

Protocol for study of who owns the child in hospital

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Abstract

Background: When a child is hospitalised, the whole family can be affected. Those caring for the child must consider the impact of the child's admission on all of the family members. In many hospitals, paediatric health professionals will use family centred care (FCC) during a child's admission to ensure care is planned around the whole family. This allows for the family to be a focal point in the care delivery of the child. However, it is known that FCC is difficult to implement successfully. Barriers to FCC need investigation and may include conflict between staff's and parents' concepts of who holds primary responsibility, or ownership of the child. This paper presents the protocol for such a study.

Aims: The primary aim is to examine the concepts of ownership of the child held by parents of hospitalised children, and by health professionals who care for the children and their family; and to investigate how communication between parents and staff are coloured by these concepts.

The secondary aim is to use the data to develop vignettes which can be used to elicit in- depth responses to this sensitive question.

Methods: The sample will consist of a total of twenty participants: eight parents, and four nurses, four allied health staff and four doctors who work in a paediatric ward. This qualitative study using data collected by interviews focuses on one question, "When a child is admitted to hospital, who owns him or her?" Thematic analysis will be used to find themes from which vignettes will be developed, in preparation for a larger study to be undertaken at a later date.

Conclusion: This protocol describes the study's background, significance, aims, methods and ethical considerations.

Introduction

A well- recognised model of care in paediatric health services is family-centred care (FCC); however, evidence of its effectiveness is limited (Shields et al, 2012) and increasing problems in its implementation are demonstrated in qualitative research (Coyne 2008; Aein et al, 2009; Coyne et al, 2011). While it is difficult to ascertain the precise reason why FCC is not functioning as it should, ineffective communication between parents and health professionals may be a factor. Language is powerful, and in children's wards one hears health professionals taking what could be perceived as "ownership" of an admitted child or patient. By referring to a child as "my patient" health professionals can unknowingly create tension between themselves and the parents (Shields et al, 2003). This can hinder the successful implementation of FCC, and may account for problems in its implementation (Shields et al, 2003). Although FCC has been accepted in theory, it is not

fully practised (Darbyshire, 1994; Coyne, 2008; Aein et al, 2009). This study will explore who "owns" the child in hospital from parents' and health professionals' perspectives.

Background

Doctor-patient and nurse-patient relationships can be affected by concepts of ownership (Slovis 2011). Previous research into doctor/nurse/parent roles has been undertaken in paediatrics but concepts of ownership within the relationships have not been identified (Shields et al, 2003). Effective health care is provided by a team of professionals who work in co-operation with each other, each with his/her own specialist, autonomous role (DeJoy et al, 2011). Unfortunately, some doctors still see themselves as the most significant contributor to the care of patients, even though nurses have taken on the role of care co-ordinator, resulting in a blurring of roles within health care teams (Reiger & Lane, 2009). The belief of an individual doctor that he/she is solely responsible for individual patients in their care can create conflict amongst health professionals; a nurse in charge of the co-ordination of care may feel the same way, causing tensions and potential conflict

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between health professionals.

The concept of who owns the child in hospital may influence communication between parents of hospitalised children, and health professionals caring for them (Shields et al, 2003). Communication between staff and parents can be coloured by who has primary responsibility over the child (Cescutti-Butler & Galvin, 2003; Ygge & Arnetz, 2004).

Much of the literature relating to this topic is over ten years old. Only three recent articles were found that discuss the ownership of a hospitalised child: a discussion paper titled "Who owns the child in hospital?" (Shields et al, 2003); a study of a neonatal intensive care unit where mothers described a transition of seeing the baby passing from the ownership of the nurses to themselves (Heerman et al, 2005); and a study of children suffering cancer, where the parents recognised that the child was theirs and therefore were involved in treatment decision-making (Pyke-Grimm et al, 2006). A gap exists in the literature that delves into the ownership of a child in hospital. The concept is relevant when a child and family present for care, but due to the paucity of research examining this topic, further investigation is required.

