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Young children's experiences of their hospitalisation for Cardiac surgery

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CHAPTER ONE

OVERVIEW OF THE STUDY

1.1 Introduction

This chapter is an overview of the study. Orientation to the study and the background of the study are described. The problem statement, significance of the study, purpose of the study, objectives and researcher assumptions are included. The principles used to ensure trustworthiness and ethical considerations are outlined.

This research report has been written in the first person, as the role of the researcher is an integral part of a qualitative study and failure to reveal self in the written report may be a threat to descriptive vividness (Burns & Grove, 2001:675).

To minimize confusion, in the discussions that follow, all general references made to the child will be 'he, his and him'. All general references made to the child's parent will be 'she, hers and her', as the parental respondents were mostly female.

1.2 Orientation to the study

Paediatrics is a discipline of medicine in which I have felt honoured to work as a Registered Nurse and to care for the children that are admitted to this area. It has

saddened me greatly though, to see how they appear to battle with their hospital experience. Children born with a cardiac defect, who undergo corrective surgery, are exposed to high stress peri-operatively due to the necessary invasive technology and procedures, constant monitoring, unfamiliar environments and medical personnel and, in many cases, unavoidable separation from their parents. As a result, these children exhibit a variety of emotional and behavioural responses. I have observed children who have spent a few days in the cardio-thoracic intensive care unit (CTICU) following surgery become tearful, withdrawn and apathetic. These children were happy and talkative prior to surgery. Some parents have observed and expressed that their children are depressed, traumatised and even angry. Researchers who have explored hospitalisation in young children (Gritti, Sarno, Comito, De Vincenzo, De Paola & Vajro, 2001 and Rennick, Johnston, Dougherty, Platt & Ritchie, 2002) argue that these children have demonstrated psychological difficulties up to six months after discharge from hospital and have demonstrated behavioural changes such as aggression, eating problems, social isolation and hyperactivity. In the setting in which I have encountered these children and in which the study took place, there was no formal preparation for hospitalisation and surgery by the hospital, at the time that this study took place.

In my experience of working with children, I have found them to be very honest. In this study, I wanted to hear from these honest little people what they felt about hospital and how they felt we, as medical personnel, could make it better for them. Sartain, Clarke and Heyman (2000:920) state that children with prolonged exposure to medical personnel and hospitalisation must be listened to. O'Malley and McNamara (1993:1076) believe that by giving these children a voice and the opportunity to

express themselves and their feelings about hospitalisation, nurses can identify concerns and misconceptions and can try to minimize stress exposure and allay anxiety and fear. Ireland and Holloway (in Sartain, et al., 2000:914) refer to children as historians in their own right and state that there has been a lack of research on children's own perspectives.

1.3 Background to the study

The focus of this study is on the young child and his experiences of hospitalisation for cardiac surgery. Central concepts reviewed around this topic were:

- *The young child,*
- *Hospitalisation of the young child and*
- *Cardiac surgery in young children.*

Recent research reviewed in order to determine what is already known about this topic included research on children suffering from chronic and critical illnesses, the effects of hospitalisation on children, children and surgery and more specifically cardiac surgery. The research studies reviewed were a mixture of qualitative and quantitative methodologies that collected data through a variety of means. No studies were found that looked specifically at children's own interpretation of their experiences of hospitalisation for cardiac surgery.

The young child

The young child, as defined in this study, is the child from five to nine years of age. This age group covers the end of the preschool years and the beginning of the school-age years.

Erik Erikson's theory of psychosocial development states that children develop through stages (Hockenberry, Wilson, Winkelstein and Kline, 2003). The age group of children in this study covers two of Erikson's stages. The five-year old grapples with 'Initiative vs. Guilt' (ages three to five). He initiates activities and becomes assertive with regard to what he wants to do. If he fails to accomplish the tasks that are initiated a sense of guilt ensues. If however, he develops a sense of initiative he will broach the next stage – that of 'Industry vs. Inferiority'. This stage covers the six- to twelve-year old. Most of the children in this study fell into this stage and are at a point in their psychosocial development where they are industrious and striving to achieve. These children are more independent and feel that they are in control of their environment (Hockenberry, et al., 2003).

Hospitalising these children, confining them to bed and putting them through ward routines may remove their sense of mastery and control over their environment. The inability of the child to communicate with medical personnel and family members, due to the administration of analgesics, sedatives and endotracheal intubation, can also lead to a loss of a sense of control (Connolly, McClowry, Hayman, Mahony & Artman, 2004).

Jean Piaget's theory of cognitive development explains how children think. The children in this study fell within two stages of cognitive development. According to Piaget (Hockenberry, et al., 2003), the two- to seven-year old is in the pre-conceptual stage of cognitive development. Children at this stage are egocentric in their thoughts. Their language skills are developed during this stage and they can use images and words to describe objects. By six-years of age, their language is refined and they can usually use all parts of speech. In the next stage of development, age seven to eleven, children develop concrete operational thought. During this stage they start to think logically about objects and events and they understand time (Hockenberry, et al., 2003).

With an understanding of Piaget's theory, it is clear that the age of children covered in this study should be able to talk, hold a conversation and should be able to describe events. From the age of seven they should be able to logically understand what is happening to them and why.

Hospitalisation of young children

Children are admitted to hospital for a variety of reasons and their length of stay varies according to their condition and the treatment that they require. The child that is hospitalised for any length of time is often seriously ill and may require invasive treatment, procedures and monitoring. Hospitalised children have been found to demonstrate emotional responses such as anxiety, fear, worry and helplessness. Behavioural changes such as restlessness, anger, aggression, withdrawal, social isolation, hyperactivity, eating problems, nightmares and tearfulness have been observed (LaMontagne, 2000; Gritti, et al., 2001 and Rennick, et al. 2002) and in

some children these changes were not resolved six months post discharge from hospital.

Hockenberry, et al. (2003) state that the major stressors of hospitalisation in young children include separation, loss of control, bodily injury and pain. Preschoolers are usually more interpersonally secure than toddlers but the stress of illness and their immature coping skills result in them being less able to cope with separation, which is demonstrated through refusal of food, difficulty in sleeping, crying for their parents and withdrawing from others (Hockenberry, et al., 2003:1033). Wilson and Yorker (in Hockenberry, et al., 2003) ranked *"being away from my family"* as the greatest fear in the younger school-age hospitalised child who has only recently left home to attend school and who is struggling with the adjustment of being separated from his parents.

Fears of the physical nature of illness are apparent in young children and due to their acquired cognitive abilities, they may be less concerned about pain than they are about their uncertain recovery and even death (Hockenberry, et al., 2003:1038). Children's reaction to pain changes as they mature from intense emotional upset and physical resistance to verbally communicating its location, intensity and description. Younger children have a passive acceptance of pain and a nondirective request for support or help: silence, lack of activity, or social isolation are nonverbal clues that the child is in need of support and will readily accept it when it is offered (Hockenberry, et al., 2003:1038).

Children's response to hospitalisation and their means of coping with the experience are directly related to their perceptions of hospitalisation and the risks that they feel are associated (LaMontagne, 2000:308). By adequately preparing children for hospitalisation and, in doing so, familiarising them with hospital equipment, routine procedures and staff has proved to address misconceptions that children may have and improves their coping skills, making hospitalisation a less stressful experience (Bonn, 1994:22). Researchers have also found that the age of child and their length of hospitalisation are more significant predictors of stress in the post-operative period than other factors, such as background and the number of previous admissions to hospital (Connolly, et al., 2004:482; Rennick, et al., 2002:140).

Cardiac surgery

Children admitted to hospital for cardiac surgery are exposed to invasive procedures pre and post surgery: drawing of blood samples, chest x-rays, echocardiography (ECHO), electrocardiogram (ECG), removal of pacing leads, removal of sutures, insertion and removal of drains, wound dressings, physiotherapy, suctioning and so on. The physiologically stressful experience of cardiac surgery is aggravated by the necessary treatment in the intensive care setting (Rennick et al., 2002:133). Adult patients who have been evaluated for traumatic memories from postoperative treatment in the CTICU have demonstrated negative psychological effects up to six months post discharge from hospital (Schelling, Richter, Roozendaal, Rothenhausler, Krauseneck, Stoll, Nollert, Schmidt & Kapfhammer, 2003). Connolly, et al. (2004) state that children with congenital heart disease (CHD) are at particular risk of developing posttraumatic stress disorder following cardiac surgery and admission to CTICU (Connolly, et al., 2004:482). Medications such as neuromuscular blockade,

sedatives and analgesics as well as lower cognitive levels present in these children can prevent effective communication with hospital staff. Due to the nature of their surgery, i.e. in most cases open-heart surgery, the children may also lack the physiologic capability to manifest non-verbal signs of pain or fear such as tachycardia and hypertension, as these signs are most often attributed to the disruption of cardiac muscle and function at the time of surgery (Connolly, et al., 2004:480). This inability to communicate with family and CTICU staff can lead to inadequate pain management and loss of a sense of control.

1.4 Problem Statement

Children hospitalised for cardiac surgery and who are exposed to invasive technology and procedures may be traumatized. Psychological difficulties and behavioural changes have been confirmed in these children up to six months post discharge. Younger children have been found to be more anxious than older children during and after hospitalisation. Little is known about the young child's experiences of his hospitalisation. There is a lack of research on this topic in South Africa and therefore a lack of knowledge and supporting evidence regarding young children's hospitalisation experience for cardiac surgery.

1.5 Significance of the study

The incidence of congenital heart disease (CHD) in children is approximately five to eight per 1000 live births (Behrman, Kliegman and Jenson, 2000 in Hockenberry, et al., 2003:1474). Connolly, et al. (2004:480) state that children with CHD are at particular risk for experiencing traumatic situations and that prolonged stays in CTICU and multiple hospitalisations are usually necessary. In the hospital in which this study was conducted, at least 300 children are admitted every year for cardiac surgery. Of those children, at least 25% are from countries north of South Africa. This number increases every year.

No research has been done in the South African, private hospital context regarding young children's experiences of hospitalisation for cardiac surgery, yet so many children with CHD are admitted for investigation and surgery. This study aims to narrow the gap in the existing knowledge regarding the hospitalisation of these children. Rennick, et al. (2002) state that little is known about hospitalisation and the intensive care experience on the children themselves and that there is an ongoing potential for psychological disturbance.

1.6 Purpose of the study

The purpose of this study is to convey the experiences of hospitalisation for cardiac surgery, from young children's perspectives and to elicit whether their behaviour had

changed or if they had demonstrated emotional responses to their hospitalisation one month after being at home.

1.7 Objectives of the study

- To describe in detail the stories that young children have to tell about their hospitalisation for cardiac surgery.
- To explore and describe the young children's parents' opinions regarding any significant changes in their child following cardiac surgery, with regard to emotional responses and behaviour.

1.8 Researcher assumptions

According to Botes (1995:9-10) the *meta-theoretical assumptions* are the researcher's views on man and society; the *theoretical assumptions* give form to the central theoretical statements of the research and the *methodological assumptions* give form to the research context, which influence the researcher's decisions about the research design.

1.8.1 Meta-theoretical assumptions

Man: In this study, man is the young child who has physical, mental, emotional and behavioural components that make up who and what he is. Man is also the child's

parent who is the primary care-giver of the child and who is witness to the child's experiences of hospitalisation, and his emotional and behavioural responses / changes related to hospitalisation while in the hospital and once at home.

The environment: The total context (physical, mental, emotional and behavioural) in which man exists. In this study the environment referred to is the hospital and the home – the unfamiliar and the familiar environments respectively.

Health: An optimal state of all the components that make up who and what the child is. Physical strength, full mental capability relative to the child's age, positive emotional responses and behaviour that is expected for the child's developmental stage.

1.8.2 Theoretical assumptions

Theories of psychosocial and cognitive development by Erikson and Piaget respectively, as well as previous research around similar topics, have influenced the development of this study. Definitions of terms have been included in order to clarify what is meant by the central theoretical concepts involved in this study.

