take place.

Research methods used with children are still unrefined. Even basic tools such as questionnaires need modification for children. This study attempted to give voice to children with the opinion that children could understand more than what was previously believed. With that purposed change in methodology for data collection, the researcher launched a pilot test from which drawings proved to be an effective tool for gaining information from children.

Communication with children is another important issue. Nowadays, children receive information from different sources including school, streets, TV programs, and other children's experiences. This information is not always correct, complete or appropriate to them. It is the duty of their parents, school, and health professionals to provide suitable education to children, trying to clarify the doubts that they could have.

Suggesting that children should be listened to does not infer that parents' opinions should be ignored. Parents are the ones who know their children best and thus their views

must be taken into consideration. Parents' knowledge is essential for understanding children, and respecting parental views reduces unnecessary distress for children during their hospitalisation and the realisation of medical procedures.

Communication appears to be a key element in the relationships between parents, children and health professionals. It is through communication and negotiation with parents that family-centred paediatric care will become a reality. Communication is needed not only for gathering information necessary for the care of children. It is also needed to understand parents' and children's worries and concerns. Through a meaningful communication, parents' trust in health professionals will be established, thereby avoiding misconceptions and misunderstandings.

The possibility of caring for children at home in order to facilitate family adaptation to the situation is seen as a possibility. As stated in the previous chapter, children are in a familiar surrounding at home, the range of freedom is wider and they are never alone. Parents can also enjoy all the facilities of their daily routine, such as catering, showers and sleeping. However, home care should not be formulated without consulting parents about the repercussions of caring for the child at home and without offering them the necessary support. The health system should provide sufficient resources in community health care services to ensure that optimal care is provided at home.

Mothers expressed their concern about caring for their children in the community when they are ill. They related how at home they would not always necessarily get all the help when caring for their ill children. What can the paediatric nursing services do to ensure adequate support to the parents? Mothers asked for more community nurses for children who would be able to give the necessary support when children stay ill at home. They suggested that a telephone line with a named nurse or doctor would also be helpful. It would be important to consider other possible innovations more proactive to health promotion such as parenting advice about healthy and unhealthy behaviour. If there is a change of hospital schemes to community care, the community health care services should be ready to receive the new income of children and families and therefore studies about community nursing are required.

Family-centred care is not a model that is designed to reduce the Health System costs. It does not aim to reduce nurses' and doctors' workloads and neither to increase them. Its objective is to provide better care for children and their families causing, as little disruption as possible to the child and his or her family. Health professionals' work is enriched with parents' participation because parents know their children best. It would be necessary for family-centred care to be considered as described above not only by health professionals but also by parents and health system managers.



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# Appendices

### Questionnaire content

The questions were grouped in four sections within the questionnaire. They were conceived to obtain information about:

**Section 1** (Formed by 16 questions):

- a. Previous experiences about hospitals (Not only with their children but also their own personal experience).
- b. Parents' thoughts about what children feel when they have to stay in hospital.
- c. Impression concerning the facilities and the decoration used in children's wards.
- d. The kind of care they would prefer (Staying in hospital, home care with/without help)
- e. Information about the hospitalisation if existed (number of children that have been in hospital, in how many occasion they have been there, for how long, reason of hospitalisation, seriousness and if parents thought that the hospitalisation was necessary)
- f. Their worries or concerns when their children are admitted in hospital.

**Section 2** (8 questions):

- g. The involvement that they would like to have during the hospitalisation
- h. Training that they would like to receive
- i. Circumstances that would prevent them from taking part in the care
- j. Do Health Professionals welcome parents' help?

**Section 3** (7 questions):

- k. Attitude towards caring for other people's children in hospital
- l. Arrangements needed if they want to help in hospital
- m. Help that they could have if needed
- n. Opinion about extra-services

- o. Information that they would like to receive
- p. Health professionals' attitudes towards parent and sharing responsibilities
- q. Short-term help that they would like to have after hospital discharge.

**Section 4** (Only for parents whose children had been in hospital formed by 7 questions)

- r. Feelings when they where in hospital
- s. Were they in control of the situation during the hospitalisation?
- t. Relationships with the health professionals
- u. Information received

Head Teacher's Cover Letter

CHESTER-LE-STREET C.E.JUNIOR SCHOOL

9<sup>th</sup> January 2001

Dear Parents,

Olga has been running the Spanish Club in school since November, and has worked with children in classrooms. It would help her in her research work, if you would complete the enclosed questionnaire, and return it to school. She would also be very grateful if any parents could talk to her individually about their experiences of having children admitted to hospital, and how procedures could be improved. If you are able to help, please fill in the form at the bottom of the page.

Olga will also be asking for volunteers from the children to fill in a questionnaire about their attitude and opinions to illness and hospitals (not about treatment and operations). The questionnaire would be sent home for parents to read. If you are willing for your child to volunteer, please indicate below.

Thank you for your co-operation.