While health research has not specifically examined the concept of ownership of a patient, some studies refer to it obliquely (Cescutti-Butler & Galvin 2003; Hallström & Elander 2003; Gabe et al, 2004; Ygge & Arnetz, 2004; Heerman et al, 2005; O'Haire & Blackford, 2005; Roden, 2005; Coyne & Cowley 2006; Pyke-Grimm et al, 2006; Coyne 2007; Wigert et al, 2007; Corlett & Twycross 2008; Priddis & Shields, 2011). These studies suggest feelings of role confusion between staff and parents; in particular, parents and nurses feel that communication between all parties could be improved to provide clearer boundaries of who does what for the hospitalised child (Cescutti-Butler & Galvin, 2003; Ygge & Arnetz, 2004; Ammentorp et al, 2005; Roden, 2005; Coyne, 2007; Coyne, 2008; Shields et al, 2008). While communication between parties is an issue, only one study suggests a solution: education for doctors, nurses and allied health staff (Shields et al, 2008). The majority of literature with regards to the hospitalised child is about the nurse-parent relationship, but there is a lack of research regarding doctors, and only two articles

were found that specifically mentioned their role within the nurse/parent/hospitalised child relationship (Hallström & Elander, 2003; Gabe et al, 2004). When assessing ownership from a legal perspective, guardianship reflects a similar concept, but ownership is not a term used in the nursing and medical literature, nor is it used synonymously with issues of guardianship. Nursing and medical readings relate to guardianship of elderly patients (Alford, 2006; Takahasi et al, 2010), while in paediatrics, guardianship is related to separated children (Martin et al, 2011), foster care (Leathers et al, 2010), grandparents (Burnette, 2009); and the use of guardianship legislation in the enforced treatment of children suffering child abuse (Winokur et al, 2009).

Several relevant themes were found: power (Shields et al, 2003; Gabe et al, 2004; Ygge & Arnetz, 2004; Hallström & Elander, 2005; O'Haire & Blackford, 2005; Roden, 2005), gate-keeping (Wigert et al, 2007; Priddis & Shields, 2011), parent participation (Hallström & Elander, 2003; Ygge & Arnetz, 2004; Roden, 2005; Coyne & Cowley, 2006; Coyne, 2007; Wigert et al, 2007; Priddis et al, 2011), and ineffective communication between staff and parents of hospitalised children (Cescutti-Butler & Galvin, 2003; Shields et al, 2003; Ygge & Arnetz, 2004; Ammentorp et al, 2005; O'Haire & Blackford, 2005; Roden, 2005; Coyne, 2007; Shields et al, 2008; Randall et al, 2013).

Some discussed a power imbalance between nurses, doctors and parents (Gabe et al, 2004; Ygge & Arnetz, 2004; Hallström & Elander, 2005; O'Haire & Blackford, 2005; Roden, 2005; Shields et al, 2003). Of these, three believed that nurses have primary power over the hospitalised child (Shields et al, 2003; O'Haire & Blackford, 2005; Roden, 2005), two stated that health-care workers in general hold the power (Ygge & Arnetz, 2004; Hallström & Elander, 2005) and one stated that doctors believed they held the power (Gabe et al, 2004). No literature was found that showed evidence of a hospitalised child's family holding any power over the child. Of the relevant articles, five were older than ten years, and a different situation may hold today (Shields et al, 2003; Gabe et al, 2004; Ygge & Arnetz, 2004; Hallström & Elander, 2005; O'Haire & Blackford, 2005).

The second theme was gatekeeping (Wigert et al, 2007; Priddis & Shields, 2011). Priddis and Shields (2011) suggested that nurses sometimes take on a gatekeeping role towards parents, and Wigert et al (2007) similarly found that care personnel set the limits for how and when parents interact with their child (but it is not possible to ascertain as to whom specifically the 'care personnel' are).

