

Summary of Proposed Research Program for Master of Philosophy

Title: Partnership-in-Care: A Descriptive Study of the Situation in Rural Western Australia

Abstract

Partnership-in-care is a concept espoused to be fundamental to achieving excellence in paediatric nursing. The basis of partnership-in-care is negotiation between parents and the nurse. The purpose of this study is to identify whether partnership-in-care is occurring in paediatric settings in rural Western Australia and will explore parents' and nurses' perceptions of the concept. A questionnaire will be designed based on the literature and common themes identified focus groups. Multi-stage sampling will be used to randomise the selection of hospitals within a rural health zone. Parents of hospitalised children and nurses involved in the direct care of children will be sought to complete the questionnaire. Analysis of quantitative data will include parametric and nonparametric methods as appropriate. Common themes will be identified from the qualitative data.

Objectives

The objectives of this study will be:

1. To explore and compare perceptions of partnership-in-care between parents and nurses in selected rural hospitals in Western Australia.
2. To determine the extent to which partnership-in-care is implemented in paediatric nursing in rural areas of Western Australia.

Background

Paediatric nursing has progressed since the 1960s 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 into the welfare of children in hospital brought about major changes to this way of thinking. 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. In the 1990s paediatric nursing is advocating partnership-in-care.

Partnership-in-care is the recognition that caring for a child 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, thereby enabling the family to retain control over this aspect of their lives (Smith, 1995). Although nurses undertaking most specialist paediatric and undergraduate nursing programs are educated in the principles of partnership-in-care and learn about the child in the context of the family (Curtin University, 1997; Princess Margaret Hospital, 1997) the literature supports the view that partnership-in-care is still not being achieved within the health care system (Derbyshire 1994; Johnson 1996a).

This study will explore parents' and nurses' perceptions of parents being partners in the care of their children when hospitalised in rural areas of Western Australia.

The basis of partnership-in-care is negotiation between the parents and the nurse cognisant of the family's wishes (Casey, 1988; Smith, 1995). Implicit in this is the nurses' recognition and respect for parents' expert knowledge of their child. Nurses should also recognise the parents' primary role and respect the family's need to attend to the responsibilities associated with that role (Johnson, 1996a). 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, 1996a; Knafl et al, 1988).

In 1992 the Australian Association for the Welfare of Children in Hospital (AWCH) conducted a nationwide survey which focused on the psychosocial care of hospitalised children. The survey included specific questions in relation to parents participating in the care of their children. Although

253 (100%) of hospitals that responded indicated that parents are able to participate in the basic care of their children, only 163 (64.4%) allowed parental involvement in nursing care such as taking temperatures. The results indicated some discrepancies between hospital policy and actual practice. When asked about parents' presence during medical procedures 244 (96.4%) respondents stated that parents are able to stay but there were a large number of qualifying statements such as "depends on the treatment", "up to a point", or "if Doctor agrees" which indicated to the author that the percentage of positive responses could be misleading and conditional. When asked if the hospital allowed parents to be present for induction of anaesthesia and in the recovery room the positive responses were 63 (26.6%) and 123 (51.9%) respectively. Reasons for not allowing parents to be present were given as the parents did not ask, lack of staff support, and inadequate facilities. While a positive response was demonstrated to parents participating in their child's care when admitted to hospital, the questionnaire was filled in by nursing staff only and the parents' views were not sought. As partnership-in-care is based on negotiation between parents and nurses the views of the parents should also be sought.

Two models of partnership predominate in paediatric nursing. 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 encompasses 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) "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.

A central issue involved in negotiation relates to power and control between the nurse and the parents. A perceived power imbalance prevents a partnership from occurring (Smith, 1995). When parents are accepted as the client, as in the Nottingham model, the perception is one of the nurse having power and control over the parents. When the parents are viewed as carer, Casey's partnership model, there is recognition that the parent has some knowledge of their child. An equal partnership is attainable only if nurses view knowledge held by parents to be of equal value to that of their own. By acknowledging the parents as carer the power balance should be more equal thus enabling partnership-in-care to commence.

