

School of Nursing and Midwifery

**Family Centred Care: A Descriptive Study of the Situation in Rural
Western Australia**

Sally Wilson

**This thesis is presented for the Degree of
Master of Science
of
Curtin University of Technology**

January 2004

Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

Signature: _____

Date: 16th January 2004.

Abstract

Family centred care is a concept espoused to be fundamental to achieving excellence in paediatric nursing. Although it is recognised that family centred care includes the child's rights to self determination the focus of this study is parental participation in the decision making and care of their hospitalised child at a partnership level. This is based on negotiation and requires frequent, effective communication between parents and nurses and for each to respect the other's knowledge and appreciate the other has something to offer in the relationship which will benefit the child.

The purpose of this study was to identify whether family centred care was occurring in paediatric settings in rural Western Australia and explored parents' and nurses' perceptions of the concept. A questionnaire was designed based on the literature and common themes identified from focus groups. Convenience sampling was used and 15 rural hospitals facilitated participation of 243 parents who had a child under ten years of age hospitalised and 108 nurses who cared for children. Exploratory factor analysis identified four subscales from the parents' questionnaire and three subscales from the nurses' questionnaire which measured separate concepts of family centred care. Descriptive statistics were generated for each subscale, and independent *t*-tests, ANOVA and correlations were examined between independent variables and subscales of family centred care. There was a statistically significant difference in scores for parents' perceptions of 'child friendly environment' between regional and district hospitals. Those parents who did not have social support scored a statistically significantly lower mean score for 'respect as parent'. Nurses in district hospitals generated statistically significantly higher mean scores for 'family focussed hospital' than those who worked in regional hospitals.

Parents and nurses both perceived that parents wanted to continue parenting their hospitalised child, however parents wanted to provide more nursing care than was perceived by nurses. Nurses' perceptions of delivering family centred care were greater than the perceptions of parents receiving it, however they were consistent in items that were scored low. Nurses did ask parents about the amount of participation they wanted in their child's care on admission however, it was not done on a regular basis. Parents perceived that nurses were unaware of other things that parents needed

to attend to while their child was hospitalised and therefore did not enable parents to attend to these needs.

More frequent negotiation of roles between parents and nurses by communicating each shift, or at least daily, could narrow the gap between differing perceptions in care provision and also enable parents to attend to their other roles thereby reducing their levels of physical and emotional stress.

Acknowledgements

A project such as this did not get completed by me alone. There are many people who have supported me along the way so I wish to acknowledge those who have assisted in some way.

Firstly, I would like to sincerely thank Professor Robin Watts and Jeanette Robertson for the support, advice, guidance, persistence and endurance provided throughout. I would also like to thank Dr Rochelle Watkins who joined this team in the latter stages and who always took the time to explain statistical concepts patiently, no matter how resistant I was to understanding them.

My appreciation is also extended to Shirley Woodger, Mo Clarkson and Sharon Kay for their expert opinions of family centred care and for reviewing the questionnaires.

I would like to thank all the Directors of Nursing/Health Service Managers who facilitated the study in their hospitals especially when they are so busy. I thank all the parents and nurses who took the time to complete the questionnaires and provide information about the care in rural Western Australia. Their time and honesty is invaluable.

Acknowledgement is given to the Nurses Board of Western Australia who assisted financially which enabled my travel to the country and covered the extra costs incurred when targeting a population over a vast distance.

Finally, I wish to thank my partner, family, friends and work colleagues who offered encouragement and support by allowing me to indulge in this study and tried to understand.

Contents

Chapter One: Introduction	Page No:
Background to the Study.....	1
Context of the Study.....	2
Statement of the Problem.....	5
Research Questions.....	6
Significance of the Study.....	6
Operational Definitions.....	6
Contents of Chapters.....	7
Chapter Two: Literature Review	
Western Historical Context.....	8
Family Centred Care.....	10
Parental Participation.....	14
Factors Affecting Parents' Decision to Participate.....	16
Critique of Studies.....	16
Summary of Studies on Parental Participation Discussed Previously.....	18
Nurses' Attitudes to Parental Participation.....	18
The Influence of Negotiation and Power.....	21
Barriers to Parental Participation.....	22
Lack of Information.....	22
Inconsistent Information.....	23
Ineffective Communication.....	24
Inadequate Facilities.....	24
Addressing Barriers.....	25
Benefits of Parental Participation.....	27
Models of Care.....	29
Operational Definition of Family Centred Care.....	31
Rationale for the Study.....	32
Summary.....	33

Chapter Three: Methodology

Research Design.....	34
Sample.....	34
Hospital Selection.....	35
Parent Selection.....	36
Nurse Selection.....	36
Instrument Development.....	37
Focus Groups.....	37
Questionnaires.....	38
Parent’s Participation Questionnaire.....	39
Nurses’ Questionnaire.....	39
Reliability and Validity.....	40
Pilot Study.....	40
Data Collection.....	40
Data Analysis.....	41
Ethical Considerations.....	44
Methodological Considerations.....	45

Chapter Four: Reliability and Validity of Instruments

Internal Consistency of Questionnaires.....	47
Parents’ Questionnaire.....	53
Factor Analysis.....	53
Summated Scales.....	55
Item Internal Consistency.....	57
Item Discriminant Validity.....	57
Subscale Reliability.....	51
Nurses’ Questionnaire.....	60
Factor Analysis.....	60
Summated Scales.....	62
Item Internal Consistency.....	64
Item Discriminant Validity.....	64
Subscale Reliability.....	66
Summary.....	67

Chapter Five: Results

Responses.....	68
Characteristics of the Families.....	69
Characteristics of the Children.....	70
Characteristics of the Nurses.....	71
Subscales of Family Centred Care.....	73
Parents' Perceptions of the Provision of Family Centred Care.....	73
Child Friendly Environment.....	73
Respect as Parent.....	74
Nurses in Supportive Role.....	76
Parents Empowered.....	77
Nurses' Perceptions of their Provision of Family Centred Care.....	78
Respect for Parent Role.....	78
Nurses in Supportive Role.....	78
Family Focussed Hospital.....	79
Group Comparisons.....	80
Parents.....	80
Level of Hospital.....	80
Social Support.....	80
Previous Hospital Experience.....	81
Child's Age.....	82
Length of Hospital Stay.....	82
Nurses.....	82
Level of Hospital.....	82
Main Area of Nursing Practice.....	83
Associations.....	84
Comparison of Perceptions between Parents and Nurses.....	84
Content Analysis.....	85
Parents.....	85
Nurses.....	87
Summary.....	89

Chapter Six: Discussion

Characteristics of Samples.....	90
Reliability and Validity of Questionnaires.....	92
Parental Participation in Care.....	94
Parents' Perceptions of the Delivery of Family Centred Care.....	95
Child Friendly Environment.....	95
Respect as Parent.....	97
Nurses in Supportive Role.....	99
Other Issues Identified.....	101
Nurses' Perceptions of their Provision of Care.....	102
Respect for Parent Role.....	102
Nurses in Supportive Role.....	103
Family Focussed Hospital.....	104
Other Issues Identified.....	105
Comparisons of Perceptions: Parents and Nurses.....	106
Limitations of the Study.....	108
Conclusion.....	110

Chapter Seven: Recommendations

Implications for Clinical Practice.....	112
Communication.....	112
Parent Feedback.....	115
Consumer Representation.....	115
Facilities.....	116
Support.....	117
Advocacy.....	118
Pre-Admission Package.....	118
Implications for Education.....	119
Areas for Further Nursing Research.....	120
Conclusion.....	121

References	123
Appendix A: Letter to Director of Nursing/Health Service Manager...	134
Appendix B: Self Administered Questionnaire for Parents.....	136
Appendix C: Self Administered Questionnaire for Nurses.....	144
Appendix D: Letters of Invitation to Parents and Nurses.....	152

Chapter One

Introduction

Paediatric nursing has progressed since the 1950s when parents handed their sick child over to the care of hospital staff and the parents were only allowed to visit once a week for a very limited time. The Platt Report of 1959 on the welfare of children in hospital brought about major changes to this way of thinking (Department of Health and Social Security). Over the following decades open visiting was introduced eventuating in parents being encouraged to live in the hospital and participate in the care of their sick child. A further development of more recent origin is the recognition of the child's right to be included in all decision making relating to their care and their right to participate in their care (Bricher, 2000; Dixon-Woods, Young & Henley, 1999; Runeson, Elander, Hermeren & Kristensson-Hallstrom, 2000; Southall, Burr, Smith, Bull, Radford, Williams et al., 2000). These developments have lead to family centred care now being the philosophy for nursing sick children.

Background to the Study

Family centred care includes caring for the family by respecting the parents' knowledge about their child and their right to be involved in decision making and the caring process when the child is not competent to make these decisions, thereby enabling the family to retain control over this aspect of their lives (Smith, 1995). Although most countries, except the United States of America, ratified the Convention on the Rights of the Child endorsed by the United Nations in 1989 which states that children have the right to express their views about things that affect them and they have the right to participate in programs and services for children, many children who are hospitalised are too young to be deemed competent to make the decisions about their care (Alderson, 1993; HDWA, 2002; Rushforth, 1996). These children have the right to participate in the decision making at their level of cognition, however parents remain the primary care givers when these young children are in hospital and the responsibility and right to be included in their child's care remains with the parents.

This study involves families in this situation. Seventy five per cent of children hospitalised in rural areas of Western Australia are three years of age or less. Therefore the majority of children are not of an age to contribute to a study on family centred care. To acknowledge the importance of the concept, the term ‘family centred care’ will be used throughout this study, although only the parental component of this concept is addressed.

When parents are included in the care and decision making relating to their child’s health, family centred care is based on negotiation between the child (where cognitively able), the parents and the nurse, cognisant of the family's wishes (Casey, 1988; Smith, 1995). Implicit in this negotiation is the nurse’s recognition and respect for the parents' expert knowledge of their child. Nurses should recognise the parents' primary role and respect the family's need to attend to the responsibilities associated with that role (Johnson, 1996). Nurses also need to recognise that the parents' role will differ with each parent and with time as parents strive to meet the needs of their hospitalised child plus maintain the integrity of the family unit (Johnson, 1996; Knafl, Cavallari & Dixon, 1988). Parents being partners with the health professionals involved in their child's care whilst their child is in hospital requires effective, frequent communication and negotiation between parents and nurses. This enables parents to participate in the care of their child whilst hospitalised and continue to maintain the integrity of their family.

Despite the acknowledged importance of this concept of care, both anecdotal evidence and the literature indicates that family centred care is still not being achieved within the health care system (Darbyshire, 1994; Johnson, 1996; Roden, 1998). This literature focuses on paediatric care in metropolitan hospitals, and no studies were identified that relate to the concept in rural settings.

Context of the Study

Western Australia’s sparsely populated rural areas, significant distances and diverse climatic conditions present unique problems to the provision of health services (HDWA, 2001a). Structural changes to the delivery of health care were introduced to Western Australia in 1995-6 to make provision of health care more customer focused (HDWA, 2001a). As a result of this restructure, Western Australia had seventeen

health services outside the metropolitan area (see Figure 1.1) at the time of this study. These health services varied in size and population and hence the number of hospitals within each health service varied from one up to five. Some hospitals within a health service were managed by the same health service board resulting in similar practice policies whereas in others each hospital had its own management board and operated independently. Therefore the care provided could vary between hospitals.

As well as the variation in the number of hospitals within each health service, there was a difference in the size and services offered by each hospital. The rural hospitals' inpatient capacities ranged from six to 178 beds. The larger, regional hospitals had dedicated children's wards which were staffed by nurses who spent the majority of their working hours caring for children. They may have the services of a paediatrician, other specialised doctors and allied health staff. The smaller, district hospitals are unable to provide this more specialised care. In these hospitals nursing staff care for all patients admitted to the hospital ranging from newborns to the elderly, including general medical and surgical cases and all acute cases who attend the emergency department. Although nursing children may be an infrequent occurrence or does not occur at all in their actual practice, all nurses registered with the Nurses Board of Western Australia are expected to be competent and therefore able to care for sick children.

A significant number of children are nursed in rural hospitals. In Western Australia an estimated 12,000 children under the age of ten years were nursed in rural hospitals during 2000 of which 75.30% were three years of age or less (HDWA, 2001b). The average length of hospital stay for children in rural Australia is estimated at 3.1 days (AIHW, 1998). The majority of children admitted to rural hospitals have common childhood illnesses such as asthma and other respiratory tract infections, diarrhoea, vomiting, fever or minor trauma. Booked admissions for surgery occur in some of the hospitals. Children whose illness and/or acuity is beyond the treatment capacity of the hospital are transferred either to the regional centre or to the only Western Australian tertiary paediatric centre which is in Perth. Transport may be by road or air and it may be many hours before an acutely sick child is evacuated from the rural hospital.



Figure 1.1. Health Service Areas of Western Australia, 2000, with South West Health Services inset (HDWA, 2001a).

Although nurses in rural areas often have to care for people across the life span and, in some instances, may have limited paediatric experience, this limitation may be balanced by an awareness of a family's many roles within the community and a respect for their need to attend to them. As this knowledge is fundamental to achieving family centred care (Johnson, 1996), it may be enhanced in rural hospitals.

As nurses in rural areas of Western Australia have added responsibilities within their practice, frequently have to nurse both adults and children and in some cases care for children infrequently, it was important to ascertain whether families were receiving family centred care. This study explored whether family centred care was occurring in hospitals in rural areas of Western Australia and comparisons were made between parents' and nurses' perceptions of whether family centred care was being provided when children were hospitalised.

Statement of the Problem

Difficulties that parents have when their child is admitted to hospital have been documented in recent years (Darbyshire, 1994; Johnson, 1996; Roden, 1998). The philosophy of paediatric nursing is now one of family centred care which in respect to the parents, enables and empowers parents to provide appropriate care for their child when sick and to manage their many family roles. This is a philosophy where parents are informed, are part of and contribute to, the care of their child and which should decrease the costs, both emotional and financial, to the family. Anecdotal evidence implies that family centred care is not occurring in Western Australia.

The literature cites studies that have been undertaken in large metropolitan paediatric hospitals mostly in the United Kingdom and North America. An extensive search of the literature failed to find any studies on family centred care which were undertaken in rural settings where paediatric nursing has a different environmental and organisational context to tertiary metropolitan paediatric hospitals.

Research Questions

The study addressed the following questions:

1. Is family centred care being practised, and to what extent, in the rural hospitals of Western Australia?
2. Is there a difference between parents' perception of receiving family centred care and nurses' perception of delivering family centred care?
3. If a deficit is identified, in what areas can nurses improve?

Significance of the Study

The results have implications for both the children and their families receiving care and for nurses providing that care. The findings will assist in the development of nurses' understanding of parents' perceptions of family centred care and will promote paediatric nursing practice which is sensitive and responsive to the needs of parents and families.

Operational Definitions

The following descriptions define some of the terminology used in this study.

Nurses providing direct care is defined as nurses who provide hands-on nursing care to the children and are not employed in staff development or management roles. This includes both registered and enrolled nurses.

Nursing care is defined as tasks that parents would not normally provide for their child at home. Examples are monitoring intravenous fluids, dressings, giving medications that they normally do not give at home.

Parenting is defined as things parents would normally do for their child as a parent at home. Examples are bathing, feeding, toileting, playing and socialising with the child.

Contents of Chapters

Chapter One provides a general background to the problem, its significance to nurses and to families, and the research questions that the study set out to answer. Chapter

Two discusses the concept of parental participation in care, partnership-in-care and family centred care, and relates these concepts to the Australian context. Results of studies on parental participation in care are presented and reviewed along with factors that enhance and act as barriers to family centred care. The relationship of parental participation in care to family centred care is discussed along with several models of care. The methodology utilised in this study is described in Chapter Three. Development of the two instruments used to collect data is explained. Methods for collecting data and all ethical and methodological considerations are described. Chapter Four presents and discusses the psychometric testing of the questionnaires and Chapter Five presents the results of this study. Chapter Six discusses the major findings and Chapter Seven identifies implications for nursing practice, education and research and recommends strategies to address these implications.

Chapter Two

Literature Review

Family centred care is a concept espoused to be fundamental to achieving excellence in paediatric nursing. It offers a framework within which parental involvement, parental participation and partnership can be provided. However, these terms are poorly defined and used interchangeably. To arrive at an operational definition to guide this study the historical context was reviewed and the literature mostly from Australia, United Kingdom and North America has been considered. A literature search identified many research articles recommending strategies which have the potential to enhance parental participation, partnership and family centred care and also the barriers to these being achieved.

Western Historical Context

Acceptance of parental participation in their child's care has fluctuated over the centuries. Paediatric nursing now promotes parents living in hospital with their sick child and participating in their child's care to the extent the family wishes. However, children's nursing has not always had this philosophy. According to Lindsay (2001) there is some evidence of parents being active in their child's admission to hospital and retaining some responsibility for care in the 19th century. Parents were expected to provide their child with clothes and bed linen and to launder same. Mothers were also resident in some hospitals during the 18th and 19th centuries. However, with the growth of formal children's nursing programs and a strong belief in 'germ theory', parents' access to their hospitalised children was discouraged from the beginning of the 20th century (Connell & Bradley, 2000; Lindsay, 2001). Parents had very limited access to their children in hospital and commonly were only permitted to visit their child once a week for one hour or less (Connell & Bradley, 2000). This restriction on parental visiting continued until the 1960's.

In the interim, Bowlby (1951) and Robertson (1958) produced evidence highlighting the psychological damage that occurred to children when they endured enforced separation from families. These findings of separation anxiety spurred the

Department of Health in the United Kingdom to commission a report on the effects of hospitalisation on children. The Platt Report into the welfare of children in hospital in 1959 reiterated the findings of Bowlby and Robertson and recommended changes to the way families were cared for when their children were admitted to hospital. The report recommended that the separation of children from their parents be avoided by the removal of the severe restrictions on parental visiting and by encouragement of parents to reside in the hospital when their child was admitted. The implementation of the recommendations was very slow both in the United Kingdom and Australia, and there was little guidance for either families or health professionals as to how to implement these changes.

In 1970, the Australian and New Zealand College of Psychiatrists issued a position statement emphasising the psychological and emotional damage being done to children under five when admitted to Australian hospitals. As there was still little change within Australian paediatric hospitals, in 1971 the Australian Association for the Welfare of Children in Hospital (AWCH) was formed. This was a voluntary organisation formed by parents and health professionals to provide a platform to 'speak and act on behalf of hospitalised children' (Hart, 1979, p. 9). AWCH promoted quality child care incorporating parental involvement in the child's care in hospitals throughout Australia. Strategies developed by AWCH included setting up a reference library, initiating programs on play and preparation of children for hospitalisation. The Association's activities raised the community's awareness of the lack of both the provision for children's emotional care when in hospital and hospital policies to rectify the situation. The recommended 'Health Care Policy Relating to Children and their Families', produced by AWCH in 1974, was published in *The Medical Journal of Australia*, August, 1975 as a special supplement and received strong support in the journal's editorial. This document listed eight principles for quality health care of children and made recommendations on the implementation of these principles. This policy document was subsequently endorsed by the National Health and Medical Research Council, accepted by the Health Commission of New South Wales and then sanctioned by other states as part of their health policies (Hart, 1979). Principles and recommendations for the implementation of parents' involvement in their child's hospitalisation in Australia were now clear.

Despite the clear guidelines, progress on implementing the recommendations continued to be very slow (AWCH, 1992). Anecdotal stories and research (AWCH, 1992; Johnson, 1996; Maxton, 1997; Roden, 1998; Rowe, 1996) provide evidence that family centred care is not practised consistently throughout Australian hospitals.

Family Centred Care

Although family centred care is a central tenet of paediatric nursing today there does not appear to be consensus on the meaning or definition of this term. Literature from North America demonstrates a much clearer conceptualisation of family centred care than that from the United Kingdom or Australia. The North American literature refers to the work done by Shelton, Jeppson and Johnson (1987), who collaborated with parents to provide care to families with children who had special educational needs. These authors identified eight elements necessary to deliver family centred care:

- Recognising that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate.
- Facilitating parent/professional collaboration at all levels of health care: care of the individual child; program development, implementation and evaluation; and policy formation.
- Recognising family strengths and individuality, and respecting different coping methods.
- Sharing with parents, on a continuing basis and in a supportive manner, complete and unbiased information.
- Encouraging and facilitating family-to-family support and networking.
- Understanding and incorporating the developmental needs of infants, children and adolescents and their families into health care systems.
- Implementing comprehensive policies and programs that provide emotional and financial support to meet the needs of families.
- Designing accessible health care systems that are flexible, culturally competent and responsive to family-identified needs (Shelton et al., 1987).

These eight elements were subsequently endorsed by the American Association of Children's Health Care and became a framework for family centred care for chronically and acutely ill children.

Many paediatric hospitals throughout America have adapted these elements to be used as their philosophy of care. Shelton and Smith Stepanek (1995) revised the framework following discussions with families and health professionals but the changes were minor. The framework is considered to be a philosophy of care that makes a difference by ensuring a partnership between families and health professionals exists and that the care promotes 'normal' patterns of living for the family. Many discussions and research studies relating to family centred care in United States of America and Canada since 1987 have used these elements as their framework.

In contrast to North America, the British and Australian literature does not adhere to such a framework. While British authors acknowledge the work of Shelton et al, (Coyne, 1995a; Darbyshire, 1994; Dearmun, 1992; Palmer, 1993), the Australian literature does not (AWCH, 1992; Johnson, 1996; Maxton, 1997; Roden, 1998; Rowe, 1996). One British author, Nethercott (1993), identified seven key components when analysing the concept of family centred care. The seven components acknowledged viewing the family in context, valued individual family members and their roles, and were supportive of the functioning of the family similar to Shelton et al. However, the components were more prescriptive than those of Shelton et al (1987), stating what nurses must do rather than acknowledging the respect required for a parent's knowledge about their child and their right to be with their child as the constant in the child's life. No documented reasons were found for the lack of acceptance and implementation of Shelton et al's framework outside North America.

In addition there is no agreed definition of family centred care, parental involvement, parental participation or partnership, and the terms are used interchangeably by many authors. Brownlea (1987, p. 605) defined participation as 'getting involved or being allowed to become involved in a decision-making process or the delivery of a service or the evaluation of a service.' This definition was chosen by several authors when

discussing parental participation in children's hospital care (Coyne, 1996; Kawik, 1996; Savage & Callery, 2000). Neill (1996a) adapted Brownlea's definition by including involvement in the delivery of 'care' thus specifying the service that was being delivered. These definitions may suggest that the nurse still retains power as the word 'allowed' is used. Neill however, further clarifies the statement by stating that participation encompasses the parent's ability to choose the level of involvement by negotiation. As the level of involvement may vary over time, continuous communication is required to ensure the parents' wishes in this respect are ascertained on an ongoing basis. During interviews with parents, Neill (1996b) substituted 'participation' with 'involvement' for clarity thus demonstrating how the terms are used interchangeably.

The variety in the conceptualisation and use of these terms is illustrated by the following descriptions. Coyne (1996) viewed family centred care as having evolved from involvement, participation and partnership, however she used the terms interchangeably. Hutchfield (1999) believed family centred care was hierarchical with involvement at the base, rising to participation, partnership and family centred care at the apex indicating that nurses should be striving to achieve the apex. Smith, Coleman and Bradshaw (2002) viewed family centred care as a continuum where families can move readily between involvement, participation, and partnership as they need and this continuum is under the umbrella of family centred care.

Regardless of whether the model is hierarchical or a continuum, there is general agreement that 'involvement' indicates the nurse exercises control over what the family can do (Nethercott, 1993; Hutchfield, 1999; Coyne, 1996; Smith et al, 2002). Participation was viewed by some as a collaborative arrangement between families and nurses where rapport was established (Hutchfield, 1999; Smith et al, 2002) but nurses still retained the power. These authors believed partnership was different to participation as partnership required equal power to be held between parents and nurses. This is at odds with the definition given earlier by Brownlea where participation and partnership appear to be the same with continuous communication and negotiation occurring between parents and nurses to ascertain the care parents wish to provide to their child.

Arnstein's 'Ladder of Citizen Participation' (1969) encompasses partnership as part of participation. Arnstein's ladder was designed to highlight the extent of citizen's power in determining plans or programmes in America where citizen's participation should have been expected as part of a democratic society. Although the concept was not developed with health consumers in mind, it is useful in helping to define participation. The ladder of participation moves from 'non-participation' through 'degrees of tokenism' to 'degrees of citizen power' reflecting the level of participation. The bottom of the ladder, 'non-participation', does not enable people to have genuine participation as the options provided - manipulation and therapy - do not encourage participation. The next level on the ladder, 'tokenism', includes informing, consultation and placation which allows people to have a voice which may be heard, however the power holders continue to make the decisions. The upper rungs of the ladder, 'degrees of citizen power', include partnership, delegated power and citizen control. If a partnership exists, negotiation and trade-offs occur between the partners therefore some decision making power is shared. The top rung of the ladder is citizen control where the people have full control of decision making and the power is handed over to them.

Smith et al (2002) agree with Arnstein in that the levels below partnership are nurse led which means the nurse holds the power. Both refer to partnership as equal status between members therefore shared power between nurse and parents/child. Parent led care at the end of Smith et al's continuum equates to Arnstein's 'citizen control'.

Arnstein's ladder (1969) is hierarchical where real participation occurs only at the upper rungs once partnership has been achieved, whereas Smith et al's (2002) tool is a continuum running horizontally implying that it is acceptable for families to be at any position along the continuum. If partnership is required for true participation to begin, then involvement and participation as defined by Smith et al should not be regarded as part of family centred care.

Brownlea's (1987) definition of participation (see page 11) appears to equate to Arnstein's definition of partnership. Families should be at least at the partnership stage as it is at this point that negotiation occurs, and with negotiation, families can contribute to as much care as they wish. Although there is a lack of agreed definitions for parental involvement and participation, most authors describe

partnership as a collaborative arrangement between parents and nurses where there is equal power and negotiation takes place as both partners respect the knowledge of the other (Casey 1988; Callery & Smith, 1991; Coyne, 1996; Curley & Wallace, 1992; Johnson, 1994; Keatinge & Gilmore, 1996; Smith, 1995; Smith et al., 2002).

The dissonance in the terminology does not appear to impact on family care as long as staff in the clinical setting are clear on the definition. Despite the terms being used interchangeably, there is consistency in the findings from studies that identified factors that either facilitate or act as barriers to parents taking part in their child's care.

Parental Participation

Research demonstrates that parents want to participate in the care of their child when hospitalised (Algren, 1985; Beck, 1973; Jackson, Bradham & Burwell, 1978; Kawik, 1996; Kristensson-Hallstrom & Elander, 1994; McDonald, 1969; Mellow & Johnson, 1968; Neill, 1996b; Webb, Hull & Madeley, 1985). In the study by Webb et al (1985) parents and nurses were given the same list of child care tasks which had been developed, piloted and used by Mellow and Johnson (1968). Parents were asked whether the tasks were ones they wished to perform for their child when hospitalised. The findings from both studies were that parents wanted to continue to provide the normal parenting tasks for their child such as bathing, feeding and comforting. The frequencies decreased as the items moved into more complex nursing tasks such as taking temperatures and counting respirations. Few parents wished to perform dressings, monitor intravenous fluids or feed via nasogastric tube. Algren (1985) used a similar list of child care tasks to that of Mellow and Johnson and also found similar results however the sample was very small. Using the eleven most frequent items of child care tasks nominated by parents in the Mellow and Johnson study, Jackson et al (1978) distributed a questionnaire on admission and again on day three of hospitalisation to see if actual involvement in their child's care changed parents' views. Their finding was that it did not. In considering this finding it should be noted that the 11 items were more related to the nurturing role rather than the delivery of nursing care. Beck (1973) used a 26 item Likert scale to assess parents' attitudes toward participating in their child's care and found a positive attitude to parental care. Hill (1978), who interviewed parents using a list of 37 child

care items, and Stull and Deatruck (1986) who asked parents to maintain a diary recording what they did while in hospital as a means of confirming data gathered by interview, also found that most parents wanted to care for their child when hospitalised. It was noted by Stull and Deatruck, however, that parents were more willing to participate in the more complex tasks if it was something that they would have to do when the child returned home or if it meant that the child would be discharged from hospital earlier.

As part of their studies, Merrow and Johnson (1968) and Webb et al. (1985) gave the same list of child care tasks that they gave to parents, to nurses and other staff. The results from both studies demonstrated that staff perceived that parents wished to participate in parenting care but the researchers concluded staff perceived parents were less inclined to participate in care traditionally regarded as nursing care. In addition, Merrow and Johnson reported statistically significant differences between mothers' and nurses' perceptions of parents' participation in child care tasks. The extent to which mothers wanted to participate in tasks that may have caused parents distress such as restraining their child for a procedure and 'nursing' tasks such as monitoring intravenous fluids was greater than nurses' perceptions of parents wanting to participate in those tasks. However, Webb et al. (1985) only reported frequencies for each child care task. Parents wished to participate in tasks and, although the frequencies decreased the more complex and 'nursing' the task became, parents still had greater interest in performing the tasks than staff perceived they would. Despite the seventeen years time difference, the different countries and thus differing health care systems in which the studies were undertaken and the small sample sizes (largest numbers were 80 parents and 54 nurses in the study by Webb et al, 1985), the results were similar, highlighting that parents do want to participate in their child's care when hospitalised and nurses are not always aware of the extent to which parents want to participate.

Other aspects of care that had not been considered and therefore not included in lists of child care tasks were identified in qualitative studies. These included parents being an advocate for their child (Hayes and Knox, 1984; Johnson, 1993) protector of their child (Darbyshire, 1994; Perkins, 1993; Robinson, 1987;) and planning or coordinating their child's care (Hayes & Knox, 1984; Johnson, 1993; Perkins, 1993;

Stull & Deatruck, 1986). Perkins (1993) identified three phases where parents moved from 'protector' in which parents gathered information about their child and participated in parenting tasks, to 'survivor' in which they became more assertive and monitored their child's care, to coordinator of care. Parents' participation progressed over time throughout the hospitalisation. Stull and Deatruck (1986) found that parents also participated in parent oriented activities which they labelled 'refuelling' which included spending time with other parents, or spending time alone. Johnson (1993) referred to this as the parent having a 'visitor' role, and Johnson (1993) and Callery (1997a) both identified that parents could be patients or co-clients where the parents actually required care as well as their child.

This information validated the belief that parents participated in more than just the provision of tasks when their child was hospitalised. The use of qualitative study methods provided rich descriptive data which also identified factors that affected parents' decisions to participate in the care of their child while hospitalised.

Factors Affecting Parents' Decision to Participate

Factors found to affect parents' decisions to participate in their child's care included parents' belief that they were experts on their child (Coyne, 1995b; Hayes & Knox, 1984), parents wanting control over the situation (Burke, Kaufmann, Costello & Dillon, 1991; Hayes and Knox, 1984; Knafl, Cavallari & Dixon, 1988; Kristensson-Hallstrom & Elander, 1997; Schepp, 1992), parents' desire for consistency or continuity in care (Burke et al, 1991; Coyne, 1995b; Darbyshire, 1994; Hayes & Knox, 1984; Kawik, 1996; Neill, 1996b; Tomlinson et al, 1993), wishing to continue their parenting role or to meet the emotional needs of the child (Coyne, 1995b; Dearmun, 1992; Hayes & Knox, 1984; Kawik, 1996; Neill, 1996b) and lack of trust in staff with the parents wanting to protect their child (Knafl et al, 1988; Robinson, 1987).

Critique of Studies

All of the above studies on parental participation, with the exception of those reported by Algren (1985), Beck (1973), Jackson et al (1978), McDonald (1969), Merrow and Johnson (1968), Schepp (1992), Tomlinson et al (1993) and Webb et al (1985), used qualitative methodology ranging from grounded theory and

phenomenology to descriptive studies. A limitation in many of the studies (Coyne, 1995b; Darbyshire, 1994; Hill, 1978; Jackson et al, 1978; Keatinge & Gilmore, 1996; Knafl et al, 1988; Merrow & Johnson, 1968; Stull & Deatrck, 1986; Webb et al, 1985) was the risk of bias as families were still patients within the hospital setting and may have been concerned that any negative comments made to the researchers might affect their child's care. Consequently they may have provided information that they believed the interviewer wished to hear so as not to compromise the care they were receiving. Darbyshire (1994), Knafl et al (1988) and Stull and Deatrck (1986) used triangulation to reduce this risk of bias. Although the remaining authors assured parents that their child's care would not be affected by their participation in the study, this risk of bias was not acknowledged within their publications.

In several of these qualitative studies (Burke et al, 1991; Callery, 1997a; Dearmun, 1992; Knafl et al, 1988) researchers included observations to obtain detailed descriptions of the settings and to verify information provided in the interviews. However, two limitations of these studies were the possible impact of the Hawthorne and halo effects. In respect to the Hawthorne effect parents were aware they were being observed and therefore may have participated in more of their child's care than they would have normally done to please the observer. In the case of the halo effect the observer may have biased their data by giving more weight or prominence to responses from parents the researcher considered more credible or insightful based on their personal opinion of that parent, for example those they considered more intelligent.

The reliability and validity of the tools used in the quantitative studies were not always reported in the articles. Keatinge and Gilmore (1996) cited reliability and validity of the State Trait Anxiety Inventory which they used, from previous studies which were carried out in a different country to where their study was undertaken. Tomlinson et al (1993) discussed face validity but there was no mention of internal reliability or construct, content and criterion-related validity.