Parent participation was the focus of several articles (Hallström and Elander, 2003; Ygge and Arnetz, 2004; Roden, 2005; Coyne, 2007; Coyne and Cowley, 2006; Wigert et al, 2007; Priddis et al, 2011). Hallström and Elander (2003), Priddis and Shields (2011) and Wigert et al (2007) suggested that nurses knew that it was in the best interest of the child that parents participate as they are the 'experts' for that child. Priddis and Shields (2011) reviewed 50 publications from 1888-2008 and one may question the relevance of those findings to today. Wigert et al (2007) states that whilst nurses considered the parent the expert in the care of their child, this was only embraced by staff after a period of time. Hallström and Elander (2003) observed and interviewed 24 children and their parents and concluded that parents have superior knowledge of their child, but then observed that the professionals often made the decisions in relation to the child. Others considered that nurses control the amount of participation that parents have in the care of hospitalised children (Ygge & Arnetz, 2004; Roden, 2005; Coyne & Cowley, 2006; Coyne, 2007).

It was unanimously agreed that effective communication is essential to successful relationships between health professionals and parents of hospitalised children (Cescutti-Butler & Galvin, 2003; Shields et al, 2003; Ygge & Arnetz, 2004; Ammentorp et al, 2005; O'Haire & Blackford, 2005; Roden, 2005; Coyne, 2007; Shields et al, 2008; Randall et al, 2013). Parents regarded good communication skills of healthcare workers as a priority (Cescutti-Butler & Galvin, 2003; Ygge & Arnetz, 2004; Ammentorp et al, 2005; O'Haire & Blackford, 2005; Roden, 2005; Coyne, 2007; Shields et al, 2008), but parents often feel uninformed, and therefore unable to partake confidently in the decision-making about their child. This constitutes a convincing argument that effective communication is essential

for empowering parents to participate in their child's care.

Family-centred care sees families and health professionals collaborating and working as equals in planning care for the child (Marshall et al, 2002; Corlett & Twycross, 2006). It is said to be the cornerstone of modern paediatric practice, although it is known to be difficult to implement effectively (Shields et al, 2007). That parent participation is beneficial for the child and the family is well accepted, and stress and anxiety can be reduced for both parent and child if a parent or familiar caregiver accompanies the child into hospital (Coyne & Cowley, 2006).

It is frequently assumed that FCC is unproblematic (Coyne, 2007) and that nurse-patient relationships are harmonious. Nurses of varying grades admitted that collaborating with parents was a complex concept that was difficult to understand and apply in practice (Franck & Callery, 2004; Coyne & Cowley, 2006; Coyne, 2007). It is difficult to know why nurses find implementing FCC challenging, although it may be related to feeling a loss of control, and role-blurring with increased parent participation in the care of the hospitalised child (Brown & Ritchie, 1990; Roden, 2005).

Hallström and Elander (2003) found that healthcare staff hold more weight than parents over who holds the best interests of the child. Some have suggested that doctors, as superior in medical knowledge, should hold primary responsibility over the hospitalised child, or that parents hold superior knowledge of their child and they should therefore have primary responsibility (Hallström & Elander, 2005). Such attitudes do not take into account the high level of education of nurses and other health professionals today. Ultimately, there needs to be a clearer allocation of responsibility between doctors, nurses and parents (Wigert et al, 2007) and effective communication. Communication is an essential component in the hospitalisation of a child, and research into parents' and health professionals' concepts of 'ownership' of the child may illuminate ways that communication can be enhanced (Shields et al, 2003).

Significance

Ownership of the patient is a concept

that has not been well investigated in the health literature. Family-centred care has been accepted in theory, but research indicates it is not fully practised. Concepts of ownership may create barriers that impede the successful implementation of FCC. This study will provide tools to investigate the concept of who "owns" the child in hospital, and how it affects care delivery. If such a difficult and subtle precept is influencing care, this study will provide ways to explore communication between parents and staff, ultimately improving FCC.