Partnership-in-care 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 upon 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).

Studies have found that where partnership-in-care does not occur the negotiation process between parents and nurses is limited (Algren, 1985; Casey, 1993; Darbyshire, 1994 & 1996; Johnson, 1996a). Contributing to this lack of negotiation is nurses' attitudes to parental participation in care (Evans, 1994; Gill, 1987a; Johnson, 1996b; Palmer, 1993) and a lack of consistency in the allocation of nursing staff (Darbyshire, 1994; Johnson, 1996a). Other studies related to the concept of partnership-in-care have been more focused on parents' participation in tasks required in the care of their child.

Algren (1985), Casey (1993) and Darbyshire (1994) found that nurses did not communicate with parents about the parents' role whilst they were in hospital with their child. Clarification of the parents' role would have reduced frustration, confusion and some of the parents' stress associated with the child's hospitalisation. Johnson (1996a) and Knafl et al (1988) found that parents' believed that their role changed throughout the hospitalisation as their child's condition changed and as the parents'

confidence level and energy fluctuated, therefore nurses should negotiate with the parents about their role throughout the hospitalisation.

An evaluation of Casey's partnership model also showed that nurses did not discuss the partnership approach with parents, therefore, the parents were confused and uncertain of their role (Casey, 1993). Parents of children newly admitted to wards learnt from other parents as to what the 'rules' were and, if the parents did not conform to the expectations, pressure was exerted from other parents and nurses resulting in feelings of guilt and stress for the parents. Darbyshire (1994) supported this view from interviews with parents who were living-in with their sick child. Parents were not informed of their role as live-in parents and they did not know what was expected of them.

Nurses who hold senior positions such as instructors, supervisors and administrators were shown to have a positive attitude towards parents participating in the care of their child (Gill, 1987a, 1987b & 1993; Porter, 1979; Seidl, 1969). These studies also showed that nurses with a tertiary nursing education were more accepting of parental participation in care. Seidl (1969) found that nurses with young children at home had a more positive attitude and Gill (1987a & 1993) demonstrated that nurses who were married or were parents themselves had a more positive attitude than those who were not parents. Nurses' orientation to family centred care increased with the nurses' age (Porter, 1979) and a more positive attitude to parental participation in care was shown to exist when nurses had greater than ten years nursing experience (Gill, 1987a).

A lack of consistency in the allocation of nursing staff was a major obstacle to parents being able to successfully work in partnership with nurses (Darbyshire, 1994; Johnson, 1996a). Three aspects which contribute to this are: differing standards of practice between nurses, inconsistency between nurses in the level of care that parents are allowed to provide for their children and parents having to develop new relationships frequently (up to three times a day) with nurses. These aspects confuse parents who are already in a stressful situation and contribute to the lack of partnership-in-care (Darbyshire, 1994; Johnson, 1996a).

Most parents want to be involved in self care tasks for their child such as feeding, bathing, playing and comforting their child (Algren, 1985; Beck, 1973; Darbyshire, 1994; Hayes & Knox, 1984; Hill, 1978; Jackson et al, 1978; Johnson, 1996a; Knafl et al, 1988; MacDonald, 1969; Mellow & Johnson, 1968; Stull & Deatruck, 1986). Parents who lived in hospital with their child assumed these tasks automatically or by instinctive reaction but they were often confused and uncertain as to the limits as no open negotiation with staff was evident (Darbyshire, 1994). Parents are less inclined to participate in technical care such as dressings, tube feeding, taking vital signs or only want to learn these skills if the parent will be required to continue them after the child has gone home or if performing these tasks will decrease the length of the hospitalisation (Algren, 1985; Beck, 1973; Hill, 1978; Jackson, Bradham & Burwell, 1978). Darbyshire (1994) found that both nurses and parents initiated technical tasks but participation was controlled by medical and nursing staff who informally assessed the parents to deem them capable of performing the task.