Triangulation was used by several researchers (Dearmun, 1992; Johnson, 1993; Knafl et al, 1988; Stull & Deatrck, 1986) to increase accuracy, to establish trustworthiness and improve the credibility of their findings. Others using qualitative

methods checked reliability by coding independently, having their codes reviewed by peers or experienced researchers (Knafl et al, 1988; Neill, 1996a; Perkins, 1993) or validated their findings by reinterviewing participants or offering the transcripts to parents for checking and feedback (Neill, 1996a; Perkins, 1993; Robinson, 1987).

These studies did not provide a comprehensive coverage of situations in which children might be hospitalised. The majority of the children whose parents were included were hospitalised with chronic conditions, were booked admissions or had conditions that were non-life threatening. In most of the studies, mothers were the main participants. Demographic data such as the age of the children, length of hospital stay, family structure and families socio-economic status were not always reported.

Summary of Studies on Parental Participation Discussed Previously

The studies discussed earlier indicated that most parents wanted to participate in their child's care when hospitalised, however the amount of care that they provided varied between individuals. Parents wanted to participate due to their sense of moral and social responsibility – they were the child's parents. Several studies (Dearmun, 1992; Kawik, 1996; Kristensson-Hallstrom & Elander, 1994; Merrow & Johnson, 1968; Webb et al., 1985) showed a difference between parents' and health professionals' perceptions of the degree of parental participation in their child's care. Other research that could help explain this difference included those that examined nurses' attitudes to parental participation in care.

Nurses' Attitudes to Parental Participation

Nurses' attitudes to parental participation in care have been studied to ascertain factors which enhance parental participation and those that may act as barriers. Seidl and Pillitteri (1969) developed the Parent Participation Attitude Scale (PPAS) which was designed to identify nurses' attitudes to parents participating in their child's care. It was a 24 item, self administered, summated rating scale which used a five point Likert scale. The total rating for each subject constituted the attitude score for the individual where the higher the score the more favourable the attitude to parental participation in care. The PPAS asked questions relating to parental presence and parental provision of direct care to their child when hospitalised. Items included

normal 'parenting' care such as bathing, feeding and comforting their child, and the provision of routine 'nursing' care such as administering medications, taking and recording pulse and temperature. There were however, no questions relating to provision of information and parents' inclusion in decision making. Seidl and Pillitteri (1969) reported a split-half reliability coefficient with Spearman-Brown correction of +.037 for the instrument. When administered with a professional data questionnaire, Siedl (1969) demonstrated factors which enhanced a more positive attitude to parental participation in care. These factors included nurses who held a baccalaureate degree, nurses with children and those with a higher social position in the hospital. In areas where the head nurse had a positive attitude to parental participation, the nurses also had a more positive attitude. Family centred care and parental participation in care were part of the baccalaureate nursing program which was thought to contribute to the more favourable attitude in those nurses.

Gill (1987a, 1987b) cited results from earlier studies where PPAS was used to survey 273 nurses in four hospitals. She reported reliability measured by Cronbach's alpha as .75 and factor analysis confirmed the scale's construct validity. Gill (1987a) reported that nurses' attitudes ranged from neutral to very positive and results reaffirmed the positive influence of position, nursing education and parental status on attitudes to parental participation in care. These findings were consistent with results from her earlier study (Gill, 1987b) when 498 nurses from 28 hospitals were surveyed. There was some variation in total attitude scores between hospitals. Differences in location, educational affiliations and the philosophy of the institutions were suggested as reasons for the differences. Gill (1993) repeated the study with 1022 health professionals, and again the results were consistent.

Johnson and Lindschau (1996) also used PPAS to survey 62 staff on four paediatric wards in a women's and children's hospital in South Australia. Minor language changes were made to the questionnaire to reflect the Australian context. While the authors suggested that the changes did not alter the structure of any questions, neither validity or reliability of the modified questionnaire were reported. Personal and professional data were also collected in the questionnaire which was sent to all staff working on the selected wards. Respondents included nurses, social workers, medical officers, physiotherapists, play leaders and ward clerks. Gill (1987a) had

established categories based on the range of scores as most rejecting, 24 - 36; rejecting, 37 - 60; neutral, 61 - 84, accepting, 85 - 108 and most accepting 109 - 120 which Johnson and Lindschau (1996) used in their study. Registered Nurses had the highest mean score to parents participating in their child's care ($M = 74.8$; $SD = 8.7$) and Enrolled Nurses had the lowest mean ($M = 63.7$). However, both these groups were in the 'neutral' attitude category. Some individual respondents, including nurses, scored between 37 - 60 which is categorised as in the 'rejecting' attitude range. Unlike earlier studies, no statistically significant differences were found between educational status and the mean attitude score and no relation found between years working with children and attitude scores. Married participants had a higher mean score ($M = 73.3$; $SD = 8.3$) than those who had never married ($M = 69.7$; $SD = 7.1$) and those who were parents scored higher ($M = 73.4$; $SD = 8.4$) than those who were not parents ($M = 70.5$; $SD = 7.8$) which is consistent with earlier studies, however the differences were not statistically significant. All these mean scores were in the 'neutral' attitude category. Interestingly, 20.7% of respondents disagreed with the statement that 'family members should have open visiting'; 27.6% thought that parents should not administer medications that they normally administered at home to their child and 37.9% did not think that parents of low socioeconomic status should be encouraged to stay with their child while in hospital through the provision of financial assistance. The small number of respondents may account for the lack of statistically significant findings and possible bias.

Another Australian study (Maxton, 1997) examined the attitudes of staff to parental presence and participation in care. The staff included nurses, doctors and other allied health professionals from a paediatric intensive care unit within an adult hospital and staff who worked in a paediatric intensive care unit within a tertiary paediatric hospital. Maxton reported that nurses who had worked in a paediatric intensive care unit for more than five years were significantly less likely than less experienced nurses to allow parents to be present at all times ($p < .05$) which differs from earlier findings (Gill, 1987a; 1987b; 1993; Seidl, 1969). The staff from a paediatric intensive care unit within an adult hospital were significantly less likely to want parents to be present all the time ($p < .05$) than staff from a paediatric intensive care unit in a tertiary paediatric hospital. A possible reason for these findings was that many of the staff did not have paediatric qualifications, especially those working

within the adult hospital, and therefore may not have been familiar with the concept of family centred care. Maxton (1997) concluded that the results were disappointing as there is no reason for parents not to participate in their child's care, despite being in an intensive care unit, especially as parents' most fundamental need is to be with their child. As with the study by Johnson and Lindschau (1996) the sample was small.

These studies looking at parental participation in their child's care have generated generally consistent findings since Siedl and Pillitteri developed the PPAS in 1969. It is suggested that education appears to play a part and those staff who have formalised education on the importance of parental participation and family centred care develop a more accepting attitude to parental participation than those who do not (Gill, 1987a; 1987b; 1993; Maxton, 1997; Siedl, 1969).

Ward culture may play a part in parental participation in care. Siedl (1969) found that where the more senior staff had a positive attitude to parental participation the more positive the attitude of the junior staff. These findings were replicated nearly thirty years later by Gill (1997a). It is difficult as a junior staff member to implement practices based on education and knowledge without support of senior staff. However, anecdotal evidence suggests that even when the collective staff attitude is accepting of parental participation it does not occur all the time. Qualitative studies have indicated possible reasons for this.

The Influence of Negotiation and Power

Many of the findings of qualitative research studies have concluded that a lack of negotiation between nurses and parents was partly responsible for the lack of parental participation (Coyne, 1995b; Darbyshire, 1994; Hayes & Knox, 1984; Johnson, 1994; Robinson, 1985; Roden, 1998; Rowe, 1996). Savage and Callery (2000) reported a further eight studies that found little negotiation took place between parents and nurses regarding their respective roles in caring for the hospitalised child. They cited studies where parents wanted to participate in their child's care and the nurses expected them not to and, conversely, studies where nurses expected parents to participate when the parents did not wish to (Dearmun, 1992; Kawik, 1996; Neill, 1996b). Negotiation would determine the extent to which

parents wished to be involved in their child's care and thus resolve this problem. Four factors that influence the negotiation process are the nurses' position of authority and power, the language used, the interpersonal style and the way in which information is presented (Davis, Day & Bidmead, 2002; Roberts & Krouse, 1988). These factors can all favour the nurse and make it very difficult for the parent in the negotiating process.

The power imbalance between parents and nurses where nurses were perceived to hold the power was a factor identified as influencing parental participation (Darbyshire, 1994; Knafl et al., 1988; Maxton, 1996; Smith, 1995; Whelan & Kirkby, 1997). An issue central to negotiation relates to power and control between the nurse and the parents.

Callery and Smith (1991) suggested that the context in which negotiation occurs needs to be considered. In the hospital ward the nurse is perceived to hold power over the parent as the nurse is familiar with the setting. The parent is a visitor to the unfamiliar environment and lacks privacy and control. The nurse has the information and can control how much the parent receives (Mishel, 1983). Added to this is the stress that parents are experiencing due to the changes to their usual parenting role as a result of the child's illness and hospital admission (Hayes & Knox, 1984). In contrast, nurses feel competent in their familiar role (Ferraro & Longo, 1985) and are in a position to control the relationship. If the nurse does not wish to negotiate, the parent is not in a very strong position to take the initiative (Robinson, 1985).

Smith (1995) proposed that when the parents are viewed as carers for their child the power balance should be equal. By acknowledging parents as carers there is recognition that the parent has some knowledge of their child. Acknowledging that parents are experts on their child (Coyne 1995b; Roden, 1998) and that parents know their child best as they are the constant in the child's life (Johnson, 1994) indicates that parents have some power and have something to offer to their child's care. Accepting that this parental knowledge is of value enables negotiation to commence. If nurses believe that the parents' knowledge of their child is of equal value to that of their own, the negotiation may lead to partnership.

Callery and Smith (1991) looked at role negotiation between nurses and parents using critical incident technique. Although their results could only be interpreted at best as suggestive due to lack of inter-rater reliability at the sub-category stage, the suggestion was that the more senior the nurse, the greater the frequency of negotiation. This implied an increasing respect for parents' decision-making abilities. The lack of negotiation by the more junior staff may have been related to their lack of power within the ward management structure. Callery and Smith suggested that if primary nursing was used, the junior staff would be empowered as they would be responsible for the care of the families and perhaps negotiation would then occur.

Barriers to Parental Participation

Lack of Information

In addition to nurses' attitudes and a lack of negotiation due to unequal power, other barriers to parental participation and formation of a partnership between parents and nurses have been identified. Although a lack of information provided to parents was the reason given by some parents for their participation in their child's care (Burke et al, 1991; Caty, Ritchie & Ellerton, 1989) it was also the reason given by parents as to why they did not participate in their child's care (Coyne, 1995b; Darbyshire, 1994; Neill, 1996b; Roden, 1998). This lack of sharing of information can also be the source of power and control by nurses. Failure to provide information ranged from parents not being oriented to the ward adequately and not knowing where things were therefore making it difficult to care for their child (Coyne 1995b; Darbyshire, 1994), through to details regarding their child's illness and care (Coyne 1995b; Darbyshire, 1994; Johnson, 1994; Neill, 1996b; Roden, 1998). Reasons why nurses did not share adequate information with parents were identified by Bruce and Ritchie (1997). The nurses perceived a lack of support from other health professionals and a lack of accountability for this aspect of their practice. Although the organisation espoused a philosophy of family centred care, nurses did not feel empowered to share information with families, such as allowing parents to read their child's case notes. Nurses perceived a lack of clarity in the roles of health professionals and were unsure of who should provide some of the information to families particularly information relating to the child's illness. Therefore, this knowledge was not shared

with parents as often or as fully as required despite knowing that such communication enhanced family centred care.

Inconsistent Information

Paucity of information was often accompanied by inconsistency thereby confusing parents. An example of inconsistent information is when nurses on different shifts cite ward policies and procedures as allowing parents to provide aspects of care and then as not allowing the same care. These inconsistencies resulted in frustration for parents (Algren, 1985; Darbyshire, 1994) and difficulty in forming a trusting relationship with nurses (Johnson, 1994).

Ineffective Communication

Along with lack of and inconsistent information, poor communication (Roden, 1998) was identified as contributing to lack of negotiation and identification of parents' roles (Bruce & Ritchie, 1997; Calabretto & Johnson, 1994; Coyne, 1995b; Johnson, 1994; Whelan & Kirkby, 1997). The poor communication ranged from being 'spoken down to', being insensitive or rude (Roden, 1998; Whelan & Kirkby, 1997) to being unapproachable (Neill, 1996b) thus disempowering parents. This poor communication contributed to lack of identification of roles for both parents and nurses.

Inadequate Facilities

Inadequate facilities were identified as reasons why parents did not stay in hospital with their child and therefore did not participate in care as much as they would have liked. The lack of facilities made parents feel unwelcome or uncomfortable (Coyne, 1995b; Roden, 1998). The issue of facilities featured prominently in Roden's study (1998) which was undertaken in a children's ward within an adult hospital. The facilities that parents wanted improved were the sleeping facilities or accommodation including washing facilities, meals and suitable play areas for siblings and children. Perhaps the hospital's philosophy of care was not focussed on families as it was primarily an adult hospital. The hospital canteen was not located close to the children's ward and there were no facilities to have meals brought to the ward for parents. In situations such as this, parents were reluctant to leave their child and as a

result of having remained with their child, had not eaten all day which increased parents' stress (Coyne, 1995b; Neill, 1996b).

Privacy for families was also identified as inadequate (Darbyshire, 1994; Roden, 1998; Taylor, 1996). Taylor (1996, p. 25) referred to parents stating 'they feel like being in a goldfish bowl' and that they were unable to show emotions such as crying in private and away from their child. Darbyshire (1994) coined the term 'parenting in public' as all the parenting is observed by health professionals and parents feel their parenting abilities are being judged therefore reducing their control and participation in care.

Addressing Barriers

Most studies identified barriers to family centred care however several factors were elicited that enhanced parental participation and partnership. Recommendations to reduce the inconsistency in information included identification of parents' roles (Johnson, 1994) and expectations (Evans, 1994; Knafl et al., 1988; Roden, 1998), documenting information on plans of care (Algren, 1985; Darbyshire, 1994; Johnson, 1994) and primary nursing (Callery & Smith, 1991; Smith, 1995).

Johnson (1994) noted that nurses gathered a lot of information from parents to assist in their care. However, she emphasised the importance of including the definition of roles within the information gathering process to decrease the inconsistency in decisions about the aspects of care in which parents were allowed to participate. Ensuring that parents' roles or expectations are assessed and the level of participation that parents wish to provide is determined is essential as each family has different needs (Calabretto & Johnson, 1994; Evans, 1994; Farrell, 1992; Knafl et al., 1988; Roden, 1998). Knafl et al., (1988), Evans (1994) and Roden (1998) noted that this assessment of parental roles and expectations must be done frequently as these needs differ from day to day. However, to gain this information, there has to be effective communication between parents and nurses (Johnson, 1994).

Johnson (1996) provided steps which may assist nurses to reach a partnership with parents to assist in the identification of parental roles and expectations. Both partners in the relationship need to:

- recognise each other's core business
- respect each other's need to attend to this core business
- have a shared understanding of the issues or problems
- define each other's roles and responsibilities that each will play and agree on these
- renegotiate roles as necessary
- recognise each partner's need for satisfaction within their roles.

Johnson (1996) recommended that these steps be implemented by nurses to attain a partnership level of participation thus enabling family centred care to commence.

These elements were the foundation of a model of shared care which was introduced into an Australian paediatric ward within a general hospital by Keatinge and Gilmore (1996). Use of the shared care model of partnership based on the steps above, did reduce parents' anxiety and increased parental participation in their provision of routine parenting tasks. Results need to be interpreted with caution as the sample was small and the reliability and validity of the instrument was based on an earlier study in another country.

Johnson (1994) also noted that despite all the information gathered from parents, parents were not included in the actual plan of care for the child. Algren (1985) and Johnson (1994) suggested that if the care that parents wanted to provide was documented and then read by staff, the inconsistency in decisions about aspects of care in which parents participated would decrease.

Another strategy to reduce the inconsistency would be to have the same staff caring for the family as often as possible (Darbyshire, 1994; Johnson, 1994; Smith, 1995). Primary nursing was identified by Smith (1995) and Callery and Smith (1991) as a strategy to maintain consistency in information and care for parents. However, primary nursing is rarely practical in Australia today with growing numbers of part time staff and the worldwide nursing shortage leading to increasing numbers of casual staff on wards.

Nurses believe that if they improve their skills in interpersonal relationships and counselling they would be better able to negotiate care and share information with

families (Bruce & Ritchie, 1997). This would enhance the provision of care that is family centred.

Both formal and informal networks assist parents. Support from other parents within the hospital is important to parents participating in their child's care. Darbyshire (1994), Casey and Mobbs (1988), Coyne (1995b) and Neill (1996b) acknowledged this source of support, with Darbyshire (1994) suggesting it was necessary because of the lack of information forthcoming from nurses. Formal networks were also identified as beneficial to families' participation in care (Smith, 1995). These groups provide information, peer support and practical advice which can reduce the parents' stress particularly when the child has a chronic condition which will require ongoing support and care.

One factor which is external to the health care system that assists parents to participate in their child's care is a supportive network of family and friends (Callery, 1997c; Coyne, 1995b; Roden, 1998). Having the support of family and friends enables parents to reside in the hospital with their sick child secure in the knowledge that their other roles are being taken care of.

Benefits of Parental Participation

Although family centred care is espoused to be the philosophy of care for hospitalised children there is little recent evidence to demonstrate that it does empower and enable parents. In a systematic review of the literature relating to parental participation in their child's hospitalisation aimed at identifying evidence of the benefits for parents, children and other family members, Savage and Callery (2000) found 28 research articles, published over a 14 year period (1984-1998), which met their inclusion criteria. Many of these have been cited earlier in this literature review. Both qualitative and quantitative studies were included in the review, with the authors providing a sound argument for adopting a comprehensive coverage of methodologies as their source of evidence, in contrast to a very narrow definition of evidence which only draws data from randomised control trials.

The results of the review were discussed under two major headings: effects of parental participation in care on hospitalised children (six studies) and the effects of parental participation on parents (24 studies). In respect to the effects on parents, the

reviewers grouped the findings into four themes: roles and responsibilities, control and decision-making, knowledge and competence, and emotional status. One factor identified as possibly contributing to negative parental experiences was the lack of planning around implementing participation of parents in care. Evidence from a small number of papers suggested that a planned and shared approach would lead to positive experiences, with the proviso that in implementing such an approach it be individualised. However there were more negative outcomes from parental participation reported than benefits which can be attributed to publication bias as suggested by Savage and Callery (2000).

Very few studies were designed to answer the question ‘what are the benefits to families of parental participation’. They were mostly focussed on whether parental participation was occurring and what enhanced or prohibited its occurrence. The studies that specifically introduced a negotiated care/shared care model and looked for the benefits of such practice did demonstrate benefits for parents such as: decreased anxiety; increased time with nurses planning the child’s care; greater control over the situation and a choice in their level of involvement (Cleary, 1992; Lau, 1993; Keatinge & Gilmore, 1996). Increased knowledge and competence to care for the child at home was also a benefit for some parents (Keatinge & Gilmore, 1996). A study by Ayer (1978) which was outside the parameters of the review, showed that increased participation provided opportunity for increased parent education therefore fewer misunderstandings post discharge.

Only six of the studies reviewed by Savage and Callery (2000) demonstrated benefits to the child of parental participation in care. Five of these reported psychological benefits such as increased sense of security, increased social attentiveness and the child spent less time crying alone. One study (Coty et al, 1989) reported mothers’ perceptions of their child’s stress during hospitalisation and how they and their child responded and only two studies gathered information from the children themselves through interviews. One study measured physiological parameters of weight and skin condition to ascertain any difference between parents and nurses caring for the hospitalised children. No significant differences either clinically or statistically, were demonstrated between groups.

However, much earlier studies, which precede the time limitation of the review by Savage and Callery (2000), show benefits to children of parental presence and participation in care as decreased emotional stress, decreased incidence of cross infection, decreased post operative complications, increased sense of security and more accurate record keeping (Ayer, 1978; Mahaffy, 1965; Robertson, 1958). The undertaking of these early studies may possibly be attributed to the influence of the publications by Bowlby (1951) and Robertson (1958) on maternal deprivation and separation anxiety. As Bowlby and Robertson's work became accepted researchers would have to focus on how parental participation could be improved to enhance these benefits.

There is some evidence to show the benefits to parents and children of parental presence and participation in care. Also, many aspects have been identified as barriers to parental participation and partnership between parents and nurses including poor communication and a lack of negotiation between parents and nurses. Several models have been developed to promote family centred care. Of these models, two are based on negotiation between parents and nurses and another based on effective communication.

Models to Enhance Care

Although both the Nottingham Model (Smith, 1995) and Casey's Partnership Model (1988) are based on negotiation and respect for the family's wishes, the two models differ in their definition of 'client'. The Nottingham Model identifies the family as the client. Care advocated in this model acknowledges the child's constant interaction with the family unit. According to Smith, (1995, p. 33) "the child is influenced by factors affecting the family unit and it is recognised that the child can only function to his/her full potential within a stable family relationship, therefore the whole family is seen as (the) client". In contrast, Casey (1993) sees the child as the client. The paediatric nurse is only concerned with the family as carers of the child. Information about the family's structure, dynamics and resources is only relevant in assessing the family's ability to care for their child.

In Casey's 'Partnership Model for Children's Nursing' (Figure 2.1) parents continue to provide all the 'family care' required to meet the child's needs and the nurse

provides the ‘extra’ care the child requires, usually classified as nursing care. The family care may be given by the nurse if the parents are unable to provide it and the family may provide the nursing care if they wish to and are given the appropriate education, guidance, support and opportunity. The goal is to meet the needs of the sick child so he/she develops to his/her maximum potential. This is successful when the nurse and the family form a partnership and negotiate the level of care that the parents wish to provide (Casey & Mobbs, 1988).

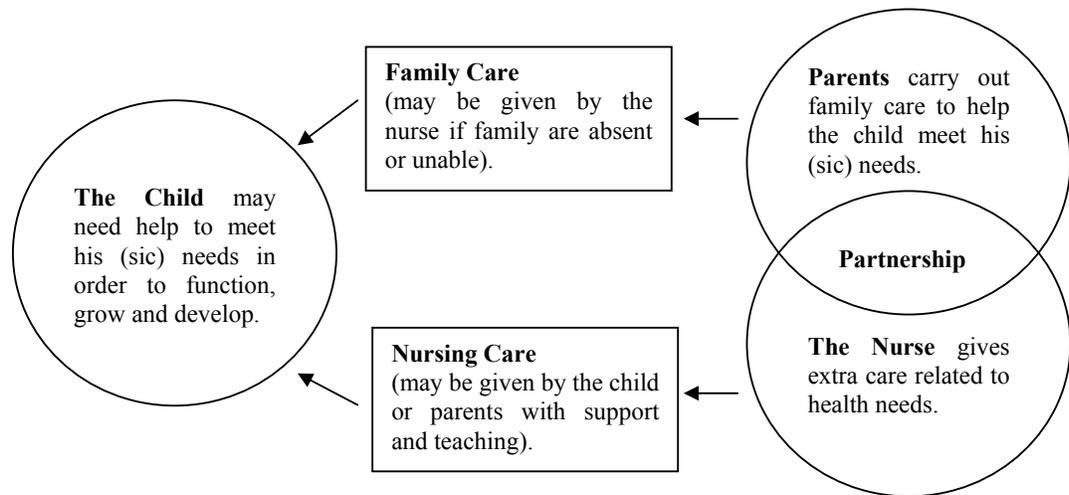


Fig. 2.1. Casey's Partnership Model of Paediatric Nursing (modified)

Casey's partnership model has been implemented successfully and the benefits identified by research included families experiencing greater feelings of confidence and competence and less stress in caring for their children. Families' dependence on professional caregivers decreased, professionals experienced greater job satisfaction and both parents and providers were empowered to develop new skills and expertise when this model of care was followed (Curley & Wallace, 1992; Johnson, Jeppson & Redburn, 1992).

To enable this model of care to be successful, a partnership needs to be formed between the nurse and the parents. This partnership equates with parents' participation in decision making and care as desired rather than an equal distribution of tasks which may incorporate technical nursing skills that will not be required at

home. When the parents wish to participate, it is the nurse's responsibility to ensure that they continue to cope with the extra demands placed on their usual roles of parent and spouse while caring for their hospitalised child. The nurse is also responsible for ensuring that parents who are not participating in the care of their child have been informed and invited to participate and that parents have the necessary support for this approach (Casey, 1993; Farrell, 1992).

The Nursing Mutual Participation Model of Care (Curley & Wallace, 1992) was developed for use in paediatric intensive care units and adapted from earlier models which were used with chronically ill adults and with adults in outpatient settings. It is based on the premise that a 'nurse knows what might be helpful to a population of parents experiencing a similar situation but does not profess to know what is best for an individual parent' (Curley & Wallace, 1992, p. 379). It is designed to reduce parents' stress and relies on a partnership between parents and nurses and sharing of expertise (the parent's knowledge of the child and the nurse's knowledge of the illness). For this model to be successful, equal power and a "mutuality" are required which are aspects identified as missing in paediatric care settings (Darbyshire, 1994; Callery & Smith, 1991; Coyne, 1995b). A positive aspect of the Nursing Mutual Participation Model of Care is that it provides a well defined process of communication. This addresses the issue of poor communication identified earlier as a barrier to successful family centred care (Coyne 1995b; Darbyshire 1994; Johnson, 1994; Neill, 1996b; Roden, 1998). Implementation of this model in a paediatric intensive care unit requires at least daily communication with parents and has been shown to reduce parents' stress levels (Curley, 1988; Curley & Wallace, 1992). Parents however, also suffer stress when their child is admitted to wards other than intensive care units. Having identified poor communication, lack of mutuality (Darbyshire, 1994) and inequality of power as barriers to family centred care, the Nursing Mutual Participation Model of Care could be of benefit in the paediatric hospital ward setting.

Operational Definition of Family Centred Care

Recognition of the rights of children to be included in care and decision making on care that directly effects them is acknowledged as an integral part of family centred care. When children are unable to make these decisions or need assistance, parents

have the right to participate in the decision making and the caring process. Most hospitalised children in rural Western Australia are three years of age or less therefore parents play a major role in the decision making for or with their child. For the purposes of this study the term ‘family centred care’ refers to the partnership between the parents and the nurse which enables the family to be included in all decision making relating to the care of the child. Inclusion in the decision making enables the parents to undertake as much of the child’s care as they desire. Achievement of the partnership level of participation requires effective communication skills to negotiate with the family on a regular, at least daily, basis while the child is in hospital. This negotiation can only be successful when nurses and parents each respect the other’s knowledge and appreciate the other has something to offer in the relationship which will benefit the child. This negotiation encompasses identifying parents’ roles and expectations by following the steps identified by Johnson (1996).

To enable family centred care to be implemented successfully, health care systems need to be designed with families in mind. The provision of facilities such as beds and quiet areas for parents to sleep, areas so families can have privacy, an environment in which children can fulfil their developmental potential and which is also suitable for siblings, will enhance family centred care. The hospital’s management must support the ethos of family centred care by having policies and programs in place to allow family centred care to occur and support staff in their implementation and promotion of the policies and programs.

Rationale for the Study

Although there are many studies investigating various aspects of family centred care such as parental participation in their child’s care and partnership in care using quantitative and qualitative methods, few studies have been undertaken in Australia. Of those, five studies have been undertaken in paediatric settings within adult hospitals (AWCH, 1992; Keatinge & Gilmore, 1996; Maxton, 1997; Roden, 1998; Rowe, 1996). No study reported findings from Western Australia. Only the survey by AWCH (1992) covered rural Australia. However, results were collated cumulatively and not reported by state, population density or level of hospital. Most of the studies from North America and United Kingdom were undertaken in tertiary

paediatric hospitals. Paediatric care is often a component of rural general hospitals which have different organisational and environmental contexts to major metropolitan tertiary paediatric centres.

It is estimated that 12,000 children under the age of ten years (HDWA, 2001b) are hospitalised in rural Western Australia each year. As the importance of family centred care is recognised in decreasing the adverse emotional and psychological impact on hospitalised children it is important to ascertain whether family centred care is indeed being practised in rural hospitals of Western Australia.

Summary

Although family centred care has been the stated philosophy of care for hospitalised children since the Platt report in 1959, the literature supports the view that family centred care is still not being achieved consistently within the health care system (Darbyshire, 1994; Johnson, 1996; Maxton, 1997; Roden, 1998).

Family centred care is the recognition that caring for a hospitalised child includes caring for the child within the context of the family by respecting the parents' knowledge about their child and their right to be involved in decision making and the caring process, thereby enabling and empowering the family to retain control over this aspect of their lives (Smith, 1995). Family centred care is based on partnership which requires negotiation. This negotiation can only occur with effective communication between parents and nurses and a supportive health care system which has policies and programs that foster family centred care.

No studies were identified that relate to the concept of family centred care in rural settings. The purpose of this study is to identify whether family centred care is occurring in paediatric settings in rural Western Australia and will explore parents' and nurses' perceptions of the concept.

Chapter Three

Methodology

This descriptive study was designed to determine the extent to which family centred care was implemented, and to explore and compare perceptions of family centred care between parents and nurses in rural hospitals in Western Australia.

Research Design

A non-experimental design was selected to identify and describe those aspects of family centred care being used and to ascertain the frequency of those characteristics (LoBiondo-Wood & Haber, 1990). Data were collected from parents who had a child hospitalised in a rural hospital in the preceding six month period, and from nurses who provided direct care to children in that same period. Both parents and nurses were surveyed so a comparison of perceptions of family centred care could be made.

Sample

Only health services south of the 26th parallel south were included in the study population. The intent was for the researcher to visit each hospital included in the study to maximise the return of questionnaires. The cost of travelling to hospitals north of the 26th parallel was considered too great. A further consideration was that the area north of the 26th parallel is sparsely populated and the majority of children who are hospitalised in this area are Aboriginal and from remote communities. Self-administered questionnaires are not an optimal method of data collection for this population due to cultural and educational differences. Consequently, the target population comprised all families who had a child hospitalised in rural Western Australia, south of the 26th parallel.

Rural hospitals were defined as all those public hospitals greater than 90 kilometres distance from Perth. This distance was selected to exclude metropolitan hospitals which are situated in the urban fringe. Private hospitals were not included as it was anticipated that gaining approval to access parents would be difficult. There were only two private hospitals within the target population.

Initially cluster sampling of hospitals was proposed within a randomly selected rural health service to maximise the representation of the rural population within the confines of cost (Burns & Grove, 1987). The researcher had planned to travel to the selected area to identify and speak with eligible participants and to distribute questionnaires. To sample the target population, the hospitals in which the children had been admitted had to be identified and a convenience sample of parents selected. The sample also included all nurses who cared for children and worked in the hospitals selected.

Hospital Selection

Thirteen rural health services, as defined by the Health Department of Western Australia (HDWA) in 1997, were eligible for selection (ie. below the 26th parallel). The first stage of the cluster sampling was to randomly select one of these health services. The second stage was to categorise the rural hospitals within the selected health service according to the number of paediatric patients admitted in a year according to the Hospital Morbidity Data System of the Health Department of Western Australia and then randomly select the hospitals from the stratified categories. As the researcher was unable to obtain accurate paediatric patient numbers from the Health Department of Western Australia to use for stratification of the hospitals, a letter (Appendix A) was sent to every Director of Nursing/Health Service Manager in the rural area requesting the number of children admitted in the preceding six months. This letter also asked whether they would agree to their hospital staff participating in the study if they were randomly selected. The invitation was not sent to the hospital where the nurses who participated in the focus group, which contributed to the questionnaire development, were employed. They were not included in the final study as all the nurses who cared for children in the hospital participated in the focus group therefore possibly biasing their responses on the questionnaire.

Fifty six rural hospitals met the inclusion criteria. Directors of Nursing/Health Service Managers of 22 hospitals indicated their inability to participate in the study. Reasons for not participating included that few children had been admitted to the hospital, the majority of children admitted were of Aboriginal descent and a low return rate was anticipated, refusal on ethical grounds, hospital patients were already

participating in a Health Department survey, and the hospital was undergoing management changes therefore staff were unable to trace children's case notes. No response was received from Directors of Nursing/Health Service Managers for seven hospitals despite two follow up letters and communication via email. It was therefore decided to include all the rural hospitals that had replied and agreed to participate in the study sample. As the rural hospitals that were included in the sample now covered all of Western Australia below the 26th parallel, it was no longer feasible for the researcher to visit each hospital. Clerical staff at the participating hospitals were offered payment for their time, therefore hospitals that had less than six children admitted within the previous six months were excluded from the study as the cost of searching the patient records and finding the addresses of so few parents outweighed the anticipated small return. This excluded a further twelve hospitals. The final number of hospitals participating in this study was 15. These hospitals ranged in size from eight to 178 beds and were located from the mid west to the far south of Western Australia.

Parent Selection

To maintain confidentiality, clerical staff at the participating hospitals identified the parents who met the selection criteria. Parents who had a child under ten years of age, admitted to any of the participating hospitals within the preceding six months were eligible for inclusion in the study. Parents did not receive the questionnaire until their child had been discharged from hospital to address the concern that hospitalised families may not answer accurately in fear of staff retaliation if their comments were negative. In each family, only one parent was required to complete the questionnaire. Parents of hospitalised children older than ten years of age were not included in the sample as children of this age may have been deemed competent and involved in decision making related to their care at the exclusion of their parents (Alderson, 1993; HDWA, 2002; Rushforth, 1996).