Yours sincerely

Mrs. J. Twomey

Head Teacher

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I am willing to discuss this questionnaire further with Olga - Yes/No

I am willing for my child to bring home a pupil questionnaire - Yes/No

Pupil's name .....Class.....

Parent's signature..... Date.....

Appendix C

Cover Letter Parents' Questionnaire

University of Durham

Centre for Health Studies

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32, Old Elvet  
Durham  
DH1 3HN  
Office: 0191 374 1840  
E-mail: CHS>Office@durham.ac.uk

Dear Parents,

I am a research student studying for a Master of Science, supervised by the University of Durham. Part of my research is to find out from parents and guardians their experiences of having their children cared for in hospital and what improvements should be made, if any. I also want to find out from parents whether they would want to help, how they could help and the training required by them in order to help to establish a friendly environment in hospital

**Any information you provide in this questionnaire will be treated as strictly confidential.**

**Thank you very much for taking part in this survey**

**Olga López de Dicastillo**  
**M.Sc. Student. University of Durham.**  
**Telephone number: 01913741840**

Parents' Questionnaire

Questionnaire Number:

Year group:

Section 1

1. Have you ever been in hospital as a patient?  
 Yes  No
2. Have you ever been in hospital as a visitor?  
 Yes  No
3. Have you ever been to a children's ward in your local hospital?  
 Yes  No

3.1. If the answer is 'yes', What was your impression of the facilities?

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---

3.2. If the answer is 'no':

- Would you like to have a guided tour?  
 Yes  No

4. How do you think a patient in a children's ward feels?  

<input type="checkbox"/> Nervous	<input type="checkbox"/> Secure
<input type="checkbox"/> Frightened	<input type="checkbox"/> Not sure
<input type="checkbox"/> Lonely	<input type="checkbox"/> Abandonment
<input type="checkbox"/> Homesick	<input type="checkbox"/> Fear
<input type="checkbox"/> Unhappy	<input type="checkbox"/> Other: _____

5. What facilities should be available in children wards?  

<input type="checkbox"/> Toys	<input type="checkbox"/> Playroom without assistant
<input type="checkbox"/> Common room	<input type="checkbox"/> Play things: sand, water, play-dough...
<input type="checkbox"/> School assistants	<input type="checkbox"/> Painting Materials
<input type="checkbox"/> Books	<input type="checkbox"/> Swimming pool
<input type="checkbox"/> Music	<input type="checkbox"/> Other: _____
<input type="checkbox"/> TV	_____
<input type="checkbox"/> Games	_____
<input type="checkbox"/> Playroom with trained play assistant	

6. How should the ward be decorated?  


---



---



---

7. If and when your child is ill and requires regular medication and nursing care, would you prefer?

- Your child to stay in hospital.
- Your child to be cared for by you at home with essential nursing support.
- Your child to be cared for by you at home with limited access to nursing help.
- To care for your child at home without any help.

Why? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

8. Have your child/children ever stayed in hospital?

- Yes  No

If the answer is 'yes':

8.1. How many of your children have been in hospital? \_\_\_\_\_

8.2. And for how many occasions have your child/children been in hospital?

- 1
- 2
- 3
- More than 3

8.3. What was the longest time that they stayed in hospital?

- Hours: <24            >24
- Days:    1        2        3        4        5        6
- Weeks:    1        2        3        4
- Months: (write the numbers of months)

8.4. What was the reason?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

8.5. How serious was your child's illness?

- Gravely ill  Serious
- Extremely serious  Fairly serious
- Very serious  Routine admission

8.6. On reflection, do you think the admission was really necessary?

- Yes
- No, Why? \_\_\_\_\_  
\_\_\_\_\_



9. If your child had to be admitted to hospital what are your worries or concerns?

- The diagnosis
  - The medical tests
  - The treatment
  - Your other children
  - Your job
  - The interruption of the child's daily activities
  - The child's feelings
  - Other \_\_\_\_\_
- 

## Section 2

10. Would you be prepared to help look after your own child/children in hospital?

- Yes  No

Why? \_\_\_\_\_

---

11. If you are willing to take part in caring for your child/children in hospital what would you like to do: (Please, tick as many activities as appropriate)

- |  |  |
|--|--|
| <input type="checkbox"/> Bath your child   | <input type="checkbox"/> Give inhalation               |
| <input type="checkbox"/> Change bed linen everyday and when it is necessary                | <input type="checkbox"/> Take temperature              |
| <input type="checkbox"/> Change nappies  | <input type="checkbox"/> Take pulse rate               |
| <input type="checkbox"/> Help to feed your child   | <input type="checkbox"/> Take blood pressure           |
| <input type="checkbox"/> If your child has to be fed by tube, help to tube-feed your child | <input type="checkbox"/> Take your child to the toilet |
| <input type="checkbox"/> Give oral medicine  | <input type="checkbox"/> Help with wound care          |
| <input type="checkbox"/> Give ointment, salve, lotion, balm, cream, ...                    | <input type="checkbox"/> Do chest physiotherapy        |

12. Do you need training for some or all the activities listed in question 11?

- Yes  No

If yes, which ones?