Methods

Aim: The primary aim of this study is to investigate staff's and parents' perceptions about, and feelings towards ownership of the hospitalized child. Because this is such a sensitive and abstract issue, ways to elicit relevant responses are needed. This project will use qualitative interviews and methods to develop a series of vignettes which will be used to trigger responses in a later, larger study.

Research Question: What are staff's and parents' perceptions about, and feelings towards ownership of the hospitalized child?

Setting: This study will be conducted in a 23-bed children's ward in a tertiary hospital in North Queensland, Australia.

Sample: Twelve health professionals (four nurses, four doctors and four allied health professionals) and eight parents of hospitalised children will constitute a convenience sample. The sample size reflects estimations of how many parents can be interviewed in the time frame for the study, and for staff, how many of each discipline are available in the study hospital.

Inclusion Criteria:

1. Parents who have a child admitted to hospital,
2. Staff (nurses, doctors, allied health staff) who work in a paediatric ward.

Exclusion Criteria:

1. Parents who cannot read English,
2. Parents whose children are dangerously ill, and/or are in the end stages of a terminal illness. These parents have different priorities and emotional experiences to parents of children

admitted for less serious illnesses;

3. Staff who care for the same categories of children as mentioned above, for the same reasons,
4. Parents of children who have been admitted under child protection protocols

Recruitment: Advertisements will be placed at strategic points in the hospital, particularly in the children's wards. The first author will visit the ward and attend ward meetings, and staff will be sent an email invitation. Then, staff and parents will be recruited by direct approach. Potential participants will be given information sheets that include information about the study, its aims, and the voluntary nature of participation. If the potential participants agree to participate in the study after having read the forms and asked questions of the researcher, they will be asked to sign a consent form.

Data collection: Individual, unstructured, audio-taped interviews will be used to gain participants' perceptions of "ownership". Individual interviews will be sought, as focus groups do not always represent the views of all individuals, and can inhibit in-depth responses (Rabiee, 2004; Rubin & Rubin, 2005; Diccio-Bloom & Crabtree, 2006). The interview will begin with the question, "When a child comes into hospital, who "owns" him/her?" The interview question is derived from the aims of the study; it is open-ended and directed towards uncovering the meaning of the participants' perception of ownership. This will allow for exploration and understanding about the meaning and interpretations of this phenomenon (Llamputtong & Ezzy, 2005). No leading cues will be given but the interviewer might request a participant to expand on what has already been said (Polit & Beck, 2014). The interviews will begin with developing trust with the participants, will take place in a quiet environment, where interruptions will not occur, and the interviewer will be receptive and listen non-judgmentally (Llamputtong & Ezzy, 2005). The first author will conduct all interviews, in a setting convenient to the participant; interviews are anticipated to last for approximately 30 – 45 minutes. Field notes will be written following each interview to capture general impressions to augment the audiotapes.

Data management/analysis: The

interviews will be transcribed verbatim as they are undertaken by the first author. An interpretative approach will be used when reading the transcripts and identifying themes, a well-established approach that involves a rigorous review and interpretation of textual data (Patton, 2002; Green & Thorogood, 2004). The goal is to derive meaning from stories told by participants and to identify and describe recurring conceptual patterns or commonalities of experience across a sample (Cohen et al, 2007). Transcripts will be read and re-read carefully, and significant words and phrases identified. As the texts are read, themes will be found, and a word describing the theme recorded. A second person will analyse subsets of the texts, and compare results. Once the themes have been identified, they will be used to craft two to three vignettes, which may be used in a future study that will explore ways to improve communication about FCC (details of that study are not part of this protocol).