Definitions

Central concepts, frequently used in this research report, have been defined:

Behaviour: In the general sense, conduct, i.e., any observable action or response of an individual (Blackwell's Dictionary of Nursing 1994:85).

Cardiac: Pertaining to the heart (Blackwell's Dictionary of Nursing 1994:120).

Emotion: A strong feeling such as fear, anger, grief, joy, or love (Blackwell's Dictionary of Nursing 1994:233).

Experience: Observation of or practical acquaintance with facts or events (The South African Pocket Oxford Dictionary 1994:322).

Hospitalisation: The placement of an individual in a hospital for observation, diagnostic tests, or treatment for some disease or disorder (Blackwell's Dictionary of Nursing 1994:329).

Surgery: The branch of medicine that treats diseases, deformities, and injuries, wholly or in part, by manual or operative procedures; usually involves making an opening in the body to remove, replace, or repair a part in order to cure or correct a pathological condition or damage caused by trauma, or to give the patient a period of remission from a disease (Blackwell's Dictionary of Nursing 1994:649).

Operational Definitions

Mouton and Marais (1994:132) define operational definitions as definitions that present specific conditions for the appropriate use of a concept.

Behavioural Changes: Any change in a child's behaviour following cardiac surgery, that is significantly different from his behaviour before hospitalisation e.g. aggression, sleep disturbances, eating disorders / changes, social isolation.

Cardiac Surgery: A specialised branch of surgery involving cardiac valve replacement and / or repair of congenital heart defects using an incision in which the sternum is split (sternotomy / thoracotomy) and the heart is stopped (cardioplegia). While this is done, the child is supported on a heart-lung machine (cardio-pulmonary bypass). The child's recovery is facilitated in a specialised cardio thoracic intensive care unit (CTICU) until he achieves full recovery and no longer requires organ support. The child is then discharged to a high care unit (HCU) for routine postoperative management and nursing care.

Emotional Responses: Those feelings that children may demonstrate about their hospitalisation for cardiac surgery e.g. anxiety, fear, depression, elation, joy and others.

Young Children: Children between the ages of five and nine years.

1.8.3 Methodological assumptions

Assumptions regarding the methodological commitments pertain to the process considered as scientific and to the methods and instrumentation by means of which a given view of what is scientifically valid may be realised (Mouton & Marais, 1994).

- Children's subjective experiences are regarded as a valid source of knowledge.
- Drawings are a source of non-verbal communication. Information gathered from the drawings adds to what was not revealed verbally as the child re-constructs his experiences. Sartain, et al. (2000) assert that drawings by children are "a practical way of bringing children into an interview situation and of encouraging them to talk about themselves and their experiences" (2000:917).
- A qualitative, exploratory, interpretive descriptive, contextual study utilising a phenomenological research approach was chosen as the best approach in this study to gain the information sought.
- Qualitative research methodology is an interactive, subjective approach that does not try to control the context but rather to capture the context in its entirety (Brink, 1996:13 and Burns & Grove, 2001:808).
- In this study it is assumed that children's lived experiences are best told through stories and descriptive, textual presentations of their stories and drawings than through numbers. Qualitative studies use text as their data

versus the numbers most often used as data in quantitative studies (Burns & Grove, 2001:27).

- It is also assumed that interviewing the children's parents one month after the children have been discharged from hospital will reveal whether the children exhibited any significant emotional and / or behavioural changes following their hospitalisation.

The research methodology used in this study will be discussed in detail, in Chapter Two.

1.9 Trustworthiness

Lucy Yardley's (2000) principles to ensure trustworthiness in a qualitative study were selected, as these principles are best suited to the context of this study, i.e. young children as primary participants. Yardley (2000) advocates three essential qualities to ensure trustworthiness in a qualitative study:

- Sensitivity to context
- Commitment, rigor, transparency and coherence
- Impact and importance

These principles offer a range of methods of establishing quality and can be applied irrespective of the particular theoretical orientation of a qualitative study. These principles in relation to the given study will be further discussed in Chapter Two.

1.10 Ethical considerations

The following authorities granted ethical approval for this study:

- The Human Research Ethics Committee (Medical) of the University of the Witwatersrand,
- The Post-graduate Committee of the Faculty of Health Sciences,
- The Hospital Manager of the private hospital, in which this study was conducted.

(See appendices for copies of the letters granting permission for the study)

The ethical principles that guided the development and construction of this study are as follows:

- Informed assent from each child and written, informed consent from his parent was obtained for voluntary participation in the study.
- Voluntary, autonomous decision-making and participation by all participants.
- Confidentiality and anonymity assured to participants. All participants were assigned pseudonyms and privacy was ensured.
- Truth telling on the part of the researcher.
- Sensitivity to emotional responses exhibited by the participants.
- All participants were given the researcher's contact details, should they wish to have access to the findings of the study.
- The findings of this study are to be disseminated among the staff caring for these children. The findings will also be published in accredited nursing research journals.

These guidelines are discussed in more detail in Chapter Two. (Sartain, et al., 2000:915 and Marais, Poggenpoel, & Myburgh, 2003:30)

1.11 Chapter division

The remainder of the research report has been divided into the following chapters:

Chapter Two - Research Methodology

Chapter Three - Presentation of Findings

Chapter Four - Summary of Findings, Recommendations, Limitations and Conclusion

1.12 Conclusion

In Chapter One the background of this study has been discussed. The problem statement, significance, purpose and objectives have been included. Researcher assumptions have been stated and the guidelines to ensure trustworthiness have been mentioned. The ethical considerations used in the study have been outlined. In Chapter Two the research methodology used in this study will be discussed with a motivation as to why it was chosen as the best methodology to elicit the experiences of hospitalisation for cardiac surgery from young children.

CHAPTER TWO

RESEARCH METHODOLOGY

2.1 Introduction

Chapter One covered an overview of the study. In this chapter the research methodology: the approach, setting, and selection of participants will be discussed. The data collection process and method of data analysis are also presented. Details of ethical considerations and evidence of methods to enhance trustworthiness of this research are included.

2.2 Research approach

A qualitative approach, grounded in phenomenology, was followed. It is an explorative, interpretive descriptive, contextual study that examines young children's lived experiences of hospitalisation for cardiac surgery.

2.2.1 Qualitative research

A qualitative research approach was chosen for this study, as this approach examines lived experiences with the aim of giving them meaning. The methods of qualitative

research focus on meaning, experience and understanding (Brink, 1996). Qualitative research studies human experiences from the viewpoint of the participants. Very little is known about young children's experiences of hospitalisation for cardiac surgery in the context chosen for the study. Qualitative methods are useful when little is known about the topic under study and are used to construct theory to guide knowledge development (Morse & Field, 1996:15). A qualitative research approach is essential in understanding the experience of childhood chronic illness (Sartain, et al., 2000) and children can competently communicate their experiences of ill health and health care. There have been very few interpretive studies within paediatric nursing where children are considered as active users of a service rather than the passive recipients of a health-care system (Sartain, et al., 2000:920). Davie, Varma & Upton (in Sartain, et al., 2000:914) comment on the passive voice of children…

We are silencing children through society's wish to protect them.

2.2.2 Phenomenology

A phenomenological approach is used in this study. To understand the experiences of young children hospitalised for cardiac surgery a phenomenological approach was chosen to elicit the emic perspective as given by the children. In phenomenological studies, the researcher seeks a deeper and fuller meaning of the experiences of the participants of a particular phenomenon (Morse & Field, 1996:20). This strategy comprehends how people experience a phenomenon without classifying it or taking it out of context (Wilson, 1993:236). The aim of this study is to understand how young children experience hospitalisation for cardiac surgery in the context described and why they experience it in this way. Findings are not transferable and cannot be

generalised. Parahoo (1997) notes that phenomenology focuses on the individuals' experiences *and the ways in which they are expressed*. This point is particularly important to this study, as it is young children themselves that are asked about their experiences of hospitalisation for cardiac surgery. The validity of the research rests in the richness of the discussion. It is a unique view on the inner-worlds of young children who have been hospitalised for cardiac surgery and who are exposed to a variety of medical personnel and invasive technology and procedures.

2.2.3 Explorative research

To explore a phenomenon is to learn about it or to enquire into it (Pocket Oxford Dictionary, 1994:323). There is paucity of knowledge about young children's experiences of hospitalisation for cardiac surgery, particularly in the chosen context. Young children's lived experiences of hospitalisation for cardiac surgery cannot be adequately described unless they are first explored. This study aims to increase the knowledge of these young children's experiences, within the given context. Research findings in exploratory studies are not to be generalised to larger populations but are designed to increase the knowledge of a particular phenomenon (Burns & Grove, 2001:374).

2.2.4 Interpretive descriptive research

The purpose of descriptive research is to obtain complete and accurate information about a phenomenon through observation, description and classification (Brink, 1996:11). Once a phenomenon has been explored it is useless unless adequately

described however, Thorne, Kirkham and MacDonald-Emes (1997) identified a limitation to traditional qualitative descriptive research. They explain that a qualitative descriptive approach focuses more on the fact that patterns may exist in human behaviour and less on an explanation as to why these patterns exist (Thorne, et al., 1997:172). An interpretive descriptive approach was therefore put forward by Thorne, et al. as a non-categorical research approach specifically tailored to nursing (Thorne, et al. 1997:171). Thorne et al. (1997) propose that knowledge, gained through formal research or by clinical interpretation, should be considered a foundational fore structure to a new enquiry. Interpretive description is grounded in an interpretive orientation that acknowledges the constructed and contextual nature of an illness experience while allowing for shared realities (Thorne, et all, 1997:172). Prolonged engagement with individual participants is recommended by Thorne, et al. (1997), in order to interpret and describe the greater and shared phenomenon of an experience, which can then be applied back to individual participants. In keeping with this, the authors also recommend analytic techniques, such as Giorgi's method of phenomenological data analysis, that encourage immersion in the data elicited from individual participants prior to beginning coding, classification and creating linkages (Thorne, et al., 1997:175).

2.2.5 A Contextual study

In this study 'context' refers to the individual variables that define who young children are and that may have influenced how and why young children experience hospitalisation for cardiac surgery as they do (Burns & Grove, 2001:184). 'Context' also refers to the setting in and about which the participants were interviewed.

All children interviewed were in the post-operative period of their hospitalisation for cardiac surgery, having undergone what previous researchers had identified as a stressful experience (LaMontagne, 2000; Gritti, et al., 2001 and Rennick, et al. 2002) and sensitivity in this regard was imperative. This contextual variable was an important factor that influenced the implementation of and therefore the outcome of the study (Burns and Grove, 2001:184). The children covered a range of socio-economic groups and cultural diversities, which may have influenced their experiences. The children were however, all at similar psychosocial and cognitive stages of development. This study acknowledges the varying contextual variables from child to child, while exploring the experience of hospitalisation in the same setting. Their homes may be very different but are all familiar environments to the children. The hospital in and about which the children were interviewed was an unfamiliar environment. The interviews took place in the HCU on the paediatric ward of a private hospital in Johannesburg and the children were asked about their experiences of hospitalisation, which included their time in the CTICU and the HCU. The children's parents were interviewed one month after their children had been discharged to their homes.

2.3 Research method

The research method used was chosen to best elicit young children's experiences of hospitalisation. The children were purposively selected using inclusion and exclusion criteria. Data were collected through semi-structured interviews with the children augmented with drawings, and semi-structured telephonic interviews with their

parents. Data were manually analysed using Giorgi's method of phenomenological qualitative data analysis (Burns & Grove, 2001:606).

2.3.1 Selection of participants and sample size

Eight children who met the inclusion criteria were purposively sampled. In purposive sampling, the researcher deliberately chooses whom to include in a study on the basis that those selected can provide the necessary information (Parahoo, 1997:232). Purposive sampling is a subjective method of sampling where the researcher uses his / her own judgement to decide who is representative of the population (Wilson, 1993:178). Young children, between the ages of five and nine years, were selected from the admission register of a paediatric ward in a private hospital in Johannesburg. Other inclusion criteria used in the purposive selection process were as follows:

- The children had to be English-speaking *or* have a parent / legal guardian present who spoke English and who could help with interpretation during the interview.
- The children had to be in the post-operative period of their hospitalisation, following cardiac surgery, having been transferred from the CTICU to the HCU on the paediatric ward.