- |  |   |
|--|---|
| <input type="checkbox"/> Bath your child   | <input type="checkbox"/> Give ointment, salve, lotion, balm, cream, ... |
| <input type="checkbox"/> Change bed linen everyday and when it is necessary                | <input type="checkbox"/> Give inhalation                                |
| <input type="checkbox"/> Change nappies  | <input type="checkbox"/> Take temperature                               |
| <input type="checkbox"/> Help to feed your child   | <input type="checkbox"/> Take pulse rate                                |
| <input type="checkbox"/> If your child has to be fed by tube, help to tube-feed your child | <input type="checkbox"/> Take blood pressure                            |
| <input type="checkbox"/> Give oral medicine  | <input type="checkbox"/> Take your child to the toilet                  |
|  | <input type="checkbox"/> Help with wound care                           |
|  | <input type="checkbox"/> Do chest physiotherapy                         |

Other training needs: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

13. If you are prepared to take part in some of the activities listed in question 10, what circumstances would prevent you from taking part?

- Domestic problems
- Your job
- Training needs
- You do not like hospitals
- Other: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

14. Do you think nurses and doctors would welcome your help?

- Yes  No

Comment \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

15. If you were able to help on the children's ward voluntarily, could you do it on a regular basis?

- Yes  No

16. If you are able to help regularly, how much time could you spare per day?

- Less than 1 hour
- 1-2 hours
- 3-4 hours
- More than 4 hours
- All the time necessary

17. If you are not able to help every day, how often could you help?

\_\_\_\_\_  
\_\_\_\_\_

### **Section 3**

18. Would you like to look after other people's children in hospital?

- Yes  No

Why? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

19. If you want to help in hospital and you have other children at home or at school, what arrangements need to be made for you to do this?

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20. When your child/children is/are ill at home, what help do you have?

- Nobody
- Another family members: Who? \_\_\_\_\_
- Friends
- Neighbours
- Other: \_\_\_\_\_

21. How important are the following extra services being available while your child is in hospital?

	Very important	Important	Fairly important	Not important	I Don't Know
Nursery room for your other children during visiting time					
Counselling support					
Health promotion					
Nutritional advice					
Breastfeeding counselling					
Breastfeeding room					
Dental hygiene care					
Physical exercise					
Foot care					
Use of medicines					
Parenting advice					
Respite care facilities for your other children					
Clinical psychology					
Family therapy					
Financial advice					

22. Would you like doctors and nurses to share with you all the information about the prognosis of your child's illness, even when there is uncertainty about the outcome?

- Yes.  No.
- Why? \_\_\_\_\_
- 
-

23. With which of the following statements do you agree?

	Always	Sometimes	Never	Don't Know
<b>Doctors respect child's opinions.</b>				
<b>Nurses respect child's opinions.</b>				
<b>Doctors respect parents' opinions.</b>				
<b>Nurses respect parents' opinions.</b>				
<b>Doctors know best.</b>				
<b>Nurses know best.</b>				
<b>Doctors expect parents to accept professional's advice.</b>				
<b>Nurses expect parents to accept professional's advice.</b>				
<b>Doctors, nurses and parents have to share responsibilities in taking care of the child.</b>				
<b>Doctors, nurses and parents have to share responsibilities in making decisions.</b>				

24. What short term (1-2 weeks) help do you think is important after hospital discharge?

	Very important	Important	Fairly important	Not important	Don't Know
Telephone help line with the ward					
Telephone help line with a named ward nurse					
Telephone help line with a named ward doctor					
Home visit by ward person					
Home visit by parent self-help group					
Private home care service					
Private education service at home					
OTHER:					

## Section 4

### Only answer the questions in this section if some of your children have been in hospital

25. When your child stayed in hospital you felt:

- Frustrated because nurses and doctors offered insufficient information.
- Worried because you did not know how to help your child inside the hospital system.
- Unable to protect your child from potential harm.
- Secure because you were confident about the health professionals' activity and knowledge.
- Satisfied with the information and support that you received from your doctor and nurses.
- Worried about bothering your doctor with question and asking your doubts.
- Satisfied with the doctor and nurses who were always readily accessible.
- Others: \_\_\_\_\_

\_\_\_\_\_

26. Did you think that you were in control of the situation when your child was in hospital?

- Yes  No

Why? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

27. Would you have wanted to have:

- More say in how your child was cared for?
- More say on food?
- More say on visiting hours?
- More information on child progress?
- More information on child treatment?
- Other: \_\_\_\_\_

28. How do you describe your relationship with the professionals in hospital?

- Satisfactory
- Unsatisfactory, why? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