Nurse Selection

All nurses, enrolled and registered, who provided direct care to children and were employed in the participating hospitals were invited to complete a questionnaire. In larger hospitals, only those nurses who regularly worked on the paediatric ward or

cared for children admitted to the hospital were included as the questionnaire concerned inpatient care.

Instrument Development

Focus Groups

Two focus groups were held in a regional centre to ascertain whether the concepts of family centred care found in the literature were representative of parents' and nurses' views in rural Western Australia. No research into family centred care in small, non-paediatric, rural hospitals had been published, and there was no literature pertaining to family centred care in Western Australia. The rural town was chosen as it met the inclusion criteria of the target population, that of being outside the metropolitan area and below the 26th parallel. The town was over four hundred kilometres from the metropolitan area.

One focus group was with parents who had recently had a child admitted to either of the local hospitals. The parents were recruited through child health clinics in the town. The meeting lasted one and a half hour and had three participants, all mothers. No fathers attended the discussion although they were invited. Two participants who had agreed to take part were unable to attend the focus group due to other commitments at the last moment. The researcher telephoned both mothers and discussed the mothers' perceptions of their child's hospitalisation and their participation in their child's care.

Permission was sought from the Director of Nursing of one of the hospitals in the same town to run a focus group with nurses involved in providing direct care to children at the hospital. Eight nurses participated in the focus group, all of whom spent the majority of their clinical work time caring for children as the hospital had a dedicated children's ward. The focus group included both registered and enrolled nurses. None of the nurses in the focus group had undertaken formal paediatric education or worked in a tertiary paediatric centre. This focus group lasted two hours.

Both focus groups were audiotaped. Due to the risk of being unable to capture data on the audiotape from excessive outside noise or when two people talked at once, a

research assistant took notes throughout the focus groups. The audiotapes were transcribed immediately on return to Perth and common themes were identified. The common themes from both focus groups matched those identified in the literature. However, one additional theme was generated by the mothers' focus group that had not been identified in the literature search. This related to fathers not feeling included in their child's care when they were unable to be with their child throughout the hospitalisation. An item was subsequently included in the questionnaires to obtain perceptions about this aspect of family centred care.

Questionnaires

Two questionnaires, one for parents and the other for nurses, were developed by the researcher following a review of the literature and the conduct of the focus group interviews. Part A of the questionnaires sought sociodemographic details of parents and nurses. (Table 3.1). All sociodemographic variables included have been identified in the literature as having significant influence in the respondents' perceptions of family centred care.

Table 3.1
Sociodemographic Variables

Parents	Nurses
Relationship to the child	Educational level
Composition of 'the family'	Number of years worked as a nurse
Previous experience with hospitals	Number of years nursed children
Previous employment/position in hospital	Current main area of nursing practice
Type of admission: booked/emergency	Gender
Length of child's hospital stay	Age
Age of hospitalised child	Parental status
Reason for hospital admission	Hospitalisation of a child
Proximity to hospital where admitted	
Level of social support provided while child in hospital	

As the common themes identified in the focus groups largely matched the literature it was assumed that the eight elements of family centred care as identified by Shelton et al. (1987) addressed the requirements which families in Western Australia had to

enhance family centred care. Therefore, the Family Centered Care Questionnaire (FCCQ) (Bruce & Ritchie, 1997) which measured the elements of family centred care with eight subscales was used for this study. The authors cited reliability measured by Cronbach's alpha ranging from .5 to .8 for the subscales with .9 for the over all scale. Test-retest reliability was reported to range from .6 to .8 for the subscales. Although the researchers reported that content validity was established by a panel of experts some items in the FCCQ appeared ambiguous. Permission was granted by the authors to amend the tool. Changes were made to the wording of some items to suit the Australian context. Where it was perceived that items in the FCCQ covered two concepts, these items were made into two questions. One further item was added to address the perceptions of partners' involvement in care as this was identified in the focus group with parents as an area of concern. Several items were worded negatively to strengthen the reliability of the tool.

Parents' Participation Questionnaire (Appendix B)

This questionnaire had three sections. The first section requested demographic information including the respondents' definition of 'family' and previous experience with hospitals (refer to Table 3.1). The second section directed parents to indicate their level of agreement or disagreement for 62 items by circling a number on a five point Likert scale. For those items that may not have been applicable to all respondents, 'NA' (not applicable) was included as a response option. The third section of the questionnaire consisted of four open ended questions which allowed parents the opportunity to elaborate on aspects of their experience of their child's hospitalisation.

Nurses' Questionnaire (Appendix C)

This questionnaire also had three sections. The first section requested demographic information including personal and professional characteristics (see Table 3.1). The second section of the questionnaire contained the 66 items adapted from FCCQ with the same five point Likert scale. The nurses' questionnaire included four more items than the parental participation questionnaire as nurses were asked additional information relating to ongoing nursing education and evaluation of nursing practices of which parents would be unaware. All other items matched the parental participation questionnaire, however the wording was altered to make the

questionnaire suitable for nurses. The third section of the questionnaire consisted of four open ended questions offering the respondent an opportunity to provide further detail or explanation of their responses to the quantitative items.

Reliability and Validity

Content validity was evaluated by inviting three registered nurses who were knowledgeable in the philosophy of family centred care to indicate whether they believed each item was measuring family centred care. They were also asked to indicate whether each item represented the element of family centred care according to the subscale in which it was grouped. This was done independently and then followed by a meeting to clarify differences. No items were deleted but five items were moved from their original elements to other elements as the nurses agreed they better represented these categories. No other changes were made to the items.

Pilot Study

The Parental Participation Questionnaire was piloted with two parents who were not health professionals and were educated to at least secondary school level.

Readability and clarity of content of the items were validated. There was no misunderstanding of the items' intent. The parents also timed themselves to see how long it took to complete the questionnaire. The average time was 14 minutes.

The Nurses' Questionnaire was distributed to seven registered nurses who were in their first year of practice and were working in a tertiary paediatric centre. The purpose of the pilot study was to determine interpretability of the questions, identify potential data processing problems and estimate the length of time a respondent would take to complete the questionnaire. The average time taken to complete the questionnaire was 13 minutes. On the basis of their feedback only minor changes were made to the layout of the form to assist with data entry.

Data Collection

The Director of Nursing/Health Service Manager of each participating hospital gave permission for a staff member to identify parents of children who met the inclusion criteria of this study and post the questionnaire to the identified parents. They also

provided data on the number of nurses who gave direct care to children admitted to the hospital.

The questionnaires for the parents were forwarded by the researcher to the nominated staff member at each participating hospital who then addressed and posted the questionnaires to parents of the children who met the inclusion criteria. A letter of introduction and explanation of the study (Appendix D), and a reply paid, addressed envelope were included with each questionnaire.

The nominated staff members were also sent the questionnaires to distribute to the nursing staff. These were already enclosed in envelopes with a letter of introduction to the participant and explanation of the study (Appendix D) and a reply paid, addressed envelope. The nominated staff member identified the nurses who matched the inclusion criteria, addressed the envelopes and delivered them to the nurses at work through the internal mailing system.

Each participating hospital was offered financial compensation to cover the cost of a staff member identifying eligible families, retrieving the addresses and addressing the envelopes. The hospital staff member was asked to return any unused questionnaires to the researcher. Seven hundred and seventy parental participation questionnaires and 249 nurses' questionnaires were sent to the nominated staff members in the participating hospitals for distribution. This amount was based on the estimated figures provided by the nominated staff member or the Directors of Nursing/Health Service Managers.

The researcher attempted to target the winter months as the number of children hospitalised is greater during that time but due to delays, including gaining approval from hospital ethics committees, the six month hospitalisation period was from October 2000 to March 2001.

To ensure confidentiality and obtain approval to survey families and nurses, the researcher did not have access to the names and addresses of the participants. The researcher therefore, was unable to follow up non returned questionnaires and did not have financial support to send the questionnaires to all participants a second time.

Data Analysis

Quantitative data were entered and analysed using Statistical Package for Social Sciences Version 10.0 (SPSS Inc. Chicago, 1999) Windows computer software. Random checks were made following data entry to ensure data quality. All scale items that were negatively worded were recoded. Descriptive statistics were generated for demographic data and all scale items.

Internal consistency of the parents' and nurses' questionnaires were assessed separately using Cronbach's alpha for each of the eight subscales. Where 'not applicable' resulted in missing data on the Likert scale, these items were removed from the calculation and are discussed separately in Chapter Six. The options of including these items by recoding the 'not applicable' response as neutral or substituting with the mean were not chosen as the variation in responses would be reduced. By recoding 'not applicable' as neutral, more responses would be grouped near the middle of the scale. To substitute the 'not applicable' responses with the mean would supply a non-neutral opinion when this may not have been the case (Polit & Hungler, 1995).

Further psychometric tests were undertaken to test data quality, scaling assumptions and reliability. A multitrait/multi-item correlation matrix was used to examine the relationship of each item to its hypothesised scale and the item's relationship to each other scale as described below.

The correlation between each item and the scale score computed from all other items in that scale was examined to test item internal consistency. Item internal consistency is considered substantial and satisfactory when an item has a correlation of 0.40 or greater with its hypothesised scale (Bjørner, Damsgaard, Watt, & Groenvold, 1998; Ware & Gadnek, 1998).

Equality of item-scale correlations was examined by considering the item's contribution to the total score of the hypothesised scale. Where the correlations ranged from 0.40 to 0.70 across items in the same scale, it was assumed that all items contributed substantially to the score (Ware & Gadnek, 1998).

Item discriminant validity was also examined. An item was considered to have adequate discriminant validity if the correlation between an item and its hypothesised

scale is significantly higher than the correlation between the item and all other scales (Polit & Hungler, 1995; Ware & Gadnek, 1998).

Inter-scale correlations were undertaken to determine whether each scale was measuring a distinct concept. When the correlation between two scales is less than their reliability coefficients, there is evidence of unique reliable variance measured by each scale (Polit & Hungler, 1995; Ware & Gadnek, 1998).

As these tests did not indicate that the original eight subscales were reliable measures of the eight elements of family centred care, exploratory factor analysis was performed to identify the constructs the items reflected and group together different measures of family centred care (LoBiondo-Wood & Haber, 1990). Single item measurements of family centred care were avoided where possible to enable evaluation of internal consistency and to reduce the number of individual comparisons. A separate principal component analysis was undertaken for both parents' and nurses' questionnaires. Psychometric testing of the factors identified four reliable concepts in the Parental Participation Survey and three reliable concepts in the Nurses' Questionnaire. The subscales were labelled, and then each subscale was summed to give overall mean scores for the concepts they were measuring.

Independent *t*-tests and One-Way Analysis of Variance (ANOVA) were used to test whether population means were equal for each subscale and to ascertain statistically significant differences between sociodemographic characteristics and perceptions of family centred care. Where ANOVA was performed, post hoc analyses were conducted with Tukey's Honestly Significant Difference test (Tukey's HSD) to determine the location of the differences among groups (Burns & Grove, 1999). Pearson's correlations were used to test if sociodemographic characteristics were significantly associated with the concepts of family centred care for both parents and nurses. All tests used .05 as the level of significance. Where rounding could make a difference to the interpretation, *p* values were reported to three decimal places.

Responses to the open ended questions from 53 parents (21.8%) and 38 nurses (35.0%) were transcribed. A simple manifest content analysis was undertaken where descriptors that were central to the research topic were identified (Morse & Richards, 2002). An assumption underlying content analysis is that the researcher knows what

he/she is searching for (Daly, Kellehear & Gliksman, 1997) therefore, to satisfy the aims of the content analysis, concepts that matched the items in the questionnaire were identified. Frequencies with which the issues were raised were reported. Numeric objectivity increases the reliability of the data (Morse & Richards, 2002). Following factor analysis and identification of the subscales, the comments from the open ended questions were revisited, looking for quotes that illustrated the concepts which were subsequently included within the results. Data generated from the open ended questions were only used for secondary purposes to highlight the outcomes of the quantitative analysis where appropriate.

Ethical Considerations

Approval was given by the Human Research Ethics Committee at Curtin University. Formal human research ethics committees of three hospitals gave permission for the study to occur in their hospitals. Where no ethics committee existed, permission to access parents and nurses from the remaining hospitals was granted by the Hospital Board, the Health Service Manager or the Director of Nursing of each hospital.

The researcher at no time had access to the children or their family's name and address as the hospital's staff identified children who had been inpatients and addressed the envelopes and posted the questionnaires to their families. Similarly, the researcher at no time knew the names of the nurses who completed the questionnaires as the hospital staff also distributed the questionnaires to the nurses. The questionnaires did not have the participant's name and address recorded on them. A code, known only to the researcher, was on each questionnaire which indicated the hospital where the child was an inpatient or where the nurse was employed. This code sheet was kept separately to the data in a locked filing cabinet.

A letter introducing the researcher and explaining the purpose of the study was used to seek consent from all participants on receipt of the questionnaire (Appendix D). The return of a completed questionnaire was deemed informed consent by the respondent. Participants were informed that they could choose not to participate in the study without compromising the care of their child or their position of employment. It was intended that if any parent had any issues of concern regarding the care of their child, and they identified themselves, the parent would have been

referred by the researcher to the health service manager or to the hospital's parent/patient advocate, whoever was appropriate. One parent did contact one of the researcher's supervisors as the family were very upset to have received the questionnaire following the death of their child. A letter of apology was sent to the family for the distress that receiving the questionnaire had caused them. No other major concerns from parents or nurses were made known to the researcher.

Transcripts of the focus groups and the completed questionnaires are being held in a locked filing cabinet in the researcher's office and will remain so for five years in keeping with University policy. The audiotapes from the focus groups are locked in a filing cabinet at the researcher's office and will be destroyed after examination of the thesis.

Confidentiality was maintained at all times. The results have been reported in aggregate and tabular form so as to protect the identity of the participants and the hospitals.

Methodological Considerations

The convenience sampling utilised in this study and the self selected respondents may be associated with several biases and thus it is not assumed to be representative of all parents and nurses in the population from which the samples are drawn. The sample of nurses who responded may be more family centred in their approach to care than nurses in the wider population and parents who responded may be either very positive or very negative regarding their experience of hospitalisation. Those who were content may not have felt a need to respond. The study was believed to be useful however, due to it being the first of its kind in rural Western Australia and its potential to raise nurses' awareness of parents' expectations of family centred care and the necessity to provide family centred care.

The response rates, 35% for parents' questionnaire and 45% for nurses' questionnaire, are estimates. Although 770 Parental Participation Questionnaires and 249 Nurses' Questionnaires were sent to the nominated staff members at the participating hospitals, the number of questionnaires then ultimately mailed from the hospitals to suitable participants was unknown. Despite the nominated staff member

at each hospital being provided with the selection criteria, it was evident that parents and nurses who did not meet the criteria received the questionnaires. (For further details, see Chapter Five.) However, the response rate achieved was considered indicative of the data collection method and not a reflection of the questionnaire. The lack of a personal approach to request participation is associated with a decreased response rate (LoBiondo-Wood & Haber, 1990). A prospective study over a six month period where the questionnaires were handed to the parents on their child's discharge from hospital, may have generated a higher response rate and enabled an accurate calculation of that response rate. This method may also have ensured respondents met the selection criteria.

Although consideration was given to the impact that the inability to identify participants to enable follow up of questionnaires would have on the response rate, the importance of ensuring confidentiality for parents and nurses was maintained as a priority. Therefore, this strategy was used despite the limitations.

Chapter Four

Reliability and Validity of Instruments

As empirical results have more meaning if a tool is reliable and valid, the reliability of both parents' and nurses' questionnaires were assessed by examining the internal consistency of the original eight subscales. These results are reported and, as reliability was not evident for the concepts of family centred care assessed by the subscales, exploratory factor analysis was undertaken for each questionnaire. Results of the factor analysis are presented followed by results of reliability testing for the new subscales. The new subscales are discussed in Chapter Five.

Internal Consistency of Questionnaires

The reliability coefficients for the subscales of both questionnaires ranged from Cronbach's alpha of .23 to .85 suggesting that at least seven subscales were not reliable measures of family centred care. Nine subscales had a Cronbach's alpha $>.70$ indicating that those subscales were homogenous however response rates were low for at least seven of the subscales. Table 4.1 provides the number of items in each subscale, the number of responses and Cronbach's alpha for each subscale.

Table 4.1
Internal Consistency for the Original Subscales of Family Centred Care

Subscale of family centred care	Parents			Nurses		
	No of items	Alpha	n	No of items	Alpha	n
Family is constant	8	.72	174	8	.55	107
Collaboration	12	.84	115	12	.63	104
Sharing information	8	.79	151	8	.72	93
Recognising family strengths	7	.77	148	7	.46	106
Meet developmental needs	5	.73	154	5	.53	107
Family to family support	2	.85	96	2	.47	97
Policies and programs	3	.23	204	4	.32	95
Health service delivery	11	.82	159	11	.74	107
Total	56	.96		57	.89	

When items were removed from subscales to increase either the response rate to the question or to increase the internal consistency, there still remained six subscales with Cronbach alpha $<.70$ which indicated that those subscales were not reliable measures of family centred care. Table 4.2 shows the amended Cronbach's alpha for

the original subscales of family centred care following removal of items to improve number of responses or to improve internal consistency.

Table 4.2
Internal Consistency for the Original Subscales of Family Centred Care - refined

Subscale of Family Centred Care	Parents			Nurses		
	No of items*	Alpha	n	No of items*	Alpha	n
Family is constant	6*	.66	231	6*	.68	107
Collaboration	9*	.78	211	9*	.74	104
Sharing information	7*	.77	230	7*	.74	93
Recognising family strengths	6*	.70	172	5*	.65	106
Meet developmental needs	4*	.74	222	4*	.57	107
Family to family support	2	.85	96	2	.47	97
Policies and programs	2*	.59	210	3*	.38	106
Health service delivery	10*	.80	201	10*	.75	107
Total	46	.95		46	.90	

*Items removed to either increase number of respondents included or to increase alpha.

When further psychometric tests were done on the data from the parents' questionnaires to validate reliability, item-scale correlations showed that 22 items correlated at a greater level with a subscale other than the one to which it was assigned and a further four items did not contribute a significant amount to the subscale to which it was assigned ($r < .40$). Table 4.3 provides the Pearson correlations for each item for the parents' questionnaire. Those items that correlated at a greater level with a subscale other than its own are presented in bold.

Psychometric tests on the nurses' questionnaire revealed that 22 items correlated at a greater level with a subscale other than the one to which it was assigned and a further seven items did not contribute a significant amount to the subscale to which it was assigned ($r < .40$) as shown in Table 4.4. Those items that correlated at a greater level with a subscale other than its own are presented in bold.

As these tests did not indicate that the subscales were reliable measures of the eight elements of family centred care, exploratory factor analysis was performed and a separate principal component analysis undertaken for both parents' and nurses' questionnaires.

Table 4. 3 Item Descriptive Statistics and Pearson Item-scale Correlations Corrected for Overlap for Original Subscales Parents' Questionnaire

Number	Label	Item	Mean	SD	Pearson item-scale correlations*							
					EI 1	EI 2	EI 3	EI 4	EI 5	EI 6	EI 7	EI 8
Scale = Element 1 (recognition that family is constant)												
12	Nurses were interested in information given about child		4.24	0.98	.40*	.43	.52	.49	.45	.16	.36	.28
13	Nurses asked what was normal for child		3.56	1.29	.45*	.59	.47	.46	.37	.24	.25	.44
20	I was able to provide as much parenting as I wished		4.57	0.67	.45*	.36	.27	.28	.24	.02	.33	.20
28	I was encouraged to continue parenting		4.00	1.10	.46*	.42	.34	.35	.31	.25	.20	.31
30	I was allowed to be present during all procedures		4.24	1.15	.31*	.23	.10	.13	.22	-.08	.30	.11
57	I felt included as part of the health care team		3.97	1.00	.63*	.60	.54	.56	.52	.33	.33	.58
Scale = Element 2 (collaboration)												
15	I determined with nurses the level of my involvement in care of child		3.47	1.22	.59	.68*	.64	.59	.47	.41	.28	.53
16	I was included in decisions of care for child		3.79	1.20	.43	.43*	.40	.37	.30	.16	.32	.23
17	Nurses asked each day about my involvement in care		2.91	1.23	.59	.65*	.61	.63	.44	.44	.19	.61
21	I was able to provide as much nursing as I wished		3.81	1.16	.38	.29*	.27	.22	.09	.16	.42	.22
23	I was expected to provide nursing care		3.86	1.21	.26	.18*	.32	.32	.40	.21	.02	.31
26	Care I wanted to provide was recorded		2.64	1.08	.31	.42*	.29	.39	.21	.29	.18	.43
27	Family members involved in care were encouraged to share information		2.06	1.16	.26	.44*	.29	.31	.10	.40	.04	.41
45	Nurses discussed things to help with other events		2.69	1.25	.35	.53*	.40	.59	.36	.37	.14	.55
51	Nurses asked about other things I had to do each day		2.52	1.24	.43	.58*	.37	.65	.37	.65	.34	.61
Scale = Element 3 (sharing information)												
1	I received information about child's hospitalisation		4.15	0.92	.23	.27	.46*	.30	.28	.17	.07	.14
2	Information included impact of hospitalisation on family		2.79	1.31	.26	.45	.50*	.32	.33	.41	.05	.33
3	All information said families are key participants in care		3.30	1.22	.39	.54	.51*	.47	.35	.40	.19	.39
7	Staff introduced themselves and explained role		3.95	1.18	.45	.44	.52*	.44	.44	.26	.18	.36
8	Nurses routinely gave information on each aspect of care		3.92	1.10	.54	.58	.66*	.59	.50	.41	.20	.51
9	Could access information about care when I wished		4.16	1.04	.36	.25	.32*	.31	.34	.34	.12	.22
14	Information provided by nurses was consistent		4.02	0.97	.51	.46	.53*	.51	.53	.22	.26	.46
Scale = Element 4 (recognise individuality)												
6	Nurses ensured I understood information		4.03	0.96	.46	.45	.55	.37*	.37	.21	.21	.37
11	Nurses helped family adjust to hospitalisation		3.73	1.09	.51	.48	.66	.50*	.55	.25	.12	.46
42	Nurses aware of increased costs when child hospitalised		2.75	1.24	.21	.36	.21	.40*	.30	.33	.13	.48
47	Nurses helped us stay in touch with extended family		2.74	1.28	.32	.48	.31	.47*	.32	.45	.11	.51
52	Family was encouraged to come and go as needed		3.38	1.30	.38	.46	.30	.47*	.41	.60	.19	.48
54	Not made to feel a bad parent if not present all the time		4.12	1.17	.28	.34	.29	.39*	.46	.31	.14	.38

Table 4.3 Item Descriptive Statistics and Pearson Item-scale Correlations Corrected for Overlap for Original Subscales Parents' Questionnaire (cont.)

Item		Mean	SD	Item-scale Pearson correlations*							
Number	Label			EI 1	EI 2	EI 3	EI 4	EI 5	EI 6	EI 7	EI 8
Scale = Element 5 (meet developmental needs of family)											
35	Care approach was appropriate to child's age	4.38	0.81	.54	.44	.52	.44	.52*	.18	.35	.41
36	Layout of ward designed to meet needs of child and family	3.95	1.11	.31	.36	.42	.40	.66*	.40	.14	.43
37	Adequate play area for children of all ages	3.81	1.24	.20	.24	.34	.33	.56*	.23	.06	.28
59	Nurses maintained familiar routines for child	3.74	1.05	.55	.52	.48	.60	.47*	.33	.30	.52
Scale = Element 6 (family to family support)											
61	Encouraged to discuss concerns with other parents	2.39	1.22	.21	.42	.29	.52	.30	.73*	.01	.51
62	Supplied with information on support groups	2.67	1.37	.30	.49	.43	.56	.46	.73*	.07	.48
Scale = Element 7 (policies and programs)											
24	Policies allow families to provide parenting	4.27	0.90	.38	.23	.17	.15	.28	.01	.53*	.20
25	Policies allow parents to provide nursing care	3.93	1.07	.37	.38	.30	.27	.26	.10	.53*	.22
Scale = Element 8 (health service delivery)											
31	Given opportunity to provide feedback to hospital on care provided	2.81	1.44	.30	.46	.32	.44	.18	.25	.10	.55*
32	Able to comment on policies and practices	2.65	1.32	.24	.43	.30	.41	.14	.34	.01	.52*
38	Discussions held in private area	3.40	1.25	.41	.46	.31	.37	.39	.31	.11	.44*
39	There was designated comfortable area for parents	3.26	1.38	.36	.41	.29	.47	.41	.28	.14	.48*
40	Able to sleep in separate room if desired	2.59	1.38	.06	.26	.20	.31	.23	.38	.15	.40*
41	Both parents could stay in hospital if they wished	2.71	1.41	.11	.26	.10	.31	.15	.31	.04	.33*
43	Nurses ensured parents ate meals regularly	2.99	1.45	.48	.56	.37	.56	.29	.49	.17	.55*
48	There was adequate staff to meet child's needs	3.78	1.26	.43	.51	.47	.45	.50	.20	.26	.50*
49	There was adequate staff to meet family's needs	3.42	1.25	.42	.49	.42	.54	.45	.30	.25	.59*
60	Same nurses assigned to care for child whenever possible	3.53	1.10	.37	.36	.35	.47	.50	.29	.11	.38*

*Item-scale correlation corrected for overlap (relevant item removed from scale for correlation)

Bold indicates item correlated at a greater level with a subscale other than its own

Table 4.4 Item Descriptive Statistics and Pearson Item-scale Correlations Corrected for Overlap for Original Subscales Nurses' Questionnaire

Item		Mean	SD	Pearson item-scale correlations*							
Number	Label			El 1	El 2	El 3	El 4	El 5	El 6	El 7	El 8
Scale = Element 1 (constant)											
12	Value info given by parents	4.66	0.51	.40*	.34	.28	.43	.17	.00	-.02	.15
13	Ask parents what is normal	4.70	0.48	.37*	.30	.38	.41	.13	.01	.09	.06
20	Parents can parent	4.55	0.54	.56*	.36	.42	.38	.10	.16	.13	.15
29	Parents encouraged to parent	4.44	0.66	.24*	.41	.21	.33	-.01	.29	.02	.00
61	Family part of health team	4.24	0.88	.42*	.27	.08	.35	.22	.33	.18	.28
62	Family included in all care	4.10	0.93	.57*	.44	.32	.40	.22	.30	.13	.42
Scale = Element 2 (collaboration)											
15	Negotiate with families	4.04	0.86	.34	.62*	.42	.34	.23	.40	.16	.32
17	Clarify level of participation	3.73	0.86	.34	.53*	.53	.32	.21	.38	.14	.38
27	Document level of participation	3.53	1.03	.12	.46*	.30	.35	.29	.41	.01	.30
28	Family encouraged to chart	3.55	1.09	.25	.35*	.25	.31	-.01	.28	.12	.23
30	Ensure parents' confident parent	4.42	0.53	.56	.39*	.25	.56	.05	.28	-.05	.00
47	Assist families meet other needs	2.95	1.07	.24	.39*	.28	.27	.17	.18	.13	.38
55	Ask family other commitments	3.38	1.10	.39	.50*	.30	.46	.16	.25	.13	.45
58	Enable family attend other business	3.83	0.85	.35	.40*	.17	.40	.29	.25	.17	.34
60	Reassure care if parents leave	4.46	0.65	.37	.11*	.09	.48	.22	.25	-.11	.05
Scale = Element 3 (information)											
1	Each receive info	4.09	0.92	.35	.38	.58*	.44	.16	.16	.05	.32
2	Includes impact of hospitalisation	3.15	1.09	.17	.28	.54*	.08	.24	.17	.07	.33
3	Conveys families key participants	3.60	1.03	.26	.33	.64*	.19	.20	.28	.23	.37
4	Written in family friendly terms	3.69	0.87	.13	.03	.34*	.13	.18	.22	.07	.15
6	Info re roles of health professionals	4.07	0.79	.18	.38	.30*	.39	.17	.27	-.04	.15
8	Regular communication	4.39	0.70	.36	.33	.41*	.41	.28	.13	.11	.19
14	Consistent with info	3.66	0.96	.37	.45	.37*	.26	.33	.34	.25	.50
Scale = Element 4 (recognise individuality)											
5	Explanations meet family needs	4.45	0.55	.34	.38	.60	.32*	.21	.23	.05	.11
11	Ensure families adjust to hospital	4.13	0.74	.42	.55	.45	.52*	.22	.33	-.04	.32
51	Families stay in touch with others	3.65	0.93	.31	.53	.17	.35*	.25	.24	.07	.40
56	Encourage family to come and go	4.24	0.79	.43	.41	.19	.50*	.25	.34	-.04	.21
59	Respect families decision not to stay	4.05	0.95	.39	.26	.09	.37*	.15	.20	.08	.08

Table 4.4 Item Descriptive Statistics and Pearson Item-scale Correlations Corrected for Overlap for Original Subscales Nurses' Questionnaire (cont.)

Item		Mean	SD	Pearson item-scale correlations*							
Number	Label			El 1	El 2	El 3	El 4	El 5	El 6	El 7	El 8
Scale = Element 5 (meet developmental needs of family)											
39	Adequate knowledge in child devpt.	3.40	0.99	.25	.31	.32	.29	.26*	.37	.21	.28
40	Ward designed for children	2.91	1.23	.04	.03	.20	.09	.49*	.12	.23	.37
41	Adequate play area for children	2.75	1.28	.12	.06	.27	.06	.49*	.40	.28	.34
50	Assess needs of siblings	3.28	0.97	.24	.45	.22	.51	.17*	.35	.24	.53
Scale = Element 6 (family to family support)											
65	Encourage parent-parent discussion	3.52	1.04	.14	.34	.29	.27	.26	.33*	.16	.39
66	Inform of support groups	4.13	0.70	.46	.59	.45	.51	.36	.33*	.25	.34
Scale = Element 7 (policies and programmes)											
25	Policies permit parenting	3.92	1.19	.23	.14	.23	.10	.26	.21	.32*	.25
26	Policies permit parents' nursing	3.33	1.23	.07	.14	-.12	.04	.15	.07	.27*	.16
34	Parents involved in programs	2.01	1.01	.00	.09	.23	-.05	.34	.30	.09*	.45
Scale = Element 8 (health service delivery)											
32	Seek feedback from families	3.23	1.14	.09	.41	.23	.17	.36	.34	.35	.51*
33	Parents contribute to policies	2.60	1.24	.11	.24	.26	.13	.29	.25	.28	.45*
42	Privacy for discussions	3.39	1.20	.24	.31	.31	.16	.24	.25	.22	.39*
43	Comfortable area for families	2.93	1.42	.24	.21	.28	.11	.49	.20	.29	.55*
44	Parents can sleep in room	2.78	1.52	.05	.15	.34	.10	.39	.15	.28	.34*
45	Both parents can stay	2.76	1.52	.22	.27	.30	.21	.41	.16	.26	.52*
48	Ensure parents eat meals	3.63	1.03	.36	.50	.15	.43	.18	.25	.27	.37*
49	Ensure parents have toiletries	3.86	0.96	.37	.48	.18	.52	.26	.25	.19	.39*
52	Staffing planned for children	2.23	1.13	.09	.15	.20	.12	.27	.26	.05	.35*
64	Same staff assigned to families	3.14	1.22	.22	.31	.21	.17	.18	.43	.10	.27*

*Item-scale correlation corrected for overlap (relevant item removed from its scale for correlation).

Bold indicates item correlated at a greater level with a subscale other than its own

Parents' Questionnaire

Factor Analysis

Factor extraction was performed by entering data into a principal components analysis. Fifteen items were not included as they had 'not applicable' available as a response reducing the number of items available for analysis to 47.

The factor structure of the items was examined and the Scree plot suggested five components were suitable for extraction. The eigenvalues and interpretability of the components were also examined. The fifth component did not have obvious meaning and was discarded. Four components provided the clearest interpretable factor structure and cumulatively accounted for 41.6% of the variance in the data. (Refer to Table 4.5).

Table 4.5
Summary of Initial Principal Components Analysis Solution Eigenvalues and Explained Variance for Parents' Questionnaire

Component	Scales	Eigenvalue	% Variance	Cumulative % Variance
1	Child friendly environment	11.89	25.30	25.30
2	Respect as parents	3.04	6.48	31.77
3	Nurses in supportive role	2.46	5.23	37.00
4	Parents empowered	2.14	4.55	41.55

These factors were subject to Varimax rotation to minimise high factor loadings on orthogonal axes and to Direct Oblimin procedure which used an oblique rotation. The matrices found using orthogonal rotation were more interpretable than the oblique solutions with fewer variables loading significantly on more than one factor, thus the Varimax rotation method was used in the final factor analyses. Table 4.6 presents the initial factor loadings. Factor loadings equal to or exceeding .40 were considered significant and are presented in bold.

Items 49, 57, 1, 27 and 33 had strong loadings on another factor, thus refinement of the solution aimed to exclude these items from the scale. Items were excluded from further analysis if factor loadings were less than .47 (15 items). Table 4.7 presents a summary of eigenvalues and variance for the final factor solution. The final factor loadings of the 32 items which were retained following the analysis described above are shown in Table 4.8.