The participants were selected as and when they were admitted to the paediatric ward, using the paediatric admission book as the sample frame. Consent was obtained from their parents either before or after cardiac surgery. The interviews were scheduled to take place one to two days after the children had been transferred from the CTICU to the HCU on the paediatric ward. This scheduling allowed the children to adjust to their new environment.

Morse and Field (1996) draw attention to two principles that must be met in qualitative sampling:

- Appropriateness
- Adequacy

Appropriateness

This principle refers to the identification and utilisation of the participants who can best inform the research according to the theoretical requirements of the study (Morse & Field, 1996:65). In this study, young children between the ages of five and nine years were selected. According to Jean Piaget's theory of cognitive development (Hockenberry, et al., 2003), children in the chosen age group can adequately articulate their thoughts and can use images and words as tools of description. Four-year olds were initially included in the selection criteria, but after interviewing the first four-year old I found that he battled with recall and did not concentrate in the interview. Further four-year olds were therefore excluded from the study.

Adequacy

This principle refers to saturation. This stage is reached in the data collection process when no new data emerges and where further interviews will not reveal anything that has not already been revealed (Morse & Field, 1996:65). The sample size in this study was not predetermined prior to the commencement of the interviews. Saturation was reached after the sixth interview. The seventh and eighth children were interviewed as a means of control.

2.3.2 The setting

The setting chosen for this study was the HCU on the paediatric ward. Children are admitted to this unit prior to surgery. Following surgery, they are admitted to the CTICU for a period of time, which varies according to their cardiac condition and the nature of their surgery. Once they no longer require invasive monitoring and organ support, they are transferred back to the HCU. Children have limited contact with their parents in the CTICU. Visiting regulations in the CTICU restrict the parents to visit their children for one hour at a time, three times a day. In the HCU, the parents are permitted to stay with their children at all times and are encouraged to participate in the care of their children. There was no manipulation nor were changes made to the HCU for purposes of the study and children were interviewed in the natural setting that they were questioned about (Burns & Grove, 2001:40).

Wilson (1993:236) claims that phenomenology aims to understand how people experience the world without classifying it or taking it out of context. Because the young children may have battled with recall if the interviews were delayed or conducted in another context, it was important to conduct the interviews in the HCU prior to discharge.

2.3.3 Data collection

Data were collected through semi-structured face-to-face interviews with the children, which were augmented with drawings. Follow-up was done one month later through semi-structured telephonic interviews with the children's parents.

Semi-structured interviews with the children

Morse and Field (1996) argue that semi-structured interviews allow the researcher to obtain the information required while permitting the participant freedom of responses and description to illustrate concepts. The young children in this study were all asked the same questions but flexibility in the phrasing and order of the questions was allowed as advocated by Hutchinson & Wilson (in Parahoo, 1997:293). At the beginning of this study I was unsure whether children of this age group would be able or willing to freely talk about their experiences without prompts, i.e. set questions. It was however my assumption that children of this age group could adequately convey their experiences. Rennick, et al. (2002:134) report that children are able to recall their intensive care experiences in great detail. Ireland and Holloway (in Sartain, et al., 2000) advocate that qualitative research with children, that involves questioning the children directly, falls within the category of 'minimal harm' if the interviews are carried out in a sensitive manner with the child's approval (Sartain, et al., 2000:914). In this study, assent was gained from all the children, following informed, written consent by their parents, before the interviews were commenced.

The children were all told that I wanted to talk to them about what it was like to be in hospital for a heart operation. I had four basic introductory questions:

- *How old are you?*
- *Do you go to school?*
- *If so, what grade are you in?*
- *What do you like doing most?*

These questions were asked in an attempt to relax the children and to encourage them to talk about themselves. Three leading questions followed these introductory

questions and the children, through their responses or lack thereof, dictated how and when these questions were asked. On occasions the children answered my questions before I asked them, by freely talking about their experiences. The quieter children responded better to the questions being asked in sequence. The three leading questions were as follows:

- *Tell me what it is like to be in hospital for a heart operation.*
- *What is the best thing that happened to you?*
- *What is the worst thing that happened to you?*

It was important to ask about positive and negative aspects of the children's hospitalisation, as one cannot presume that all their experiences were negative. Some of the children were more talkative than others and some more willing to share their experiences.

A fourth question was added:

- *What would you tell another little boy / girl who was going to hospital for a heart operation?*

I had asked the first child this question towards the end of the interview. It opened doors that the other questions had not and I therefore asked the remaining seven children the same question with good results.

The interviews lasted between 20 and 40 minutes. All the interviews were captured on a micro-cassette recorder. These recordings were directly transcribed for analysis purposes.

Drawings

The drawing technique has been used successfully in studies with children before as it provides a focal point for the interview (Sartain, et al., 2000:916). Drawing is familiar and non-threatening to children (O'Malley & McNamara, 1993: 1079). During the interviews, the children were asked to draw a picture of themselves in hospital. Children's drawings are a significant means of nonverbal communication and are the universal language of children, which is easy and enjoyable. O'Malley and McNamara (1993:1078) describe the use of drawings by hospitalised children as "a way to express fears, concerns, and fantasies; or as a way to communicate nonverbally when verbal communication might be frightening". Sartain, et al. (2000:917) are in agreement with this and describe the drawings by children as a practical way of interviewing children and of encouraging them to talk about themselves and their experiences. By asking the children to talk about their drawings in the interview, further information was elicited.

> *One of the children drew the paediatric ward's procedure room and when asked about it, she pointed towards it on the ward and verbalised that it was a horrible room where they 'prick you'. She had not mentioned this room until the point in the interview when she was questioned about her drawing.*

Semi-structured telephonic interviews with the parents

Semi-structured telephonic interviews were conducted with the children's parents one month after the children had been discharged from hospital. The aim of these interviews was to determine from these parents whether their children's behaviour had changed, either progressively or regressively, and whether their children had demonstrated any significant emotional responses to their hospitalisation.

Telephonic interviews were chosen, as they were convenient and not restrictive with regard to contacting the parents. The telephone calls were well received by the parents and they were very willing to discuss their children's behaviour and emotions. These interviews were short interviews, most of them lasting less than five minutes. The questions asked were as follows:

- *Has your child's behaviour changed in any way since he / she has been home from hospital?*
- *If yes, has it improved or regressed?*
- *Has your child demonstrated any significant emotional responses to his / her hospitalisation?*
- *If so, please explain.*

As in the interviews with the children, the questions were not asked in any specific order. Conversation with the parents dictated when the questions were asked. Most often, the parents answered the questions before they needed to be asked, by talking about their children.

In addition to these questions, I referred back to anything significant that the children had mentioned e.g. one child mentioned that she thought the doctors and nurses were trying to kill her. When I spoke to her mother I asked if this child still felt this way one month later. A number of the children had nightmares in the hospital setting. When speaking to their parents, I asked if these children were still having nightmares.

Some of the parents made suggestions / recommendations about the ward and the hospitalisation of young children. These views have been presented in Chapter Three.

2.3.4 Data analysis

There are several variations used to analyse phenomenological data. Giorgi's method of analysis of phenomenological data is used in this study (Burns & Grove, 2001:606-607). Giorgi advocates that a sense of whole be maintained and that relationships should be drawn between the identified themes and to the whole (Burns & Grove, 2001:607). This is important in understanding why children experience hospitalisation for cardiac surgery as they do and how the identified themes affect these experiences.

Application of Giorgi's Method of Analysis of Phenomenological Data:

- Read through each interview to obtain a sense of the whole.
- Reread each interview to delineate each time a switch in meaning occurs. This results in a series of meanings or themes.
- Examine the previously determined meanings / themes for redundancies, clarification, or elaboration by relating themes to each other and to a sense of the whole.
- Reflect on the themes (as expressed by the participant) and comprehend the essence of the experience for each participant. Systematic interrogation of each theme is undertaken for what it reveals about the phenomenon under study for each participant.
- Formalize a consistent description of the structure of the phenomenon under study across participants by synthesizing and incorporating the insights achieved in the previous steps.

The drawings that the children drew during their interviews have been analysed by a clinical psychologist who is based at a children's clinic within a psychiatric hospital in Johannesburg. The findings from the analysis of the drawings have been used to support the findings from the interviews to strengthen the data elicited.

Chapter Three will cover the data analysis process in more detail and report on the findings through means of thick description.

2.4 Ethical considerations

As briefly discussed in the last chapter, certain guidelines were adhered to in this study in order to ensure that it was ethically conducted:

- **Informed assent from each child and consent from his / her parent:** Assent was obtained from each child interviewed after a verbal explanation (in simple terms) of what the time spent with me would involve. The verbal assent from the child was captured on a micro-cassette recorder along with the recorded interview. This assent was supported by informed written consent obtained by the child's parent to participate in the study and for the interviews to be tape-recorded. Everybody who was involved in the research received written information and consent forms relating to the study.
- **Autonomy:** I informed the children and their parents that the interview could be terminated at any point and that they need not participate. Fortunately, none of the children or their parents refused to participate in this study. I did

however, cut one or two of the interviews short, as the children expressed that they had nothing more to say and that they were tired.

- **Confidentiality and anonymity:** All names have been replaced with pseudonyms to ensure the confidentiality and anonymity of the children and their families. All hard copies and recordings of the interviews will be destroyed once they are no longer required for purposes of the study.
- **Truth telling:** Due to the fact that the interviews took place with children and taking their psychosocial and cognitive development into consideration, I cannot ask them to verify that what I have written about their interviews is the truth. I therefore undertake to be truthful in my explanation and description of their experiences of hospitalisation.
- **Sensitivity to emotional responses:** One of the children appeared to be very depressed and a psychologist was offered to speak to the child and his parents. His parents refused and said that they were sure he would be happier once at home. One month later, I confirmed with the child's mother that he was much happier at home and that they, as parents, did not feel that is was necessary for him to speak to a psychologist. On analysis of this child's drawing and following a discussion with a clinical psychologist another call was made to the parents, three months later. It was at this stage that they agreed for the child to see a psychologist.
- **Access to reported findings:** Feedback has been offered to all participants in the study, should they request it. The findings of this research will be disseminated among the staff caring for these children and articles arising from the findings of this study will be published in accredited nursing research

journals. This study will also be presented at the University of the Witwatersrand's Nursing Research Day.

(Polit & Hungler, 1995:134-142; Sartain, et al., 2000:915 and Marais, et al., 2003:30)

2.5 Trustworthiness of this study

Yardley's principles for ensuring trustworthiness in a qualitative study were chosen, as they were most appropriate for the nature of the context and participants of this study. Children are a vulnerable group of participants. As mentioned earlier in this chapter, they are however considered by many researchers as a valuable source of knowledge with regard to how they experience health care.

Yardley's principles are presented, followed by a discussion as to how they relate to this study (Yardley, 2000:219-224).

2.5.1 Sensitivity to context

Yardley asserts that the researcher should be aware of literature that relates both to the topic and to the research methodology used in the study. Evidence from the participants and how it supports the argument of the study will verify sensitivity to the context. The researcher should also demonstrate awareness with regard to how the socio-cultural milieu in which the study takes place could have influenced its conduct and outcome (Yardley, 2000:220).

Literature reviewed that relates to the topic is covered in the *Background to the Study* in Chapter One. This literature was used as a starting point for this study and guided the selection of participants, with regard to age group, and the choice of research approach and methodology. It is acknowledged that children are a vulnerable group of participants. The use of drawings in the interviews created a familiar and non-threatening environment for the children. The fact that the findings cannot be given back to the children to verify that they are a true reflection of how they feel is a limitation of this study. As discussed in the ethical considerations I undertook to be truthful of the children's account of their hospitalisation and hope that the thick description of their experiences will validate the findings. Choosing to interview the young children in the HCU prior to discharge was important, as visual stimuli helped the children with recall. These children do not necessarily have the vocabulary to describe medical procedures and equipment and while pointing at familiar objects, they spoke about their experiences:

> *One of the children pointed at his nebulizer mask and explained that a similar mask is used to put you to sleep before surgery.*

One could argue however, that the surroundings could influence the children's reports of their hospitalisation due to medical personnel around the children or procedures that may have been carried out directly before the interviews.