29. Do you think the information that you received was:

- Too much    Enough    Little    Too little    Don't know

30. Did you understand the information that you received?

Yes

No, Why? \_\_\_\_\_  
\_\_\_\_\_

31. Was the information helpful and clear enough for you to look after your child?

Yes

No

Why? \_\_\_\_\_  
\_\_\_\_\_

### **Section 5:**

**Age:**

25-29

30-35

36-40

>40

**Sex:**

Male

Female

**Number of children:**

1

2

3

4

5 or more

**Age of your children:**

< 1

5

10

15

1

6

11

16

2

7

12

3

8

13

4

9

14

**Do are you employed...**

Full time

Part time

Unemployed

Self-employed

**Occupation (optional):** \_\_\_\_\_

**Thank you very much for answering this questionnaire**

## Appendix E

### Children's Workshops

The five workshops took place within the Spanish Club at Chester-le-Street:

- **First workshop: 'Ice breaking'.** This was the first contact with children who would be taking part in the research. Therefore, its purpose was that researcher and children to get to know each other. Some difficulties were experienced due mainly to the fact that the researcher was new to the English language and many children spoke with local accent. Limitations arose from the way in which children use the language. In addition, managing groups of children presented some practical difficulties, especially those who misbehaved. These factors also had an effect on interaction and responses offered by children. In some cases, the process of obtaining complete information from children was impeded.

The activities done were just learning some basic Spanish vocabulary. The session finished singing a song in Spanish. This increased their interest for the activity that they were starting.

- **Second workshop: 'Fruits'.** One of the reasons for starting with this theme was that in their curriculum the children study 'teeth and eating' when they are in Year 3. Hence, it was sure that all of them had a basic knowledge about food and they would be able to participate in a group discussion. They were shown some pictures of different groups of food. Using a picture of a child they were asked to choose a menu for him. Although all the children had knowledge about this subject not all of them participated equally. According to their different personalities there were some who did not offer their opinions in the group discussion. It was not easy to involve all of them in the conversation and to keep their constant attention. This presented a serious handicap in the use of group discussion as a method of collecting data from children. It was extremely difficult to use the group discussions with children of these ages. It was supposed that the members of the group would listen to each other, and then give their opinion about the theme in order to facilitate and register the formation of ideas as a whole group. However, children tended to talk at the same time failing to pay attention

to other opinions. This problem of not listening to each other in group work and all talking at the same time has been also observed when working with groups of adults. Children were asked to put their hands up to ask permission to start talking, in an effort to control this situation. Nevertheless, in most of the cases children were free to say what they wanted when they wanted, and this rule was not always applied, just when the dynamic of the group made the session impossible to continue.

- **Third workshop: 'Sport'**. Working with the theme of 'Sports', children were taught the Spanish words for their favourite sports. Cards were also used in order to facilitate their understanding. Children were asked to write about an accident that they have had while doing sport. The intention was to test children's writing skills. The following day they were asked to produce a drawing on the story that they had described. Some difficulties arose. Depending on the children's ability the stories that they wrote lacked continuity or sufficient information. They wrote very short stories and became bored easily. However, when they were asked to draw a picture which referred to the story that they had described before in this session, they showed more interest than in writing the story.
- **Forth workshop: 'Professions'**. This theme was chosen in order to link this activity with the health professionals that work in hospital and the hospital itself. The use of a stethoscope in class provoked better participation from the children in the group. The use of cards seemed effective when teaching vocabulary in Spanish. Thus, cards were used once more in this case with the name of the professions in Spanish and a picture providing the meaning of every term.
- **Fifth workshop: 'The family'**. Children were going to be asked to draw their own family. Then, they were going to be taught the Spanish terms used to name every member of the family. The theme was designed with the purpose of obtaining information on how the children feel when they are ill at home, in contrast to being ill in hospital. This session was particularly difficult to manage as it was the end of the term and all of them were exited about the Christmas activities they were getting involved.



## Appendix F

### Cover Letter children's questionnaire

University of Durham

Centre for Health Studies

---

32, Old Elvet  
Durham  
DH1 3HN  
Office: 0191 374 1840  
E-mail: CHS>Office@durham.ac.uk

Dear Parents,

First of all, thank you very much for your collaboration with the previous survey and for allowing your child to take part in this last survey.

The purpose of the attached questionnaire is to obtain information from children about 'being ill', 'being examined by doctors' and 'being given medicines'. The results obtained will be useful to complement the information that parents have already provided, contributing to improve the care of the children when they are ill in hospital.

In order to find out what children think about these subjects it is very important that children provide answers by themselves. Please, let your child to fill out the questionnaire by him or herself.