Table 4.6
Rotated Factor Loadings for the Initial Four Factor Solution for Parents' Questionnaire

	Items	Component			
		1	2	3	4
35	care approach was appropriate to child's age	.652	.216		.227
23	not expected to provide nursing care	.646	.179		-.137
11	nurses helped family adjust to hospitalisation	.604	.135	.401	
14	info provided by nurses was consistent	.600	.203	.177	.317
36	layout of ward designed to meet needs of child & families	.578	.255		
48	adequate staffing to meet child's need	.569	.309	.151	.117
37	adequate play area for children of all ages	.559	.192		-.183
8	nurses routinely gave info on each aspect of care'	.537	.152	.462	.247
12	nurses interested in information about child	.531		.245	.174
59	nurses maintained familiar routines for child	.528	.352	.197	.252
7	staff introduced themselves and explained role	.488	.109	.321	.213
9	could access information about care if I wished	.474		.118	
49	adequate staffing to meet family needs	.468	.443	.133	.144
6	nurses ensured I understood the information	.450		.394	.261
57	felt included as part of care team	.436	.310	.319	.429
1	received information about hospitalisation	.409	-.166	.399	
22	not expected to do parenting	.387	.236		
16	decisions made on care with our input	.359		.233	.356
5	did understand all explanations about child'	.339		-.101	
51	nurses asked about other things I had to do each day	.141	.662	.287	.140
45	nurses discussed things to help with other events	.249	.590	.285	
43	nurses ensured parents ate meals regularly	.122	.587	.300	.215
47	nurses helped us stay in touch with extended family	.161	.569	.244	
41	both parents could stay in hospital if they wished		.556		
42	nurses aware of increased costs when child in hospital		.548	.210	
40	able to sleep in separate room if desired		.546		
52	family was encouraged to come and go as needed	.234	.542		.203
39	designated comfortable area for parents	.239	.496	.126	.119
38	staff/ family discussions held in private area	.269	.436	.142	.171
60	same nurses assigned whenever possible	.373	.391		.195
2	info included the impact on the family	.259		.675	
32	able to comment on policies and practices		.407	.609	-.117
17	each day nurses asked about involvement in care	.261	.374	.601	.260
3	all info said families are key participants in care	.313		.582	.141
31	gave feedback on hospital meeting our needs		.403	.558	
15	determined with nurses the level of care	.429	.231	.538	.251
13	nurses asked what is normal for child	.219	.206	.483	.335
27	families involved in care encouraged to share info		.364	.462	
33	invited to speak to staff on parent involvement		.388	.456	-.218
26	care I wanted to provide was recorded		.265	.409	.129
20	able to do as much parenting as I wished	.230			.665
21	able to do as much nursing care as I wished	-.117	.139	.229	.628
18	want to continue parenting in hospital				.624
19	want to provide nursing whilst in hospital	-.239	.104	.258	.535
24	policies allowed families providing full parenting	.205		-.172	.452
30	allowed to be present during all procedures	.117	.133	-.178	.429
28	encouraged to continue parenting	.102	.215	.274	.382

Bold indicates factor loadings considered significant

Table 4.7
Summary of Principal Components Factor Analysis Solution and Explained Variance for Parents' Questionnaire

Component	Scales	Eigenvalue	% Variance	Cumulative % Variance
1	Child friendly environment	9.09	28.41	28.41
2	Respect as parents	2.39	7.45	35.86
3	Nurses in supportive role	2.16	6.75	42.61
4	Parents empowered	1.76	5.49	48.10

Table 4.8
Rotated Factor Loadings for the Final Four Factor Solution for Parents' Subscales of Family Centred Care

	Item	Component			
		1	2	3	4
35	Care approach was appropriate to child's age	.709		.209	.178
11	Nurses helped family adjust to hospitalisation	.650	.385	.106	
14	Info provided by nurses was consistent	.646	.146	.208	.301
23	Not expected to provide nursing care	.618		.153	-.215
8	Nurses routinely gave info on each aspect of care'	.608	.408	.121	.219
36	Layout of ward designed to meet needs of child & families	.590		.265	
7	Staff introduced themselves and explained role	.579	.254		.222
37	Adequate play area for children of all ages	.561		.217	-.207
12	Nurses interested in information about child	.556	.242		.110
59	Nurses maintained familiar routines for child	.551	.249	.298	.195
9	Could access information about care if I wished	.493	.144		
32	Able to comment on policies and practices		.698	.299	
31	Gave feedback on hospital meeting our needs		.675	.304	-.107
17	Each day nurses asked about involvement in care	.306	.614	.318	.251
2	Info included the impact on the family	.247	.609		
13	Nurses asked what is normal for child	.240	.558	.117	.318
15	Determined with nurses the level of care	.468	.534	.184	.225
3	All info said families are key participants in care	.292	.528		.186
40	Able to sleep in separate room if desired			.667	
41	Both parents could stay in hospital if they wished		-.142	.658	.112
51	Nurses asked about other things I had to do each day	.162	.361	.619	.129
52	Family was encouraged to come and go as needed	.264	.108	.565	.164
45	Nurses discussed things to help with other events	.227	.377	.558	
47	Nurses helped us stay in touch with extended family	.177	.305	.547	
43	Nurses ensured parents ate meals regularly	.143	.371	.538	.190
42	Nurses aware of increased costs when child in hospital		.277	.537	
39	Designated comfortable area for parents	.246	.205	.475	
48	Adequate staffing to meet child's needs	.390	.256	.409	
19	Want to provide nursing whilst in hospital	-.188	.167	.131	.690
21	Able to do as much nursing care as I wished		.220	.130	.683
18	Want to continue parenting in hospital	.158			.647
20	Able to do as much parenting as I wished	.332			.642

Summated Scales

Data quality, scaling assumptions and reliability were tested for the four components to examine whether the components could produce a valid summated scale. Each item was examined for distribution, mean and standard deviation and results are shown in Table 4.9.

Table 4.9 Item Descriptive Statistics for Parents' Questionnaire

Number	Item Label	Missing %	Mean	SD	Response frequency				
					1*	2*	3*	4*	5*
Child friendly environment									
7	Staff introduced themselves & explained role	0.0	3.95	1.18	14	22	24	84	99
8	Nurses routinely gave information on each aspect of care	0.0	3.92	1.10	8	27	28	94	86
9	Could access information about care of child when I wished	0.4	4.16	1.04	4	20	31	66	121
11	Nurses helped family adjust to hospitalisation	1.6	3.73	1.09	10	24	51	90	64
12	Nurses were interested in information given about child	0.0	4.24	0.98	3	16	28	68	128
14	Information provided by nurses was consistent	0.0	4.02	0.97	6	16	28	111	82
23	I did not feel as if I was expected to provide care for child	1.6	3.86	1.21	13	25	40	66	95
35	Nurses' approach to care was appropriate to child's age	0.8	4.38	0.81	3	6	14	92	126
36	Physical layout of ward met developmental needs of child	1.2	3.95	1.11	11	17	35	86	91
37	There was adequate play area for children	2.9	3.81	1.24	18	23	31	79	85
59	Nurses maintained familiar routines for child	5.3	3.74	1.05	10	18	50	96	56
Respect as parents									
2	Information included the impact of hospitalisation on the family	3.7	2.79	1.31	48	57	53	47	29
3	Information conveyed that families are key participants in care	2.5	3.30	1.22	21	42	66	61	47
13	Nurses asked what was normal for child	0.8	3.56	1.29	22	34	44	70	71
15	Nurses worked with family to determine amount of involvement	2.5	3.47	1.22	19	36	48	82	52
17	Nurses asked every day how much involvement I wanted in care	4.5	2.91	1.23	35	54	65	52	26
31	Given opportunity to provide feedback to hospital on care provided	1.6	2.81	1.44	60	52	42	43	42
32	Given opportunity to comment on hospital practices	1.6	2.65	1.32	60	59	51	43	26
Nurses in supportive role									
39	There was a designated area for parents	2.1	3.26	1.38	36	39	47	60	56
40	I was able to sleep away from child if I wished	9.9	2.59	1.38	61	53	52	20	33
41	Both parents could stay in hospital if wished	7.4	2.71	1.41	63	40	58	27	37
42	Nurses aware of increased costs	4.1	2.75	1.24	50	40	87	31	25
43	Nurses ensured I ate meals regularly	5.8	2.99	1.45	54	36	41	55	43
45	Nurses discussed strategies to help with other events	6.2	2.69	1.25	46	60	64	34	24
47	Nurses helped us to maintain contact with other family/friends	8.6	2.74	1.28	50	45	64	39	24
49	Adequate nursing staff to meet family's needs	2.9	3.42	1.25	25	29	55	76	51
51	Nurses asked about other things I had to do each day	5.3	2.52	1.24	57	68	54	31	20
52	Family encouraged to come and go at any time	4.5	3.38	1.30	27	35	45	73	52
Parents empowered									
18	I wanted to continue parenting	0.8	4.53	0.74	0	5	20	58	158
19	I wanted to provide nursing	0.8	3.16	1.46	42	48	45	41	65
20	I was able to provide as much parenting as I wished	0.0	4.57	0.67	1	3	10	72	157
21	I was able to provide as much nursing as I wished	1.2	3.81	1.16	9	28	50	65	88

*1 = strongly disagree; 2 = disagree; 3 = undecided; 4 = agree; 5 = strongly agree

Item Internal Consistency

Pearson correlation was used to ascertain item internal consistency. The relationship of each item with the scale defining the concept it was hypothesised to measure was undertaken. Each scale was corrected for item-scale overlap by removing the item being tested from the scale prior to the correlation. Table 4.10 shows that the item internal consistency was considered satisfactory for all but two items. Items 41, 'my partner and I could both have stayed in hospital if we wished' and 18 'I wanted to continue parenting' were retained as they correlated significantly higher within the hypothesised scale than with the other scales, were only slightly below the criterion .40, the factor loadings for the components were high without significant crossloadings to other components and conceptually, the items fitted the hypothesised scales. Item 18 'I wanted to continue parenting' was highly skewed with a mean of 4.5 and a standard deviation of 0.74 which can account for the lower correlate. All items have roughly equal item-scale correlations therefore contributing roughly equal proportions of information to the total scores of each scale (Ware & Gandek, 1998).

Item Discriminant Validity

The relationship of items to the other scales were also tested to determine the extent to which item measured other concepts, item discriminant validity (see Table 4.11). Two items, 15 and 49 'nurses worked with family to determine amount of care family wished to give' and 'there was adequate nursing staff to meet family's needs', did not have significantly higher correlations with the hypothesised scale than all other scales. Item discriminant validity is supported if the correlation between an item and its hypothesised scale is significantly higher than the correlation between that item and all other scales. Both items had high crossloadings with a second component during factor analysis, however conceptually these items fitted their hypothesised scales and were retained on a preliminary basis.

Table 4.10 Item Descriptive Statistics and Pearson Item-scale Correlations Corrected for Overlap for Parents' Questionnaire

Item		Pearson item-scale correlations*					
Number	Label	Mean	SD	Comp 1	Comp 2	Comp 3	Comp 4
Child friendly environment							
7	Staff introduced themselves & explained role	3.95	1.18	.57*	.40	.32	.23
8	Nurses routinely gave information on each aspect of care	3.92	1.10	.68*	.55	.44	.24
9	Could access information about care of child when I wished	4.16	1.04	.45*	.22	.22	.06
11	Nurses helped family adjust to hospitalisation	3.73	1.09	.66*	.51	.41	.09
12	Nurses were interested in information given about child	4.24	0.98	.52*	.34	.25	.14
14	Information provided by nurses was consistent	4.02	0.97	.65*	.41	.44	.27
23	I did not feel as if I was expected to provide care for child	3.86	1.21	.43*	.22	.27	-.14
35	Nurses' approach to care was appropriate to child's age	4.38	0.81	.68*	.31	.39	.17
36	Physical layout of ward met developmental needs of child	3.95	1.11	.55*	.33	.36	.06
37	There was adequate play area for children	3.81	1.24	.45*	.21	.27	-.05
59	Nurses maintained familiar routines for child	3.74	1.05	.59*	.45	.52	.23
Respect as parents							
2	Information included the impact of hospitalisation on the family	2.79	1.31	.37	.52*	.30	.12
3	Information conveyed that families are key participants in care	3.30	1.22	.42	.53*	.37	.25
13	Nurses asked what was normal for child	3.56	1.29	.43	.54*	.40	.31
15	Nurses worked with family to determine amount of involvement	3.47	1.22	.62	.62*	.53	.28
17	Nurses asked every day how much involvement I wanted in care	2.91	1.23	.55	.73*	.58	.33
31	Given opportunity to provide feedback to hospital on care provided	2.81	1.44	.29	.56*	.46	.09
32	Given opportunity to comment on hospital practices	2.65	1.32	.22	.56*	.44	.12
Nurses in supportive role							
39	There was a designated area for parents	3.26	1.38	.40	.35	.48*	.15
40	I was able to sleep away from child if I wished	2.59	1.38	.19	.24	.43*	.12
41	Both parents could stay in hospital if wished	2.71	1.41	.14	.14	.39*	.14
42	Nurses aware of increased costs	2.75	1.24	.29	.32	.46*	.11
43	Nurses ensured I ate meals regularly	2.99	1.45	.36	.49	.62*	.25
45	Nurses discussed strategies to help with other events	2.69	1.25	.42	.46	.64*	.06
47	Nurses helped us to maintain contact with other family/friends	2.74	1.28	.33	.40	.59*	.07
49	Adequate nursing staff to meet family's needs	3.42	1.25	.50	.43	.50*	.14
51	Nurses asked about other things I had to do each day	2.52	1.24	.42	.50	.70*	.22
52	Family encouraged to come and go at any time	3.38	1.30	.41	.35	.53*	.19
Parents empowered							
18	I wanted to continue parenting	4.53	0.74	.19	.13	.12	.38*
19	I wanted to provide nursing	3.16	1.46	.06	.23	.17	.50*
20	I was able to provide as much parenting as I wished	4.57	0.67	.35	.21	.15	.41*
21	I was able to provide as much nursing as I wished	3.81	1.16	.12	.30	.21	.52*

*Item scale correlation corrected for overlap (relevant item removed from its scale correlation).

Subscale Reliability

The reliability of scale scores was estimated using the internal consistency method (Cronbach's alpha coefficient) and is shown in Table 4.11.

Table 4.11
Subscale Internal Consistency for Parents' Questionnaire

Scale	No of cases	No of items	Cronbach's alpha	SD	Mean
Child friendly environment	216	11	.86	7.69	43.69
Respect as parents	220	7	.83	6.36	21.51
Nurses in supportive role	195	10	.84	8.38	28.82
Parents empowered	237	4	.64	2.92	16.11
Total		32	.91	19.54	109.65

To evaluate the distinction between each scale, correlations between each scale were computed and compared with reliability estimates (see Table 4.12). The reliability is greater than the inter-scale correlations thus demonstrating that each scale is measuring a distinct concept.

Table 4.12
Pearson Correlation Coefficients for Subscales and Inter-scale Correlations for Parents' Questionnaire

Scale	Comp 1	Comp 2	Comp 3	Comp 4
Comp 1 Child friendly environment	(.86)			
Comp 2 Respect as parents	.57	(.83)		
Comp 3 Nurses in supportive role	.54	.61	(.84)	
Comp 4 Parents empowered	.21	.31	.23	(.64)

NB. Scale internal consistency reliability (Cronbach's alpha coefficient) is presented in the diagonal.

The use of factor analysis and the results from the psychometric tests reported in this chapter provide evidence to support validity and reliability of the four subscales extracted from the parents' questionnaire suitable for construction. Therefore, the subscales were labelled and the mean for each subscale was calculated to give the average scores for the concepts they were measuring and the mean for the overall scale (see Table 4.13). The higher the mean indicates the greater the parents' perception that family centred care was being provided. The minimum and maximum scores possible for the total scale were 32 and 160.

Table 4.13
Descriptive Statistics for Subscales for Parents' Questionnaire

Subscale	No of items	Minimum	Maximum	Range	Mean
Child friendly environment	11	18	55	37	43.69
Respect as parents	7	7	35	28	21.51
Nurses in supportive role	10	11	50	39	28.82
Parents empowered	4	8	20	12	16.11
Total	32	44	160	116	109.65

Nurses' Questionnaire

Factor Analysis

The same process was followed with the questionnaire completed by nurses. The frequency distribution demonstrated that all response choices were used and responses showed variability in all items. Standard deviations are roughly equivalent within each scale. Principal component analysis was performed by entering 60 items. Six items were omitted from the analysis as they had 'not applicable' as a possible response. The scree plot suggested there were five components and the eigenvalues all exceeded two. The interpretability of the components was examined. No obvious meaning was found for the fourth component, therefore only three components were retained. The three components accounted for 30% of the variance in the data (see Table 4.14).

Table 4.14
Summary of Initial Principal Components Analysis Eigenvalues and Explained Variance for the Nurses' Questionnaire

Component	Scales	Eigenvalue	% Variance	Cumulative % Variance
1	Respect parent role	10.02	16.70	16.70
2	Family focussed hospital	4.55	7.59	24.28
3	Nurse in supportive role	3.42	5.69	29.98

These components were subject to Varimax rotation to minimise high factor loadings on orthogonal axes. Table 4.15 provides the initial rotated factor loadings for three factors. Factor loadings equal to or above .5 were considered significant and are presented in bold.

Table 4.15
Rotated Factor Loadings for the Initial Three Factor Solution for Nurses' Questionnaire

	Item	Component		
		1	2	3
7	routinely tell parents about child's progress	.747		
30	ensure parents are confident in parenting	.688	-.259	.233
5	I provide explanations according to individual needs	.672	.145	-.119
11	try to ensure families adjust to hospitalisation	.651	.148	.231
8	ensure information is regularly communicated	.629	.192	
13	ask parents what is normal for child	.612		-.109
20	parents do as much parenting as they wish	.583		.185
12	value all information from parents	.573		
29	encourage parents to continue parenting	.572	-.240	.127
15	negotiate level of families direct care	.555	.269	.123
6	I provide info on roles of health professionals	.524	.176	-.123
17	clarify parents level of care each shift	.524	.381	
56	encourage families to come and go as needed	.494		.228
63	try to maintain home routine while in hospital	.457	.229	.233
59	respect family decisions not to stay in hospital	.454	-.125	.147
1	every family receives information about hospitalisation	.447	.216	.229
60	reassure on care if parents leave the ward	.390	-.166	.206
27	document parents desired level of child care	.379	.312	
58	organise child's care so families can be elsewhere	.357	.211	.264
39	have adequate knowledge of child development	.312	.269	.126
18	parents want to continue parenting in hospital	.142		
22	do not expect parents to do parenting	-.117		
34	families involved in hospital staff education	-.190	.655	
43	designated comfortable area for families		.654	
32	seek feedback from families on meeting their needs		.572	.205
33	parents contribute to policies and practices		.569	.200
38	special skills recognised		.551	.141
40	layout of ward designed to meet needs of child & families		.509	-.124
41	adequate play area for children of all ages		.509	-.137
36	expected to know child development, paediatric nursing etc		.496	
14	staff maintain consistency with info to parents	.309	.491	.118
45	both parents can stay in hospital if they wish		.489	.332
52	staffing patterns planned for needs of children		.484	
2	info includes the impact on the family	.210	.473	
42	staff / family discussions held in private area	.153	.461	.123
44	parents can sleep in separate room if desired		.461	.152
3	all info says families are key participants in care	.277	.457	
64	same staff assigned to care for child and family	.201	.302	.162
25	policies allow families providing full parenting	.158	.243	.161
57	do not expect parent to be with child all the time	-.140	-.228	
49	ensure adequate toiletries after sudden admission	.260	.130	.702
48	ensure parents eat meals regularly	.231	.163	.633
51	help hospitalised children / families contact others	.264	.104	.626
50	always assess needs of siblings	.178	.294	.615
21	parents do as much nursing as they wish			.489
31	parents welcome during all procedures	.173	-.187	.479
55	always ask about other family commitments	.325	.261	.469
26	policies allow parents providing nursing			.467
62	family included in all aspects of child's care	.331	.229	.464
61	family is integral part of health care team	.198	.120	.451
9	families can access information whenever they wish	.106	.146	.431
28	families involved in care encouraged to share info	.239	.127	.399
23	do not expect parents to provide nursing	.107	-.207	-.318
53	ward is not frequently short staffed	-.146		.312
54	ward is not frequently busy	-.247		.297
47	assist families manage other needs during hospitalisation	.216	.240	.293
19	parents want to provide nursing whilst in hospital		.141	.292
24	ask parents to help with care when busy	.213		.289
46	families incur increased costs when child in hospital		-.227	-.262
16	staff do not decide on child's care then tell family			.198

Twenty three items were retained when all items that failed to load above .50 were excluded. Table 4.16 presents a summary of eigenvalues and variance for the final factor solution and Table 4.17 presents the final rotated factor solution.

Table 4.16
Summary of Final Principal Components Factor Analysis Solution and Explained Variance for Nurses' Questionnaire

Component	Scales	Eigenvalue	% Variance	Cumulative % Variance
1	Respect parent role	6.08	23.39	23.39
2	Family focussed hospital	3.34	12.85	36.24
3	Nurse in supportive role	2.64	10.15	46.39

Table 4.17
Rotated Factor Loadings for the Final Three Factor Solution for Nurses' Questionnaire

Item	Component			
	1	2	3	
7	Routinely tell parents about child's progress	.784		
8	Ensure information is regularly communicated	.736	.154	
5	I provide explanations according to individual needs	.703		
13	Ask parents what is normal for child	.701		-.124
20	Parents do as much parenting as they wish	.629		.110
12	Value all information from parents	.614	.122	
30	Ensure parents are confident in parenting	.613	-.254	.301
11	Try to ensure families adjust to hospitalisation	.576		.436
17	Clarify parents level of care each shift	.558	.264	.204
15	Negotiate level of families direct care	.543	.182	.311
29	Encourage parents to continue parenting	.513	-.279	.195
6	I provide info on roles of health professionals	.505		
34	Families involved in hospital staff education	-.141	.736	
43	Designated comfortable area for families	.101	.685	.113
40	Layout of ward designed to meet needs of child & families		.648	-.196
33	Parents contribute to policies and practices		.629	.253
41	Adequate play area for children of all ages	.156	.602	-.187
32	Seek feedback from families on meeting their needs		.597	.330
38	Hospital recognises knowledge needed to care for children		.564	.103
49	Ensure adequate toiletries after sudden admission	.133		.786
51	Help hospitalised children / families contact others	.138		.767
50	Always assess needs of siblings		.255	.735
48	Ensure parents eat meals regularly	.141	.122	.719

Summated Scales

The three components were tested for data quality, scaling assumptions and reliability to test whether the components could produce a valid summated scale. Each item was examined for missing data, distribution, mean and standard deviation (see Table 4.18). No item had large amounts of missing data indicating that respondents were able to answer the questions.

Table 4.18

Item Descriptive Statistics for Nurses' Questionnaire

Number	Item Label	Missing %	Mean	SD	Response frequency				
					1*	2*	3*	4*	5*
Respect parent role									
5	Provide explanations according to family needs	1.9	4.45	0.55	0	0	3	52	51
6	Provide information on health professionals roles	0.9	4.07	0.79	0	5	14	56	32
7	Routinely tell parents about their child's condition	0.9	4.51	0.62	0	1	4	41	61
8	Ensure regular communication about child's care	0.9	4.39	0.70	0	2	7	45	53
11	Ensure families adjust to hospitalisation	0.9	4.13	0.74	0	2	17	53	35
12	I value all information parents give about child	0.9	4.66	0.51	0	0	2	32	73
13	I ask parents what is normal for their child	0.9	4.70	0.48	2	4	13	57	31
15	Negotiate with families level of participation in care	0.9	4.04	0.86	0	0	1	30	76
17	Clarify with parents participation in care each shift	1.9	3.73	0.86	1	8	27	53	17
20	Parents continue as much parenting as they wish	0.9	4.55	0.54	0	0	2	44	61
29	Parents are encouraged to continue parenting	0.0	4.44	0.66	1	0	4	49	54
30	Ensure parents feel confident to continue parenting	0.9	4.42	0.53	0	0	2	58	47
Family focussed hospital									
32	Seek feedback from families about needs met	0.0	3.23	1.14	5	30	23	35	15
33	Parents contribute to hospital policies and practices	0.0	2.60	1.24	25	30	23	23	7
34	Families involved in hospital staff orientation/cont. ed.	0.0	2.01	1.01	40	39	19	8	2
38	Hospital recognises knowledge needed to care for children	0.0	2.64	1.22	24	28	25	25	6
40	Layout designed to meet children and family needs	0.0	2.91	1.23	16	27	27	27	11
41	Adequate play area for children	0.0	2.75	1.28	20	34	18	25	11
43	Designated comfortable area for families	0.0	2.98	1.42	22	29	9	31	17
Nurses in supportive role									
48	Ensure parents eat meals regularly	0.0	3.63	1.03	4	11	27	45	21
49	Ensure parents have adequate toiletries	0.0	3.86	0.96	3	7	19	52	27
50	Always assess concerns of siblings	0.0	3.28	0.97	3	21	36	39	9
51	Help children and family remain in contact with friends	0.0	3.65	0.93	2	11	27	51	17

*1 = strongly disagree; 2 = disagree; 3 = undecided; 4 = agree; 5 = strongly agree

Item Internal Consistency

Each item was evaluated for its relationship with each other item in the scale defining the concept it was hypothesised to measure. Item internal consistency was calculated and results presented in Table 4.19. All items had roughly equal item-scale correlations therefore contributing equal proportions of information to the total scores of each scale.

Item Discriminant Validity

The relationship of each item to other components were also tested to determine the extent to which the item measured the other concepts. The correlation for each item and its hypothesised scale is significantly higher than its correlation with the other scales thus supporting item discriminant validity. These data are also included in Table 4.19.

Table 4.19

Item Descriptive Statistics and Pearson Item-scale Correlations Corrected for Overlap for Nurses' Questionnaire

Item		Mean	SD	Pearson item-scale correlation*		
Number	Label			Comp 1	Comp 2	Comp 3
Component 1: Respect parent role						
5	Provide explanations according to family needs	4.45	0.55	.59*	.08	.14
6	Provide information on health professionals roles	4.07	0.79	.44*	.07	.11
7	Routinely tell parents about their child's condition	4.51	0.62	.70*	.10	.21
8	Ensure regular communication about child's care	4.39	0.70	.61*	.18	.15
11	Ensure families adjust to hospitalisation	4.13	0.74	.59*	.12	.49
12	I value all information parents give about child	4.66	0.51	.47*	.14	.16
13	I ask parents what is normal for their child	4.70	0.48	.53*	.08	.06
15	Negotiate with families level of participation in care	4.04	0.86	.58*	.23	.32
17	Clarify with parents participation in care each shift	3.73	0.86	.56*	.25	.24
20	Parents continue as much parenting as they wish	4.55	0.54	.51*	.04	.18
29	Parents are encouraged to continue parenting	4.44	0.66	.43*	-.90	.13
30	Ensure parents feel confident to continue parenting	4.42	0.53	.57*	-.06	.25
Component 2: Family focussed hospital						
32	Seek feedback from families about needs met	3.23	1.14	.20	.49*	.33
33	Parents contribute to hospital policies and practices	2.60	1.24	.12	.49*	.24
34	Families involved in hospital staff orientation/cont. ed.	2.01	1.01	-.03	.59*	.08
38	Hospital recognises knowledge needed to care for children	2.64	1.22	.10	.41*	.20
40	Layout designed to meet children and family needs	2.91	1.23	.04	.54*	-.01
41	Adequate play area for children	2.75	1.28	.12	.48*	-.01
43	Designated comfortable area for families	2.93	1.42	.16	.56*	.25
Component 3: Nurses in supportive role						
48	Ensure parents eat meals regularly	3.63	1.03	.30	.17	.60*
49	Ensure parents have adequate toiletries	3.86	0.96	.26	.19	.68*
50	Always assess concerns of siblings	3.28	0.97	.24	.27	.69*
51	Help children and family remain in contact with friends/family	3.65	0.93	.30	.16	.68*

* Item-scale correlation corrected for overlap (relevant item removed from its scale correlation).

Subscale Reliability

Correlations between scales were evaluated to measure the reliability of the scales using the internal consistency method (Cronbach's alpha coefficient). Results are shown in Table 4.20.

Table 4.20
Subscale Internal Consistency for Nurses' Questionnaire

Subscale	No of cases	No of items	Cronbach's alpha	SD	Mean
Respect parent role	105	12	.86	5.02	52.05
Family focussed hospital	108	7	.78	5.65	19.06
Nurses in supportive role	108	4	.83	3.17	14.42
Total Scale		23	.83	9.81	85.57

Correlations between each scale were computed and compared with reliability estimates to evaluate the distinction between each scale (see Table 4.21). The reliability is greater than the inter-scale correlations thus demonstrating that each scale is measuring a distinct concept.

Table 4.21
Pearson Correlation Coefficients for Subscales and Inter-scale Correlations for Nurses' Questionnaire

Subscale	Comp 1	Comp 2	Comp 3
Comp 1 Respect parent role	(.86)		
Comp 2 Family focussed hospital	.16	(.78)	
Comp 3 Nurses in supportive role	.33	.24	(.83)

NB. Scale internal consistency reliability (Cronbach's alpha coefficient) is presented in the diagonal.

The use of factor analysis and the results from the psychometric tests reported in this chapter provide evidence to support validity and reliability of the three subscales extracted from the nurses' questionnaire suitable for construction. Therefore, the subscales were labelled and the mean for each subscale was calculated to give the average scores for the concepts they were measuring and the mean for the overall scale (see Table 4.22). The higher the mean indicates the greater the nurses' perception that family centred care was delivered. Table 4.22 provides the mean for individual scales and for the total scale. The minimum and maximum scores possible for the total scale were 23 and 115.

Table 4.22
Descriptive Statistics for Subscales for Nurses' Questionnaire

Subscale	No of items	Minimum score	Maximum score	Range	Mean
Respect parent role	12	37	60	23	52.05
Family focussed hospital	7	8	32	24	19.06
Nurses in supportive role	4	4	20	16	14.42
Total	23	49	112	63	85.57

Summary

Tests for internal consistency of the subscales thought to measure the eight elements of family centred care for both the parents' questionnaire and the nurses' questionnaire did not provide evidence to support the reliability and validity of the original subscales. Therefore, factor analysis was undertaken for each questionnaire to determine the components of family centred care assessed. Four components were identified from the parents' questionnaire and three components from the nurses' questionnaire. Further psychometric tests were presented to support the construction of multi-item scales for each questionnaire.

Internal consistency of the scales and inter-scale correlations supported the scales were measuring separate concepts of family centred care. Each subscale was labelled and descriptive statistics generated for each subscale and the overall scales for parents and nurses.

Chapter Five

Results

Chapter Four provided the results relating to reliability and validity of the new subscales following exploratory factor analysis of both the parents' and nurses' questionnaires. This chapter describes the parents who completed the questionnaires, the children who were hospitalised and the nurses who completed the questionnaire. These data are followed by the results of parents' and nurses' perceptions of the provision of family centred care as assessed by the new subscales. The subscales for each questionnaire are described. Comparisons of means are presented between dependent variables and measures of family centred care for the parents followed by results from the nurses' questionnaire. Comparisons between the two groups are reported. The questionnaires invited further comments from parents and nurses if they wished to clarify or give examples of incidents when family centred care was or was not practised. The simple manifest content analysis and frequencies of the descriptors from these open ended questions complete the chapter.

Responses

In response to the request to identify parents (who had a child under the age of 10 years admitted as an inpatient within the previous six months), nominated staff at each of the fifteen hospitals estimated 770 parents and 249 nurses who provided direct care to hospitalised children. (See Chapter Three for the limitations of this data collection method.) Twenty six questionnaires were returned to the researcher as parents were no longer at the address where they resided when their child was hospitalised. Two hundred and sixty parents returned the questionnaire (response rate of 35.0%) however, thirteen could not be included as the children were older than ten years of age and a further four were excluded as they did not meet the inclusion criteria of being inpatients in the hospital. A total of 243 parents were included in the results.

One hundred and eleven nurses returned the questionnaire to the researcher which is a response rate of 45.0%. Of those, three were deemed unsuitable for inclusion. Two did not provide sufficient data and one respondent was an Aboriginal Health Worker

and not a nurse therefore not meeting the inclusion criteria. There remained a total of 108 Nurse respondents.

Characteristics of the Families

The parents' questionnaire was completed by the mother of the hospitalised child for 230 (94.7%) families. Twelve (4.9%) fathers completed the questionnaire. One respondent did not identify their relationship to the child.

One hundred and thirty four (55.1%) respondents described the composition of their family as having two parents, 56 (23.0%) described their family as having at least one parent plus significant input into the daily care of the children by grandparents, aunts, uncles, friends or carers, and 23 (9.5%) described their family as single parent. Thirty respondents did not define their 'family'. One hundred and thirty three (54.7%) of the hospitalised children had siblings whereas for eighty families (32.9%) the hospitalised child was the only child. Data were not available for thirty respondents.

Parents were asked if anyone offered social support while their child was hospitalised. Social support included caring for other children in the family while the parents were busy with the hospitalised child. All but 23 (9.5%) said they had social support and that it was offered by friends, immediate family, parents, or parents-in-law.