2.5.2 Commitment, rigor, transparency and coherence

Commitment can be tested through the degree of engagement demonstrated. This commitment is evident through the qualitative approach or the chosen field of

research. Rigor refers to the thoroughness of the study regarding the suitability of the sample and the completeness of the analysis. Transparency and coherence refer to the clarity of the stages of the research process in the written report (Yardley, 2000:222).

In this study, the data collection process took place over six months. Each interview lasted at least 20 minutes. Prolonged exposure to these children prior to the commencement of data collection gave me an understanding of the children and the environment in question. The chosen field of research, i.e. young children, cannot be understood through brief encounters. Spending time with these children in order to gain their trust is imperative in allowing them to relax and to feel comfortable to share their experiences.

No new information was revealed after the sixth interview. The seventh and eighth children were interviewed to ensure that saturation had in fact been reached. The data collected from each interview have been systematically broken down into themes. These themes had to be synthesized across the eight participants before an adequate description of young children's experiences of hospitalisation for cardiac surgery could be presented. Thick description has been used in presenting these findings with the aim of putting the reader in the place of the researcher. Chapter Three presents the findings of this study in a logical format, in which the clarity of the various stages in the research process is evident.

2.5.3 Impact and importance

This final principle is a key test of the value of the study and the influence that it will have on nursing in future. Does the study reveal anything important, shedding any light on existing work, or will it make any difference to the practice of nursing? (Yardley, 2000:223)

This study has revealed new information about how young children experience their hospitalisation for cardiac surgery. The parents of these children have also given useful and practical suggestions about how the hospitalisation of young children in the given context, can be improved. During the data collection process of this study, the staff of the paediatric ward (doctors and nurses) became interested in what the children had to say about the staff and their hospitalisation experience. An awareness of the potential for behavioural changes and negative emotional responses from these children was created among the staff members on the ward before the findings were reported. Various changes were made on the ward, including booklets for the children on hospitalisation and surgery and medals for bravery that are now given to each child after they have had their surgery. Abstracts of this study have been requested for the National Cardiac Congress and the Critical Care Congress.

2.6 Conclusion

This chapter has detailed the research approach and methodology used in this study. Ethical considerations, specific to this study have been discussed in more detail. The

chapter was brought to a close with a discussion on Yardley's principles of trustworthiness in qualitative research studies and how they pertain to this study. Chapter Three will present the findings of this study.

CHAPTER THREE

PRESENTATION OF FINDINGS

3.1 Introduction

In this chapter, a profile of the participants is provided. The process of data analysis, using Giorgi's method of phenomenological data analysis, is explained. This is followed by a presentation of the findings from the interviews with the young children, which are supported by the analysis of their drawings. The parent's reports of their children's progress / regress one month following discharge from hospital are given as well as their concerns and suggestions regarding the hospitalisation of young children for cardiac surgery.

3.2 The participants

A total of eight children were interviewed. The children were a mixture of boys and girls and ranged from four to nine years of age. Most of the children spoke and understood English. Three children battled with English and in those cases, their mothers acted as interpreters – all were fluent in the use of English. The parent participants comprised mainly of mothers, with only one father interviewed in the

follow-up telephonic interviews. Table 3.1 includes a breakdown of the children and their parents interviewed, the children's ages and their first languages.

Table 3.1 A profile of the participants

Young Children (Pseudonym)	Age	First Language	Parent present during interview	Interpreter	Parent respondent one month later
Mark	Six	English	No	No	Mother
Leo	Four	Sotho	Mother & Father	Yes– Mother	Mother
Michael	Seven	Ndebele	Mother	Yes- Mother	Father
Pamela	Six	Tswana	Mother	Yes- Mother	Mother
Thomas	Nine	Zulu	No	No	Mother
Adrian	Six	English	Mother	No	Mother
Tania	Seven	English	Mother	No	Mother
Brett	Six	English	Mother	No	Mother

3.3 The data analysis process

As mentioned in Chapter Two Giorgi's method of phenomenological data analysis was followed in this study. I chose this method of analysis as Giorgi advocates *maintaining a sense of the whole,* which I felt was important in understanding how young children experience hospitalisation for cardiac surgery. Giorgi also claims that the researcher should acknowledge the relationship of the themes identified to the whole *and to each other* (Burns & Grove, 2001:607). These two points directed my

analysis of the raw data – What does any one of the young children's interviews reveal about young children's experiences of hospitalisation for cardiac surgery? What is the relationship between the identified themes to these experiences and to each other, e.g. *how does a child's fear relate to his parent's presence at his bedside?*

An explanation of each step in Giorgi's analysis process is presented to illustrate how the findings were reached:

- **Read through each interview to obtain a sense of the whole.**

Each interview was recorded on a micro-cassette recorder and directly transcribed following the interview. I then wrote a narrative about each child, which included the transcripts, my observations and the parents' comments before and after each interview. The information received from the follow-up telephonic interviews with the children's parents was added to the narratives. Reading through each transcript and then the narrative provided me with a sense of the whole experience of hospitalisation for cardiac surgery for each child.

- **Reread each interview to delineate each time a switch in meaning occurs. This results in a series of meanings or themes.**

The narratives and transcripts from the interviews were reread a number of times. The children interviewed in this study often gave one or two word answers to the questions asked and it was therefore clear each time a switch in meaning occurred (Burns & Grove, 2001:610).

For example, the answers *"I didn't like it when my mommy left me", "I liked being with my mom"* and *"I missed my dad"*, made it clear to me that the presence of the children's parents was important. Similarly, answers like *"it was scary"* and simply *"scary"* allowed me to clearly identify that the children were scared.

- **Examine the previously determined meanings / themes for redundancies, clarification, or elaboration by relating themes to each other and to a sense of the whole.**

I examined the themes that I had identified. I thought about what these themes meant to the phenomenon of *young children's experiences of hospitalisation for cardiac surgery* and what these themes meant to each other. I searched for redundancies and classified what I felt were less significant themes within more significant themes – Giorgi advocates that the importance of the themes identified are judged by the researcher and not by the frequency with which they occur (Burns & Grove, 2001:607).

Example: *One of the children referred to a nebulizer mask as one of the sources of his fear. The nebulizer mask was only mentioned once by this particular child and not by any other child. I therefore highlighted the emotion of 'fear' that he demonstrated and not the nebulizer mask.*

- **Reflect on the themes and comprehend the essence of the experience for each participant. Systematic interrogation of each theme is undertaken for what it reveals about the phenomenon under study for each participant.**

The narratives and the transcripts were reread as I tried to understand what the themes that I had identified from each child's interview had meant to each child. I discovered that each child had experienced their hospitalisation differently, or at least had given different accounts of their experiences. Although I was initially frustrated by these different accounts I realised that it was a significant finding in itself. Despite the common themes identified across the eight children I could not make generalisations about how young children experience hospitalisation for cardiac surgery. Each child is unique.

Investigator triangulation was used to remove the potential for bias, which can occur in single-investigator studies (Burns & Grove, 2001:240). A clinical psychologist was consulted for her expertise in analysing children's drawings. A child nurse specialist and a psychiatric nurse specialist were also consulted in the analysis process. Both specialists read the narratives that I had written. The specialists shared their views and helped direct the analysis process.

- **Formalize a consistent description of the structure of the phenomenon under study across participants by synthesizing and incorporating the insights achieved in the previous steps.**

The final step of this analysis process was to group the findings under identified main themes. The main themes will now be described. The drawings have been included to illuminate and support the discussion.

3.4 Discussion of findings

A total of 16 interviews were conducted with the eight young children and their parents. The themes that were identified from the interviews are presented in Table 3.2.

Table 3.2 Themes identified during the interviews

Interviews	Themes
The young children's interviews	❑ "I liked having my mommy with me" ❑ "It was very sore" ❑ "I had nothing to do" ❑ Behavioural changes and emotional responses observed by the parents in hospital ▪ Positive behavioural changes and emotional responses ▪ Negative behavioural changes and emotional responses ❑ Unique coping mechanisms
The parents interviews	❑ "He was not himself" ❑ "He is much better" ❑ "The nurses didn't talk to him" ❑ "Only another parent can understand what it is like"

3.4.1 The young children's interviews

The common themes that were identified from the children's verbal accounts of their hospitalisation were: "I liked having my mommy with me", "It was sore" and "I had nothing to do". Common behavioural changes and emotional responses were elicited through observation and were supported by the children's reports of how they felt. The fifth theme identified was the children's unique coping mechanisms to hospitalisation.

As discussed in Chapter Two, the children are admitted to the HCU on the paediatric ward prior to surgery. Following surgery, the children spend their initial recovery period in CTICU until they no longer require organ support and invasive monitoring. From CTICU they are transferred back to the HCU for recovery until discharge. Mention of this movement from the CTICU and readmission to the HCU has been repeated, as both the children and their parents drew comparisons between their experiences as they moved from the CTICU to the HCU.

3.4.1.1 **"I liked having my mommy with me"**

Without question, the most dominant theme that emerged from the interviews with the children was their parents. All children verbalised that they were happy when their parents were with them and sad when they were not. From observation, the children interviewed appeared to be happier when their mother and / or father were at their bedsides.

MARK said the best thing that happened to him while in hospital was, *"When my mom and dad stayed with me."* The worst thing that happened to MARK in hospital was, *"When I was in the other ward* (referring to the CTICU)... *I didn't like that because my mom and dad had to just sit and wait."* In the CTICU parental visitations are regulated and restricted to one hour at a time, three times a day. The parents that live far from the hospital and who do not go home between visiting hours, wait in a waiting room. MICHAEL and THOMAS agreed: *"I like having my mother with me." "The best thing was that my mother was with me."* BRETT said that he didn't like being in hospital because, *"I miss my dad."* BRETT, on the day that he was transferred to the HCU, wandered around the ward and asked all the nurses, *"Have you seen my mommy?"*

The importance of allowing parents to stay with their children cannot be overemphasized. The illness period in young children is known to increase the attachment behaviour between children and their parents (Hockenberry, et al., 2001:1033). Any separation during this time is not handled very well. According to Rutter (in Hill, 1996) children's anxiety as a result of being in a strange environment is exacerbated by the absence of their parents. Researchers (Bonn, 1994; Hill, 1996; Endacott, 1998; Bennett, 2001 and Baker, 2004) that have examined parental involvement and presence, both in intensive care settings and at ward level, report that children are less anxious and often demonstrate fewer negative effects post hospitalisation if their parents are permitted to stay with them. Increased separation anxiety, sleep disturbances and aggression towards authority as well as apathetic withdrawal have been observed in children whose mothers did not stay with them, up to one month following discharge from hospital (Bonn, 1994:20).



Figure 3.1 MARK'S drawing of himself in hospital

In MARK'S drawing he has drawn a figure of himself in his hospital bed with figures of both his parents at his bedside. His mother's figure is closest to him and is over-lapping his own indicating increased attachment / separation anxiety. The drawing is heavily shaded which usually symbolizes anxiety. None of the figures in the drawing have hands or feet representing a feeling of loss of control.

3.4.1.2 **"It was sore"**

In answer to the questions: *"What is the worst thing that happened to you while you were in hospital?"* and *"What would you tell another little boy / girl who was going to hospital for a heart operation?"* the young children's answers often made reference to pain. ADRIAN mentioned that the worst thing about being in hospital was, *"The op. It was sore."* LEO said that he would tell another little boy who was going to hospital for a heart operation, *"They cut you and it's painful"*. PAMELA agreed, *"They stitch you and it's painful."* Even MICHAEL who was very positive about his hospitalisation said that he would tell another little boy, *"If you have an operation it is very painful."* All but one of the children interviewed mentioned that they had been in pain at least once during their interview.