**Any information your child provides in this questionnaire will be treated as strictly confidential.**


**Thank you very much for letting your child to take part in this survey**

**Olga López de Dicastillo**  
**M.Sc. Student. University of Durham.**  
**Telephone number: 01913741840**



Health Matters



1. Do you remember your last injection  in the school?

- Yes
- No

2. How did you feel before going to see the school nurse?

---




---

3. Did the injection hurt?

- Yes
- No



4. Did the school nurse comfort you after she put the  in you?

- Yes
- No

5. Did you talk to your **mum** about how you felt

- ◆ Before the injection?  Yes  No
- ◆ After the injection?  Yes  No

6. Did you talk to your **dad** about how you felt

- ◆ Before the injection?  Yes  No
- ◆ After the injection?  Yes  No

7. Did you talk to your **brother and sister** about how

- ◆ Before the injection?  Yes  No
- ◆ After the injection?  Yes  No




8. If you needed an  again in the future, would you be ...


- More worried
- Less worried

9. Did you forget about it quickly?

- Yes
- No

10. Did you have a sore spot from the  for a long time?

- Yes
- No

11. Do you mind the doctor using the  ?

- Yes
- No

12. Is it funny to say "99" when the doctor listens to your chest?

- Yes
- No



13. Do you mind when the doctor examines your mouth?

- Yes
- No



14. Do you mind when the doctor looking into your ears?

- Yes
- No



15. What do you like most about going to the doctor when you are ill?

---

---

16. What do you like least about going to the doctor when you are ill?

---

---

---



17. Do you mind when the doctor pokes your tummy?

- Yes
- No

18. Does the doctor talk directly to you?



- Yes
- No

19. Do you always understand what the doctor says to you?

- Yes
- No

20. If you did not understand what the doctor says, would you ask questions?

- Yes
- No

21. When you have a sore throat, what sort of medicine do you take? Draw a green circle around it:



22. Do you like the taste?

- Yes
- No

23.If you did not like the taste of medicine but know it would help you to get better, would you still take it?

- Yes
- No

24.Which one don't you really like? Draw a red circle around it



25.Do you think it is a nuisance having to take medicines for your sore throat?

- Yes
- No

26.What other sorts of medicines have you taken (e.g. an inhaler,...)?

---

---

27.Have you ever been in hospital?

- Yes
- No

28.If you have been in hospital, how did you feel?



29.How do you think visit to the doctors' surgery or the hospital can be made less scary for you?