Fifty six (23.0%) of the parents who responded had worked within a hospital prior to their child being admitted. Thirty one (12.8%) had worked as nurses, ten (4.1%) had been employed as domestics, orderlies or patient care assistants and four (1.6%) classified themselves as allied health professionals. Eleven respondents did not specify the capacity in which they had worked in a hospital.

The socio-economic situation of individual families such as social class and employment were not sought. However, the socio-economic status (SES) rank of the areas where the hospitals were located can be reported using the SES ranking provided by Australian Bureau of Statistics (2003). The SES rank is based on educational background and occupation of the population within a specified area with the top 25% in the state ranked as 'high', the next 50% ranked as 'middle' and the bottom 25% ranked as 'low'. This ranking reflects the average family income in the area. Eight hospitals included in this study were situated in areas ranked as

‘middle’ SES with seven hospitals in areas ranked as ‘low’. However, the eight hospitals ranked as middle SES, accounted for 215 of the families included in this study compared with only 28 families being hospitalised in the areas with ‘low’ SES ranking.

Characteristics of the Children

The ages of the children when they were admitted to hospital ranged from two days old to a child who was 9 years and 11 months of age. The average age was three years and eleven and a half months (47.5 months) and the average length of hospitalisation was 3.5 days with a range of one day to three months.

The majority (72.0%) of children were emergency admissions and 77.4% children were admitted to regional hospitals. Table 5.1 provides numbers for the ‘level of hospital’ and ‘admission mode’. Most parents (68.7%) stated that their child was hospitalised within the district where they lived. This does not mean however, that the hospital was close. Several parents commented that it would take anything from 50 minutes to one and a half hours to drive from their home to the hospital.

Table 5.1
Level of Hospital and Mode of Admission

Hospital Type	Emergency admission		Booked admission		Total	
	Frequency	Percent*	Frequency	Percent*	<i>n</i>	Percent*
Regional	126	52	62	25.5	188	77.4
District	49	20	6	2.5	55	22.6
Total	175	72	68	28.0	243	100.0

* = Percent of total (*N* = 243)

Respiratory dysfunction was the most frequent cause of admission for children with 66 (27.1%) admissions. Thirty five (14.5%) children were admitted with dysfunction of the gastrointestinal tract which was the next most frequent cause. ‘Other infections’ were those that were not included under the body systems listed in the table, or the infection was not specified by the parent; these accounted for 34 (13.9%) admissions. Five (2.1%) preterm babies were transferred to rural hospitals from the metropolitan area to establish feeding and maintain thermoregulation.

Miscellaneous reasons for admission accounted for 11 (4.5%) admissions and included renal investigations, Henoch Schonlein Purpura, thrombocytopenia, nephrotic syndrome and ‘routine procedure’. Table 5.2 gives a further breakdown of the reasons why the children were hospitalised. One hundred and twenty three

(50.6%) of the children had been hospitalised previously. These figures are based on data reported by the parents.

Table 5.2
Reasons for Child's Admission to Hospital Reported by Parent

Reason for hospitalisation	Frequency	Percent
Respiratory dysfunction		
Asthma	27	11.1
Respiratory tract infections	27	11.1
Tonsillitis/tonsillectomy	12	4.9
Gastrointestinal dysfunction		
Gastroenteritis	29	12.0
Appendicitis	6	2.5
Trauma and poisoning		
Bony fractures	19	7.8
Burns	8	3.3
Ingestion	3	1.2
Near drowning	1	0.4
Scorpion bite	1	0.4
Surgery (unspecified)	30	12.5
Neurological dysfunction		
Seizures	9	3.7
Meningitis	5	2.1
Head injury	3	1.2
Migraine	1	0.4
Dental surgery	12	4.9
Other infections		
Pyrexia (unspecified)	15	6.2
Infection (unspecified)	9	3.7
Viral infection	4	1.6
Urinary tract infection	3	1.2
Varicella	2	0.8
Septic arthritis of hip	1	0.4
Establish feeding/thermoregulation	5	2.1
Miscellaneous	11	4.5
Total	243	100.0

Characteristics of the Nurses

Table 5.3
Age Range of Nurses, Parental Status and whether Child had been Hospitalised

Age Range	Frequency	Percent	Parent		Child hospitalised	
			Frequency	Percent	Frequency	Percent
21 – 25 years	4	3.7	0	0.0	0	0.0
26 – 30 years	9	8.3	2	1.9	0	0.0
31 – 35 years	15	13.9	6	5.6	5	4.6
36 - 40 years	23	21.3	17	15.7	8	7.4
41 – 45 years	22	20.4	21	19.4	18	16.7
46 – 50 years	12	11.1	10	9.3	10	9.3
> 50 years	23	21.3	21	19.4	18	16.7
Total	108	100.0	77	71.3	59	54.6

One hundred and four (96.3%) of the nurses who responded to the questionnaire were female, two (1.9%) were male and two respondents did not answer this question. The majority of respondents (88%) were over 31 years of age, 71.3% were

parents and 54.6% of the nurses had their child hospitalised at some time. Table 5.3 provides details of nurses categorised by age who are parents and whether their child has been hospitalised.

Thirty five respondents were enrolled nurses and 73 were registered nurses. Table 5.4 presents the level of nurses and the level of hospital in which they were working.

Table 5.4
Level of Nurses by Level of Hospital

Level of hospital	Registered Nurse		Enrolled Nurse		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Regional hospital	17	15.7	7	6.5	24	22.2
District hospital	56	51.9	28	25.9	84	77.7
Total	73	67.6	35	32.4	108	100.0

Twenty three registered nurses indicated they had post registration qualifications. Table 5.5 shows level of registration with the Nurses Board of Western Australia (NBWA) and further qualifications indicated by the nurses. Other related post registration qualifications included five registered nurses who had received a child health nursing qualification. Midwifery was the only other certificate indicated by 13 nurses. (Some of the nurses had both midwifery and child health qualifications).

Table 5.5
Highest Level of Nursing Qualification

Nursing qualification	Frequency	Percent
Enrolled Nurse:		
Hospital Certificate	28	25.9
Associate Diploma of Health Science	7	6.5
Registered Nurse:		
Hospital Based Diploma	40	37.0
Bachelor of Nursing/Applied Science/Science	33	30.5
Further qualifications:		
Midwifery	13	12.0
Child Health Nursing	5	4.6
Paediatric Certificate/qualification for RN	3	2.8
Paediatric Certificate for Enrolled Nurses	1	0.9
Higher degree qualification	3	2.8

The number of years worked as a nurse ranged from one to 43 years, with a median of 20 years. Fifty percent of the nurses had worked with children for up to ten years and 25% had nursed children for less than five years. One hundred and three (95.4%) of the nurses stated their main area of nursing was clinical with 58.3% of them classifying themselves as generalists. Five respondents classified their main roles as management and nine (8.3%) stated their main area was paediatrics. Table 5.6 lists

the main areas of nursing practice as described by nurses. The total is greater than 108 as those who nominated nursing management also nominated a main area of clinical practice and are therefore included twice.

Table 5.6
Main Area of Nursing Practice

Area of nursing	Frequency	Percent
Clinical nursing:		
Generalist	63	58.3
Medical	16	14.8
Midwifery	9	8.3
Paediatrics	9	8.3
Emergency	7	6.5
Gerontology	2	1.9
Operating rooms	1	0.9
Surgical	1	0.9
Nursing management	5	4.6

Subscales of Family Centred Care

Following reliability and validity testing, the subscales were labelled according to the concept of family centred care that they were assumed to measure. The results of each subscale are provided here and quotes from nurses and parents included where appropriate to highlight points being made. Item descriptive statistics for the parents' questionnaire are provided in Table 4.9 and Table 4.18 for the nurses' questionnaire. Descriptive statistics for the subscales of family centred care are provided in Table 4.13 for parents' questionnaire and Table 4.22 for nurses' questionnaire.

Parents' Perceptions of the Provision of Family Centred Care

Child Friendly Environment

Of the four subscales identified from the parents' questionnaire, 'child friendly environment' rated the highest with a mean score of 3.98. This encompassed things that nurses did for parents and children to make the hospital a less threatening place and included the physical layout of the area where the child was hospitalised and information relating to the child.

The highest scoring item within this scale was parents' perception that the nurses' approach to their child's care was appropriate for the child's developmental stage ($M = 4.38$; $SD = 0.81$) and one of the lower scoring items ($M = 3.74$; $SD = 1.05$) was parents' perception of 'nurses maintaining normal routines for the child' when hospitalised. This latter perception is highlighted by a comment from a parent of a two year old child:

“The nurses should ask you about the child’s daily routine and help you stick to it. ...bed lower to the ground so if your child is potty trained they can hop out themselves and go.” (02-027).

This comment also includes reference to the lack of provision of equipment appropriate to the child’s developmental needs which was included in this subscale. Other comments by parents referred to staff maintaining the hospital routine at the expense of providing individualised care and the inability of parents to maintain the child’s routine when hospitalised, for example:

“Hospital is a busy place – jobs need to be done – cleaners/nurses – more important in their day to complete tasks than to consider the needs of individuals.” (01-241)

Although ‘physical layout of ward met developmental needs of child’ was perceived to occur ($M = 3.95$; $SD = 1.11$) there were occasions when it did not as illustrated by the previous comment referring to the bed being too high and the following comment from a parent whose child was admitted to a district hospital and placed in a ward with an adult patient:

“A child’s (sic) ward would be great; my six year old daughter was in with a 70 year old lady”. (07-001)

Despite the few negative comments provided by parents to highlight aspects of ‘child friendly environment’, overall parents in this study responded positively to these questions and agreed that these areas of care were delivered when their child was hospitalised.

Respect as Parent

The mean item score for this subscale was 3.07 with four of the seven items below ‘3’ indicating that parents did not perceive the recognition and acknowledgement due to them, occurred consistently. Parents perceived that nurses asked them what was normal for their child and conveyed that families were key participants in the care of their child. Nurses asked what care the family wished to be involved in ($M = 3.47$; $SD = 1.22$), however the amount of involvement in care was not clarified on a regular basis ($M = 2.91$; $SD = 1.23$). Parents’ comments from the open ended questions demonstrate both the strengths and weaknesses within this theme of ‘respect as parents’:

“I was pleased to be asked ‘what would you like to do’ regarding my child’s care. I was permitted to make decisions; I did not expect this.” (01-198)

“I felt that I had lost any control I should have had over my child’s health care. I was kept informed of his medical needs but not included in any decisions regarding his care. We were expected to conform to hospital practices.” (02-121)

The same mother went on to say:

“...more open discussion and understanding of the fact that the person they are treating is not their patient, but my child.” (02-121)

Another parent wrote:

“There was an instance where my son would not take his medication and while I was downstairs they put a tube down his throat which made him more upset. They should have waited for me to come back.” (16-132)

The latter comments imply a lack of respect by nurses for a parent’s role. These parents were completely disempowered by having any decision-making taken away from them. They wanted to be included in decisions regarding their child and acknowledgement that the patient is their child.

One of the lower scoring items within this subscale was parents’ perception of receiving information related to the impact of hospitalisation on the family ($M = 2.19$; $SD = 1.31$). This is highlighted by comments written by one mother who, in retrospect, would have liked nurses to have suggested to her:

“...that my child’s stay may impact on her sibling. ...found out in later weeks the distress (sic) caused to her sister through reading her school diary”. (01-059)

The child who was ill was an emergency admission and remained in hospital for four days with asthma.

The other aspect within this theme of ‘respect as parent’ related to parents being asked to provide feedback on the care they received. Parents did not recall being asked to evaluate the care they received or comment on hospital practices or policies that impacted their child and family’s care ($M = 2.81$; $SD = 1.44$ and $M = 2.65$; $SD = 1.32$ respectively).

Nurses in Supportive Role

Parents rated items that were classified in the subscale ‘nurses in supportive role’ less positively than those in the ‘child friendly environment’. Seven of the ten items had a mean below ‘3’ which indicates that parents perceived that nurses did not consistently support parents. This subscale encompassed parents’ perception of the support nurses provided for them particularly in helping parents attend to other roles that they had and also enabling parents to obtain meals, access appropriate sleeping arrangements and have some privacy while in hospital with their child. This subscale measured things that nurses could offer to support parents when their child was hospitalised thus making it easier for parents to care for their child. It did not measure care related directly to the child.

The item that received the lowest score was parents being asked about other things they had to do each day ($M = 2.52$; $SD = 1.24$). Examples given by parents which demonstrated nurses’ lack of support relate to the nurses’ lack of awareness that parents wanted a break from caring for their child in order to have time to care for themselves. Parents wanted the nurses to offer to sit with their child thus enabling the parent to leave to get a meal, sleep, or have a shower. The following examples of comments by parents highlight this aspect:

“a nurse to look after my child whilst I ducked home to grab a change of clothes and something to eat as I wasn’t offered anything for dinner...some soap and a towel to have a shower...a chance to go to the toilet for myself.” (34-002)

“I informed staff that I’d been without sleep almost 48 hours yet I was not given time to rest and still expected to care for my child...” (13-049)

“...at times I didn’t have a meal ‘cause I could not leave her. Perhaps nursing staff could have stayed with her and encouraged me to go.” (1-063)

Two parents commented that they had just had surgery themselves yet still were expected to care for their child. They suggested that they would have appreciated help to organise family or friends to care for their child so they could rest and recover from surgery.

There were positive comments regarding the support that nurses offered parents:

“they encouraged me to stay.... When (child) was settled after her fit they encouraged me to go home, shower, clean clothes, food etc. (time out) and to then come back and settle for the night. Very happy to look after her.” (1-128)

This illustrates that the mother was given the support she required to make decisions about her own care. The mother was able to leave her child as she trusted the nurses to care for her child in her absence while she cared for herself. The following is a comment from a parent illustrating that the support was beyond her expectations:

“The level of care was superb and exceeded expectations ...looked after us as friends.” (16-058).

Many comments from the parents written in the open ended questions related to the rudeness of staff, parents being made to feel as if they were a nuisance, nurses being loud and rough with the child and the inappropriate attitude of some nurses. Parents usually clarified their comments by saying it ‘was only one nurse’ or ‘the rest were fine’. Being rude classifies as nurses being non - supportive and here are some examples:

“I was made to feel that I was wasting hospital beds that my child was not sick enough...” (13-050)

“My daughter’s condition had been happening for 10 days and when I got to hospital several nurses (NOT ALL) made me feel like a paranoid mother.” (04-016)

“Need more old fashioned bed side manner and treat people the way you would want to be treated.” (16-132)

“I had my period at the time and my friend forgot to pack my supplies. I asked a nurse if they had sanitary pads, she said no. I had no one to ask to bring my supplies and I ended up using a nappy from my son’s bag.” (01-028)

The mother’s problem solving abilities are to be admired, however the hospital did have a maternity unit and would therefore have had sanitary pads. The child was an emergency admission to the hospital following a febrile convulsion.

Parents Empowered

The fourth subscale identified from the parents’ questionnaire relates to parents’ wishes to participate in their child’s care. Parents wanted and were able to provide all the parenting they wished ($M = 4.53$; $SD = 0.74$ and $M = 4.57$; $SD = 0.67$)

respectively). Not as many wished to provide nursing care ($M = 3.16$; $SD = 1.46$) however a higher score was given for parents' ability to provide as much nursing care as they wished ($M = 3.81$; $SD = 1.16$). The results from this subscale are discussed in Chapter Six in comparison to nurses' perceptions in the section on parental participation in care.

Nurses' Perceptions of their Provision of Care

Respect for Parent Role

'Respect for parent role' was the highest scoring subscale perceived by nurses ($M = 4.34$) with eleven of the twelve items scoring a mean greater than '4' which indicates that nurses perceive that they consistently deliver these aspects of care to families. This theme included items about the information provided to parents, the regularity of provision, the relationship of the information to the child's care and its tailoring to the family's needs. The other aspect encompassed by this theme related to nurses listening to the parents' information about their child, valuing the information and then promoting and encouraging parents to be involved in their child's care as much as the parents wished. The lowest score in this subscale was nurses' perception that on each shift they discuss the amount of care parents wish to provide. Although it scored the lowest within this subscale, the mean was 3.73 ($SD = 0.86$) on the five point Likert scale indicating that nurses believe they do this consistently.

Nurses in Supportive Role

'Nurses in supportive role' reflects the extra support that nurses believe they offer parents. This support is aimed at assisting parents and families with aspects that are not directly associated with the child's care such as adequate toiletries for parents when the admission was unexpected and scored a mean of 3.61. Each item scored a mean greater than '3' which indicates that nurses perceive they mostly provide this aspect of care for families. Assessing the concerns of siblings was the lowest scoring item in this subscale ($M = 3.28$; $SD = 0.97$).

The following comments from nurses to the open ended questions reflect their views on the 'nurse in supportive role':

"I feel families require more time with staff, more information sessions and a private venue allocated for such times. Time and staff are issues." (01-014)

“Often busy/short staffed in an acute situation therefore don’t necessarily have the time.” (04-003)

“Time allocated to care is limited. We do the best to our ability and the length of stay on each admission. Parents are usually very stressed...” (10-008)

These comments all reflect that nurses believe they are too busy. The direct care for the child is attended to but supporting the family is seen as ‘extra’ and therefore doesn’t get provided consistently.

Another reason why nurses may not provide support to parents is their reluctance to ask questions of families as they may discover problems that they feel unable to manage. This is highlighted in the comment from a nurse:

“Not enough education given to staff to deal with social problems.” (02-026)

Family Focussed Hospital

This subscale reflects organisational level factors and not care that nurses offer directly to children and families. It covers the physical layout of the ward and whether policies and practices promoted by the health service implied a family focus. Across all the subscales, for both parents and nurses, this scored the lowest item mean ($M = 2.73$) with all but one item scoring a mean below ‘3’. This indicated that these aspects are not consistently addressed. The only item that scored a mean higher than ‘3’ referred to something that nurses could include in their individual practice - seek feedback from families. Parents were not invited to participate in staff orientation to include the parental perspective of having a child hospitalised or consulted on policies and practices that impinge on family care. The lack of support and infrastructure provided by the health service is reflected in the following comments by nurses:

“Little experience in children’s care – but huge organisational expectation that children are ‘just little adults’ and can be nursed in an adult unit – maybe near elderly people. Hospital Managers should be targeted to provide appropriate time for care of children but of course, this does come back to funding so one needs to look at the HDWA and government funding. (05-009)

“No area to include parents in the hospital as ward too small, often in way – space issue.” (02-026)

Group Comparisons

Parents

Comparisons were made between level of hospital, respondents' characteristics and parents' perceptions of family centred care as assessed by the subscales.

Level of Hospital

The number of respondents for each subscale ranged from 195 for 'nurses in supportive role' to 237 for 'parents empowered'. Table 5.7 shows the descriptive statistics and summarises results of *t*-test for subscales by level of hospital.

There was a statistically significant difference between parents' perception of 'child friendly environment' and whether the hospital was a regional or district hospital. The mean score for parents' perception of 'child friendly hospital' was greater for those whose child was admitted to a regional hospital. No significant differences were observed between the level of hospital for the remaining subscales.

Table 5.7
Summary of *t*-test for Parents' Perceptions of Family Centred Care by Level of Hospital

Subscale	District		Regional		<i>df</i>	<i>t</i>	<i>p</i>
	Mean	<i>SD</i>	Mean	<i>SD</i>			
Child friendly environment	41.18	8.69	44.45	7.22	70	2.42	.02
Respect as parents	21.52	5.32	21.51	6.63	218	-0.10	.99
Nurses in supportive role	29.64	9.07	28.56	8.17	193	-0.77	.44
Parents empowered	16.15	2.66	16.10	3.00	235	-0.11	.91

Social Support

Comparisons were made between the amount of social support parents reported having while their child was hospitalised and the four subscales of family centred care (Table 5.8). Social support was grouped into immediate family which included partner and children over 15 years of age; extended family/friends which included in laws, other relatives and friends and the third group who reported they had no one to offer social support while their child was hospitalised.

There was a significant difference between the parents' perception of their 'respect as parents' according to the amount of social support received ($F = 3.78$, $df = 2, 217$, $p = .02$). Results of Tukey's Honestly Significant Difference (HSD) post-hoc test, identified that the significant difference was between those who had immediate family for support and those parents who had no social support ($p = .02$) with those who had support perceiving they received more 'respect as parents'.

Table 5.8
Descriptive Statistics for Parents' Perceptions of Family Centred Care by Amount of Social Support

Amount of support by subscale	n	Scores for subscales		
		Mean	SD	Range
Child friendly environment				
Immediate family	152	43.57	7.56	24 – 55
Extended family	49	44.39	7.60	23 – 55
No support	15	43.69	9.51	18 – 55
Respect as parents				
Immediate family	152	22.06	6.26	7 – 35
Extended family	51	21.16	6.31	7 – 35
No support	17	17.71	6.34	7 – 29
Nurses in supportive role				
Immediate family	141	29.02	8.56	11 – 50
Extended family	40	29.03	7.60	15 – 45
No support	14	26.21	8.82	12 – 43
Parents empowered				
Immediate family	159	16.08	2.95	8 – 20
Extended family	55	16.24	2.99	10 – 20
No support	23	16.04	2.69	10 – 20

Previous Hospital Experience

Differences in parents' perceptions of family centred care according to parents' previous experience with hospitals were examined. Parents' previous experience with hospitals was categorised as follows: no previous experience with hospitals; the parent had worked in a hospital or they have had a child or other immediate family member hospitalised. Table 5.9 shows the descriptive statistics for previous hospital experience by subscales.

Table 5.9
Descriptive Statistics for Parents' Perceptions of Family Centred Care by Previous Hospital Experience

Previous hospital experience	n	Scores for subscales		
		Mean	SD	Range
Child friendly environment				
Immediate family member hospitalised	138	44.06	7.33	23 - 55
Worked in hospital	50	42.36	8.79	18 - 54
None	26	43.92	7.25	28 – 55
Respect as parents				
Immediate family member hospitalised	141	21.28	6.24	7 – 35
Worked in hospital	51	21.29	6.72	7 – 35
None	26	22.85	6.44	9 – 35
Nurses in supportive role				
Immediate family member hospitalised	126	28.52	8.39	11 – 50
Worked in hospital	41	27.39	8.14	12 – 43
None	26	32.81	8.00	17 – 49
Parents empowered				
Immediate family member hospitalised	152	15.86	2.82	9 – 20
Worked in hospital	54	16.76	3.15	8 – 20
None	29	16.14	3.01	11 - 20

There was a significant difference in parents' perceptions of 'nurses in supportive role' according to level of previous hospital experience. ($F = 3.70$, $df = 2$, 190 , $p = .03$). Parents who had no previous hospital experience had statistically significantly greater perceptions of family centred care compared with those who have worked in a hospital and those who have had a family member hospitalised previously ($p = .02$ and $p = .04$ respectively).

No significant differences in perceptions of family centred care were identified according to whether the hospitalisation was a booked or emergency admission, whether the family lived in the district or family composition.

Child's Age

Associations between the age of the child when hospitalised and parents' perceptions of family centred care were examined. There was a significant weak negative correlation between the age of the child and parents' scores for 'respect as parent' ($p = .00$, $r = -.31$) which showed that the younger the child, the greater 'respect as parent' perceived by parents. A weak negative correlation was found between the child's age and greater parents' perception of 'nurses in a supportive role' ($p = .00$, $r = -.28$) and also 'empowered parents' ($p = .00$, $r = -.23$). This indicates that the younger the child, the more supportive parents found nurses and parents felt greater empowerment.

Length of Hospital Stay

No associations were found between the child's length of stay in hospital and parents' perceptions of family centred care.

Nurses

Comparisons were made between levels of hospital, respondents' characteristics and nurses' perceptions of family centred care as assessed by subscales.

Level of Hospital

There was a significant difference in nurses' perception of 'family focussed hospital' between staff in a regional hospital and staff in a district hospital ($t = -2.25$, $df = 49.98$; $p = .03$) with nurses working in district hospitals perceiving their hospital had a higher level of 'family focus'. There were no significant differences between the other subscales, 'respect parent role' and 'nurses in supportive role' when compared

with whether nurses worked in a regional or district hospital. Table 5.10 shows descriptive statistics for nurses' perceptions of family centred care by the level of hospital where nurses worked.

Table 5.10
Descriptive Statistics for Nurses' Perceptions of Family Centred Care by Level of Hospital

Level of hospital	n	Scores for subscales		
		Mean	SD	Range
Respect parent role				
District	82	51.90	4.97	37 - 60
Regional	23	52.57	5.28	43 - 60
Family focussed hospital				
District	83	19.67	5.87	8 - 32
Regional	24	17.21	4.33	10 - 28
Nurse in supportive role				
District	84	14.57	3.18	4 - 20
Regional	24	13.88	3.14	8 - 20

Main Area of Nursing Practice

There was a significant difference in nurses' perceptions of 'respect as parent' and 'nurses in supportive role' according to categories of nurses' main area of practice ($F = 3.20$, $df = 2, 102$, $p = .045$ and $F = 3.98$, $df = 2, 105$, $p = .02$ respectively). Tukey's HSD identified the difference between those who categorised their main area of practice as midwifery and those categorised as 'other' for 'respect as parent' and the difference between midwifery and paediatrics for 'nurses in supportive role' ($p = .04$ and $p = .02$ respectively). Table 5.11 provides data indicating that midwives perceive they provide family centred care at a higher level than do other nurses for the previously mentioned sub scales.

Table 5.11
Descriptive Statistics for Nurses' Perceptions of Family Centred Care by Main Area of Practice

Main area of practice	n	Scores for subscales		
		Mean	SD	Range
Respect parent role				
Other	87	51.59	4.76	37-60
Midwifery	9	55.89	6.55	44-60
Paediatrics	9	52.67	4.70	43-60
Family focussed hospital				
Other	89	19.47	5.90	8-32
Midwifery	9	18.56	4.10	14-26
Paediatrics	9	16.22	3.42	11-21
Nurse in supportive role				
Other	90	14.50	3.17	4-20
Midwifery	9	16.00	2.29	13-20
Paediatrics	9	12.00	2.74	8-16

Associations

No significant association was demonstrated between the length of time the nurses had nursed children nor the length of time nursing with any of the components of family centred care. There were no statistically significant differences between nurses' age, level of education, being a parent, having had a child hospitalised and any components of family centred care.

Comparison of Perceptions Between Parents and Nurses

Both parents and nurses were asked whether they thought parents wanted to provide 'parenting' care and whether they wanted to provide 'nursing' care. They were also asked whether parents were allowed to provide as much of the 'parenting' and 'nursing' care as they wished. There was a statistically significant difference between the mean scores of parents' and nurses' perceptions of 'want to continue parenting', 'want to provide nursing' and 'able to provide as much nursing as wished'. Parents and nurses both perceived parents could provide as much parenting care as they wished. Table 5.12 provides the descriptive data.

Table 5.12
Summary of *t*-tests between Parents' and Nurses' Perceptions of Care Provided for Child

Item	Parents		Nurses		<i>df</i>	<i>t</i>	<i>p</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			
Want to continue parenting	4.53	0.74	4.14	0.82	346	4.42	.00
Want to provide nursing	3.16	1.46	2.77	1.09	268	2.81	.005
Able to provide as much parenting as wished	4.57	0.67	4.55	0.54	348	0.22	.82
Able to provide as much nursing as wished	3.81	1.16	3.01	1.24	345	5.82	.00

All of the items which had 'not applicable' as a possible answer and were excluded from the factor analysis, were subjected to *t*-test to compare the mean scores between parents and nurses. Those who indicated that the question was not applicable were excluded from the analysis. There were significant differences between each item except the item asking about a pre admission program being offered to parents and children prior to a booked hospitalisation. Table 5.13 provides descriptive statistics and '*t* score'.

Table 5.13

Summary of *t*-tests for Items with 'Not Applicable' by Parents and Nurses

Item	Parents		Nurses		<i>df</i>	<i>t</i>	<i>p</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			
Family understood all written info. given	4.07	0.95	3.69	0.87	247	3.16	.002
Policies allow parents provide nursing care	3.93	1.07	3.33	1.23	191	4.27	.00
Nurses assisted confidence in parenting	3.57	1.26	4.42	0.53	231	7.61	.00
Nurses aware of siblings needs	2.83	1.38	3.28	0.97	268	3.15	.002
Care organised to meet family needs	2.95	1.33	3.83	0.85	276	7.51	.00
Nurses aware of parental respite	3.27	1.24	4.05	0.95	262	5.80	.00
Parent would leave child without worry re care	3.77	1.35	4.46	0.65	297	5.97	.00
Spouse included in all aspects of care	3.69	1.11	4.10	0.93	254	3.34	.001
Parents encouraged to discuss concerns	2.39	1.22	3.52	1.04	223	7.37	.00
Parents supplied with info on support groups	2.67	1.37	4.13	0.70	151	9.59	.00
Preadmission program was offered	2.65	1.47	2.98	1.30	206	1.70	.90

Content Analysis

Open ended questions were the third section of both questionnaires. A simple manifest content analysis was undertaken and frequencies are reported here. Parents and nurses primarily commented when expectations were not being met.

Parents

The third section of the questionnaire invited parents to comment about the experience their family had when their child was hospitalised. When asked whether parents perceived a difference between how they wanted their family to be cared for and what actually occurred when their child was hospitalised, 53 (21.8%) parents commented that there was a difference. Of those, four perceived a difference that was positive for the family. The reasons why the care exceeded the parents' expectations were that the family was asked if they wished to participate in their child's care and the family felt included in the decision making which they did not expect. The parents felt trusted by the nurses. Another family felt that they were treated as friends and the care exceeded expectations. They thought this was due to being a small community and that they were known by the staff prior to hospitalisation. Another respondent wrote that they did not expect the nurses to be so open to the family 'doing their own thing' and that the experience had exceeded their expectations.

The remaining 49 parents responded with negative comments about the care not meeting their expectations. These included comments about staff being very busy, which led to lack of information for parents about their child and a perception by the parents that they were expected to care for their child. Three parents commented that they had to stay with their child at all times. If they left the hospital, the parents had

to find someone else to remain with their child. Seven parents commented that they perceived that nurses expected them to care for their child without any discussion or negotiation. Conversely, seven parents felt that nurses did not want them to be with their child. They were not encouraged to stay in hospital and felt as if they were in the way.

Several parents commented on their exhaustion due to caring for a sick child prior to admission and then being required to continue caring in hospital. Twelve parents commented on the inadequate sleeping arrangements which exacerbated their exhausted state and reduced their coping mechanisms. They did not believe that nurses were aware of their tired state. Parents believed that not having access to a bed contributed to their fatigue. Some parents had to share their sick child's bed and others were given a chair beside their child's bed in which to sleep for the night which they believed was not conducive to adequate sleep. One parent commented that both parents wished to stay with their child however the hospital did not allow this and another parent wrote that the only way both parents could stay in hospital was to share the recliner chair and therefore they slept in shifts.

Thirteen parents commented on the lack of information provided to them whilst their child was hospitalised. This lack of information related to either their child's condition or the parent's role whilst staying in hospital. Three parents commented on their lack of inclusion in decision making about their child's care. Several parents commented on the inability to be able to talk with the doctor about their child. One parent had requested to read her child's case notes and this was not allowed.

Eleven parents believed that there was a lack of facilities within the hospital. These facilities varied from a public telephone to play facilities for children and siblings. Eight parents said that they were unable to access meals despite the long periods of time they spent on the ward. Some suggested access to a microwave oven and a fridge would suffice as support people could then supply nutritious food for them. One parent commented that she was unable to live in the hospital with her child, however the staff rang her frequently at home to come in and look after her child. When she went in, no food or drinks were offered to her although she was in the hospital for long periods of time.

Seven parents wrote that they were not offered respite while caring for their child. They would have liked nurses to have offered to sit with their child while the parents

had a shower or went to the toilet. Two parents wrote that they did not trust the nurses and therefore would not leave their child.

Thirteen parents commented on the rudeness, abruptness, negative attitudes and lack of caring shown to parents by individual nurses and seven parents commented on individual nurses' lack of bedside manner and inappropriate care given to their children. The following is a comment from a parent of a four and a half year old commenting about the inappropriate care the child received from a phlebotomist.

"...the person who came and took my son's blood tests was extremely unpleasant, my son had had a fit and was unconscious when she tried to put the needle in his arms (had to try both). My son responded by wriggling and crying – she yelled at him and told him he was being a stupid little boy..." (04-019)

The nurses did not appear to have an awareness of age appropriate care as perceived by five parents. This included a lack of individualised care for their child and that the ward routine was adhered to despite the child's and family's needs.

Twenty (8.2%) parents said there were instances when their family was not included in their child's care however only four parents wrote about instances where they were not allowed to be with their child and had been asked to leave the room while procedures were being performed such as intravenous cannulation and preparation for operating theatre. Two hundred and nine (86%) parents said there were no instances where this occurred.

Suggestions parents gave that could have assisted them when their child was hospitalised included the following: privacy, adequate discharge planning, no interference with disciplining their child, opportunity or assistance to make a phone call by providing a phone, having change for a public phone or being allowed to use the hospital phone for a phone call on admission.