Referring to literature it is clear that there is a direct relationship between the presence of a parent at a child's bedside and the appropriate management of the child's pain. Researchers (Bennett, 2001 and Holmes, 2004) advocate involving children's parents in the assessment of their pain. Parents know their children best and can distinguish pain behaviour from others (Wilson, 1993 and Abu-Saad & Hamers, 1997 in Bennett, 2001:27). Without the presence of the parents, nurses tend to rely on physiological signs of pain and on the child reporting that he is in pain. Due to the nature of cardiac surgery and its effect on cardiac function, the normally recognised physiological signs of pain such as tachycardia, hypertension and sweating may be masked (Connolly, et al., 2004:480). In addition these children are intubated and sedated in the immediate post-operative period and communication is therefore decreased. Bennett (2001) advocates that children should receive regular, balanced analgesia, as it is safer to presume that every child is in some degree of pain when communication is decreased.

Hill (in Bennett, 2001) asserts that parents are also an important non-pharmacological form of pain relief, as they instinctively provide therapeutic touch and comfort.

3.4.1.3 "I had nothing to do"

It was apparent in the analysis process that the children were not provided with enough age-appropriate stimulation in the hospital, particularly in the CTICU. Most of the children preferred being in the HCU to the CTICU and one of their reasons for this was that there was more for them to do. The HCU is situated on the paediatric ward, which has a playroom, a variety of toys and a selection of videos that the children can watch. Once the children are well enough, they can leave the HCU and spend time in the playroom with other children. The CTICU accommodates a mix of adults and children. Due to their illness, the children are confined to their beds in the CTICU and the choice of TV channel, if it is switched on, is not always appropriate for children. ADRIAN said that he preferred the HCU as he could, *"Colour in and play."* When asked what he thought of the CTICU ADRIAN replied, *"Not so nice. Boring. Because I don't do anything."* BRETT confirmed that he had been sad in the CTICU and his reasons were, *"I had nothing to play with."* He said that he enjoyed watching the TV in the HCU and that in the CTICU, *"I had nothing to watch."*

One of the introductory questions in the interviews with the children was, *"What do you like doing most?"* In response to this question all of the children said that they liked to play. Most of the children mentioned that they wanted to go home so that they could play with their friends and their toys. THOMAS didn't like being in hospital, *"Because you stay in bed and don't see your friends."* When asked what he would like to do, THOMAS said, *"Play outside"*. MICHAEL said that he did not

want to go home and one of his reasons was because he could play in the playroom on the paediatric ward.

Play is an important aspect of a young child's life and an effective tool for managing stress (Hockenberry, et al., 2003:1069). Play in a hospital setting includes a variety of age-appropriate activities that do not necessarily require physical exertion that would be difficult for an ill child. Play therapy in the hospital setting provides diversion and relaxation for children as it helps children feel secure in an unfamiliar environment (Hockenberry, et al., 2003:1069). Knowledge of Piaget's theory of human development is important for ICU nurses in order to assess the stage of a child's development and to provide the correct level of stimulation (Green in Endacott, 1998:67).

Drawing a relationship between the parents' presence and the children's boredom, one can conclude that the inclusion of parents in their children's care can result in the appropriate stimulation of the children. Parents know their children intimately and are aware of what type of activities their children prefer. Parents can provide favourite toys, comforts and stories at appropriate times.

3.4.1.4 Behavioural changes and emotional responses observed by parents in hospital

The children in this study demonstrated behavioural changes and emotional responses following their cardiac surgery and admission to CTICU. Behavioural changes and emotional responses rarely occur in isolation. None of the children interviewed demonstrated a single behavioural change without any emotional responses and vice

versa. Behavioural changes and emotional responses, when referring to literature, are grouped together as 'changes' or 'the effects of hospitalisation on children'. These 'changes' or 'effects' are not uncommon and have been reported in the findings of many studies (O'Malley & McNamara, 1993; Bonn, 1994; Hill, 1996; LaMontagne, 2000; Gritti, et al., 2001; Rennick, et al., 2002 and Connolly, et al., 2004).

Negative behavioural changes and emotional responses

Six out of eight parents reported, without prompt, that their children's behaviour had changed. The parents were clearly distressed by the changes they had observed. These changes included withdrawal, tearfulness and nightmares.

PAMELA'S mother said, *"It is just since the operation. She is not usually like this. She is a very happy little girl at home and does not stop talking"*.

The parents reported that their children appeared to be sleeping restlessly and felt that their children may have been having nightmares. THOMAS mentioned that he did not want to sleep at night because of *"the dreams"* and the *"bad people"*. The nightmares were one source of the children's disturbed sleep. The CTICU environment also contributed to disturbed sleep patterns. CTICU is a noisy, busy and frightening environment for young children (Connolly, et al., 2004:483). Dyer (in Baker, 2004) likens the ICU patient to a torture victim, claiming that sleep deprivation and lack of human contact are two of the factors used to produce debility and dependence in torture victims. Children in the CTICU are deprived of contact with their parents due to visiting regulations.

Three of the children wet their beds, two while still in hospital and one soon after discharge to home. Although these incidences caused concern, they were not recurrent. All three children were on Frusemide (a diuretic) at the time. Hockenberry, et al. (2003) cite that bedwetting is a concern if it occurs at least twice a week for at least three months and that it must not be related to the direct physiological effects of a substance e.g. diuretics (Hockenberry, et al., 2003:783).

Negative emotional responses observed and reported by the children themselves during their interviews, were sadness, fear, anger and depression.

The children gave a variety of reasons for their sadness. MARK was sad because his parents could not stay with him in the CTICU. BRETT similarly reported that he was sad because he missed his dad and his home and ADRIAN, when asked why he was sad, simply said, *"I want to go home."*

The children's reasons for their fear also varied. In answer to the question, *"What would you tell another little boy who was going to hospital for heart operation?"* MARK replied, *"Don't be afraid"*. When asked what the little boy would have to be afraid of MARK said, *"Because he mustn't… you know those stuff that went here?* MARK indicated his sternum and below his left nipple. At first I thought he was referring to the drains that are inserted post-surgery and asked him if that was what he meant. *"No. They stuck things… that shocked, so that it wouldn't shock me, so that it shocked the pads. So, it was like a shock machine and it was meant to actually shock me!!"* MARK pulled a face as he said this. MARK'S recall of the defibrillator pads and his experience of 'the shock machine' worried his parents and his mother reported

that MARK had nightmares about being shocked. This recall was reported to MARK'S doctors for verification. The doctors were puzzled by MARK'S recall, as he had been given sedation with amnesic properties prior to the event. One month later MARK'S mother reported that MARK continued to talk about the fact that the doctors had 'shocked him'. She said, *"I think he has come to terms with it though. He doesn't seem to be so scared anymore when he talks about it"*. Despite adequate and appropriate pharmacological measures to protect children from traumatic memories, they have been found to recall their intensive care experience in great detail (Rennick, et al., 2002:134). Visintainer and Wolfer (in Bonn, 1994) explain that children's most significant fears of hospitalisation are of physical harm or bodily injury in the form of discomfort, pain and mutilation. Fears of death and permanent injury contribute to these children feeling a loss of control (Hockenberry, et al., 2003:1034). PAMELA was afraid because she believed that the doctors and nurses were going to kill her, *"The nurses and doctors. I don't like them. They kill me."*



Figure 3.2 PAMELA'S drawing of herself in hospital

PAMELA drew herself in a hospital bed attached to a monitor by various leads. The emphasis of these leads in her drawing suggests that she may have felt threatened by them. PAMELA drew a doctor on her right. He appears ghostly and is touching the equipment emphasising his control over life/death. She drew her mother to her left emphasising her importance by using a number of colours and placing a heart and a flower at her side. Both PAMELA and her mother's figures look frightened with open mouths and panicky eyes. PAMELA'S fear and worry may have been exacerbated by her belief that her mother was also afraid. A parent's close relationship with her child results in her emotions being manifest in the child (Endacott, 1998:67).

Some parents reported that they thought their children were angry. PAMELA said to her mother as she was taken to theatre, *"Why mommy? Why are you giving me to these people?"* LEO was visibly angry with his mother. *"It's your fault mommy. You brought me here for them to hurt me."* ADRIAN did not express his anger verbally but it was evident in his drawing.



Figure 3.3 ADRIAN'S drawing of himself in hospital

ADRIAN'S drawing lacks detail. Poor pencil control and little effort give the drawing a rushed appearance and may signify his anger or irritability while drawing the picture.

Researchers (Clatworthy, et al. 1999; Rennick, et al. 2002 and Baker, 2004) report that children are at a disadvantage when they encounter situational stress, as they have less knowledge and decreased cognitive abilities to solve new problems and often exhibit anger, withdrawal, regression, bedwetting and sleep disturbances (Clatworthy, et al., 1999:2). Children have also been observed to demonstrate anxious, withdrawn, fearful, restless and hostile behaviour while still in the intensive care setting (Rennick, et al., 2002:133).

Although a number of parents reported that their children were depressed, THOMAS'S depression was most apparent during his interview. Unlike the other children, THOMAS'S surgery was not successful – he is on a waiting list for a lung transplant, as his condition cannot be improved through corrective surgery. THOMAS associated *"being in hospital"* with *"being ill"*. THOMAS reported that being in hospital made him sad, *"because you stay in bed and don't see your friends"*. THOMAS was very sad, his hands were shaky and he was evidently holding back tears. Hockenberry, et al. (2003) confirm that easily identified manifestations of depression in children are sadness, a downcast face, tearfulness, irritability and withdrawal (Hockenberry, et al., 2003:798). When THOMAS was asked what would make him feel happy he said, *"Being better"*. THOMAS battled to verbalise his feelings but did write a letter to his mother, following his interview, detailing how he felt. THOMAS said in his letter that *he was sad because he was ill. He did not want to be sick. He did not want to be in hospital. He wanted to be well and to play with*

his friends and his mother. He said that he would only be happy again once he was better. Following THOMAS'S interview, I offered to organise counselling for THOMAS. His mother refused stating that she was sure he would be better once he was at home. One month later THOMAS'S mother confirmed that he was better but that he continued to write letters, the content of which varied. The psychiatric nurse specialist that read the narrative of THOMAS'S hospitalisation experience during the analysis process confirmed his depression. Her notes read, "*This child is severely depressed. Exhibits signs of hopelessness – thinks he is going to die. Follow up!!"* The clinical psychologist who assisted in analysing the children's drawings agreed and suggested that THOMAS'S mother may have been in denial when stating that THOMAS was better. She felt that both THOMAS and his mother would require counselling and suggested that I telephone THOMAS'S mother again to find out how THOMAS was. The psychologist also suggested that THOMAS'S doctor should be made aware of his possible depressive state. I telephoned THOMAS'S mother again which was three months after her initial, telephonic interview and four months after THOMAS'S interview. THOMAS'S mother confirmed that he was very depressed, that he hardly spoke and continued to write numerous letters about his feelings. At this stage THOMAS'S mother agreed that THOMAS could benefit from counselling. She said that she too would like to attend counselling as she had recently been discharged from hospital following an admission for stress, which she attributed to THOMAS'S condition. I phoned THOMAS'S doctor to inform him of our findings. THOMAS and his mother have been put in touch with a psychologist for counselling.

Positive behavioural changes and emotional responses

Not all of the children's emotional responses to their hospitalisation were negative. A number of the children showed a sense of gratitude and relief following their surgery. LEO said that the best thing that had happened to him in hospital was, "m*y heart is fixed"*. TANIA was seen to give one of the surgeons a hug as she left the ward and heard to say, *"thank you for fixing my heart"*.

MICHAEL enjoyed his experience of hospitalisation. *"I enjoyed being in hospital. I liked eating and sleeping and sitting around. It felt like home."* Unlike the other children, MICHAEL did not want to go home. *"No. I like it here. I like the food and I like being with my mother. I don't want to go home yet."* He appeared to be so happy and smiled continuously. MICHAEL would gladly play with the other children on the ward. He did not shy away from the nurses who needed to check his observations and perform other procedures. MICHAEL'S positive account of hospitalisation disconfirms much of the evidence drawn from previous research that was reviewed in the background to this study. Bonn (1994) agrees that hospitalisation can be a positive experience for those children who engage in and cope with the risks associated with the hospital experience (Bonn, 1994:23).