Parents being partners with the health professionals involved in their child's care whilst their child is in hospital is a concept espoused to be fundamental to achieving excellence in paediatric nursing. Effective, frequent communication and negotiation between parents and nurses are required for partnership-in-care to occur which enables parents to participate in the care of their child whilst hospitalised. The literature supports the view that partnership-in-care is still not being achieved in metropolitan paediatric hospitals. No studies were identified that relate to the concept in rural settings. The purpose of this study is to identify whether partnership-in-care is occurring in paediatric settings in rural Western Australia and will explore parents' and nurses' perceptions of the concept.

Significance

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 partnership-in-care which were undertaken in rural settings. A significant number of children are nursed in rural hospitals. In Western Australia (WA) 19,483 children were nursed in rural

hospitals during 1995-1996 financial year which is 29% of all children hospitalised in WA that year (HDWA, 1997). Nurses in rural areas often have to care for people across the life span and in some instances may have limited paediatric experience. However, this limited experience 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 partnership-in-care (Johnson, 1996a) this study will determine whether the setting influences the extent of parental participation.

The results will be significant to children, parents and to paediatric nurses. It is anticipated that the data will assist in the development of nurses' understanding of parents' perceptions of partnership-in-care and to promote paediatric nursing practice which is sensitive and responsive to the needs of parents and families.

Research Method

This will be a descriptive study which uses both qualitative and quantitative data.

Instrumentation

Two focus group interviews will be conducted by the researcher in the rural area. The focus groups will be with nurses and parents in separate groups to encourage open discussion of partnership-in-care. Six to ten volunteers will be recruited for the focus groups and the interviews will be audiotaped and transcribed. (See Appendix A for interview questions). Common themes will be identified from the data and the questionnaire will be developed to reflect these themes.

Using the information obtained from the literature and the focus groups, two questionnaires with Likert scale, closed and open ended questions will be designed for distribution to parents and nursing staff.

Face and content validity will be sought by a panel of experts and the questionnaire will be piloted to ensure readability and clarity of content prior to conducting the research. Demographic details will also be sought in the questionnaire.

Sample Selection

One hundred and fifty parents and 75 nurses will be sought in the selected rural zone. Only one parent of each child will be asked to participate. Multi-stage sampling will be used to maximise the representation of the rural population within the confines of cost (Selltiz et al., 1965). This approach will consist of three stages:

1. random selection of one health service zone
2. random selection of hospitals from the stratified categories according to paediatric patient numbers
3. identification from admission registers of parents whose children are admitted to the selected hospitals over a three month period

All the registered and enrolled nurses who are responsible for the direct care of children in the selected hospitals will be approached to participate in the study.

Exclusions from the Sample

The area above the 26th parallel will be excluded due to travel costs. Parents of children over the age of ten years. Older children may be involved in the decision making of their care at the partial exclusion of their parents.

Data Collection

The researcher will visit all the hospitals selected in the study to explain to staff the reason for the study as personal contact should improve response rates. The questionnaire will be given to nurses and parents who are available when the researcher visits. The remaining nurses and parents will have the questionnaire mailed to them. A letter of introduction and explanation of the study, and a reply paid, addressed envelope will be included with all the questionnaires.

Hospital policies relating to parents' participation in the care of their child whilst hospitalised and brochures given to parents when their child is admitted will be sought from all of the hospitals included in the study to ascertain the extent of the hospitals stated commitment to partnership in care.

Data Analysis

The quantitative data from the questionnaire will be analysed using Statistical Package for Social Sciences (SPSS - X) Windows computer software. Comparisons between parents' perceptions and nurses' perceptions will be made. Univariate analysis will be carried out for all continuous variables with frequencies performed for categorical data items. Comparisons will be made using parametric and nonparametric methods as appropriate. The qualitative data from the open ended questions will be analysed for common themes.

Ethical Issues

Approval will be sought from the Human Research Ethics Committee at Curtin University and from the managers of the selected health services to obtain the names and addresses of parents of hospitalised children from the admissions register prior to the study taking place. A letter introducing the researcher and explaining the purpose of the study will be used to seek consent from all participants at the time of initial contact. Written consent will be obtained from both parents and nurses. Participants will be informed that they can choose not to participate in the study without compromising their position, or the care of their child. Should any parent have any issues of concern regarding the care of their child the parent will be referred to the health service manager or to the hospital's parent/patient advocate, whoever is appropriate.