Nurses

When nurses were asked whether they perceived a difference in what they were currently able to do and what they thought was necessary in terms of inclusion of families in care 35 (32.4%) nurses responded in the affirmative stating they perceived a difference. Thirty five (32.4%) nurses said there was no difference and 38 (35.2%) nurses did not answer that question. Of those that said they perceived a difference, ten nurses reported that the reason for the difference was due to the lack

of staff and the high workloads thus not allowing nurses time to provide the care that they wished. Seven nurses reported lack of equipment, lack of space or lack of hospital facilities as a reason for the inadequate provision of family centred care. The individual nurses' lack of paediatric knowledge, education and lack of paediatric experience were the reasons stated by several nurses. The following are a few examples of the nurses' comments:

"...lack of knowledge regarding rights and needs of parents and children..." (02-026)

"There is not enough evaluation of staff practices or ongoing education for staff at any of the last three rural hospitals I have worked in over the last 20 years. I must rely on self directed learning practices and the occasional agency RN who is updated in paediatric care to give advice and direction for same." (10-012)

"Need understanding of parental support related to wellbeing of child." (05-009)

"I feel I don't have enough education when dealing with paed. Education is only available in the city." (11-002)

Another reason given by nurses as to why the care provided was less than what they would like to provide was that the main focus of care was on adults and not children, as illustrated by the following comments from nurses:

"Because paediatric nursing makes up a smaller part of our work, it is sometimes difficult to remain focused on the importance of paediatric care. We hope parents will remain highly involved but because of A & E Department, gerontology and maximum staffing of two nurses, the other issues may get overlooked at times." (10-018)

"...Due to short inpatient stay and multifocus of staff, care of family is not a priority and although we encourage family participation, the time spent is relative to activity through A & E and medical inpatients." (34-003)

The organisation's expectations that 'children are little adults', the ward culture, children being nursed in an adult unit, lack of information provided by doctors on the child's condition and care, and lack of interest from the child's family were other reasons cited by the nurses for not providing family centred care as much as they would like.

The nurses were asked to give examples, if any, of instances where they might become focussed on the child's care and not include the family in that care. Seven nurses responded that in cases of emergency treatment they were unable to include the parents. When parents were disinterested, upset, did not want to be present, were drunk, or when parents were hostile were other reasons provided for the lack of parents' inclusion in care. Four nurses commented that when the doctor did not allow the parents to be included in their child's care, the nurses excluded them.

Nurses suggested education in rural areas, new facilities and printed information sheets for parents would all enhance inclusion of families in their child's care when hospitalised. Other suggestions included policies to ensure child appropriate care, standardised information and increasing staff numbers when children were admitted. Follow up phone calls to parents on discharge was a further suggestion by one nurse and employing more staff with paediatric qualifications was another.

Summary

These results indicate that parents and nurses perceive that family centred care is being provided in rural Western Australia when a child is hospitalised. However, nurses perceive they are providing family centred care at a higher level than parents perceive they are receiving it. There are statistically significant differences between the level of hospital and the perceptions of care delivery. Parents with no social support perceive a lower level of care provision than those with social support. Previous hospital experience influences parents' perception of care and nurses who are midwives believe they deliver care that is family centred at a higher level than other nurses. Nurses believe that their delivery of care is hampered by inadequate staffing and equipment and a lack of knowledge and experience in paediatric nursing. The following chapter discusses these findings.

Chapter Six

Discussion

The study aimed to establish whether family centred care was being practised when families had a child hospitalised in rural Western Australia. This was assessed by surveys seeking the perceptions of parents whose child had been hospitalised recently and the perceptions of nurses who cared for the hospitalised children. Specifically, the aims of the study were to answer the following questions:

1. Is family centred care being practised, and to what extent, in rural hospitals of Western Australia?
2. Is there a difference between parents' perception of receiving family centred care and nurses' perception of delivering family centred care?
3. If a deficit is identified, in what areas can nurses improve?

The findings of this study suggest family centred care is practised in rural Western Australia. However, parents are of the view that it is not practised consistently and nurses perceive they are delivering family centred care at a higher level than do parents.

In respect to the findings, discussion of the main themes identified by factor analysis from the parents' questionnaire are followed by discussion of the themes from the nurses' questionnaire. Comparisons between parents' and nurses' perceptions are considered.

Prior to discussing the findings of the study, this chapter compares the two study samples to the equivalent sectors of the Australian population where appropriate to the study's focus. Also, the outcomes of the psychometric testing of the questionnaires are discussed along with factors which may have influenced the results.

Characteristics of Samples

There were many similarities between the samples and the Western Australian populations of hospitalised children and nurses. The leading causes of hospitalisation for the children in this study were consistent with figures published by the Australian Institute of Health and Welfare (AIHW) (1998), with respiratory conditions being the

primary causes for the hospitalisation of children, followed by gastrointestinal problems. Dental surgery and injuries both rank within the top seven most frequent diagnostic related groups as causes for hospitalisation (AIHW) as they did in this survey.

A second comparison was the age of the children at the time of hospitalisation. This was also consistent with AIHW (1998) statistics with the majority of hospitalised children being between the ages of one to four years.

The length of stay in hospital among children aged 0-14 years living in rural and remote Australia for 1996-1997 was 3.1 days (AIHW, 1998) which is slightly less than the average length of stay for children in this survey of 3.5 days. The AIHW figures included 10–14 year old children and their main reasons for hospitalisation are different to those of younger children which may account for this small difference. Distance from the hospital may also have influenced the increased length of stay in this study. Several parents commented that they could travel up to one and half hours to reach the hospital from their home although they classified themselves as being ‘local’ to the hospital. Distance from medical assistance is believed to delay time of discharge from hospital thereby extending the length of stay, whereas children who live nearby would be discharged earlier.

The socio-economic status (SES) rank of the areas where the hospital was situated was reported. As SES is based on educational background and occupation it may reflect income of the population in that area. As the majority of parents came from middle SES ranked areas it was thought that SES ranking would have had little influence on families’ responses to the questionnaire. However, collection of SES data from each respondent would have provided the opportunity to compare responses to ascertain whether there was a statistical difference in parents’ perceptions to the provision of family centred care. Earlier studies have reported social class (Callery, 1997; Knafl, 1985; Neill, 1996a) to demonstrate that their population samples reflected all social classes, however, these studies did not consider the impact of social class on parents’ perceptions of the provision of family centred care. There is a financial cost to having a child hospitalised (Callery, 1997) and for those who were financially insecure, hospitalisation may have increased the family’s stress which may have influenced their perception of care received. The distances the families lived from the hospitals were considered, however no

statistical differences were found in parents' perceptions of the provision of family centred care and distances travelled.

The sample of nurses also reflected the Australian nursing workforce, with 30% over the age of 45 years and approximately 40% aged between 36 to 45 years (DETYA, 2001). The educational level of the respondents in this sample was less than that of Western Australian nurses. Of the respondents in the sample, 22.3% had completed at least one post basic nursing qualification compared to 36% of nurses in the state (AIHW, 2001).

Reliability and Validity of Questionnaires

In discussing the results, it is important to place these within the context of the results of the psychometric testing of the questionnaires. The intent of the original subscales was to measure the eight elements of family centred care as identified by Shelton, et al. (1987). Bruce and Ritchie (1997) reported Cronbach's alpha ranging from .5 to .8 for the original subscales however, in this study the range was .2 to .8. This measure of internal consistency should be greater than .7 (Lo Biondo-Wood & Haber, 1990; Polit & Hungler, 1995) when making group comparisons as in this study. Given only nine of the 16 subscales in this study demonstrated acceptable internal consistency, it was considered necessary to undertake further psychometric tests. As indicated in Chapter Four, further psychometric tests confirmed the lack of homogeneity within the original subscales.

Several possible reasons for the lack of reliability in the subscales can be identified. The Family Centered Care Questionnaire (FCCQ) was designed for use in 1997 in a Canadian tertiary paediatric hospital and changes were made to reflect the Australian rural context. The four years time difference between design and use of the FCCQ should not have impacted on the reliability as there were minimal changes in the context of family centred care reflected in paediatric nursing in Australia within this time frame. The differing health care systems between Canada and Australia was acknowledged however the culture of care was not deemed to be different and therefore little influence on the reliability of the questionnaire was expected from this aspect. The hospital where the reliability was tested was a tertiary paediatric centre where there is a commitment to enhancing family centred care and the centre had a philosophy and position statement supporting family centred care. Most staff would

be aware of this philosophy as they had input into the position statement (Bruce & Ritchie, 1997). The hospitals used in Western Australia were all rural primary or secondary care centres where staff cared for both adults and children and the focus of care is primarily towards adults.

The original questionnaire was also designed only for nurses, not for parents. As parents' perceptions were being sought as well as nurses, the items in the questionnaire for parents were reworded to reflect that parents were responding. The intent of the question was assessed as not having altered. Despite being based on a nurses' questionnaire, consistency of the subscales for the parents were stronger than that of the nurses. The larger size of the parent sample may have contributed to the higher alpha scores whereas the lower number of respondents for the nurses' questionnaire may have contributed to the low reliability of the related subscales.

An extra item was added to the questionnaire to identify nurses' and parents' perceptions of whether they thought the primary carer's partner was included in the care of the child. Exploration of this aspect was deemed necessary given that during the focus group conducted with parents to ascertain whether the concepts of family centred care found in the literature were representative of parents in rural Western Australia, it was evident that partners of primary carers felt left out and not included in the child's care as much as they would have liked. This aspect did not appear to be considered in the FCCQ. A further change was made to the original tool in that the wording of several items was altered to improve clarity of the questions. Although it was thought that this did not alter the intent of the items, it may have altered the reliability of the questionnaires.

However, following factor analysis and identification of new subscales for both parents' and nurses' questionnaires, internal consistency was supported with Cronbach's alpha ranging from .64 to .86 for the subscales and .91 and .83 for the total scales for parents and nurses respectively. Construct validity was supported by factor analysis and further psychometric tests of convergence and discriminability. Face validity was also acceptable for the new scales.

Parental Participation in Care

Family centred care is based on families being able to provide all the care, both parenting and nursing care, that they wish while their child is hospitalised. Therefore, it was deemed important to ascertain whether parents were able to participate in all the care they wanted to. Nurses' perceptions were also sought and are discussed here.

Parents wanted to provide parenting care for their children when hospitalised and they were able to provide that parenting. The results also indicated that nurses believed parents wanted to and were able to provide parenting care. This is consistent with findings from Algren (1985), Beck (1973), Merrow and Johnson (1968) and Webb et al. (1985) who all reported that parents wanted to participate in their child's care by undertaking parenting tasks such as comforting, bathing and feeding. These earlier studies also reported that parents' involvement in their child's care decreased as the tasks became more complex. In this study, when parents were asked whether they wanted to provide nursing care the responses from parents were distributed evenly across the range of scores, however almost 44% of parents agreed that they would like to have participated in the nursing care of their child.

Nurses' perception of whether parents wanted to participate in the child's nursing care was significantly lower than that of the parents. This again is consistent with earlier studies where the main task for parents may be considered to be one of entertaining and comforting their child but Merrow and Johnson (1968) and Webb et al. (1985) demonstrated that parents are prepared to do far more. Family centred care is based on the premise that parents can participate in all the care that they wish to and that nurses will support the parents' decision by providing appropriate information and education to enable the parents to do so. If nurses do not have an awareness that parents wish to provide nursing care for their child, it is unlikely that they will discuss or invite parents to participate in this aspect of care when their child is hospitalised. Gill (1987a, 1987b, 1993) and Seidl (1969) reported that nurses' attitudes to parental participation in care were influenced by their level of education and parental status. However, this study did not reflect a statistically significant difference between level of education or parental status and nurses' perception of parental participation in care which is consistent with Johnson and Lindschau's findings (1996). As parental participation has been promoted in Australia since the 1970's, and 68% of the nurses who responded to this questionnaire were below 45

years of age, these nurses' education would have included paediatrics and, in all likelihood, the importance of family centred care, whether they were educated in a hospital system, vocational education and training or university sectors. This could account for the lack of statistically significant findings for level of education.

Parents' Perceptions of the Provision of Family Centred Care

Child Friendly Environment

The ability to access information about their child whenever they needed, being given information about their child's care and that information being consistent have been identified as barriers to family centred care (Coyne, 1995b; Darbyshire, 1994; Johnson, 1994 & Roden, 1998). However, overall, parents in this study responded positively to these questions and agreed that these areas of care were delivered when their child was hospitalised. Previous studies were undertaken in tertiary paediatric settings where wards were larger and therefore more staff were involved in the care of the families. The designated children's wards in the regional hospitals and the number of staff working in the district hospitals were much smaller which may assist in providing consistent information to families.

Within the subscale of 'child friendly environment', one of the lower scoring items was parents' perception of 'nurses maintaining normal routines for the child' when hospitalised. A factor influencing the amount of stress imposed on a child by hospitalisation is the amount of control that a child perceives they have (LaMontagne, 1984). Loss of control for infants, toddlers and preschoolers results from altered routines and rituals that increase the child's perception of threat. This perceived threat can affect their coping skills. The main areas of control for younger children are rituals which include eating, sleeping, bathing, toileting and play. Maintaining a child's normal routine therefore contributes to reducing the child's stress. While the mean score and parent comments give some indication that usual routines are not always being followed, further information needs to be elicited to ascertain which aspects of the child's routine were disrupted and whether it was related to budgetary restraints, catering or cleaning schedules or whether nursing staff are unaware of the importance of this aspect of a child's care.

Parents did perceive that the nurses' approach to their child's care was appropriate for the child's developmental stage. This is heartening when only 8% of the nurses

indicated paediatrics as their main area of practice and reinforces the importance of nursing undergraduate curricula continuing to include theories of child development and their application.

Parents whose children were admitted to regional hospitals perceived a statistically significantly higher level of care in respect to 'child friendly environment' than did parents who had children admitted to district hospitals. Several reasons may account for this differing perception. The three regional hospitals included in this study have dedicated areas for the care of children where a child - friendly environment is provided and also have staff who are rostered to care exclusively for the children so it is an integral part of their practice. Nurses in the district hospitals care mainly for adults and paediatric patients are the exception. As the nurses in regional hospitals care for children every day they may be more aware of the importance of provision of consistent, regular information to parents and this may be part of the ward culture.

Children's wards are essential to cater for the specific needs of children. Rather than nurse adults and children together, separate facilities provide for both children's developmental needs and adults' privacy and peace (AWCH, 1992). The district hospitals could enhance this aspect of family centred care by decorating one room so it is suitable for use by children and their families. Bright colours, ample light, a play area, and appropriate furniture are all highly desirable to help fulfil the total needs of the child (AWCH, 1992). Some of these aspects can be achieved readily with posters, mobiles and paint. AWCH (1992) found that 47.4% of hospitals surveyed considered play arrangements to be inadequate. One of their recommendations was that all hospitals that accept child patients should provide an adequate budget for the purchase and appropriate maintenance of play equipment and materials. This recommendation could be extended to include an adequate budget to provide an appropriate environment for children and families.

Although parents who had children admitted to district hospitals perceived a lower level of care from the perspective of 'child friendly environment', overall parents' perception was positive for this aspect of family centred care.

Respect as Parent

The subscale labelled 'respect as parent' encompasses the first element of family centred care (Shelton et al., 1987): nurses' recognition that the family is the constant in the child's life and concomitant acknowledgement that parents know their child the best. The mean scores for four of the seven items indicated that parents did not perceive this recognition and acknowledgement to occur consistently. Parents perceived that nurses asked them what was normal for their child and conveyed that families were key participants in the care of their child. Nurses asked what care the family wished to be involved in, however the amount of involvement in care was not clarified on a regular basis. Evans (1994), Knafl et al. (1988) and Roden (1998) discussed the importance of asking parents regularly what care they wanted to be involved in as parents' needs fluctuate. Parents often commence the hospitalisation in a passive, dependent role due to their uncertainty in a strange environment and their beliefs about appropriate behaviour (Brooking, 1989). As parents become more familiar with the hospital environment and their child's condition, their desire for involvement in care often alters therefore their needs should be assessed at least daily. Johnson (1996) suggested steps necessary to form a partnership which recognise the importance of renegotiating as necessary to assist with identification of roles and expectations. Nurses may not be aware when renegotiation is necessary if they do not know the family. The inclusion of an area on the child's plan of care which allows for parental involvement in care may prompt nurses to ask parents about their involvement on a daily basis and amend the plan of care accordingly. This would provide readily available information that all nurses could access so they would know the degree of involvement in care which parents wish at that particular stage in the hospitalisation. Changes could be recorded when necessary.

One of the lower scoring items within this subscale was parents' perception of receiving information related to the impact of hospitalisation on the family. The effect a sudden hospitalisation has on the rest of the family, particularly siblings, is often not known by parents and forgotten by health professionals. The hospitalisation of a family member does impact on the whole family particularly if the admission has not been planned. The effects on siblings can be minimised with appropriate interventions and accommodation of parents' other roles, such as parenting other children, so they can attend to them. Simon (1993) found that the level of stress

perceived by siblings was equal to that of the hospitalised child. Craft (1993) found that when siblings are cared for outside their home, receive little information about their ill brother or sister or perceive that they are being treated differently compared to before their sibling's illness, they have increased feelings of loneliness, fear, anxiety, anger, jealousy, resentment and guilt about their sibling's hospitalisation. Interventions to reduce these feelings include explicit explanations about the illness, provisions for the sibling to remain at home with someone who knows the child well, and the parent who provides the primary care to spend a night at home or spend a 'special' time at home with the sibling, if possible (Craft, 1993). To be able to achieve this nurses need to be aware of parents' need to leave the hospital to spend time with siblings and encourage parents to do so.

Recognition by nurses that parents know their child was evident by nurses asking parents 'what was normal for their child'. This recognition of parental knowledge is required as it acknowledges that parents have some power. Negotiation of roles can only occur when nurses acknowledge parents have power (Callery & Smith, 1991). Nurses asked parents about the involvement that parents wished in their child's care which is the beginning of negotiation and partnership. This negotiation was commenced but not carried out regularly or comprehensively. The negotiation only included involvement in the hospitalised child's care and did not consider any of the other things that a parent may have to do which is apparent in the next theme 'nurses in supportive role'.

Parents without any social support recorded a statistically significantly lower score for this subscale than those who had immediate family to support them. Seventeen parents who responded to the items in 'respect as parents' stated that they had no social support when their child was hospitalised. As this number is small the results need to be interpreted with caution. However, earlier research has highlighted that parents without a supportive network of family and friends were unable to participate in their child's care as much as they would have liked as they were unable to reside in hospital with their sick child secure in the knowledge that their other roles were being taken care of (Coyne, 1995b; Roden, 1998). The parents without support in this study may not have been able to spend very much time in hospital with their child and therefore were not asked about their involvement in the care of their child and did not feel included and respected as a parent. It is important to identify the

parents with limited or no support when their child is admitted to hospital so that interventions are included to increase their participation in family centred care. Although a parent may have limited time to spend with her or his hospitalised child, nurses should involve the parents to schedule the child's day so parents are present for aspects of care that they wish to be involved in. Another intervention that may be considered is the use of community services to assist with the other roles that the parent may have so the parent is able to spend more time with the hospitalised child or provision of accommodation for a sibling within the hospital if that is what is preventing the parent from living in with the sick child.

The other aspect within this theme of 'respect as parent' related to parents being asked to provide feedback on the care they received. Parents did not recall being asked to evaluate the care they received or comment on hospital practices or policies that impacted their child and family's care. Seeking feedback from consumers of a service demonstrates a willingness to improve services and respect for the consumer's view. One aspect of health care quality that is being increasingly recognised for its importance is the influence of consumers' perceptions (Wadhwa, 2002). Although consumers' perceptions of quality rely more on service aspects of health care, they correlate well with objective measures of health care quality. An organisation's ability to satisfy consumer demands for convenience and information can significantly influence the quality of health care it ultimately delivers. Although individual hospitals did not seek information on parent satisfaction with the care provided, the HDWA does survey hospitals on a rotational basis and hospitals that were involved in the HDWA survey being conducted at the same time were not able to participate in this study. The HDWA survey does not however seek feedback related to family centred care. It is important that nurses seek feedback from families about how their needs have been met. Nurses perceive the level of family centred care they provide is adequate, however parents' perception of the care is rated much lower. If nurses seek feedback they can then identify the differences and put in place strategies to narrow that gap.

Nurses in Supportive Role

This subscale encompassed parents' perception of the support nurses provided for them particularly in helping parents attend to other roles that they had and also enabling parents to obtain meals, access appropriate sleeping arrangements and have

some privacy while in hospital with their child. This subscale measured things that nurses could offer to support parents when their child was hospitalised thus making it easier for parents to care for their child. It did not measure care related directly to the child.

The item that received the lowest score was parents being asked about other things they had to do each day. Although parents were asked about the involvement in their child's care in the previous subscale, nurses did not appear to be aware of the other roles that parents had and therefore did not ask parents about their need to attend to these roles. The basic functions and roles of parents do not change in the presence of a child's illness and hospitalisation. Parents must continue to care for themselves, other family members and maintain the functioning of the family (Ahmann, 1994). Parents need acknowledgement of this to empower them to organise the other roles. As parents were not asked about other needs, the nurses therefore did not provide strategies to deal with these needs. Examples given by parents which demonstrated nurses' lack of support relate to the nurses' lack of awareness that parents wanted a break from caring for their child in order to have time to care for themselves. Having time away from their hospitalised child to 'refuel' was identified by Stull and Deatruck (1986). Parents wanted the nurses to offer to sit with their child thus enabling the parent to leave to get a meal, sleep, or have a shower.

Physical support items such as adequate sleeping arrangements, meals and privacy were not consistently available. Many parents wrote comments in the open ended questions pertaining to these things. As so much feedback from the open ended questions related to sleeping and meal facilities it can only lead to the conclusion that these aspects were very important to parents. Comments relating to inadequate sleeping arrangements were the most frequent and encompassed all aspects of sleeping arrangements from having to 'beg' for a bed which was obviously vacant, to having to share the bed with the sick child, to sleeping in a recliner chair for seven nights as no bed was available, and sleeping in shifts with the partner as both wished to stay due to the vast distance travelled from home (150 kilometres). Consideration needs to be given to supplying adequate sleeping facilities and facilities that meet the families' needs.

Not only were parents not supported to leave their child to access meals but meals were not always available. This is consistent with findings from Coyne (1995b) and

Roden (1998) who reported that parents therefore go without eating which is supported by the comment from a parent cited previously. AWCH (1992) reported inadequate meal arrangements when they carried out their national survey of 253 hospitals. Despite the publication of these findings it is apparent that little has changed in this regard, at least in respect to the hospitals included in this study. Suggestions to improve meal arrangements include availability of a microwave oven in the patient area that parents could access without leaving their child and/or provision of meals by hospital catering staff with parents receiving a bill for the meals. Some parents commented that they did not eat as they did not have any money due to the suddenness of their child's admission.

There was a statistically significant difference between means for this subscale, with parents who had no previous hospital experience perceiving a higher level of support from nurses than those who had previous experience with hospital by either being a hospital employee or having a close family member hospitalised. A possible reason for this difference could be based on parents' expectations. Knafl, Cavallari and Dixon (1988) wrote that parents with no previous hospital experience based their expectations on childhood stories and media reports and therefore these expectations were outdated. Consequently these parents were pleasantly surprised with the facilities and the support provided by nurses. Those who had experienced hospitals were aware of what could be offered and had higher expectations of support.

Other Issues Identified

An aspect which was mentioned several times by parents in the open ended questions related to the difficulty they had in communicating with the doctor about their child's illness. They mentioned difficulty being able to speak with the doctor due to the doctor not visiting the ward at a set time or not turning up when he said he would and also not understanding what the doctor said when he did speak with them. The nurse has an advocacy role to enable this communication to occur at appropriate times for both parties and to ensure the parents understand the information. The nurse also acts as an advocate by ensuring all health care providers, including phlebotomists, are aware of the appropriate responses to children based on their developmental age.

The younger the child was on admission, the higher the score by parents for family centred care, except for 'child friendly environment'. This could be explained by the

older the child is the more likely the child is to be included in decision making with parental involvement diminishing, whereas with infants decisions are made exclusively by parents. The significant association was only weak so needs to be considered with caution.

Parents perceived that aspects of family centred care were being delivered by nurses, however not consistently. Parents would have liked more support from nurses particularly so they could attend to other tasks such as eating meals and sleeping which would in turn assist them to care for their child. Parents also would have liked nurses to acknowledge their other roles which pertain to family functioning and assist with strategies to enable the parents to attend to them. The conflict between roles can lead to feelings of anxiety, guilt, and fear (Palmer, 1993) therefore it is important that support is provided for parents to protect them against mental and physical exhaustion.

Nurses' Perceptions of their Provision of Care

Three themes that were identified following factor analysis of the nurses' questionnaire were labelled 'respect for parent role', 'nurses in supportive role' and 'family focussed hospital'. The 'respect for parent role' and 'nurse in supportive role' both relate to aspects of care that individual nurses are responsible for whereas 'family focussed hospital' relates to the organisation.

Respect for Parent Role

'Respect for parent role' reflects the first element of family centred care (Shelton et al., 1987) which is recognition that the family is the constant in the child's life and acknowledging that the parents know their child. It also reflects nurses' belief that parents have the right to participate in their child's care as much as they wish to therefore encouraging parents to continue parenting and to feel confident in the care they provide. Nurses perceived that they did respect the parent role when caring for children however, their low rating on the item 'clarify parents participation each shift' is consistent with parents' perception. The importance of seeking this information has been discussed earlier.

The nurses were asked to indicate their main area of nursing practice and those who selected midwifery as their main area of nursing scored a statistically significantly higher mean for 'respect for parent role' than did nurses who were classified as

‘other’. ‘Other’ included all clinical areas apart from paediatrics and midwifery. Although the numbers of respondents in the ‘midwifery’ and ‘paediatric’ categories were very small and thus the results need to be interpreted with caution, the finding is worthy of consideration. Earlier studies (Siedl, 1969; Gill, 1987a, 1987b,) identified level of nursing education, position of seniority and parental status as factors that influence nurses’ attitudes to parental participation in their child’s care. In this study consideration of ‘position of seniority’ was not possible and parental status was not demonstrated to make a difference to nurses’ perceptions of delivery of family centred care. All those who classified their main area of nursing as ‘midwifery’ were registered midwives so the assumption that education may influence the perception of ‘respect for parent’ could be investigated further. Midwifery practice is based on a model of wellness and a major aim of care is to empower parents by teaching parenting skills. The emphasis on this aspect of care may transfer across to their care of children and their families. Of the nine nurses who classified their main area of nursing as paediatrics, only two had a paediatric certificate demonstrating they had undertaken studies particular to paediatric nursing. Perhaps this lack of further education together with the small number of nurses in this category explains why there was not a significant difference between paediatric nurses and ‘others’ in their perception of delivery of family centred care.

Despite this significant difference between those that categorised their main area of practice as midwifery and ‘other’, all the nurses who responded perceived that they consistently showed ‘respect as parent’ when caring for children and their families.

Nurses in Supportive Role

‘Nurses in supportive role’ reflects the extra support that nurses believe they offer parents, however they offer it inconsistently. Things such as not ensuring parents eat meals regularly, have adequate toiletries and maintain the family network while a child is in hospital are aspects identified in the literature as being barriers to family centred care (Coyne, 1995b; Roden, 1998) and when provided, made a positive difference to families and the hospitalisation experience for the family.

A reason for not asking parents about issues that may help families when children are hospitalised could be because a problem may be identified for which the nurse may feel inadequately prepared. Referring families to a social worker or other appropriate

health professional is not always possible in the rural sector and if a problem is identified the nurse will have to implement interventions to begin resolution of the problem. Bruce and Ritchie (1997) identified nurses' lack of ability in interpersonal relationships and counselling as a reason for not providing family centred care, and it appears that nurses in rural Western Australia may also feel the same. It is recognised that a child can only function to his/her full potential within a stable family relationship and is influenced by factors affecting the family unit. Therefore if problems are identified, nurses require strategies to help the families.

For this theme, there was a statistically significant difference between the nurses who categorised their main area of practice as midwifery and those whose main areas of practice were paediatrics or 'other'. As with the previous subscale, this result needs to be interpreted with caution as the number of nurses in both paediatrics and midwifery were very small. As discussed previously, the difference may be related to the educational preparation of midwives.

This subscale measured the support parents needed in order to maintain their other roles and ensure they coped with the extra demands placed on them by having a child hospitalised. Although nurses believed they provided this support it is evident that it was not consistent. It is important that professional support is provided for the parents by the health care team to assist them deal with these demands.

Family Focussed Hospital

This subscale reflects organisational level factors and not care that nurses offer directly to children and families. It covers the physical layout of the ward and whether policies and practices promoted by the health service imply a family focus. The low scores indicated that these aspects were not consistently addressed. Parents were not invited to participate in staff orientation to include the parental perspective of having a child hospitalised or consulted on policies and practices that impinge on family care. Participation of consumers or carers in decision making in health is being advocated to improve the safety and quality of health care (Johnson, 2001). Consumers, in this case parents, need to be actively involved in working with health professionals for the purpose of influencing decision making processes to bring about changes to health care, health services and the health care system (Johnson, 2001). Involving a parent as a consumer representative on hospital committees which make

decisions on care impacting on families would bring the family perspective to the discussion.

Nurses working in district hospitals provided a statistically significantly higher score for 'family focussed hospital' than did the nurses employed in regional hospitals which was not consistent with parents' perceptions. Several reasons for this are considered. The nurses' belief of greater provision in the district hospitals may be due to a sense of pride in the service provided to the local community where people all know each other and they see themselves as being more flexible in a smaller organisation. Another reason may be due to the nurses' lack of knowledge of what is needed to facilitate family centred care. There were no data collected which indicated why nurses in district hospitals perceived this aspect of family centred care to be better than did those nurses practising in regional hospitals.

Other Issues Identified

Despite nurses believing they provided family centred care when caring for children it is not without its difficulties. Inadequate staffing and lack of facilities were the most common reasons presented by nurses for instances when family centred care was not delivered. Several nurses and parents commented that if a child was admitted to the hospital, parents had to remain with their child throughout the hospitalisation as no extra staff were available and parents were expected to carry out all the parenting care. If a parent could not remain with the child at all times, the child would be transferred to another hospital, usually further away, for admission. This occurred in some district hospitals where there was no dedicated children's ward. Staffing ratios for children are different to adults (AWCH, 1992) and consideration is needed on an individual basis whether it is appropriate to employ more staff when a child is admitted or whether to transfer the family to another hospital.

Another theme was lack of knowledge in caring for children. Some nurses believed this was because children are a very small part of their workload and they lack experience in caring for sick children. Nursing children is a minor part of the nurses' workload for those who work in district hospitals, therefore, nurses' educational priorities may not include paediatric nursing. Paediatric nursing has been a core requirement of pre-registration programs by the Nurses Board of Western Australia for over 20 years, however those nurses who acquired their initial registration outside

of Western Australia may never have been exposed to basic paediatric nursing theories and skills. Others may not have maintained currency as their learning has been adult focussed due to the nature of their work. Education relating to paediatric nursing is offered to rural nurses via several delivery modes and is provided by both the tertiary paediatric hospital in the state and the Association of Paediatric and Child Health Nurses (WA), a paediatric nursing special interest group. However, the numbers participating are usually small with greater interest shown when acute illnesses are being discussed and not when the psychosocial aspects of families' health are addressed. Educators need to look at better ways of disseminating the information on family centred care for example, by including it within presentations that are usually medically focussed.

Previous studies demonstrated the positive influence nurses' duration of nursing practice, age, level of education and parental status had on nurses' attitudes to parental participation in care (Siedl, 1969; Gill, 1987a, 1987b). However, this study did not demonstrate any significant relationships or significant differences between those attributes and any of the subscales of delivering family centred care. This may be attributed to the small sample size.

Forty years after the release of the Platt report and more than twenty five years since the formation and acceptance of AWCH's 'Health Care Policy for Children and their Families', nurses are now aware of the importance of family centred care and therefore believe they incorporate it into their care. However, they believe the health care organisation still needs to improve the facilities, and recognise that 'children are different' by increasing staff numbers to enable nurses to deliver family centred care consistently.

Comparisons of Perceptions: Parents and Nurses

In all aspects that related to the nurse delivering direct care to the child and family, nurses perceived they deliver family centred care to a greater extent than parents believed they received it. This is consistent with earlier studies (Brooking, 1989; Callery, 1997b; Knafl et al., 1988). However, the reverse occurred in aspects of family centred care that related to the organisation and the wider health care system and not to nurses' direct care.

The higher rating given by nurses is particularly noticeable in ‘respecting parents’ role’ with all items rated greater than ‘4’. Nurses need to be aware that parents’ perception of this respect being accorded is not as high as nurses. One way to ascertain how parents feel about the care they receive and whether it meets their needs is to ask the parents regularly while their child is in hospital. As part of the delivery of family centred care, nurses should ask parents whether their expectations are being met and negotiate the care accordingly. This would hopefully relieve the stress for parents and enable them to participate in the care as much as they wanted to.

Parents wanted more support from nurses so they could attend to other roles that they had and to care for themselves while their child is in hospital. This would assist them to cope with their sick child without becoming exhausted. Nurses believed they were attending to this aspect of care. Again, more frequent and better communication is needed between parent and nurses to identify this discrepancy in perceptions.

Despite the higher ratings by nurses for provision of direct care, both parents and nurses were consistent in the individual aspects that were not attended to on a regular basis: ascertaining the amount of parental involvement in care daily, assisting families to recognise the effect hospitalisation has on a family and requesting feedback from families on care.

Several items on the questionnaire were compared individually as they were not included in the factor analysis due to ‘not applicable’ being an available response. Nurses had a statistically significantly higher mean for all but three items which is consistent with other findings in this study where nurses believed the care they provided was done more consistently than parents believed they received it. Only those with implications for nursing practice are discussed. Both parents and nurses agreed that preadmission programs were not offered to families, although as most children in this study were emergency admissions the program would not have been relevant in these cases. However, the nurses indicated that preadmission programs are not consistently offered at either district or regional hospitals even in situations where they would have been appropriate. With small numbers of admissions being booked (28%), particularly to district hospitals (2.5%), the patient numbers could be considered insufficient to warrant face-to-face programs when staff are already in short supply and have to prioritise their tasks. Many families also travel a long

distance for hospital admission so preadmission programs held on site would not be appropriate. However, alternative delivery modes could be considered for example paper based brochures, videos or information on CD Rom.

The other two items that parents rated higher than nurses related to parents understanding the written information which was given to them which parents say they understood consistently. Also, parents thought that policies allowed them to provide nursing care to their child and, although nurses thought this was so, they were inconsistent in allowing parents to provide that care.

Parents and nurses felt that spouses were included in all aspects of care. This finding contrasts with the feedback from the parents' focus group that this was an area of care that was lacking, and which led to the inclusion of this item in the questionnaire. The contrasting finding from the study indicates that it does occur, however it has the potential to be missed and nurses should not become complacent.

Although parents rated aspects of the health care service and facilities more highly than nurses, both groups' ratings were below '4' and there is sufficient evidence from the responses to the open ended questions to show there is room for improvement in this area, particularly for some district hospitals.

There were differences in what a nurse believed she was providing to families and what parents believed they were receiving. The nurse and the parent should be able to negotiate to bring their expectations into closer alignment.

Limitations of the Study

Limitations relating to the reliability and validity of the FCCQ have been discussed earlier in this chapter (p92) and methodological considerations were discussed in Chapter Three. Further possible limitations of the study are presented here.

Only parents who were able to read English could participate in the study.

Generalisation of the results to non-English speaking groups, including Aborigines, are limited as they did not participate in the study. Participants were not required to disclose their ethnicity so generalisation of the results to parents of groups other than Caucasian cannot be made.

Ideally, the questionnaires would have been administered within four weeks of discharge however, as it took so long to receive ethics approval from some hospitals

it was not feasible to wait a further six months to gather the data so a retrospective approach was used. Because of this approach, the length of time between the childrens' discharge and completion of the questionnaire by parents varied. This had the potential to affect parents' perceptions as accuracy is attained when questionnaires are given as close to the service encounter as possible (Urden, 2002). Therefore, although unable to be assessed, there was an increased risk of recall bias as the time between discharge and completion of the questionnaire increased.

A non-response bias is an important source of bias in survey research. Despite the identity of the participants being known only to the hospitals and the researcher unable to follow up those who did not complete their questionnaires the chances of non-response bias were minimised by the inclusion of a well designed cover letter and introduction to the study, pre-paid envelopes, well-designed survey which was piloted, several contact numbers and email addresses for questions and confidentiality was assured. Also, there is a risk that only those with strong views may have completed the questionnaires although this does not appear to be evident in the results.

In efforts to maintain participants' anonymity the researcher did not have control over the distribution of the questionnaires. Hospital employed staff members were responsible for the distribution of questionnaires to parents and nurses and a clear criteria was provided. These staff members had the opportunity to act in a gate keeper role and had the potential to restrict who the questionnaires were delivered to, however there is no evidence to show that this occurred.

Data related to socioeconomic status were not collected for individual participants so it is unknown whether socio-economic status affected parents' perceptions of the delivery of family centred care in Western Australia.

Nurses' perception of their delivery of family centred care was higher than parents which could in part be due to nurses grading their delivery of family centred care higher than what they actually provided due to the effects of being studied (Polit & Hungler, 1995). Despite confidentiality being assured, as some hospitals were very small with few nursing staff employed, the participants may have believed they or the hospital could be identified and therefore rated the care provided more positively than was actually the case.

This thesis does not consider the perceptions of children which is acknowledged as important to gain a complete assessment of family centred care as they are the direct consumers. However, as 75.30% of hospitalised children in rural Western Australia are three years of age or less it is difficult to explore their perceptions in detail and parents should play a major role in decision making regarding their child's care. As such, the perceptions of parents were also considered very important in the evaluation of family centred care in rural Western Australia.

Conclusion

Despite the limitations two major aspects of family centred care are highlighted by the results. These are firstly those aspects of care that nurses have control over such as provision of direct care to the child, parent participation and supporting parents to participate in their child's care and secondly, those aspects of family centred care which the health service is responsible for such as provision of facilities that are appropriate for children and families.

Although nurses believe they facilitate family centred care, parents claim it occurs far less than nurses indicate. It is apparent that many nurses are only focussing their attention on the child and the direct involvement that parents want with the child's care. Little consideration is given to the other aspects which impact on a family when a child is hospitalised such as support for and comfort needs of the parents and assisting parents to attend to other roles. For those nurses who are including parents in the care of their child, the parents' involvement is being assessed on admission but not renegotiated routinely throughout the hospital stay.

Nurses need to communicate more frequently with parents. Nurses must actively and objectively assess the parents' desire for participation on a regular basis, at least daily. Parents and nurses must become partners in the care of the child. Each partner needs to articulate their expectations and understand the expectations of the other so they can work with each other. Nurses who work through this process of assessment and negotiation with families will find that there will be better communication with all involved, fewer misunderstandings and lost opportunities for care and teaching.

The health care system also has to improve facilities available to children and families. Adequate accommodation, meal arrangements and phone access for families are required. Separate rooms for children that are decorated to make the

hospitalisation experience less threatening, the provision of a play area and equipment are basic requirements when incorporating paediatric beds in a hospital profile.

Family centred care needs to be defined in the broadest possible sense to encompass the whole family of the child. As health professionals nurses need to see beyond the child to the parents who are trying to maintain their life at home as well as support the child in hospital and to siblings who need to visit the sick child or establish other lines of communication. Consistent with Knafl et al. (1988), some nurses have begun to achieve this wider view of the family, but many still focus their attention only on the child, and do not provide for the family to assist them through a stressful time.

Chapter Seven

Recommendations

From the discussion of the results it is apparent there is room within nursing practice to narrow the gap between the family centred care nurses believe they deliver and the care that parents perceive they receive when their child is hospitalised. This chapter presents implications from the study's findings for nursing practice, education and research and recommends strategies to address these implications.

Implications for Clinical Practice

Communication

Effective communication by nurses with parents is required so negotiation can occur. Nurses and parents need to negotiate not only their participation in their child's care, but also other demands on parents if they are to align their perceptions of care. This discussion needs to happen at least daily and may be facilitated by an area on the plan of care for parents and/or nurses to complete about the parent's involvement in the child's care which is checked every shift.

The Nursing Mutual Participation Model of Care (Curley, 1988) is based on communication that encourages parent-nurse collaboration. Use of this model may assist nurses in their communication with parents to identify what parents may consider to be of most use to them when their child is sick. The model is based on the premise that optimal therapeutic interventions result from partnerships between parents and nurses by sharing expertise – the parents' knowledge of the child and the nurses' knowledge of the illness (Ahmann, 1994). Results from this study provide evidence that nurses acknowledge that parents 'know their child' and therefore value parents' input into their child's care which is the beginning of negotiation as there is some sharing of power (Callery & Smith, 1991; Davis et al, 2002). The following steps are based on the Nursing Mutual Participation Model of Care from Ahmann (1994) and Curley and Wallace (1992) and are suggestions for the type of daily communication that nurses should initiate with parents:

1. Establish a caring relationship by asking 'How are you today?' This could elicit information about the parent – whether they are tired, worried, and how they are coping with their child's hospitalisation.
2. Ascertain parent's perception of the child's condition by asking 'How does he/she look to you today? How do you think he/she is doing?' This provides information so the nurse can target gaps in information and support parents' needs. The nurse can validate observations, clarify misconceptions and explain nursing actions.
3. Establish and focus on parent goals and expectations by asking 'How can I help you parent/care for your child today?' This demonstrates the nurses' respect for the parent's role and acknowledges that the child belongs to them. It also allows for the parent to talk about the care they wish to be involved in and what they need help with.
4. Seek suggestions, any preferences and negotiate any disagreements about the plan of care by asking 'Do you have any questions, suggestions about your child's care?'
5. Establish whether parents have other things that they need to attend to during the day. 'Is there anything you wish/need to do today?' This provides another opportunity for parents to discuss their participation in the child's care, clarifies any misconceptions by either parent or nurse and allows for discussion of other tasks that parents have to attend to so the child's care can be scheduled around their absence.

The above model requires use of core communication skills where the nurse asks the questions in a meaningful way, at an appropriate time, attends, actively listens, responds empathically, explores and summarises what has been heard (Davis et al, 2002). This leads to a partnership model of caring which ensures the parent is being valued thus empowering them to participate in their child's care and undertake the other roles that they may have.

This communication model could be a useful guide to assist nurses restructure communication with parents so it becomes more collaborative. This collaborative, interactive communication style is person-centred which enables the nurse to adapt communication to the specific needs and values of the family (Cilliers & Terblanche,

2000; Roberts & Krouse, 1988). It differs from a position-centred approach by using influence rather than control during the interaction. The position-centred approach can be likened to the 'expert model' where the expertise of the nurse is seen as superior to that of the family with the relative power attributed used to control the interactions and decision making (Davis et al, 2002).

The Nursing Mutual Participation Model of Care can be compared to the Partnership Model which is based on acknowledging the control which families have in a relationship as they initiate the relationship when seeking assistance initially, can chose which aspects they wish to follow and can terminate the relationship whenever they desire (Davis et al, 2002). Using the elements of the partnership model: working together, sharing power, complementary expertise, mutual respect, open communication and negotiation; the Nursing Mutual Participation Model of Care given above provides direction to the nurse in a paediatric setting to assist in forming the partnership to enable families to participate in decision making.

It needs to be acknowledged that forming a partnership with families may take time which is a concern with the current shortage of nursing staff and financial restraints in the health system (Callery, 1997a; Davis et al, 2002). Active listening is also potentially more tiring and can be more demanding emotionally. These potential difficulties can be overcome by some service changes and careful selection of staff (Davis et al, 2002). Increased resources, the selection of staff who have the qualities of emotional strength and communication skills or the provision of resources to train staff in those areas are required for a partnership model of care to be reality in rural hospitals in Western Australia.

If this form of communication was to be followed, there would be a greater chance that the child's normal routine would be adhered to as the parents would be able to keep the nurses informed of the child's routine and it would be documented in the plan of care. Parents may ask to participate in nursing care thus raising nurses' awareness of this aspect of involvement in care. This should decrease the difference between parents' and nurses' perceptions of delivery of care as parents' expectations are now being discussed at least daily.

Parent Feedback

A further recommendation is to obtain feedback from families about the care they received. This study identified gaps between parents' and nurses' perceptions of delivery of family centred care. One way to reduce this gap is for nurses to obtain feedback from families. The model of communication discussed earlier includes an informal approach to obtaining feedback by eliciting parents' expectations of care and being able to assist in meeting those expectations. This would start to reduce the gap between the parents' expectations and the nurses' perceptions of care delivered.

A more formal way of evaluating parents' experience is to use a parent satisfaction survey. The survey needs to ask questions pertaining to family centred care and whether parents' expectations were met. Parents' opinions are a critical measure of the achievement of goals (Marino & Marino, 2000) and consumer perceptions, in this case parents, correlate well with objective measures of health care quality (Wadhwa, 2002). As previously stated (page 99), the influence of consumers' perceptions is an aspect that is being increasingly recognised for its importance to health care quality (Urden, 2002; Wadhwa, 2002). As the HDWA patient satisfaction surveys are not specific to the care of children and do not pertain to the delivery of family centred care, a satisfaction survey for parents is required. Collaboration between nurses and parents about nursing practices and nursing care that was tailored to parents' needs were most strongly associated with overall parental satisfaction in a large study by Marino and Marino (2000) so the survey should include questions relating to these aspects of care. This would provide formal feedback direct to the hospital which would enable each hospital to tailor care and facilities to families' identified needs. This should be completed following discharge to avoid the concern that hospitalised families may not answer accurately in fear of staff retaliation and undertaken within one to four weeks post discharge from the hospital to maximise accuracy by being administered as close to the service encounter as possible (Urden, 2002).

Consumer Representation

The process of collaboration between the health care consumer and the hospital should be facilitated through the involvement of children, parents and community groups in continuous quality improvement and community advisory committees. As parents indicated that they were not included in decisions about policies and practices that affected children's hospitalisation, the assumption was made that

children also were not consulted. Individual hospitals need to invite and include the children and parent's perspectives of care when revising hospital policies and procedures that influence care. Consumers need to be actively involved in working with health professionals for the purpose of influencing decision making processes to bring about changes to health care, health services and the health care system (Johnson, 2001). The increasing emphasis on the role of the health care consumer within the health care system, has empowered 'health consumers' to develop greater knowledge of their rights (AWCH, 1992). The Guidelines for Maternal and Infant Care Services which are incorporated into the Evaluation and Quality Improvement Program (EQuIP) of the Australian Council of Healthcare Standards (ACHS, 1999) recognise consumer involvement in healthcare facilities activities as a standard and criterion for improving performance. Consumer satisfaction is identified as one of the clinical indicators which may be used as a measure of management and outcome of patient care (ACHS, 1999). The Association for the Welfare of Child Health (formerly the Australian Association for the Welfare of Children in Hospital) is an organisation which represents families and is available for consultation on issues relating to hospitalised children and care of families if a local representative is unavailable in the smaller districts.

This study was specifically looking at parents' perceptions of family centred care. However, it is the child who is the direct recipient of care and it is their best interest to which is strived. Children have the inherent right to express their views about things that affect them and to participate in communities, programs and services for children (United Nations, 1989). As Australia has ratified the United Nations Convention on the Rights of the Child it is imperative that children are enabled to live in accordance of the Convention by being included in planning hospital policies and practices that impact on them and providing them the opportunity to comment on their hospitalisation.

Facilities

There is a need to improve facilities in hospitals, particularly district hospitals, to enhance family centred care. Although hospitalised children form a small proportion of inpatients in district hospitals, an effort needs to be made to increase the family focus of these hospitals. If the hospital is prepared to accept children as inpatients, there should be an adequate budget allocated for the care of those children. Hospital

managers should ensure facilities are available for provision of an appropriate environment that enables children to be nursed in a room apart from adults and also for an adequate play area and equipment. To augment the budget allocated from the government, funding may be found by lobbying local community groups who are often able to support the local hospital. Another source is the Variety Club of Australia whose mission is the health and welfare of children and who have assisted financially with building and redecorating many children's wards in Western Australia in recent years.

The room decorated appropriately for children, should be large enough for a parent to sleep in with their child. A bed should be available for parents to sleep in if the child's hospitalisation is longer than one night to promote adequate rest for the parent.

A system for the supply of meals to parents so that parents do not have to leave their child also should be considered. It may be that provision of a microwave oven on the ward so parents can heat up food that has been brought in for them, is appropriate. Consideration should be given to introducing a system where parents are able to order a meal through the hospital's catering service and the meal is delivered to the ward. Parents are then billed for the cost of the meals as many parents find they do not have any money with them when their child is hospitalised. In larger hospitals where volunteers visit wards with a trolley, a choice of nutritious meals and fruit for parents to purchase could be available so parents do not have to leave the ward.

Parents often wish to make a phone call particularly on admission to arrange other tasks yet they do not want to leave their sick child. The availability of a cordless phone provides the opportunity of a phone call without leaving the child and also the opportunity for a private conversation during a stressful time. These modifications meet with the EQUIP standards (ACHS, 1999) to minimise the impact of admission on the family by integrating the family unit as much as possible.

Support

As well as extra facilities, extra staff are required when caring for children. Children require different patterns of nursing from adult patients which often means more staff. Callery's (1997a) study found that when parents were encouraged to be resident within the ward, they became co-clients and caring for parents was a hidden

part of paediatric nurses' work. Thus, caring for parents needs to be a recognised part of the nurse's role and included in the determination of staffing levels and skill mix to enable family centred care to be delivered as required. Forming a partnership between parents and nurses to enhance effective communication and provide family centred care, also requires more time (Davis et al, 2002) therefore an increase in staffing levels is required to adequately care for children and families.

Identification of those parents with no social support should be sought on admission. Where nurses use an admission 'check list', the addition of an extra question relating to family support will remind nurses to consider this when a child is admitted.

Having identified the lack of social support, then further interventions can be implemented where needed to assist those parents with the tasks of caring for their hospitalised child and continuing their other roles.

Advocacy

Enabling the parents to speak with the doctor by implementing various strategies is a further recommendation. Although information about this aspect of the nurses' role was not sought within this study it was apparent from the comments in the open ended questions volunteered by parents that they frequently had difficulty in accessing information from their child's doctor. If nurses are aware of this difficulty for parents they can advocate for the families. Strategies that may be considered are enabling the parents to speak with the doctor at the doctor's surgery by telephone, encouraging the doctor to be consistent in the time that he/she visits the hospital or organising a meeting time with the family and doctor, and ensuring the doctor is aware of the importance of communicating with the family when the family are seeking information or reassurance. Persistence by the nurses may change the doctors' behaviour.

Pre-admission Package

Providing information to parents prior to their child's booked hospital admission is another recommendation. As an in-house preadmission program is not appropriate in many circumstances for booked admissions, a suitable mode of providing information would be a package posted to families which could give all the relevant information. As well as providing information about parental participation in care, meals, accommodation, any costs, parking, possible impact of hospitalisation on the

family and any relevant hospital policies and practices, information should be included for the child where developmentally appropriate. Evidence supports the sharing of relevant knowledge and information as central to family empowerment when children are hospitalised (Robertson, 1995; Swanwick, 1995) and pre-admission information provides the opportunity for children to explore their beliefs about hospitals with their family who can then correct any misconceptions which should reduce the stress associated with hospitalisation (Stone, 2000).

Implications for Education

Ongoing professional education of nurses should be encouraged and supported by hospital managers. Managers need to acknowledge that ‘children are not little adults’ and recognise the specialist care that children and families require when sick. Nurses would appreciate the financial support from managers when making a commitment to attend relevant educational programs.

Those who provide the education need to emphasise the psychosocial aspects of nursing children in conjunction with the medical aspects of care. Aspects of care that this study showed were not attended to consistently were the impact of hospitalisation on families, particularly for siblings and the importance of maintaining routine for the child. These could be incorporated within the umbrella of any topic that was being presented so that the importance of such aspects of care are heightened.

One suggestion by a respondent in this study was a poster-education scheme where posters are designed on aspects of care and circulated through hospitals. Another suggestion was for a ‘buddy system’ where a relationship is developed between two nurses, one in a district hospital and one in another hospital, and information is exchanged regularly. Coordination of these ideas could be undertaken by either the tertiary paediatric hospital in the state or the Association of Paediatric and Child Health Nurses (WA).

As nurses perceive they have inadequate skills to address families’ social problems that may be identified during the hospitalisation, they therefore need to know the resources to which to refer the families when a social worker or psychologist is not available. Ensuring there is a list of resources that are available within the region so families can be referred is one strategy. Liaison with and/or referral to the

Community Child Health Nurse is another strategy to assist the family as they are often better able to assist with counselling and interpersonal relationships for families due to their education, experience and role.

Areas for Further Nursing Research

Family centred care is practiced in the belief that it improves outcomes for hospitalised children. The interpretation of the results of this study are limited as it only sought parents' perceptions and not the perceptions of the children who had been hospitalised and other family members for example, siblings which would have enhanced the understanding of the provision of family centred care. Contemporary thinking, particularly within the United Kingdom, now includes children's perceptions of their hospitalisation however, the average age of the hospitalised children whose parents were included in this study was less than four years of age. This precluded the majority of children in this study from being able to complete a questionnaire. Studies were identified where researchers have interviewed children between five to twelve years of age seeking their perspective on parental participation but these were not in Australia so it is timely to seek children's perceptions of their hospital care in this country. This would also adhere to the United Nations Convention on the Rights of the Child (1989) which was ratified by Australia and the recent document 'Vision for Children in Western Australia' (NIFTeY, 2003) by ensuring all children are consulted, participate in and, where appropriate, act on any decisions that affect them so they are shown respect.

On the basis of the findings from the psychometric tests on the subscales it is recommended that these modified instruments be refined and undergo additional testing to derive valid and internally consistent indicators of family centred care for parents and nurses. As several items on the parents' questionnaire - 18 and 41 - did not demonstrate satisfactory item internal consistency and items 15 and 49 did not demonstrate satisfactory item discriminant validity, further studies with larger samples are required to validate inclusion of these items in the hypothesised scales if these scales are to be used regularly.

The primarily quantitative nature of this study has highlighted a number of aspects of family centred care that were not being provided consistently. These need to be explored in more depth using qualitative research methods. For example, while this

study gives some indication that children's usual routines were not being followed, further information needs to be elicited to ascertain which aspects of the child's routine were disrupted and whether it was related to budgetary constraints, catering or cleaning schedules or whether nursing staff are unaware of the importance of this aspect of a child's care. Also, this study identified that parents who had no social support when their child was hospitalised perceived they received family centred care at a statistically significantly lower level than did those who had social support. This requires further exploration to identify why they perceived this and which aspects of care these parents particularly required. Further research could explore the lack of awareness by nurses that parents want to provide nursing care to their child. Another potential area for research is the evaluation of some of the strategies suggested to improve family centred care in this chapter. Of particular interest would be a study to ascertain whether the introduction of the modified Nursing Mutual Participation Model of Care (Curley, 1988) recommended earlier, improves communication between parents and nurses and leads to a partnership model of care being established.

Conclusion

The importance of delivering family centred care when a child is hospitalised has been advocated since the Platt Report in 1959 (Department of Health and Social Security). Many studies from North America, United Kingdom and Australia have shown there are difficulties with the delivery of this care and demonstrated that nurses believe they are providing family centred care when parents do not believe they are receiving it to the same extent. This study showed that parents and nurses from rural hospitals in Western Australia have perceptions consistent with earlier studies. Although they both believe family centred care is delivered when a child is hospitalised, there were aspects of care that could be improved. One area identified was that nurses ask parents about their participation in the child's care on admission but do not follow this up each shift or at least daily when it is recognised that parents' needs related to this aspect of care change during their child's hospitalisation. Also, although nurses provide the direct care to the child they are far less likely to support the parents so they can care for themselves or attend to other tasks that they may have thus adding to the stress and exhaustion that parents already feel. Nurses may become aware of these needs if they improve their communication

with parents and become more collaborative in their provision of care. However, despite the lack of adequate staff and equipment, the additional roles that rural nurses frequently have to attend, and in some cases, the infrequent opportunities to nurse children, nursing care that is family centred is provided to families in rural Western Australia.

REFERENCES

- Ahmann, E. (1994). Family-centred care: Shifting orientation. *Pediatric Nursing*, 20(2), 113-117.
- Alderson, P. (1993). *Children's consent to surgery*. Buckingham, England: Open University Press.
- Algren, C. (1985). Role perception of mothers who have hospitalised children. *Children's Health Care: Journal of the Association for the Care of Children's Health*, 14(1), 6-9.
- Arnstein, S. R. (1969). A ladder of participation. *Journal of the American Institute of Planners*, 35, 216–223.
- Association for the Welfare of Children in Hospital. (1975). A recommended health care policy relating to children and their families. *Medical Journal of Australia*, August 9 (Suppl. 1), 1-16.
- Australian Association for the Welfare of Children in Hospital. (1992). *National survey report on psycho-social care of children (and families) in hospital*. Sydney: Author.
- Australian Bureau of Statistics. (2003). *ABS publication 2039.0*. Retrieved August, 22, 2003, from [http://www.ausstats.abs.gov.au/ausstats/free.nsf/Lookup/AFF5E8542B58B94ECA256DD5007A3DF8/\\$File/20390%5F2001.pdf](http://www.ausstats.abs.gov.au/ausstats/free.nsf/Lookup/AFF5E8542B58B94ECA256DD5007A3DF8/$File/20390%5F2001.pdf)
- Australian Council on Healthcare Standards. (1999). *Guidelines for maternal and infant care services*. Ultimo, NSW: Author.
- Australian Institute of Health and Welfare. (1998). *Australia's children 1998 – Their health and wellbeing*. Retrieved September 6, 2002, from <http://www.aihw.gov.au/publications/health/ac98/index.html>

- Australian Institute of Health and Welfare. (2001). *Nursing labour force 1999: National health labour force series*. Retrieved September 6, 2002, from <http://www.aihw.gov.au/publications/hwl/nurslf99/nurslf99.pdf>
- Ayer, A. (1978). Is partnership with parents really possible? *American Journal of Maternal Child Nursing*, March/April, 107-109.
- Beck, M. (1973). Attitudes of parents of paediatric heart patients toward patient care units. *Nursing Research*, 22(4), 334-338.
- Bjørner, J., Damsgaard, M., Watt, T., & Groenvold, M. (1998). Tests of data quality, scaling assumptions and reliability of the Danish SF-36. *Journal of Clinical Epidemiology*, 51(11), 1001-1011.
- Bowlby, J. (1951). *Maternal care and mental health*. Geneva: World Health Organization
- Bricher, G. (2000). Children in the hospital: Issues of power and vulnerability. *Pediatric Nursing*, 26(3), 277-282.
- Brooking, J. (1989). A survey of current practices and opinions concerning patient and family participation in hospital care. In J. Wilson-Barnett & S. Robinson (Eds.), *Directions in Nursing Research*. (pp. 97-107). London: Scutari Press
- Brownlea, A. (1987). Participation: Myths realities and prognosis. *Social Science and Medicine*, 25(6), 605-614.
- Bruce, B., & Ritchie, J. (1997). Nurses' practices and perceptions of family-centered care. *Journal of Pediatric Nursing*, 12(4), 214-221.
- Burke, S. O., Kaufmann, E., Costello, E. A., & Dillon, M. C. (1991). Hazardous secrets and reluctantly taking charge: Parenting a child with repeated hospitalisations. *Image: Journal of Nursing Scholarship*, 23(1), 39-45.
- Burns, N., & Grove, S. (1987). *The practice of nursing research: Conduct, critique and utilization*. Philadelphia: W. B. Saunders Co.
- Cahill, I. (1996). Patient participation. *Journal of Advanced Nursing*, 24, 561-571.
- Calabretto, H., & Johnson, A. (1994). Partnership-in-care. *Journal of Association for the Welfare of Child Health*, 20(1), 6-8.

- Callery, P. (1997a). Caring for parents of hospitalized children: A hidden area of nursing work. *Journal of Advanced Nursing*, 26, 992-998.
- Callery, P. (1997b). Maternal knowledge and professional knowledge: Co-operation and conflict in the care of sick children. *International Journal of Nursing Studies*, 34(1), 27-33.
- Callery, P. (1997c). Paying to participate: Financial, social and personal costs to parents of involvement in their children's care in hospital. *Journal of Advanced Nursing*, 25, 746-752.
- Callery, P., & Smith, L. (1991). A study of role negotiation between nurses and the parents of hospitalised children. *Journal of Advanced Nursing*, 16, 772-781.
- Casey, A. (1988). A partnership with child and family. *Senior Nurse*, 8(4), 8-9.
- Casey, A. (1993). Development and use of the partnership model of nursing care. In E. A. Glasper & A. Tucker (Eds.), *Advances in child health nursing* (pp. 183-193). London: Scutari Press.
- Casey, A., & Mobbs, S. (1988). Partnership in practice. Spotlight on children. *Nursing Times*, 84, 67-68.
- Caty, S., Ritchie, J., & Ellerton, M. (1989). Helping hospitalised preschoolers manage stressful situations: the mother's role. *Child Health Care* 18(4), 209.
- Cilliers, F., & Terblanche, L. (2000). Facilitation skills for nurses. *Curationis*, 23(4), 90-97.
- Cleary, J. (1992). *Caring for children in hospital: Parents and Nurses in partnership*. London: Scutari Press.
- Connell, J., & Bradley, S. (2000). Visiting children in hospital: A vision from the past. *Paediatric Nursing*, 12(3), 32-35.
- Coyne, I. T. (1995a). Parental participation in care: A critical review of the literature. *Journal of Advanced Nursing*, 21, 716-722.

- Coyne, I. T. (1995b). Partnership in care: Parents' views of participation in their hospitalised child's care. *Journal of Clinical Nursing*, 4, 71-79.
- Coyne, I. T. (1996). Parent participation: A concept analysis. *Journal of Advanced Nursing*, 23, 733-740.
- Craft, M. J. (1993). Siblings of hospitalized children: Assessment and intervention. *Journal of Pediatric Nursing*, 8(5), 289-297.
- Curley, M. A. Q. (1988). Effects of the nursing mutual participation model of care and parental stress in the paediatric intensive care unit. *Heart and Lung*, 17(6), 682-688.
- Curley, M., & Wallace, J. (1992). Effects of the nursing mutual cooperation model of care on parental stress in the pediatric intensive care unit – a replication. *Pediatric Nurse*, 7(6), 377-385.
- Daly, J., Kellehear, A. & Gliksman, M. (1997). *The public health researcher: A methodological guide*. Melbourne: Oxford University Press Australia
- Darbyshire, P. (1994). *Living with a sick child in hospital: The experiences of parents and nurses*. London: Chapman & Hall.
- Davis, H., Day, C., & Bidmead, C. (2002). *Working in partnership with parents: The parent adviser model*. London: Psychological Corporation Limited.
- Dearmun, A. (1992). Perceptions of parental participation. *Paediatric Nursing*, 4(7), 6-9.
- Department of Education, Training and Youth Affairs. (2001). *Job growth and replacement needs in nursing occupations*. Canberra: AusInfo.
- Department of Health and Social Security. (1959). *The welfare of children in hospital: Report of the committee*. London: Her Majesty's Stationery Office.
- Dixon-Woods, M., Young, B., & Heney, D. (1999). Partnerships with children. *British Medical Journal*, 319(7212), 778-780.

- Evans, M. (1994). An investigation into the feasibility of parental participation in the nursing care of their children. *Journal of Advanced Nursing*, 20(3), 477-482.
- Farrell, M. (1992). Partnership in care: Paediatric nursing model. *British Journal of Nursing*, 1(4), 175 – 177.
- Ferraro, R., & Longo, D. C. (1985). Nursing care of the family with a chronically ill, hospitalised child: An alternative approach. *Image*, 17(3), 77-81.
- Gill, K. (1987a). Nurses' attitudes towards parent participation: Personal and professional characteristics. *Children's Health Care: Journal for the Association for the Care of Children's Health*, 15(3), 149-151.
- Gill, K. (1987b). Parent participation with a family health focus: Nurses' attitudes. *Pediatric Nursing*, 13(2), 94-96.
- Gill, K. (1993). Health professionals' attitudes toward parent participation in hospitalised children's care. *Children's Health Care: Journal for the Association for the Care of Children's Health*, 22(4), 257-271.
- Hart, D. (1979). Parents and professionals as partners. *New Horizons in Education*, 16, 8-11.
- Hayes, V., & Knox, J. (1984). The experience of stress in parents of children hospitalised with long term disabilities. *Journal of Advanced Nursing*, 9(4), 333-341.
- Health Department of Western Australia. (2002). *Guidelines for the clinical management of child abuse and neglect*. Perth: HDWA.
- Health Department of Western Australia. (2001a). *The Western Australian Health Services Directory*. Retrieved June 29, 2001, from <http://www.health.wa.gov.au/services/map.cfm>
- Health Department of Western Australia. (2001b). [Epidemiology and analytical branch]. Unpublished raw data.

- Health Department of Western Australia. (1997). [Hospital morbidity data system]. Unpublished raw data.
- Hill, C. (1978). The mother on the pediatric ward: Insider or outlawed? *Pediatric Nursing*, 4(5), 26-29.
- Hutchfield, K. (1999). Family centred care: A concept analysis. *Journal of Advanced Nursing*, 29(5), 1178-1187.
- Jackson, P., Bradham, R., & Burwell, H. (1978). Child care in the hospital: A parent-staff partnership. *American Journal of Maternal Child Nursing*, 3, 104-107.
- Johnson, A. (1994). *Patient/nurse working relationships – perspectives of parents of hospitalised children*. Paper presented at the international conference convened by the Australian Confederation of Paediatric Nurses, Melbourne, Australia.
- Johnson, A. (1996). *Partnership-in-care: A principle of practice or a cliché*. Paper presented at the international conference convened by the Australian Confederation of Paediatric Nurses, Brisbane, Australia.
- Johnson, A. (2001). An outline of consumer participation in health. *Collegian*, 8(2), 25-27.
- Johnson, A., & Lindschau, A. (1993). [Women's and Children's Hospital: Parent's Survey]. Unpublished questionnaire.
- Johnson, A., & Lindschau, A. (1996). Staff attitudes toward parent participation in the care of children who are hospitalized. *Pediatric Nursing*, 22(2), 99-102.
- Johnson, B. H., Jeppson, E. S., & Redburn, L. (1992). *Caring for children and families: Guidelines for hospital*. Bethesda: Association for the Care of Children's Health.
- Kawik, L. (1996). Nurses' and parents' perceptions of participation and partnership in caring for a hospitalized child. *British Journal of Nursing*, 5(7), 430-434.

- Keatinge, D. & Gilmore, V. (1996). Shared care: A partnership between parents and nurses. *Australian Journal of Advanced Nursing*, 14(1), 28-36.
- Knafelz, K., Cavallari, K., & Dixon, D. (1988). *Pediatric hospitalisation: Family and nurses perspectives*. Illinois: Scott Foresman and Co.
- Kristensson-Hallstrom, I., & Elander G. (1994). Parental participation in the care of hospitalised children. *Scandinavian Journal of Caring Science*, 8, 149-154.
- Kristensson-Hallstrom, I., & Elander G. (1997). Parents' experiences of hospitalisation: Different strategies for feeling secure. *Pediatric Nursing*, 23(4), 361-367.
- LaMontagne, L. (1984). *Children's locus of control beliefs as predictors of preoperative coping behaviours*. *Nursing Research*, 33(2), 76-79.
- Lindsay, B. (2001). Visitors and children's hospitals, 1852-1948: A re-appraisal. *Paediatric Nursing*, 13(4), 20-24.
- LoBiondo-Wood, G., & Haber, J. (1990). *Nursing research: Methods, critical appraisal, and utilization* (2nd ed.). St. Louis: Mosby.
- MacDonald, E. (1969). Parents participation in care of the hospitalised child. *Canadian Nurse*, 65(12), 37-39.
- Mahaffy, P. (1965). The effects of hospitalisation on children admitted for tonsillectomy and adenoidectomy. *Nursing Research*, 14(1), 12-19.
- Marino, B., & Marino, E. (2000). Parents' report of children's hospital care: What it means for your practice. *Pediatric Nursing*, 26(2), 195-198.
- Maxton, F. (1997). Old habits die hard: Changing paediatric nurses' perceptions of families in ICU. *Intensive and Critical Care Nursing*, 13, 147-150.
- Merrow, D., & Johnson, B. (1968). Perception of the mother's role with her hospitalised child. *Nursing Research*, 17(2), 155-156.
- Mishel, M. H. (1983). Parents' perception of uncertainty concerning their hospitalised child. *Nursing Research*, 32(6), 324-330.

- Morse, J. M., & Richards, L. (2002). *Read me first for a user's guide to qualitative methods*. Thousand Oaks: Sage Publications.
- Neill, S. J. (1996a). Parent participation 1: Literature review and methodology. *British Journal of Nursing*, 5(1), 34-40.
- Neill, S. J. (1996b). Parent participation 2: Findings and their implications for practice. *British Journal of Nursing*, 5(2), 110-117.
- Nethercott, S. (1993). A concept for all the family. Family centred care: A concept analysis. *Professional Nurse*, 8(12), 794-797.
- NIFTeY WA. (2003). *A vision for children in Western Australia: Discussion document. October 2003*. (Available from the National Investment for the Early Years, Western Australia, PO Box 510, West Perth, WA 6872).
- Palmer, S. (1993). Care of sick children by parents: A meaningful role. *Journal of Advanced Nursing*, 18(2), 185-191.
- Perkins, M. (1993). Patient-nurse collaboration: using the caregiver identity emergence to assist parents of hospitalised children with disabilities. *Journal of Pediatric Nursing*, 8(1), 2-9.
- Polit, D., & Hungler, B. (1995). *Nursing research: Principles and methods* (5th ed.). Philadelphia: J. B. Lippincott.
- Roberts, S., & Krouse, H. (1988). Enhancing self care through active negotiation. *Nurse Practitioner*, 13(8), 46-52.
- Robertson, J. (1958). *Young children in hospital*. London: Tavistock.
- Robertson, L. (1995). The giving of information is the key to empowerment. *British Journal of Nursing*, 4(12), 692.
- Robinson, C. A. (1985). Parents of hospitalised chronically ill children: Competency in question. *Nursing Papers*, 17(2), 59-68.
- Robinson, C. A. (1987). Roadblocks to family-centred care when a chronically ill child is hospitalised. *Maternal-Child Nursing Journal*, 16(3), 181-193.

- Roden, J. (1998). *Parental participation in the care of acutely ill children in a non-children's hospital*. Paper presented at the international conference convened by the Australian Confederation of Paediatric and Child Health Nurses, Hobart, Australia.
- Rowe, J. (1996). Making oneself at home? Examining the nurse-parent relationship. *Contemporary Nurse*, 5(3), 101-106.
- Runeson, I., Elander, G., Hermeren, G., & Kristensson-Hallstrom, I. (2000). Children's consent to treatment: Using a scale to assess degree of self-determination. *Pediatric Nursing*, 26(5), 455-461.
- Rushforth, H. (1996). Nurses' knowledge of how children view health and illness. *Paediatric Nursing*, 8(9), 23-27.
- Savage, E. & Callery, P. (2000) Parental participation in the care of hospitalised children: A review of the research evidence. In E. A. Glasper & L. Ireland (Eds.), *Evidence – based child health care* (pp. 57-89). London: Macmillan Press Ltd.
- Schepp, K. (1992). Correlates of mothers who prefer control over their hospitalised children's care. *Journal of Pediatric Nursing*, 7(2), 83-89.
- Seidl, F. (1969). Pediatric nursing personnel and parent participation: A study in attitudes. *Nursing Research*, 18(1), 40-44.
- Seidl, F., & Pilitterri, A. (1969). Development of an attitude scale on parent participation. *Nursing Research*, 16, 71-78.
- Shelton, T., Jeppson, E., & Johnson, B. (1987). *Family-centred care for children with special health care needs*. Washington: Association for the Care of Children's Health.
- Shelton, T., & Smith Stepanek, J. (1995). Excerpts from family centred care for children needing specialized health and development services. *Pediatric Nursing*, 21(4), 362-364.

- Simon, K. (1993). Perceived stress of nonhospitalized children during the hospitalization of a sibling. *Journal of Pediatric Nursing*, 8(5), 298-304.
- Smith, F. (1995). *Children's nursing in practice: The Nottingham model*. Oxford: Blackwell Science.
- Smith, L., Coleman, V., & Bradshaw, M. (2002). *Development and use of the practice continuum tool to enhance consumer participation in the new millennium*. Paper presented at the international conference convened by the Australian Confederation of Paediatric and Child Health Nurses, Sydney, Australia.
- Southall, D., Burr, S., Smith, R., Bull, D., Radford, A., Williams, A. et al. (2000). The child friendly healthcare initiative (CFHI): Healthcare provision in accordance with the UN Convention the Rights of the Child. *Pediatrics*, 106(5), 1054-1064.
- Stone, K. (2000). Can information leaflets assist parents in preparing their child for hospital admission? In E. A. Glasper & L. Ireland (Eds.), *Evidence – based child health care* (pp. 163-184). London: Macmillan Press Ltd.
- Stull, M., & Deatrick, J. (1986). Measuring parental participation: Part 1. *Issues in Comprehensive Pediatric Nursing*, 9(3), 157-165.
- Swanwick, M. (1995). Power where it belongs: Empowerment in child health. *Child Health*, 2(6), 232-236.
- Taylor, B. (1996). Parents as partners in care. *Paediatric Nursing*, 8(4), 24-27.
- Tomlinson, P., Kirschawm, M., Tomczyk, B., & Peterson, J. (1993). The relationship of child acuity, maternal responses, nurses' attitudes and contextual factors in the bone marrow transplant unit. *American Journal of Critical Care*, 2(3), 246-247.
- United Nations. (1989). United Nations Convention on the Rights of the Child. Retrieved September 24, 2003, from <http://www.unhchr.ch/html/menu3/b/k2crc.htm>

- Urden, L. (2002). Patient satisfaction measurement: Current issues and implications. *Outcomes Management*, 6(3), 125-131.
- Wadhwa, S. (2002). Customer satisfaction and health care delivery systems: Commentary with Australian bias. *The Internet Journal of Nuclear Medicine*, 1(1). Retrieved September 5, 2003, from <http://journals/ijh/vol3n1/bias.xml>
- Ware, J. E., Jr. & Gandek, B. (1998). Methods for testing data quality, scaling assumptions, and reliability: The IQOLA project approach. *Journal of Clinical Epidemiology*, 51(11), 945-952.
- Webb, N., Hull, D., & Madeley, R. (1985). Care by parents in hospital. *British Medical Journal*, 291, 176-177.
- Whelan, T., & Kirkby, R. (1997). Parent empowerment: The hospitalisation of a child. *Journal of Family Studies*, 3(1), 94-107.

Appendix A

Letter to Director of Nursing/Health Service Manager

Date

Dear Director of Nursing/Health Service Manager,

I am a Registered Nurse and a graduate student enrolled in the School of Nursing at Curtin University. As part of my studies for a masters degree I am conducting a study on the extent to which nurses provide care which meets parents expectations when their child is in hospital in Western Australia. The results of this study will assist in the development of nurses' understanding of the role parents have to play when their child is in hospital and thus promote nursing practice which is sensitive to the needs of parents and families.

I am seeking approval and assistance to access parents who currently have, or have recently had, a child admitted to your hospital. I am also seeking permission to access the nurses who deliver direct care to children in your hospital. If you agree to them participating in this project, I am also requesting your assistance in accessing these people. I will cover the cost of all stationery, postage and labour and simply ask you to identify the parents who have had a child as an inpatient in your hospital within the last six months, address the questionnaires and mail them to each family? Also, could you please post a separate questionnaire to each nurse who is involved in the direct care of children in your hospital? This maintains anonymity of all participants.

This study has been approved by the Human Ethics Committee at Curtin University. My supervisors are Professor Robin Watts, School of Nursing, Curtin University and Ms Jeanette Robertson, Nurse Researcher, Princess Margaret Hospital for Children. This research has been assisted financially by the Nurses Board of Western Australia.

I am enclosing a draft copy of each questionnaire for your interest and do not anticipate that the final form will be very different to this draft copy. Could you please complete the accompanying form and return it in the reply paid envelope indicating your hospitals willingness to participate in the study?

Thank you very much in anticipation of your interest. Should you have any questions regarding the study or the questionnaire, please contact myself on (08) 9266 2370, email: wilsons@nursing.curtin.edu.au or Jeanette Robertson, Nurse Researcher at Princess Margaret Hospital on (08) 9340 8407, email: jeanette.robertson@health.wa.gov.au.

Thank you for your assistance.

Sally Wilson
Registered Nurse.

*** PLEASE RETURN ***

**Family Centred Care: A Descriptive Study of the Situation in Rural
Western Australia.**

I do / do not give approval for the study to be carried out in this hospital. (Please circle the appropriate response.)

I will organise for someone to forward questionnaires to the nurses who provide direct care to children and are employed by this hospital.

There are approximately _____ nurses eligible to participate.

I will organise for someone to identify parents who have had a child hospitalised here within the last six months and to post questionnaires to the families of those children.

I estimate _____ children have been admitted to this hospital within the last six months.

I anticipate that the cost of staff time in accessing the parents' addresses and mailing the questionnaires will be \$_____ .

Yours sincerely

DON/HSM

_____ Hospital.

10. Who provided social support while your child was in hospital? (Social support refers to the person/s who assisted you with other roles/jobs you usually do thus enabling you to spend time with your hospitalised child eg. collect other children from school, cook a meal.)

Immediate family (partner, children over 15 years old).....	1
Your parents/parents-in-law.....	2
Other family (your brothers, sisters; brothers/sisters-in-law).....	3
Friends.....	4
No one.....	5

PART B

How to complete this section.

Throughout this section you are asked to indicate your level of agreement with each statement by circling the appropriate number opposite each statement. The code is:

1	= Strongly disagree
2	= Disagree
3	= Undecided - neither agree nor disagree
4	= Agree
5	= Strongly agree
NA	= Not applicable

Information

Listed below is a series of statements related to information that you may have received or been asked for when your child was admitted to hospital on this occasion. Please indicate your level of agreement with each statement by circling the appropriate number opposite each question.

	Strongly Disagree	1	2	3	4	Strongly Agree	
1. I received information (verbal or written) about our child's hospitalisation.	1	2	3	4	5		
2. The information included the impact our child's hospitalisation could have on the family.	1	2	3	4	5		
3. The written and/or verbal information that I was given from the hospital, conveyed the sense that families are the key participants in care.	1	2	3	4	5		
4. I understood all the written material that was given to my family.	1	2	3	4	5	NA	
5. I did not understand all the explanations regarding my child's care and condition.	1	2	3	4	5		
6. Nurses ensured that I understood the information they gave to me.	1	2	3	4	5		
7. All staff who cared for my family introduced themselves and informed us of their role.	1	2	3	4	5		
8. Nurses routinely informed me of each aspect of care that my child would experience.	1	2	3	4	5		

	Strongly Disagree				Strongly Agree	
	1	2	3	4	5	
9. I could not access information about my child's care and progress if I wished.	1	2	3	4	5	
10. My child and family were offered the opportunity to take part in a preadmission program which familiarised us with hospital staff, routines and equipment prior to a booked admission.	1	2	3	4	5	NA
11. Nurses assisted my child and family to adjust to the hospitalisation.	1	2	3	4	5	
12. Nurses were not interested in the information I gave them about my child.	1	2	3	4	5	
13. The nurses asked me what was normal for my child (behaviour, routine, parenting practices).	1	2	3	4	5	
14. The information provided by nurses was consistent.	1	2	3	4	5	

Participation

Listed below is a series of statements related to the extent of the participation you had in your child's care when she/he was hospitalised. Please indicate your level of agreement with each statement by circling a number opposite each one.

	Strongly Disagree				Strongly Agree
	1	2	3	4	5
15. The nurses worked with my family and I to determine how much involvement we would have in our child's care.	1	2	3	4	5
16. Decisions were made about our child's care without our input.	1	2	3	4	5
17. Every day nurses asked to what extent I wanted to be involved in my child's care.	1	2	3	4	5

In the following questions, "**parenting**" relates to the things you would normally do for your child as a parent at home eg. bathing, toileting, feeding. "**Nursing care**" relates to tasks that you would not normally provide at home eg. giving medications, monitoring intravenous fluids, dressings, feeding via a tube, holding your child during procedures. Please indicate your agreement with each statement by circling a number next to each one.

	Strongly Disagree				Strongly Agree
	1	2	3	4	5
18. I wanted to continue parenting my child whilst in hospital.	1	2	3	4	5
19. I wanted to carry out nursing care for my child whilst in hospital.	1	2	3	4	5
20. I was able to carry out as much of my child's parenting as I wanted.	1	2	3	4	5
21. I was able to participate in as much of the nursing care of my child as I wished.	1	2	3	4	5

	Strongly Disagree				Strongly Agree	
	1	2	3	4	5	
22. I felt I was expected to provide parenting for my child.	1	2	3	4	5	
23. I felt I was expected to provide nursing care for my child.	1	2	3	4	5	
24. Hospital policies prevented us from providing all the parenting we wished for our child.	1	2	3	4	5	
25. Hospital policies prevented us from providing nursing care for our child.	1	2	3	4	5	NA
26. All the care I wanted to provide for my child was recorded.	1	2	3	4	5	
27. I was encouraged to discuss or write information on the chart about the care of my child.	1	2	3	4	5	
28. The nurses encouraged me to continue parenting my child whilst in hospital.	1	2	3	4	5	
29. Nurses helped me become confident in parenting when unfamiliar equipment was present.	1	2	3	4	5	NA
30. I was allowed to be present during all procedures and treatments carried out on my child if I wished to be.	1	2	3	4	5	

Input for Quality Improvement

Following are statements relating to evaluation of nursing practices and ongoing education for staff. Please circle a number next to each statement to indicate your agreement.

	Strongly Disagree				Strongly Agree	
	1	2	3	4	5	
31. I was offered the opportunity to give feedback as to how well the hospital met my needs while my child was in hospital.	1	2	3	4	5	
32. I was given the opportunity to comment on hospital practices that involved my child.	1	2	3	4	5	
33. My family has been invited to speak to nursing staff about promoting parents involvement in the care of their hospitalised children.	1	2	3	4	5	
34. I would not express any concerns relating to aspects of my child's care for fear that my child would suffer.	1	2	3	4	5	NA

Family Friendly Hospitals

The following statements relate to the facilities and whether they were appropriate for your child and family.

	Strongly Disagree					Strongly Agree
	1	2	3	4	5	
35. The nurses' approach to providing care was appropriate to my child's age.	1	2	3	4	5	
36. The physical layout of the ward was designed to meet the developmental needs of my child.	1	2	3	4	5	
37. There was an adequate play/entertainment area for all of my children.	1	2	3	4	5	
38. Discussions between staff and my family were conducted in a private location.	1	2	3	4	5	
39. There was a comfortable area set aside for parents to gather.	1	2	3	4	5	
40. I was able to sleep in the hospital in a room away from my child if I wished.	1	2	3	4	5	
41. My partner and I could both have stayed in hospital with our child if we wished.	1	2	3	4	5	

Recognition of Impact of Hospitalisation

This group of statements relate to nurses recognising the impact hospitalisation of a child can have on the whole family. Please indicate your agreement with each statement by circling the appropriate number.

	Strongly Disagree					Strongly Agree	
	1	2	3	4	5		
42. Nurses appeared to be aware of the increased costs incurred by parents when a child is in hospital.	1	2	3	4	5		
43. Nurses ensured that I ate meals regularly.	1	2	3	4	5		
44. Nurses ensured that I had adequate toiletries when my child's admission to hospital was sudden.	1	2	3	4	5		NA
45. Nurses discussed with my family things that might help us deal with other events during hospitalisation of our child.	1	2	3	4	5		
46. Nurses appeared aware of the needs and concerns of my hospitalised child's brothers and sisters.	1	2	3	4	5		NA
47. Nurses helped my child and family to stay in touch with extended family and friends.	1	2	3	4	5		

Staffing

		Strongly Disagree				Strongly Agree	
		1	2	3	4	5	
48.	I felt there was adequate nursing staff to meet my child's needs at all times.						
49.	I felt there was adequate nursing staff to meet my family's needs at all times.						
50.	I was aware of times when the nurses were very busy.						NA

Time away

Parents have many roles and may need to leave the hospital to attend to them. Please indicate your agreement with the following statements.

		Strongly Disagree				Strongly Agree	
		1	2	3	4	5	
51.	Nurses asked about other things that I had to do each day.						
52.	My family and I were encouraged by staff to come and go at any time that met our needs.						
53.	The nurses organised our child's care to allow us to attend to other business.						NA
54.	I was made to feel as if I was a bad parent if I could not stay at the hospital all of the time.						NA
55.	The nurses realised it was important to me to be able to spend time away from the hospital.						NA
56.	I would not leave the hospital for fear that my child would not receive all the care/attention needed.						NA

Teamwork

		Strongly Disagree				Strongly Agree	
		1	2	3	4	5	
57.	I felt included in my child's care and part of the team from the time my child was admitted.						
58.	My spouse/partner felt included in all aspects of our child's care.						NA
59.	Nurses maintained familiar routines for my child.						
60.	The same nurses were assigned to care for my child whenever possible.						

Networks

		Strongly Disagree				Strongly Agree	NA
61.	Nurses encouraged me as a parent to discuss concerns with other parents with similar needs.	1	2	3	4	5	NA
62.	Nurses supplied us with information of support groups that might help us manage our child's condition.	1	2	3	4	5	NA

PART C

Open ended questions for parents.

1. Did you think there was a difference between how you wanted your child and family to be cared for, and what actually occurred when your child was in hospital? (Please circle the appropriate response.) Yes / No

If yes, what was the difference?

Do you have any ideas of why there was a difference?

2. Were there instances where you felt that you or your family were not included in the care of your child? Yes / No

Please describe the occasion/s.

Appendix C

Self Administered Questionnaire for Nurses

(Reduced format)

Background questions:

First, a few background questions about yourself. Please circle the number against the most appropriate response and/or fill in the spaces.

1. Which of the following apply to you? (You may need to circle more than one response.)

- | | |
|---|---|
| Hospital Certificate (Enrolled Nurse)..... | 1 |
| Associate Diploma of Health Science (Enrolled Nurse)..... | 2 |
| Paediatric certificate/qualification for Enrolled Nurses..... | 3 |
| Hospital based diploma (Registered Nurse)..... | 4 |
| Bachelor of Nursing/Science..... | 5 |
| Paediatric certificate/qualification for Registered Nurses..... | 6 |
| Postgraduate tertiary qualification (please state) _____ | |
| Other (please state) _____ | |

2. How many years have you worked as a nurse? _____ years.

3. How many years have you nursed children in hospital? _____ years.

4. What is your **main** area of nursing practice? (Please circle **one** from **list A** and **one** from **list B**.)

- List A: Clinical..... 1
Management..... 2
Staff development..... 3

- List B: Emergency..... 4
Generalist..... 5
Gerontology..... 6
Medical..... 7
Midwifery..... 8
Operating rooms..... 9
Paediatrics..... 10
Surgical..... 11
Other _____

5. Your gender:

- Male..... 1
Female..... 2

6. What is your age in years?

< 20 years.....	1	36 – 40.....	5
21 – 25	2	41 – 45	6
26 – 30.....	3	46 – 50.....	7
31 – 35	4	50 >	8

- | | | |
|--------------------------------------|-----------|---|
| 7. Are you a parent? | Yes..... | 1 |
| | No..... | 2 |
| 8. Have you had a child in hospital? | Yes | 1 |
| | No | 2 |

PART B

How to complete this questionnaire.

Throughout this section you are asked to indicate your level of agreement with each statement by circling the appropriate number opposite each statement according to the following code:

- 1 = Strongly disagree
- 2 = Disagree
- 3 = Undecided - neither agree nor disagree
- 4 = Agree
- 5 = Strongly agree
- NA = Not applicable

Section A

Listed below is a series of statements related to information that you may have received, or given to parents, when their child was admitted to hospital. Please indicate your level of agreement with each statement by circling the appropriate number opposite each question.

- | | Strongly
Disagree | | | | Strongly
Agree | |
|---|----------------------|---|---|---|-------------------|----|
| | 1 | 2 | 3 | 4 | 5 | |
| 1. Every family receives information (written or verbal) about their child's hospitalisation. | 1 | 2 | 3 | 4 | 5 | |
| 2. This information includes the impact their child's hospitalisation could have on the family. | 1 | 2 | 3 | 4 | 5 | |
| 3. All information (written or verbal) conveys the sense that families are the key participants in care. | 1 | 2 | 3 | 4 | 5 | |
| 4. All written material for families is in family friendly terms. | 1 | 2 | 3 | 4 | 5 | NA |
| 5. I provide explanations to families according to individual family needs. | 1 | 2 | 3 | 4 | 5 | |
| 6. I provide information to help families understand the roles of health professionals with whom they will come in contact. | 1 | 2 | 3 | 4 | 5 | |
| 7. I routinely tell parents about their child's progress. | 1 | 2 | 3 | 4 | 5 | |
| 8. I ensure information is regularly communicated to help families understand each aspect of care that their child will experience. | 1 | 2 | 3 | 4 | 5 | |
| 9. Families cannot access information about their child whenever they wish. | 1 | 2 | 3 | 4 | 5 | |
| 10. Preadmission programs which familiarise children and families with hospital staff, routines and equipment prior to a booked admission are provided. | 1 | 2 | 3 | 4 | 5 | |
| 11. I try to ensure that families adjust to their child's hospitalisation. | 1 | 2 | 3 | 4 | 5 | |

	Strongly Disagree	1	2	3	4	Strongly Agree
12. I value all the information that parents give to me regarding their child.	1	2	3	4	5	
13. I ask parents what is normal for their child (behaviour, routine, parenting practices).	1	2	3	4	5	
14. Staff maintain consistency when providing information to parents.	1	2	3	4	5	

Section B.

Listed below is a series of statements related to the extent of participation that families have in their child's care when their child is hospitalised. Please indicate your level of agreement with each statement by circling a number opposite each one.

	Strongly Disagree	1	2	3	4	Strongly Agree
15. I negotiate with families to determine the level of participation in direct care that suits the family's needs best.	1	2	3	4	5	
16. Staff decide on the child's care then inform the family.	1	2	3	4	5	
17. I clarify parents' level of participation in their child's care each shift.	1	2	3	4	5	

In the following questions, "**parenting**" relates to the things parents would normally do for their child as a parent at home eg. bathing, toileting, feeding. "**Nursing**" relates to tasks that parents would not normally provide at home eg. giving medications, monitoring intravenous fluids, dressings, tube feeding, holding their child during procedures. Please indicate your agreement with each statement by circling a number next to each one.

	Strongly Disagree	1	2	3	4	Strongly Agree
18. Parents want to continue parenting their child whilst in hospital.	1	2	3	4	5	
19. Parents want to provide nursing for their child whilst in hospital.	1	2	3	4	5	
20. Parents are allowed to carry out as much parenting for their child as they wish.	1	2	3	4	5	
21. Parents are allowed to carry out as much nursing for their child as they wish.	1	2	3	4	5	
22. I expect parents to provide parenting for their child whilst they are in hospital.	1	2	3	4	5	
23. I expect parents to provide nursing to their child whilst they are in hospital.	1	2	3	4	5	
24. I ask parents to help with their child's care when I am really busy.	1	2	3	4	5	
25. Hospital policies prevent families providing all the parenting they wish for their child.	1	2	3	4	5	

		Strongly Disagree				Strongly Agree	
		1	2	3	4	5	
26.	Hospital policies prevent parents providing nursing care if they wish.						
27.	I document the parents' desired level of participation in their child's care.						
28.	Family members involved in their child's care are encouraged to discuss or chart information about the care of their child.						
29.	I encourage parents to continue parenting their child when in hospital.						
30.	I ensure parents are feeling confident to continue parenting their child in hospital.						NA
31.	Parents are welcome to be present during any procedures involving their child.						

Section C.

Following are statements relating to evaluation of nursing practices and ongoing education for staff. Please circle a number next to each statement to indicate your agreement.

		Strongly Disagree				Strongly Agree	
		1	2	3	4	5	
32.	I seek feedback from families about how well their needs were met when their child was hospitalised.						
33.	Parents contribute to the development and review of hospital policies and practices which relate to children.						
34.	Families are involved in hospital staff orientation or continuing education programs.						
35.	I am able to express concerns to my superior related to the demands of providing care for children and families.						NA
36.	Job descriptions and performance appraisal systems incorporate expectations of knowledge of child development, paediatric nursing and interventions that address families' needs.						
37.	Continuing education programs provide opportunities for staff to learn to deal effectively with families.						NA
38.	The hospital recognises and rewards special knowledge and skills that are needed to care for children and their families.						
39.	I have an adequate knowledge in child development to support developmental needs of the child and family.						

Section D.

The following statements relate to the hospital facilities and whether they are appropriate for children and families.

	Strongly Disagree				Strongly Agree
	1	2	3	4	5
40. The physical layout of the ward is designed to meet the developmental and psychosocial needs of the child and family.	1	2	3	4	5
41. There is an adequate play/entertainment area for children of all ages.	1	2	3	4	5
42. Discussions between staff and families are conducted in a private location.	1	2	3	4	5
43. There is a designated comfortable area for families to gather.	1	2	3	4	5
44. Parents can sleep in a room away from their child if desired.	1	2	3	4	5
45. Both parents can stay in hospital if they wish.	1	2	3	4	5

Section E.

This group of statements relate to the possible impact the hospitalisation of a child can have on a family. Please indicate your level of agreement with each statement by circling the appropriate number.

	Strongly Disagree				Strongly Agree
	1	2	3	4	5
46. Families incur increased costs when a child is hospitalised.	1	2	3	4	5
47. I assist families in managing their other needs whilst their child is hospitalised.	1	2	3	4	5
48. I ensure parents eat meals regularly.	1	2	3	4	5
49. I ensure that parents have adequate toiletries when their child is an emergency admission.	1	2	3	4	5
50. I always assess the needs and concerns of siblings.	1	2	3	4	5
51. I help hospitalised children and their families to stay in touch with their family and friends.	1	2	3	4	5

Section F.

	Strongly Disagree				Strongly Agree
	1	2	3	4	5
52. Staffing patterns are planned according to the developmental and psychosocial needs of the children.	1	2	3	4	5
53. The ward is frequently short staffed	1	2	3	4	5
54. The ward is frequently very busy	1	2	3	4	5

Section G.

Please indicate your agreement with each statement relating to parents presence in the ward.

	Strongly Disagree	1	2	3	4	Strongly Agree
55. I always ask the family about other commitments that they might have while their child is in hospital.	1	2	3	4	5	
56. I encourage the family to come and go at any time that meets the family's needs.	1	2	3	4	5	
57. I expect a parent to be with their child in hospital all of the time.	1	2	3	4	5	
58. I organise the child's care so that the family can attend to other business if necessary.	1	2	3	4	5	
59. I respect a family's decision if they do not stay in hospital with their child.	1	2	3	4	5	
60. I reassure parents that their child will receive all care if they wish to leave the ward.	1	2	3	4	5	

Section H.

	Strongly Disagree	1	2	3	4	Strongly Agree
61. The family is an integral part of the health care team from admission.	1	2	3	4	5	
62. The family are included in all aspects of their child's care.	1	2	3	4	5	
63. I try to maintain each child's home routine whilst in hospital.	1	2	3	4	5	
64. Whenever possible, the same staff are assigned to care for the child and family.	1	2	3	4	5	

Section I.

	Strongly Disagree	1	2	3	4	Strongly Agree	NA
65. I encourage parents to discuss concerns with other parents with similar needs.	1	2	3	4	5		NA
66. I ensure families are provided with information of appropriate support groups.	1	2	3	4	5		NA

PART C

Open ended questions for nurses.

1. Do you think there is a difference between what you are currently able to do and what you think is necessary in terms of including families in care? Yes / No

Please give reasons for your answer.

2. If there are instances in which you become focused on the child's care and do not include the parents please describe why/when this occurs.

3. Please list any suggestions as to what is needed to enhance inclusion of families in their child's care in your hospital.

4. Please write any additional comments below.

Thank you very much for completing this questionnaire.
Your assistance is greatly appreciated.

Please place your completed form in the reply paid,
addressed envelope and drop it into a post box.

Appendix D

Letters of Invitation to Parents and Nurses

Dear Parent,

I am a Registered Nurse and a graduate student enrolled in the School of Nursing at Curtin University. As part of my studies for a masters degree I am conducting a study on the extent to which nurses provide care which meets parents expectations when their child is in hospital in Western Australia. The results of this study will assist in the development of nurses' understanding of the role parents have to play when their child is in hospital and thus promote nursing practice which is sensitive to the needs of parents and families.

The study involves the completion of a questionnaire by parents whose child is in hospital or has recently been hospitalised. Parents of children admitted to hospital during the last six months are eligible for inclusion in this survey and your name has been selected. The questionnaire asks about your involvement in your child's care whilst your child was in hospital. I am also asking nurses to complete a similar questionnaire. Your decision whether to participate or not in this study, will not compromise the care of you or your child in any way. All information given will be strictly confidential and no name will be used at any time. This study has been approved by the Human Research Ethics Committee at Curtin University and I have also received permission from the hospital where your child was admitted to conduct this study.

Upon completion of the study, it is expected that the results will be sent to the Australian Association of the Welfare of Child Health Inc (formerly the Association for the Welfare of Children in Hospital) so they can be made available to parents. I also expect to publish my results in nursing journals and present my findings at conferences.

As with all research, a good response rate is essential to eliminate errors in the interpretation of the information. I would appreciate your support by completing and returning the questionnaire in the enclosed addressed, reply paid envelope as quickly as possible. A stamp is not necessary. The form should take about 10 minutes to complete. I will assume I have your consent to participate if you return the completed questionnaire.

Thank you very much for considering participation in this study. Should you have any questions regarding the study or the questionnaire, please contact myself on (08) 9266 2370; email: wilsons@nursing.curtin.edu.au or Jeanette Robertson, the Nurse Researcher at Princess Margaret Hospital for Children on (08) 9340 8407; email: jeanette.robertson@health.wa.gov.au.

Should you have any complaints regarding the conduct of this study complaints may be directed to Professor Charles Watson, Chair, Human Research Ethics Committee, Curtin University.

Thank you for your assistance.

Sally Wilson
Registered Nurse.

Date

Dear Nurse,

I am a Registered Nurse and a graduate student enrolled in the School of Nursing at Curtin University. As part of my studies for a masters degree I am conducting a study on the partnership between nurses and parents in paediatric settings in Western Australia. The results of this study will assist in the development of nurses understanding of the concept of partnership-in-care and thus promote nursing practice which is sensitive to the needs of parents and families.

The study involves the completion of a questionnaire about your perception of the partnership you form with parents. All nurses in your hospital who provide direct care to children are being asked to participate. I will also be asking parents to complete a similar questionnaire. Your decision to participate in this study will not compromise your position at work in any way. All information given will be strictly confidential and no names will be used at any time. This study has been approved by the Human Ethics Committee at Curtin University and I have also received permission from the hospital where you are employed to conduct this study.

Upon completion of the study, it is expected that the results will be presented at a national paediatric conference and may be published in an appropriate nursing journal.

As with all research, a good response rate is essential to eliminate errors in the interpretation of the information. I would appreciate your support by completing and returning the questionnaire in the enclosed addressed, reply paid envelope as quickly as possible. A stamp is not necessary. The form should take about 15 minutes to complete. I will assume I have your consent to participate if you return the completed questionnaire.

Thank you very much for considering participation in this study. Should you have any questions regarding the study or the questionnaire, please contact myself on (08) 9266 2370; email wilsons@nursing.curtin.edu.au or Jeanette Robertson, Nurse Researcher at Princess Margaret Hospital on (08) 9340 8407; email jeanette.robertson@health.wa.gov.au.

Thank you for your assistance.

Sally Wilson

RN., RM., BSc.(Nursing).