Figure 3.4 MICHAEL'S drawing of himself in hospital

MICHAEL'S drawing of himself in hospital confirmed his feelings. He has encapsulated the happy little figure of himself in a ring indicating that he felt secure.

From the discussion above it is clear that a relationship exists between negative and positive outcomes of experiences and the three previously identified themes of "I liked having my mommy with me", "It was sore" and "I had nothing to do". As discussed earlier under "I liked having my mommy with me" negative behavioural changes and emotional responses have been associated with the absence of a parent at a child's bedside and children whose parents have remained with them show fewer adverse effects of hospitalisation following discharge from hospital. Pain is also a significant source of the children's fears, which could be decreased through adequate and appropriate pain assessment and management. Young children's anxiety may be decreased through appropriate stimulation with diversion or play therapy.

3.4.1.5 Unique coping mechanisms

The children interviewed each had different accounts of their hospitalisation for cardiac surgery. Despite the common themes that were identified, each interview shed a different light on the phenomenon of young children's experiences of hospitalisation for cardiac surgery. Some children appeared to be very sad, tearful and withdrawn while others did not appear to be distressed by their experiences. Children respond to and cope with their hospitalisation according to their coping styles, cognitive level, temperament, developmental stage, parental support and their ability to adapt (Bonn, 1994; Hill, 1996; Endacott, 1998; LaMontagne, 2000 and Connolly, et al., 2004). Children appraise a situation as stressful according to their

individual understanding of how the situation can produce harm and the resources that are available for dealing with it (LaMontagne, 2000:308).

3.4.2 The parents' interviews

The aim of the follow-up, telephonic interviews with the children's parents was to elicit whether the children had demonstrated or continued to demonstrate any significant behavioural changes and emotional responses to their hospitalisation one month after having been discharged from hospital. As discussed in the background to this study in Chapter One, children have been found to demonstrate significant changes up to six months following a period of critical illness and hospitalisation (LaMontagne, 2000; Gritti, et al., 2001 and Rennick, et al., 2002).

Four themes were identified from the interviews with the children's parents. The parents spoke about their children's progress / regress at one month following discharge, they highlighted that a lack of communication exists between the nurses and the young children and that only other parents whose children have been admitted to hospital for cardiac surgery could truly understand their experiences.

3.4.2.1 **"He was not himself"**

According to the parents' reports of their children one month after discharge from hospital, three of the eight children interviewed continued to demonstrate negative behavioural changes and emotional responses in the first month that they were at home.

MARK'S mother was unhappy with MARK'S emotional state. *"Physically he is fine but emotionally he is not well at all."* MARK'S mother felt that he had regressed, showing signs of separation anxiety that he had not shown prior to his surgery. MARK'S mother reported that he did not like to sleep in his own bed at night and that he was afraid to be left at school. MARK continued to be withdrawn and tearful. Baker (2004) reports that separation anxiety, sleep disturbances, school phobia and underachievement are common among children who show signs of developmental regression following discharge from hospital (Baker, 2004:32).

ADRIAN'S mother reported that he had been withdrawn and tearful for two weeks following his discharge. ADRIAN, like MARK, had shown evidence of separation anxiety which was manifested by him not wanting to leave his mother's side and not wanting to sleep on his own at night. He continued to wake in the middle of the night from what appeared to be nightmares. One month after his discharge however, at the time of my telephonic interview with his mother, ADRIAN was *"back to himself"*. PAMELA'S mother reported that PAMELA had continued to have nightmares once at home but only for a week. Thereafter, PAMELA had returned to her pre-hospitalisation behaviour, with her mother reporting that she was *"more talkative and much happier"*.

3.4.2.2 **"He is much better"**

The other five parents had very positive reports about their children with most of the children demonstrating no ill effects from their hospitalisation at all. The parents reported that their children were very happy and very active. BRETT'S mother said, *"He is running around like a lunatic and does not seem to be perturbed at all."*

BRETT'S resilient nature had been apparent while he was still in hospital and was illustrated in his drawing.



Figure 3.5 BRETT'S drawing of himself in hospital

BRETT was the only child that drew a figure of himself out of his hospital bed, indicating that he felt that he was in control. The figure he has drawn has a happy face symbolising his confidence. BRETT'S drawing is however framed by cot-sides, which indicate that he was aware of his vulnerability in hospital.

Vernon and Schulman (in Bonn, 1994:21) found that the changes in children following hospitalisation and surgery, although significant, are not serious and that 25% of children show an improvement once at home. Bonn (1994) explains that most children do not suffer permanent scars from a stay in hospital even though a significant proportion of them do experience some sort of behavioural or emotional disturbance. Children's positive, adaptive behaviour and coping is facilitated by the

support of their parents and parents should therefore be encouraged to stay with their children in hospital (Bonn, 1994:23).

3.4.2.3 "The nurses didn't talk to him"

Lack of communication between the nurses and their children was reported by most of the parents.

MARK'S mother was first to point out the problem of communication between the nurses and MARK. *"Some of the nurses didn't talk to MARK. I found that when the nurses explained what they were going to do to MARK, like take his blood or whatever, he was quite relaxed. Some of the nurses didn't explain what they were going to do and I could see that he was scared."* PAMELA'S mother said that PAMELA and the nurses did not understand each other. Her mother reported that on one occasion when she visited PAMELA in the CTICU, the nurse that was looking after PAMELA had approached her and said that PAMELA had been asking for something the whole morning and the nurse was not sure what it was. When PAMELA'S mother asked PAMELA what she wanted she had replied, *"a glass of water"*. PAMELA had said to her mother, *"Mommy I can't understand these people. I can't talk their language."* This had distressed PAMELA'S mother, as she felt that Tswana (PAMELA'S fist language) is not an unusual language in Johannesburg and that the nurses could have made more of an effort to find out what PAMELA had wanted. PAMELA'S mother thought that PAMELA would have been less distressed if the nurses had reassured her, *"to explain that she is fine and that she is in good hands."* ADRIAN'S mother said that when she visited ADRIAN in the CTICU he had asked her for all sorts of things, e.g. another blanket because he felt cold, a glass

of water because he was thirsty. This had distressed ADRIAN'S mother, as she didn't like to think of ADRIAN lying in CTICU needing something and being too afraid to ask for it.

The importance of communicating with ill children must be stressed. Baker (2004) cites that the egocentric nature of children and their belief that the whole world revolves around them may lead them to believe that if they are not being spoken to they are going to die (Baker, 2004:34). As mentioned earlier, each child copes with hospitalisation differently. Each child needs an individualised approach when nurses and other medical personnel provide information and reassurance to alleviate specific worries (LaMontagne, 2000:310). O'Malley and McNamara (1993) state that it is easier for nurses to offer reassurance to hesitant or tearful children but the quieter and more cooperative children are likely to experience just as much anxiety or fear. All children need support and help in expressing fears and concerns (O'Malley & McNamara, 1993:1078). Parental involvement in the intensive care setting is advised, as parents have the ability to understand their child's non-verbal language and can act as a communication bridge between the nurse and the child (Cunliffe, 1987 in Hill, 1996:156).

An important relationship exists between the main theme identified from the children's interviews – *"I liked having my mommy with me"* and the theme *"The nurses didn't talk to him"* that was identified from the interviews with the parents. Admission to an intensive care setting removes children from familiar people and routines and this is worsened by a lack of communication (Dyer, 1996:58).

3.4.2.4 "Only another parent can understand what it is like"

ADRIAN'S mother mentioned that ADRIAN'S admission to hospital had affected the whole family. She said that she had not realised prior to ADRIAN'S surgery just how much it would affect them as a family. *"The doctors and nurses are very good at telling you what your child will look like in the CTICU and how long he will be there but they can't tell you how you will feel when you see your child in that state – only another mother can."* Later in her conversation she said, *"and the medicine… we were told that ADRIAN would need to take his medicine at home for a month. What we didn't know is how much we would battle to get him to take it. His medicine times were a huge ordeal, very stressful. It would be nice if you could be warned about this sort of thing."* ADRIAN'S mother is a member of a "Cleft Lip and Palate Support Group" and strongly advised that a support group be set up among the parents of the children who require cardiac surgery. She said, *"All that it involves is a list of mothers who have been through it all and their contact details. I would be happy for someone to contact me. At least then, parents can phone someone who has been through what they are going through and ask the questions that only other parents can answer. The doctors are great, but they haven't been through it with their own children and don't know how you feel."* Darbyshire (1993) reported that parents felt that no one, other than another parent, could understand the nature of their experiences (Knox & Hayes in Darbyshire, 1993:1676).

Carol & Frost (1992) and Cook (1999), as cited in Holmes (2004), report that knowledge reduces stress and that information given to families reduces anxiety. Providing parents with accurate information about what to expect after surgery and how the parents can become involved with their child's care and progress will

increase the parent's self confidence and decrease their anxiety (LaMontagne, 2000). An individualised approach in formulating interventions to strengthen both the child and the parent's coping is advocated, as each experience and the related stress and anxiety is unique (LaMontagne, 2000:311).

3.5 Conclusion

This chapter has provided a profile and description of the young children and their parents that were interviewed. The process of data analysis has been explained in order to clarify how the findings in this study were reached. Results have been presented under the main themes and discussed with reference to relevant literature. The analysis of the children's drawings has been used to support the findings wherever appropriate. In the next chapter a summary of the findings will be presented. This summary will be followed by recommendations for the future, limitations in this study and the study conclusion.

CHAPTER FOUR

SUMMARY OF FINDINGS, RECOMMENDATIONS, LIMITATIONS AND STUDY CONCLUSION

4.1 Introduction

In this concluding chapter the findings of this study are summarized. Recommendations for the future are presented, followed by the limitations of this study. The study is then concluded.

4.2 Summary of findings

The purpose of this study was to convey the experiences of hospitalisation for cardiac surgery, from the young child's perspective and to elicit from parents whether their behaviour had changed or if they had demonstrated emotional responses to their hospitalisation one month after being at home. Eight young children and their parents were interviewed comprising the 16 interviews that formed the data of this study. Themes that were identified in the data analysis process were divided under the two sources from which they were derived – the young children's interviews and the parents' interviews.

4.2.1 The young children's interviews

The young children were interviewed in the HCU on the paediatric ward following transfer from the CTICU and prior to discharge. The children spoke about different aspects of their hospitalisation and some were more distressed than others. Common themes that emerged from the young children's interviews were: "I liked having my mommy with me", "It was sore" and "I had nothing to do". Common negative and positive behavioural changes and emotional responses were identified as well as the unique coping mechanisms that children have to their hospitalisation.

4.2.1.1 "I liked having my mommy with me"

A number of the young children reported that the worst thing that happened to them while they were in hospital was when their parents left them. The children preferred being in the HCU on the paediatric ward to being in the CTICU, as their parents were not restricted by visiting regulations and could stay with them continuously. Children were observed to increase their attachment behaviour towards their parents while they were in hospital. The children generally appeared to respond better to the nurses and other medical personnel when their parents were with them.

4.2.1.2 "It was sore"

Seven out of the eight young children interviewed mentioned the fact that they had been in pain a number of times during their interviews. Their pain appeared to be anxiety and fear provoking. Even the happier children who appeared to be less distressed about their hospitalisation reported that they remembered being in pain.

4.2.1.3 "I had nothing to do"

Another reason that the young children gave for preferring the HCU to the CTICU was that there was more for them to do. The children verbalised that they were bored and that they wanted to go home so that they could play. It was evident from talking to the children that they did not receive enough age-appropriate stimulation or play therapy while they were in hospital.

4.2.1.4 Behavioural changes and emotional responses observed by parents in hospital

Behavioural changes that were observed and volunteered by the children's parents while the children were still in hospital were withdrawal, tearfulness and sleep disturbances that were attributed to nightmares and bedwetting. Emotional responses included fear, sadness, anger and depression. Positive emotional responses were also identified and these included a sense of relief, happiness and gratitude.