Rigor in qualitative research is assessed by slightly different terms than in quantitative research. In 1985, Lincoln and Guba promulgated standards for the trustworthiness of qualitative research that parallel the standards of reliability and validity in quantitative research (Polit & Beck, 2014). Trustworthiness in qualitative research includes four criteria: credibility (to parallel internal validity in quantitative research), transferability (to parallel external validity), dependability (to parallel reliability) and confirmability (to parallel objectivity) (Lincoln & Guba, 1985; Shenton, 2004; Polit & Beck, 2014). Credibility will be ensured by giving a sample of the transcripts to two experts in qualitative data analysis who will code and categorize the data individually to check for overall agreement and consistency between the experts' analysis and that of the researcher. Confirmability and dependability will be supported by documenting the procedures for checking and rechecking the data throughout the study. Completeness and availability of auditable documents, and the degree and significance of researcher influence will be evaluated. Transferability will be established by developing rich descriptions and maintaining an audit trail to allow comparison of this study with those conducted in similar contexts.

Ethics considerations: This study is being conducted in accordance with Australia's National Health and Medical

Research Council (NHMRC) guidelines. A low/negligible risk ethics application submitted to the Townsville Hospital and Health Service Human Research and Ethics Committees (HREC/13/QTHS/15) and James Cook University (H5485) has been approved. The corresponding site specific research governance application has been authorised. All potential participants will have adequate time to read about the study on the participant information sheets, will be encouraged to ask questions if they wish to do so. Written consent to participation will be attained from all participants.

The novice researcher (first author) will be supervised throughout the study, which is being undertaken as an Honours degree project. There are regular supervisory meetings occurring throughout the student's candidature. At these meetings, training is provided about all stages of the research process, including undertaking a literature review, ethics guidelines, recruitment of participants, interview techniques, transcription, and analysis of transcripts. The student is thus fully supported by experienced researchers.

This project constitutes less than minimal risk, with slight inconvenience for the participants in relation to the interviews being the only risk. There will be no direct, individual benefit to participants, apart from the altruism of contributing. However, from the knowledge gained, communication between staff and parents may be enhanced and the care of children and families may benefit. Some parents feel uncomfortable giving care to their child in hospital because the presence of nurses made them feel they were 'parenting in public', while nurses, for similar reasons, felt they were 'nursing in public', that is, with the parents watching what they were doing (Darbyshire, 1994). Sensitivities such as these may inhibit open and honest responses to this topic. If any complaints are received about the study, data collection will stop.

Only the investigators will have access to the data. The interviews will remain confidential, and the transcripts anonymous. Audiotapes will be wiped after transcription and checking. Interview transcripts and all study documentation will be stored in a locked filing cupboard in a locked office in the School

of Nursing, Midwifery and Nutrition at James Cook University. Data will continue to be securely retained for a minimum of five years after completion of the study. When results are published, no identifying data will be included. Individual subjects will be advised that while participation will remain confidential, if they wish to receive an individual copy of the report we will send one and, in this case, will be invited to provide their contact details.

Limitations of study: This is a small scale research study using qualitative methods. As such, there is no expectation that the findings will be generalizable. Also, due to potential cultural mores, the findings of this project may pertain to North Queensland, or Australia, and may warrant further study at a later date. The selection of hospital staff with varying levels of paediatric experience and seniority may, however, provide a broader range of viewpoints.

Children's views are not being sought and they may have a significant contribution to make at a later date. Children are valid research subjects (Coad, 2007; Coyne, 2008; Randall et al, 2013) and could contribute significant responses to this topic; however, they are outside the scope of this present study.

Proposed dissemination of findings:

Once the study is completed, a thesis will be written for the degree of Bachelor of Nursing Science (Honours), as will a final report for the hospital's executive, and the ethics committees. Papers will be prepared and submitted to nursing, medical and/or allied health journals for publication and presented at relevant paediatric conferences.

Conclusion

This paper describes the protocol for a study being undertaken in north Queensland, using qualitative methodology, by a nurse completing a Bachelor of Nursing Science (Honours) qualification. The study sits within the framework of FCC, and will use interviews to elicit responses to the question of 'who owns the child in hospital'? It is anticipated that the themes arising from the viewpoints of different hospital staff and of parents will be able to be incorporated into vignettes, that will be used in a larger, future study to more fully explore the concept of ownership and the application of FCC in practice.

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