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# **Appendix H**

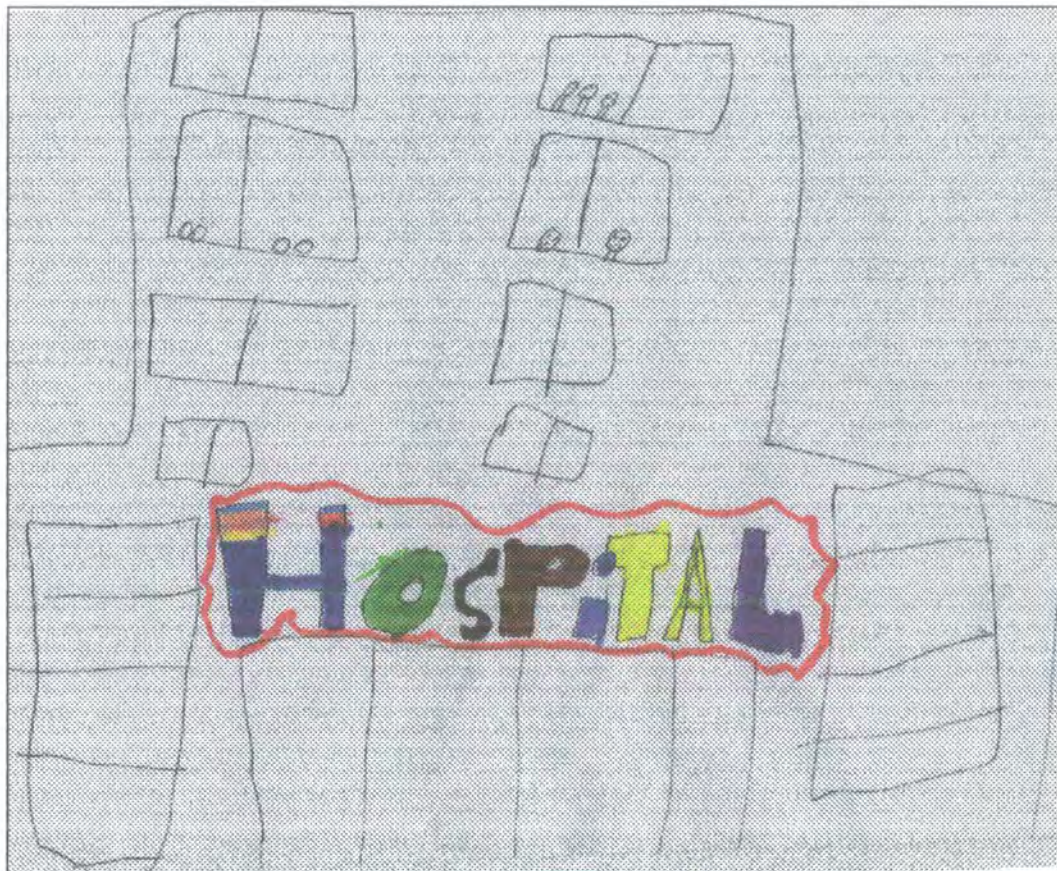
## **Children's Drawings**



**Drawing 1: Tom (aged 7)**



**Drawing 2: Wiley (Aged 7)**





**Drawing 3: Andy (aged 7)**



**Drawing 4: Lyn (aged 7)**





**Drawing 5: Sarah (aged 7)**



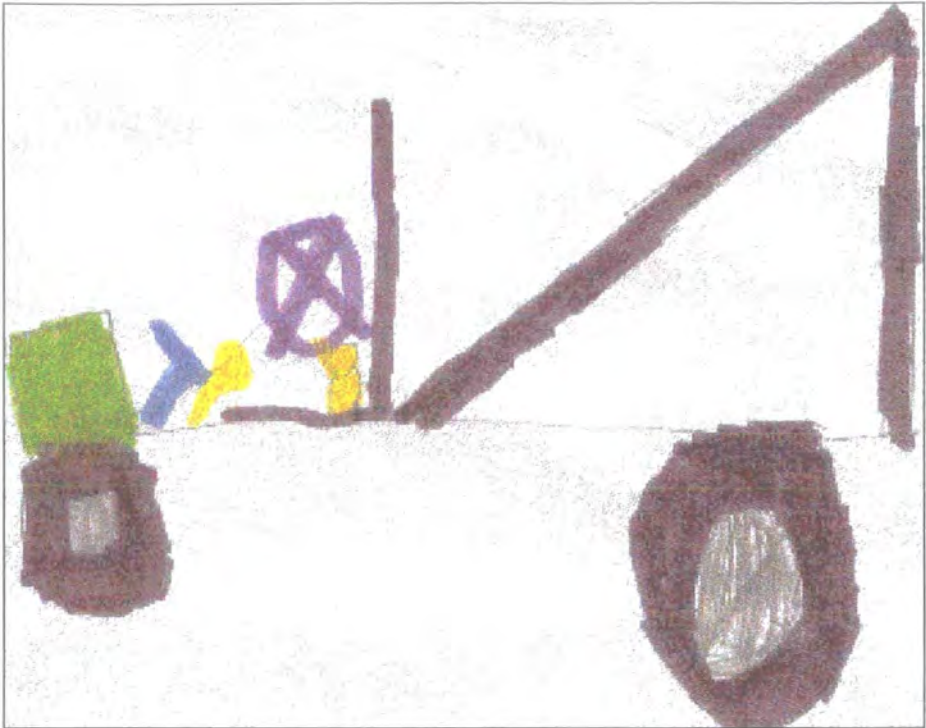
Drawing 6: Brenda (aged 7)



Drawing 7: Eva (aged 7)



Drawing 8: Jeremy (aged 7)



Drawing 9: Shelly (aged 7)



**Drawing 10: Sylvia (Aged 8)**



**Drawing 11: Joe (aged 8)**

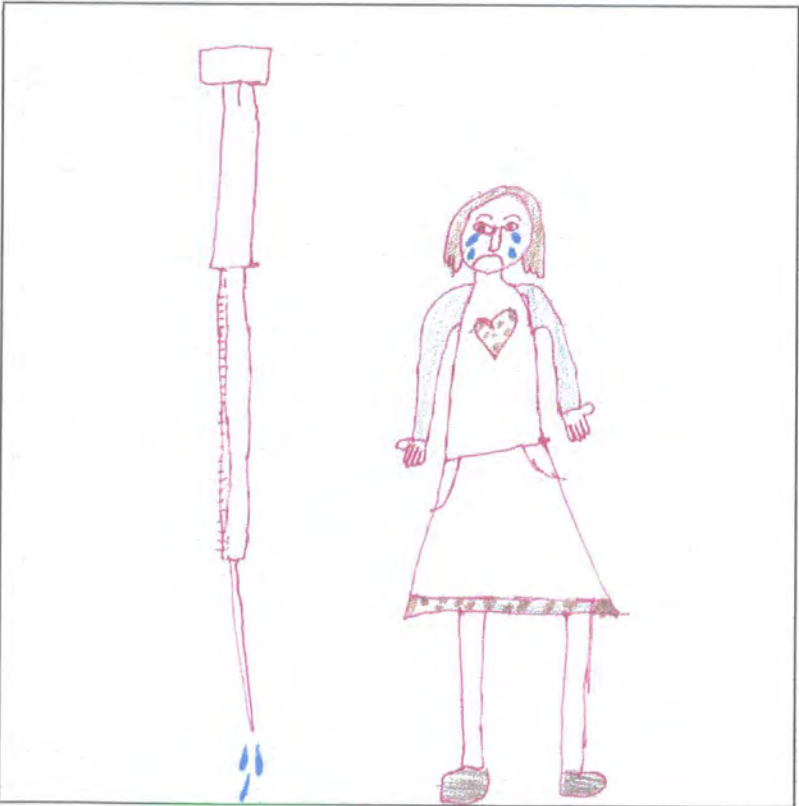




**Drawing 12: Valerie (aged 8)**



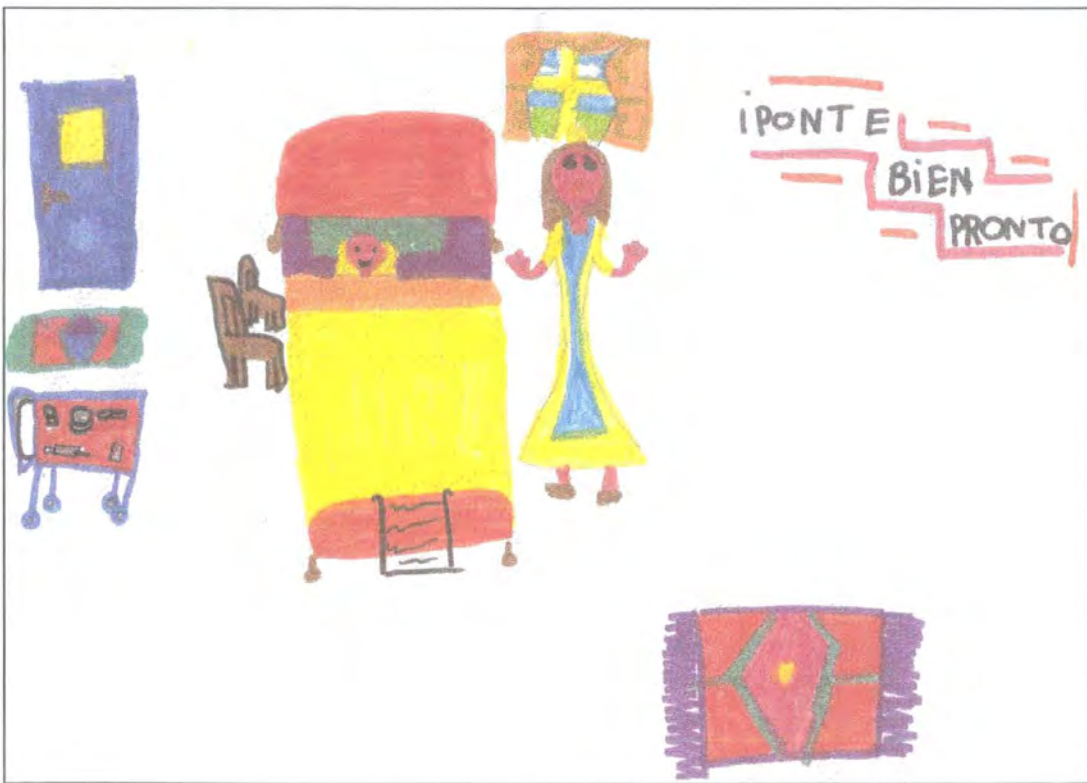
**Drawing 13: Denise (aged 9)**



Drawing 14: Pamela (aged 9)



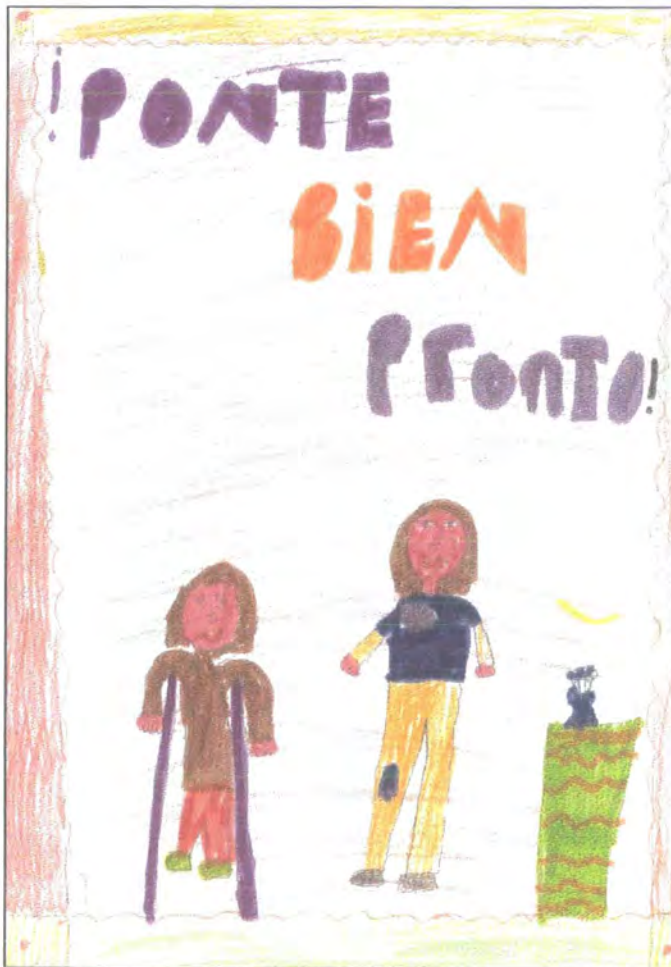
Drawing 15: Sheila (Aged 10)



Drawing 16: Alice (aged 10)



Drawing 17: Cassie (aged 10)



**Drawing 18: Katy (aged 10)**



**Drawing 19: Mark (aged 11)**





Drawing 20: Johan (aged 11)



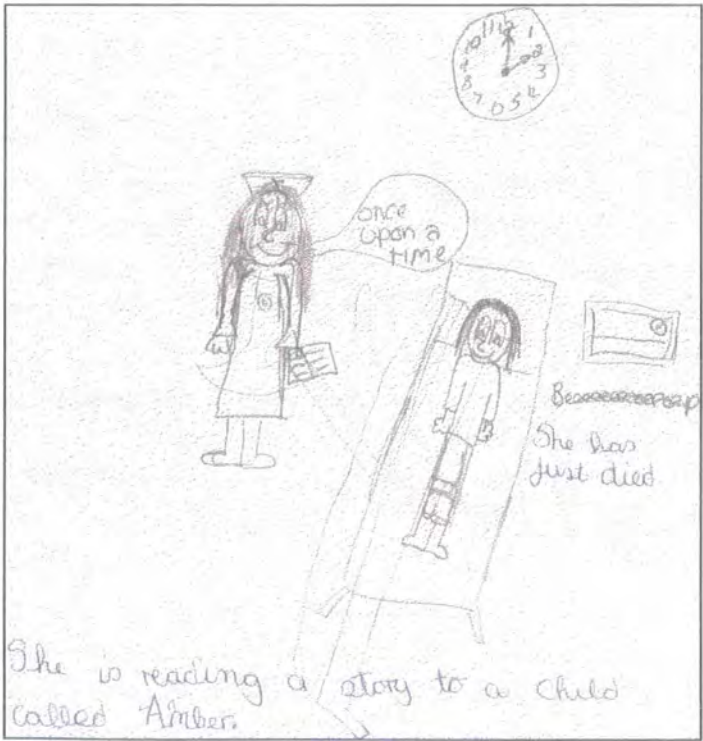
Drawing 21: Scott (aged 11)



**Drawing 22: Aida (aged 11)**



**Drawing 23: Chloe (aged 11)**



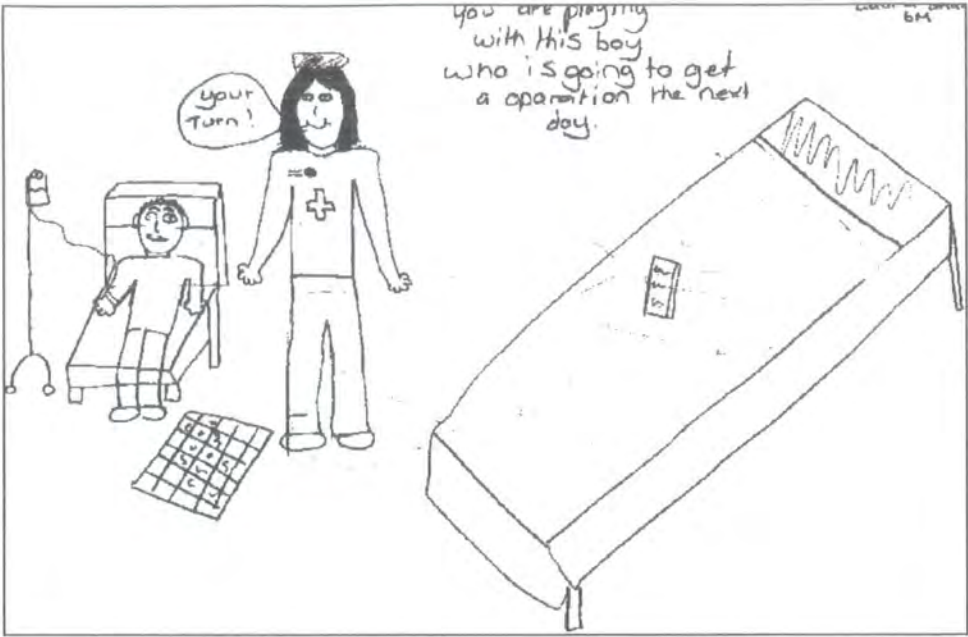
**Drawing 24: Gabrielle (aged 11)**



**Drawing 25: Julie (aged 11)**



**Drawing 26: Lesley (aged 11)**



**Drawing 27: Rebecca (aged 11)**