4.2.1.5 Unique coping mechanisms

A significant finding in this study was that young children's experiences of hospitalisation for cardiac surgery differ from child to child. Generalisations cannot be made with regard to how young children experience hospitalisation. It was evident that each child is unique and that they cope with the stress of illness and hospitalisation differently.

4.2.2 The parents' interviews

The parents were interviewed telephonically one month after their children had been discharged from hospital to determine if their children had demonstrated any significant behavioural changes and emotional responses to their hospitalisation following discharge. Four themes were identified from the parents' interviews: "He was not himself", "He is much better", "The nurses didn't talk to him" and "Only another parent can understand what it is like".

4.2.2.1 "He was not himself"

Three parents reported that their children had continued to have disturbed sleep patterns and continued to demonstrate separation anxiety following discharge – two of the children had improved after two weeks and one child still showed negative effects at one month. Another child, whose depression was not initially acknowledged by his mother at one month following discharge, has since been referred with his mother to a psychologist for counselling. His situation does differ from the other children in that his surgery was not successful in correcting his defect and he is awaiting a lung transplant.

4.2.2.2 "He is much better"

On the whole the parents had positive reports about their children one month after discharge. Most of the parents reported that their children were happier, more active and back to their pre-hospital behavioural and emotional state.

4.2.2.3 "The nurses didn't talk to him"

A number of the parents reported that there was a lack of communication between the nurses and their children. The parents felt that their children may have been less distressed and more comfortable if the nurses had explained procedures to their children and if they had paid attention to the children's requests.

4.2.2.4 "Only another parent can understand what it is like"

One mother explained how the hospitalisation of her child had affected the entire family. She reported that only another parent who had been through the experience of having a young child hospitalised for cardiac surgery could understand how she felt.

4.3 Recommendations for the future

Based on the findings of this study, recommendations have been made for nursing education, nursing practice and nursing research with regard to the hospitalisation of young children for cardiac surgery.

4.3.1 Recommendations for nursing education

- **Undergraduate education**

  When paediatrics is first introduced to student nurses, emphasis should be placed on parents taking a more active role in the care of their hospitalised children. Children should not be nursed in isolation from their parents. Current literature and the results of this study support the presence of

children's parents during times of illness and hospitalisation. The presence and participation of parents will assist in pain assessment and management and in play / diversion therapy for hospitalised children.

Emphasis should also be placed on the uniqueness of children and their differing responses to hospitalisation.

- **Continuing education**

  Nurses, who chose to continue their education in paediatrics, need to have an intimate knowledge of 'the child' and where he is at with regard to cognitive and psychosocial development at different stages of his life. This knowledge will help nurses to assess each child's needs and to plan his care appropriately.

  Nurses should also be made aware of the associated stressors that hospitalisation of young children brings to both the child and his parents. Teaching paediatric nurses to look beyond the ill child in a hospital bed to the effect that hospitalisation has on the child, his parents, family and life after hospitalisation, will empower paediatric nurses to provide holistic care to children *and* to their families.

- **In-service education**

  In-service education should be ongoing and should address all problems that are highlighted on a day-to-day basis regarding the care of young children hospitalised for cardiac surgery. By asking children and their parents for feedback on the care that the children receive *during* their hospitalisation, and

sharing this with colleagues, nurses will be better equipped to address any possible adverse effects that the hospitalisation experience may bring to the child and his family.

4.3.2 Recommendations for nursing practice

Because this is a contextual study, recommendations for practice have been made with the hospital in which this study was conducted in mind.

- **Pre-admission preparation of children and their parents**

  Hospitalised children and their parents need to be adequately prepared for the hospitalisation experience. Preparing children for admission to hospital and surgery has proved to be successful in addressing misconceptions and reducing the negative effects that hospitalisation has on these children (Bonn, 1994 and Hockenberry, et al. 2003). Children should be armed with age-appropriate knowledge regarding their hospitalisation and impending surgery. Bonn (1994) explains that knowledge implies predictability and feelings of control, which will decrease the negative effects of hospitalisation. Children who are adequately prepared for hospitalisation and surgery, through preparatory films, nurses' visits and / or play therapy related to hospitalisation demonstrate increased cooperation and decreased levels of anxiety and upset (Bonn, 1994:22). Preparation for the parents should also include the fact that children have been known to recall traumatic experiences in the intensive care setting, as MARK did in this study, and advice should be given as to how parents could address such traumatic memories.

Pamphlets could be designed to help both parents and children prepare for the hospitalisation experience, including what to expect and suggestions regarding how best to cope with various situations and experiences.

- **Individualised care plans**

  The individuality of a child and the unique way in which he experiences hospitalisation needs to be considered. Holistic care plans should be individualised and should address all aspects of the child's care, including: the need for parent's presence, pain control, stimulation, behavioural changes, emotional responses and communication needs.

- **Parental involvement and continual presence**

  Parents should be included in the care of their children and should be permitted to stay with their children *at all times*. Encouraging parents to communicate with their children and involving parents in their children's care is strongly recommended to help relieve the children's anxiety (Baker, 2004:34). The presence of a parent is important for children's coping reactions and the inclusion of parents should become part of the hospital routine (Bonn, 1994:20). Hill (1996) reports that parents have expert knowledge and skill in caring for their children as well as a commitment to their children's future, which the nurse does not have. Parents can also assist in bridging the communication gap between the nurses and their children. The nurse should act as a facilitator, promoting child-parent attachment behaviours through barriers imposed by the ICU environment (Cunliffe in Hill, 1996:157).

- **Pain assessment and management**

  Pain assessment tools should be updated and should cover all possible manifestations of pain, e.g. physiological responses, verbal complaints and pain behaviours. Pain behaviours such as grimacing, head shaking, drawing up of knees and generalised body movements should also be used as indicators that analgesia is required (Bennett, 2001:28). Parents, if permitted to spend more time with their children, should be involved in the pain assessment of their children. Parents are also important non-pharmacological sources of pain management.

- **Age appropriate stimulation**

  Children should be encouraged to play in hospital. Playing is what most of the children in this study said they liked to do most. A number of the children interviewed said that they had been bored in hospital. Parents should be encouraged to bring their children's favourite toys and story books to hospital, which would provide age-appropriate stimulation that is familiar and that would also serve as a distraction from the necessary but often stressful experience that hospitalisation brings.

- **Letter writing / journal keeping**

  Children should be given the opportunity to write letters and / or to keep a journal of their experiences of hospitalisation for cardiac surgery. This will provide a medium of expression for those children who may be afraid or unwilling to articulate their feelings.

- **Drawing**

  Children should be given the opportunity to draw. Like toys and storybooks, drawings will provide stimulation for the children and help to alleviate boredom. Drawings are also another useful medium of expression. By asking children to talk about their drawings; fears, concerns and misconceptions could be identified and addressed, as has been evidenced in this study.

- **Communication with children**

  Nurses should be encouraged to talk to hospitalised children and every attempt should be made to bridge any gaps that may exist in communication, e.g. language barriers. Children should continuously be given information regarding their care and the necessary procedures that are carried out as a part of their care. Children should be reassured at all times that they are being looked after and that they need not be afraid. Nurses and other medical personnel should be aware of what they say in the presence of young children, as they are egocentric and may believe that everything said around them pertains to them personally (Baker, 2004:34).

- **In-hospital counselling**

  If significant behavioural changes and emotional responses are identified while the child is still in hospital, he should receive the appropriate counselling and follow-up post discharge to minimise long-term negative psychological effects. Referring to THOMAS'S depressive state (page 53-54), appropriate and timely counselling may have prevented his long-term

depression and delayed referral to a psychologist and may have prevented his mother's admission to hospital for stress-related reasons.

On discharge from hospital, parents should be given the details of counselling and family therapy resources available, which they could approach, should the need arise.

- **A parent support group**

  This study has focused on the hospitalisation of young children for cardiac surgery, in a context where this is a specialty. A support group for parents whose children require cardiac surgery should be started to give these parents the opportunity to talk to others who have gone through similar experiences. The parents will benefit more from hearing from other parents than from the doctors and nurses.

- **Pamphlet of suggestions by parents for parents**

  A pamphlet could be designed by parents for parents, whose children are hospitalised for cardiac surgery. As parents in this study pointed it out, only other parents can truly understand what it is like to have a child hospitalised for cardiac surgery and are therefore the best source of information and useful suggestions with regard to expectations and how to cope with the experience.

4.3.3 Recommendations for nursing research

Recommendations that have been made for nursing research in the future are as follows:

- Further research should be done on how and why children experience hospitalisation differently. Why do some children cope with illness and hospitalisation so much better than others? If we are aware of which children will battle more than others, we may be in a position to diminish their distress and the negative effects that hospitalisation may have on them.

- This study should be repeated on an older group of children hospitalised for cardiac surgery to determine how their experiences differ from younger children.

- Future research should explore the stringent visitation regulations in the CTICU and the effect that it has on hospitalised children.

- Research should be conducted to explore the traumatic memories and experiences that young children have after a period of hospitalisation for cardiac surgery and admission to an intensive care settings, with the aim of finding ways to diminish and address these memories.

4.4 Study limitations

The following limitations have been acknowledged in this study:

- Due to the age of the children included in this study, it was best to interview them while they were still in hospital to assist them with recall of their experiences. However, the fact that they were interviewed in hospital can be argued to have affected their responses, as their interviews may have been soon after a negative or positive hospital experience and may have biased the overall account of their experience.

- A couple of the young children in the sample were aware that I was one of the registered nurses that worked in the HCU on the paediatric ward. This may also have biased their responses, as they may have associated me with providing care to them, which may have been part of a favourable or unfavourable experience while in hospital.

- As discussed in Chapter Two, due to the young children's cognitive and psychosocial level of development, they could not be asked to verify the truth of the interpretation that was drawn from the verbal accounts of their experiences of hospitalisation for cardiac surgery.

4.5 Study conclusion

In this study young children's experiences of hospitalisation for cardiac surgery were explored. Children were purposively selected and semi-structured interviews, augmented by drawings were used to elicit the information from these children. Children's accounts of their hospitalisation experience differed but common themes were identified and clear relationships between these themes were established. The drawings helped the children relax and to focus on their interviews. A clinical psychologist was consulted to analyse the drawings and the findings have supported the children's verbal accounts of their experiences and their apparent emotions.

Follow-up semi-structured, telephonic interviews were conducted with the young children's parents one month after they had been discharged from hospital. These interviews added valuable information to the findings already received from the children's interviews and the analysis of their drawings.

A total of nine themes were identified from the interviews with the children and their parents. Recommendations have been made, based on the findings of this study, for nursing education, nursing practice and future nursing research. Limitations to this study have also been acknowledged.

This study will hopefully contribute to the knowledge that already exists regarding the hospitalisation of young children for cardiac surgery. I hope that we, as medical personnel, can improve the hospitalisation experience for young children in the future by paying attention to the knowledge that we gain from this and related studies.

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INTERVIEW – CHILD

1. Introductory Questions:

1.1. How old are you?

1.2. Do you go to school?

1.3. *If so,* what grade are you in?

1.4. What do you like doing most?

2. Leading Question:

2.1. Tell me what it is like to be in hospital for a heart operation?

2.2. What was the best thing that happened to you?

2.3. What was the worst thing that happened to you?

2.4. What would you tell another little boy / girl who was going to hospital for a heart operation?

TELEPHONIC INTERVIEW – PARENT / LEGAL GUARDIAN

1. Has your child's behaviour changed in any way since he / she has been home from hospital?

   Yes □ No □

2. *If yes*, has it improved or regressed?

   Improved □ Regressed □

   (If no, clarify that behaviour is exactly the same as before admission to hospital for cardiac surgery.)

3. Please explain:

_____

_____

_____

Has your child demonstrated any significant emotional responses to his / her hospitalisation?

Yes □ No □

4. Please explain:

_____

_____

_____

DIRECT TRANSCRIPTION OF INTERVIEW WITH A CHILD

PAMELA'S INTERVIEW

(Pamela's mother acted as interpreter during the interview)

NINA: Pamela, I'm going to talk to you now, ok? *Pamela nods.* How old are you?