Confidentiality will be maintained at all times. While it is likely that some hospitals will be identifiable, the results will be reported in aggregate and tabular form so as to protect the identity of the participants. Neither electronic nor paper records will have the subject's name or address attached. Names and addresses will be stored separately. Subjects will be identified by a code known only to the researcher. Transcriptions of the focus group interviews and the completed questionnaires will be held in a secure place for five years in keeping with University policy. The audiotapes will be held securely and destroyed after examination of the thesis.

Facilities and Resources

Travel expenses to a country area and costs associated with the printing and administration of questionnaires will be required. See budget, attached.

Data Storage

The data storage provisions are outlined in the attached Research Data Management Plan and meet the Curtin University Research Data and Primary Materials Policy.

Time Line

Nursing Postgraduate Committee	October Year 1
Division of Health Sciences Committee	November Year 1
Ethics Committee	November Year 1
Pilot study	February Year 2
Data collection	April-June Year 2
Data entry and analysis	August-September Year 2
Thesis preparation	July Year 3

References

- 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.
- Australian Association for the Welfare of Children in Hospital. (1992). *National survey report on psycho-social care of children (and families) in hospital*. Sydney: AWCH.
- Beck, M. (1973). Attitudes of parents of paediatric heart patients toward patient care units. *Nursing Research*, 22(4), 334-338.
- 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 Glasper, E. & Tucker, A. (Eds.), *Advances in Child Health Nursing*. London: Scutari Press.
- Curtin University. (1997). *School of Nursing, undergraduate curriculum document*. Perth: Curtin University.
- Darbyshire, P. (1994). *Living with a sick child in hospital: The experiences of parents and nurses*. London: Chapman & Hall.
- Darbyshire, P. (1996). Parents, nurses and paediatric nursing: A critical review. In Smith, J. (Ed.), *Nursing care of children* (pp.177-195). Cornwall: Blackwell Science.
- 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.
- 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.
- 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. (1997). *Hospital morbidity data system*. Perth: Health Information Centre.
- Hill, C. (1978). The mother on the pediatric ward: Insider or outlawed? *Pediatric Nursing*, September/October, 26-29.
- 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. (1996a). *Partnership-in-care: A principle of practice or a cliché*. Paper presented at the conference convened by the Australian Confederation of Paediatric Nurses, Brisbane, Australia.
- Johnson, A. (1996b). Staff attitudes toward parent participation in the care of children who are hospitalized. *Pediatric Nursing*, 22(2), 99-102.
- Knafl, K., Cavallarri, K., & Dixon, D. (1988). *Pediatric hospitalisation: Family and nurses perspectives*. Illinois: Scott Foresman and Co.
- MacDonald, E. (1969). Parents participate in care of the hospitalised child. *Canadian Nurse*, 65(12), 37-39.
- Merrow, D., & Johnson, B. (1968). Perception of the mothers role with her hospitalised child. *Nursing Research*, 17(2), 155-156.

Palmer, S. (1993). Care of sick children by parents: A meaningful role. *Journal of Advanced Nursing*, 18(2), 185-191.

Porter, L. (1979). Health care workers' role conceptions and orientation to family centered child care. *Nursing Research*, 28(6), 330-337.

Princess Margaret Hospital. (1997). *Postgraduate paediatric nursing programme*. Perth: Staff Development Centre.

Seidl, F. (1969). Pediatric nursing personnel and parent participation: A study in attitudes. *Nursing Research*, 18(1), 40-44.

Selltiz, C., Jahoda, M., Deutsch, M., & Cook, S. (1965). *Research methods in social relations*. New York: Harper & Row.

Smith, F. (1995). *Children's nursing in practice: The Nottingham model*. Oxford: Blackwell Science.

Stull, M., & Deatrick, J. (1986). Measuring parental participation: Part 1. *Issues in Comprehensive Pediatric Nursing*, 9(3), 157-165.