PAMELA: Six years.

NINA: Do you go to school?

PAMELA: I go to crèche.

NINA: Crèche. What do you like doing most? What is the best thing to do?

PAMELA: To play.

NINA: To play. Ok. And now, I want you to tell us what it is like to be in hospital for a heart operation.

PAMELA: It's ok.

NINA: What is the best thing that happened to you?

PAMELA: The operation. It was good.

NINA: Why was it the best thing?

PAMELA: It wasn't good. They hurt me.

NINA: What is the worst thing that happened, since you have been in hospital?

PAMELA: They cut me.

NINA: Can you tell me anything else? Good or bad. I want to know about the operation.

PAMELA: The nurses and the doctors.

NINA: What about the nurses and doctors?

PAMELA: I don't like them.

NINA: Why don't you like them?

PAMELA: They kill me.

NINA: Why do you think that?

Pamela didn't answer but sat very quietly for a while, despite her mother repeating the question to her.

NINA: What would you tell another little girl who was going to hospital for a heart operation?

PAMELA: I will tell her that the place is not good.

NINA: Why is it not good? What else would you tell her?

PAMELA: They kill people there. They stitch you and it's painful.

NINA: Ok… What will make you happy?

PAMELA: To go home.

NINA: How can we make it better for you here? *After a long pause.* What is going to make it better?

PAMELA: You must just leave people alone.

NINA: Do you understand that we are trying to make you better?

PAMELA: The work of the doctors is to make people better.

NINA: *To Pamela's mother* – So she does understand that they are trying to make her better?

PAMELA'S MOTHER: Yes. The thing is that when we came here, she wasn't sick so that is why I didn't know how to prepare her for this kind of operation.

NINA: Was this her first operation?

PAMELA'S: No, the first one was when she was five months.

NINA: Oh, so she won't remember that.

PAMELA'S MOTHER: I was afraid to tell her because she would have been scared. I didn't know how to…

NINA: to approach it?

PAMELA'S MOTHER: Yes. If we had known, I could have told her that we are going there and the doctors are going to do this and that.

NINA: When did she know that she was having an operation?

PAMELA'S MOTHER: When we came for a check-up, I told her that there is something in her heart that they need to remove. She said 'how are they going to remove it?'

NINA: Was this after her cardiac catheterisation?

PAMELA'S MOTHER: No, before. I told her that they needed to remove something from her heart so that she does not get sick. The worst part was, 'How are they going to remove it. Are they going to kill me? Am I going to die?' I said no you are not going to die. They are going to remove it fine. She said 'Are they going to cut me?' So, instead of answering her, I…

NINA: You didn't know how to tell her?

PAMELA'S MOTHER: Ja.

NINA: Was she angry with you at all?

PAMELA'S MOTHER: No, she is not. When we went for the operation, we got there together and she said 'Mommy how can you do this? I am a little girl, how can you give me to these people?'

NINA: Was that when you took her down to theatre? *Mother nods.* Did she say anything to you when you saw her in CTICU?

PAMELA'S MOTHER: She said, 'Mommy, are they through? Have they removed that thing?' I said yes, they have removed it. And I saw that every day she got better.

NINA: She got better slowly? *Mother nods.* I noticed when she was transferred to the ward that she was very withdrawn and over the last three days that I have seen her here, she has improved. She is a bit better today. But still very withdrawn. Is she more lively at home, or is she always quiet?

PAMELA'S MOTHER: No. It is only here that she is quiet. Maybe the other thing is that in CTICU there is no good communication because she doesn't understand English. Maybe if they could find someone so that they could understand each other to put her at ease. She was afraid. She said 'Mommy, I can't hear these people, I can't talk their language.'

NINA: So, in your opinion, it would have been better for her if there were someone who could communicate with her?

PAMELA'S MOTHER: Ja, maybe. To explain that she is fine and that she is in good hands. You will find they are busy and she doesn't know what is happening. The one time the other sister told me that she didn't know what Pamela was asking. I asked her and she said that she wanted water. It was ten o'clock and she had been asking since early that morning. The sisters didn't know what she was telling them.

NINA: What is her first language?

PAMELA'S MOTHER: It is Tswana.

NINA: Tswana. The nurses downstairs don't speak Tswana?

PAMELA'S MOTHER: Some. But they are rotating.

NINA: It might help if the sisters that speak her language or are of the same culture look after her.

PAMELA'S MOTHER: Yes, it would.

Pamela had drawn a picture of herself in hospital but did not describe it in great detail..

NINA: Tell me about your picture.

PAMELA: That’s me in bed, with the wires. That’s my mommy and that’s the doctor.

NARRATIVE WRITTEN FROM INTERVIEW WITH A CHILD AND HER MOTHER - PAMELA

Obtaining Consent for participation in the study

I met Pamela after transfer from the CTICU to the ward. She was very withdrawn and quiet and wouldn't smile or talk to anyone other than her mother. Her mother was very happy for me to talk to Pamela and agreed to be the interpreter, as Pamela did not understand or speak much English.

Pamela's interview

Pamela would not look at me at all during the interview. She spoke to her mother only and was very quiet and withdrawn. Her mother had to repeat the questions a number of times before Pamela would answer her. Pamela confirmed that she went to crèche and that she liked playing at home most of all. When asked what it is like to be admitted to hospital for a heart operation, she answered simply that it is 'ok'. She would not elaborate on much. She said that the best thing that happened to her while she was in hospital was her heart operation. This answer she quickly changed when asked why, to saying that it wasn't good at all because 'they' hurt her. She went on to say that the worst thing that happened to her was the fact that the doctors had 'cut' her. It was very difficult to get her to talk. She looked out of the window for the duration of our time together and would very quietly answer the questions that her mother interpreted. I asked if there was anything else, good or bad, that she could tell me about the hospital. She said that the doctors and nurses 'kill me'. When I asked why she thought that the doctors and nurses 'kill her', she pointed at her wound (sternotomy). She said that she would tell other children who were to be admitted to hospital for cardiac surgery, that hospital is a bad place because they kill people there. They stitch people and it is painful. She appeared to be so sad and so scared. I asked her what would make her feel better. She said that she wanted to go home. I asked what we could do to make it better for children in hospital. She said that we (doctors and nurses) should leave people alone. I asked her mother to confirm with her if she realised that we weren't there to harm her but that we were trying to make her better. She confirmed that she knew that the job of a doctor is to make people better. Pamela's mother opened up at this stage and said that she hadn't known how to

prepare Pamela for surgery – she hadn't known what to say or what to prepare her for. She was worried that Pamela would be afraid. She had told Pamela that the doctors needed to remove something from her heart. Pamela had asked her mother if she was going to die. Her mother said no. She asked her mother if the doctors were going to cut her. Her mother did not know how to answer this. I asked Pamela's mother if Pamela had been angry with her at all for taking her to hospital (this had come up in previous interviews). Pamela's mother said that she hadn't been angry but had asked her mother why she was giving her to these people (in theatre) because she was only a little girl. When Pamela woke up in the CTICU, she hadn't been cross with her mother but had asked if the doctors had removed 'the thing' from her heart. Pamela's mother confirmed that they had and said that every day she visited Pamela she saw an improvement. I asked if Pamela was always withdrawn and her mother said that it was only since her surgery that she was so sad and withdrawn. She confirmed that Pamela is a happy child at home. Pamela's mother said that Pamela had not understood the nurses in CTICU and that she probably would have been better off with someone who could speak her language and who could understand her, looking after her. She said that one of the days when she had visited Pamela the nurse looking after Pamela had said that she had been asking her for something the whole morning but that the nurse hadn't known what she wanted. Pamela's mother confirmed with Pamela that all she had wanted was a glass of water. Could something so simple not have been given if the nurse had only made more of an effort to find out what it was that she was asking? Pamela told her mother that she didn't understand 'these people' and that she couldn't talk their language.

Pamela drew herself lying in bed, attached to a monitor. Her mother, drawn very colourfully, was standing next her to bed and next to her mother, she had drawn a flower and a heart. On the other side of her bed, she had drawn a doctor in brown. On the other side of the page, Pamela had drawn the hospital and her home with many cars between the two. She told her mother that the cars would take her home.

While nursing Pamela I had observed that she woke up frequently at night and that she appeared to be having nightmares. Like Michael, Pamela also wet her bed a couple of times post transfer from CTICU to the High Care Unit in the ward.

Follow-up telephonic interview with Pamela's mother

I phoned Pamela's mother a month after she had been discharged from hospital. Pamela's mother confirmed that her behaviour had changed a lot since discharge to home. Pamela was more like herself – more talkative and much happier. Pamela's mother said that she felt that all Pamela had needed was a change in environment. Pamela had still had nightmares when she was at home but these had only lasted about a week. Pamela's mother told me that she had had a long talk to her about why she had been admitted to hospital and had explained the importance of the nurses and doctors and their work to her. Pamela had already seen her doctor for a follow-up when I spoke to her mother. Apparently, she had responded very well to her doctor and had actually requested to her mother that they go to the ward to say hello to the nurses there. Pamela's mother mentioned that Pamela had recently graduated from crèche and had been very happy – dancing and singing in the crèche graduation ceremony. Pamela's mother was very happy with her progress and said that she felt that Pamela had completely recovered, both physically and emotionally.

In summary, I can highlight the following that emerged from my interview with Pamela and that could have caused Pamela to become distressed during her hospitalisation:

1. She felt that the nurses and doctors were going to kill her and was clearly very scared.
2. She hadn't been told much about her surgery or what was going to happen to her and didn't understand how her mother could leave her with the theatre staff.
3. Language-barriers had caused her to become upset in the CTICU – she did not understand the nurses and knew that they didn't understand her.

Due to the fact that Pamela appeared to respond so well to her mother's talk post discharge about the hospital and the nurses and doctors, perhaps she would have been less distressed if she had been adequately prepared?

P.O. Box 1202

Gallo Manor

2052

Hospital Manager

Dear Madam,

Re: RESEARCH STUDY

Title: Young children's experiences of their hospitalisation for cardiac surgery.

I hereby request permission to undertake research as part of the requirements for my Masters Degree in Nursing.

The purpose of this study is to explore and describe young children's (age five to nine years) experiences of hospitalisation for cardiac surgery and to elicit from their parents / legal guardians if they have demonstrated any significant emotional responses and behavioural changes once at home, that can be attributed to their hospitalisation.

Qualitative methodology will be followed. Children, aged five to nine years, will be purposively selected from the admission register in the paediatric ward. Written consent will be obtained from these children's parents / legal guardians and assent will be obtained from the children (refer to appendices). Data will be collected

through in-depth semi-structured interviews with these children, augmented with a drawing. Drawings are a way in which these children can communicate non-verbally information that might be difficult to express verbally. By asking these children to talk about their drawings in the interview, themes can be identified that were not revealed initially. Telephonic, semi-structured interviews with the children's parents / legal guardians, one month after the child has been discharged from hospital, will determine any significant behavioural changes following their hospitalisation for cardiac surgery. The findings of the study will be disseminated to all staff working with these children.

The Ethics Committee for Human Subjects of the University of Witwatersrand has approved this study.

Attached please find a copy of my research proposal.

Thanking you for your kind co-operation.

Yours sincerely,

_____

NINA POWER

9 July 2004

Nina Power RN
Peadiatric ward

To Whom It May Concern:

_____ herewith gives permission for your research study with the understanding that written patient consent will be obtained in every instance.

We wish you all the best with your research project and studies for the future.

Yours sincerely

ADELLE JOHNSTONE
Hospital Manager

NetCare Hospitals

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Power

CLEARANCE CERTIFICATE | **PROTOCOL NUMBER M040438**

PROJECT Children's experiences of their hospitalisation for cardiac surgery, three months post discharge.

INVESTIGATORS	Ms N Power
DEPARTMENT	Nursing Education
DATE CONSIDERED	04.05.07
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 04.10.25 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Ms A Tjale

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES