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[Intervention Review]

Family-centred care for hospitalised children aged 0-12 years

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ABSTRACT

Background

This is an update of the Cochrane systematic review of family-centred care published in 2007 (Shields 2007). Family-centred care (FCC) is a widely used model in paediatrics, is thought to be the best way to provide care to children in hospital and is ubiquitous as a way of delivering care. When a child is admitted, the whole family is affected. In giving care, nurses, doctors and others must consider the impact of the child's admission on all family members. However, the effectiveness of family-centred care as a model of care has not been measured systematically.

Objectives

To assess the effects of family-centred models of care for hospitalised children aged from birth (unlike the previous version of the review, this update excludes premature neonates) to 12 years, when compared to standard models of care, on child, family and health service outcomes.

Search methods

In the original review, we searched up until 2004. For this update, we searched: the Cochrane Central Register of Controlled Trials (CENTRAL, *The Cochrane Library*, Issue 12 2011); MEDLINE (Ovid SP); EMBASE (Ovid SP); PsycINFO (Ovid SP); CINAHL (EBSCO Host); and Sociological Abstracts (CSA). We did not search three that were included in the original review: Social Work Abstracts, the Australian Medical Index and ERIC. We searched EMBASE in this update only and searched from 2004 onwards. There was no limitation by language. We performed literature searches in May and June 2009 and updated them again in December 2011.

Selection criteria

We searched for randomised controlled trials (RCTs) including cluster randomised trials in which family-centred care models are compared with standard models of care for hospitalised children (0 to 12 years, but excluding premature neonates). Studies had to meet criteria for family-centredness. In order to assess the degree of family-centredness, we used a modified rating scale based on a validated instrument, (same instrument used in the initial review), however, we decreased the family-centredness score for inclusion from 80% to 50% in this update. We also changed several other selection criteria in this update: eligible study designs are now limited to randomised controlled trials (RCTs) only; single interventions not reflecting a FCC model of care have been excluded; and the selection criterion whereby studies with inadequate or unclear blinding of outcome assessment were excluded from the review has been removed.

Data collection and analysis

Two review authors undertook searches, and four authors independently assessed studies against the review criteria, while two were assigned to extract data. We contacted study authors for additional information.

Main results

Six studies found since 2004 were originally viewed as possible inclusions, but when the family-centred score assessment was tested, only one met the minimum score of family-centredness and was included in this review. This was an unpublished RCT involving 288 children post-tonsillectomy in a care-by-parent unit (CBPU) compared with standard inpatient care. The study used a range of behavioural, economic and physical measures. It showed that children in the CBPU were significantly less likely to receive inadequate care compared with standard inpatient admission, and there were no significant differences for their behavioural outcomes or other physical outcomes. Parents were significantly more satisfied with CBPU care than standard care, assessed both before discharge and at 7 days after discharge. Costs were lower for CPBU care compared with standard inpatient care. No other outcomes were reported. The study was rated as being at low to unclear risk of bias.

Authors' conclusions

This update of a review has found limited, moderate-quality evidence that suggests some benefit of a family-centred care intervention for children's clinical care, parental satisfaction, and costs, but this is based on a small dataset and needs confirmation in larger RCTs. There is no evidence of harms. Overall, there continues to be little high-quality quantitative research available about the effects of family-centred care. Further rigorous research on the use of family-centred care as a model for care delivery to children and families in hospitals is needed. This research should implement well-developed family-centred care interventions, ideally in randomised trials. It should investigate diverse participant groups and clinical settings, and should assess a wide range of outcomes for children, parents, staff and health services.

PLAIN LANGUAGE SUMMARY

Family-centred care for hospitalised children aged 0-12 years - an update

This is an update of the Cochrane systematic review of family-centred care published in 2007 ([Shields 2007](#)). For this update, we have changed the title to show that it is about children aged 0 to 12 years only. We have now excluded premature neonates, and we have changed several other selection criteria: study designs are now limited to randomised controlled trials only; the way in which family-centredness of interventions is assessed for inclusion has changed; single interventions not reflecting a FCC model of care have been excluded; and the selection criterion whereby studies with less than adequate blinding of outcome assessment were excluded from the review has been removed.

When a child comes into hospital, the whole family is affected. In giving care, nurses, doctors and those caring for the child must consider the impact of the child's admission on all family members. 'Family-centred care' is one way of caring for children in hospital. It is "a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognised as care recipients" ([Shields 2006](#), p. 1318). However, with changes in family structures, for example, development of the single parent family, questions arise about how care is best delivered. To ensure that children are cared for in ways that minimise emotional trauma and assist in recovery, it is important that such ways of delivering care are measured to see if they are effective.

This review has tried to do that by examining research about family-centred care. We looked for randomised trials of family-centred care interventions for children aged 0-12 years, in hospitals. We assessed potentially-relevant studies against criteria that identify important parts of family-centred care. Despite extensive searching we identified only one moderate-quality study ([Bolton 2004](#)) for inclusion. This study, from a doctoral thesis, showed that the family-centred care model had a positive effect on the adequacy of children's care, parental satisfaction, and costs. For other indicators such as clinical outcomes and children's behaviour there was no significant difference between the family-centred care model and standard inpatient care. There were no harms reported.

In this searches for this update, we also found 25 qualitative studies which described aspects of family-centred care, and a review of these will be published by the Joanna Briggs Institute. Our main conclusion from this Cochrane review update, however, is that further, rigorous research is needed to assess the effects of family-centred care on children's experience of hospitalisation, as well as on their parents, hospital staff, and service delivery outcomes such as costs.

BACKGROUND

While this is an update of a previously published review (Shields 2007), this background about the development of family-centred care has changed little. Until at least the late 1950s, hospitals worldwide tended to be bleak places for children. It was believed that visits from parents would inhibit effective care (Nethercott 1993) and were detrimental to the child, who would become distressed when the parents left (Johnson 1990; Shields 1999). Researchers began to suggest, however, that children whose parents did not visit them suffered acute emotional trauma which may have long-term psychological consequences in adolescence and adulthood (Bowlby 1971; Bowlby 1973).

In 1956, the British government commissioned a report into the welfare of children in hospital. The resulting report, the Platt Report (Platt 1959), recommended that visiting be unrestricted, that mothers stay in hospital with their child, and that training of medical and nursing staff should promote understanding of the emotional needs of children. The process of change has resulted in a humanisation of paediatrics (Darbyshire 1994; Jolley 2009), although the movement away from traditional approaches to health service delivery to the involvement of families in all aspects of the planning, delivery, and evaluation of health care has been slow (Coyne 2007a; Palmer 1993). The foundation for a family-centred approach to paediatric health care is the belief that a child's emotional and developmental needs, and overall family wellbeing, are best achieved when the service system supports diligently the ability of the family to meet the needs of their child, by involving families in the planning and delivery of care (Allen 1998; Neff 2003).

Much of the literature concerning family-centred care has originated from the UK and USA, which are developed and culturally distinctive (predominately Anglo-Saxon) societies (Irlam 2002). In low and middle income countries with fewer technological, economic and human resources, specific information about the psychosocial care of children in hospital is limited (Irlam 2002; Shields 2001c). Shields found that in some developing countries, parents were encouraged to stay with their hospitalised child only if it fitted with hospital rules (Shields 2001c). Stanford reported that in Central America where children's health is poor, some hospitals allowed parents to stay when their child was acutely ill, while some restricted parental visiting to one hour per day (Stanford 1986). These restrictions on parental visiting were thought to be the result of space limitations and lack of facilities rather than a philosophical objection to parents being present. A study in Tanzania found that mothers were concerned about environmental conditions such as overcrowding and lack of food while their children in hospital, while staff's concerns included lack of trained staff, overwork and low pay (Mwangi 2008), and a study from Iran has also highlighted problems with the implementation of family-centre care models (Aein 2007).

Family-centred care in high-income countries has been explored as care that is led by parents, with the health professional acting as a consultant, encouraging open and honest dialogue with the family (Hutchfield 1999; Irlam 2002). The family is acknowledged as expert in the care of their child, and the perspectives and information provided by the family have been described as important to clinical decision-making (Irlam 2002; Neff 2003; Webster 1999).

In the UK, the importance of promoting the role of families in the care of the hospitalised child has been acknowledged (DOH 2003). A number of related terms has been used to describe the attributes of family-centred care (Hutchfield 1999); these include partnership-in-care (Coyne 1996), parental involvement (Hurst 1993), nurse-parent partnership (Hill 1996), parental participation (K-Hallstrom 1999), and care-by-parent (Costello 1998; Evans 1994).

In 1992, the Institute for Patient- and Family-Centered Care was established in the USA, taking over the role of the Association for the Care of Children's Health, whose task it had been to develop a nationwide program to enhance the implementation of a family-centred approach to the care of infants, children, and adolescents. Much of the family-centred care literature from the USA refers to the seminal work of Shelton (Shelton 1987), who developed a framework for offering family-centred care to children. Within this framework, Shelton and colleagues delineated eight elements which characterise health services which are family-centred (Trivette 1993). Subsequently, a ninth element was included (Johnson 1990). The nine elements of family-centred care include:

- recognising the family as a constant in the child's life;
- facilitating parent-professional collaboration at all levels of health care;
- honouring the racial, ethnic, cultural, and socio-economic diversity of families;
- recognising family strengths and individuality and respecting different methods of coping;
- sharing complete and unbiased information with families on a continuous basis;
- encouraging and facilitating family-to-family support and networking;
- responding to child and family developmental needs as part of healthcare practices;
- adopting policies and practices that provide families with emotional and financial support; and
- designing health care that is flexible, culturally competent, and responsive to family needs.

According to the Institute for Patient- and Family-Centered Care's definition:

“Family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships between and among consumers and health providers. Family-centered practitioners recognise the vital role that families play in ensuring the health and well being of infants, children, adolescents, and family members of all ages. They acknowledge that emotional, social, and developmental supports are integral components of health care. They promote the health and well being of individuals and families and restore dignity and control to them. Family-centered care is an approach to health care that shapes policies, programs, facility design, and staff day-to-day interactions. It leads to better health outcomes and wiser allocation of resources, and greater patient and family satisfaction” (Webster 1999, IPFCC 2010).

It has been suggested that to practice in a family-centred manner requires a shift in the orientation of health services from a standard model to a collaborative model which recognises family involvement as central to their child’s care. Within this view, the healthcare provider is an equal partner and facilitator of care, and families are invited to participate actively in the decision-making, planning and provision of their child’s care to the extent they choose (Ahmann 1998; Ahmann 2001).

Potential advantages and disadvantages of family-centred care

There is a range of potential benefits and difficulties associated with the provision of family-centred care. For instance, in one study, the stress levels of parents whose children were intensive care unit inpatients were reduced (Melnyk 2004). However, researchers have also reported challenges when trying to implement changes which would result in meaningful family involvement in the care of their hospitalised child. Healthcare providers have reported a lack of adequate education in relation to understanding and implementing the concept of family-centred care in a practice situation, as well a lack of shared understanding of, and commitment to, family-centred care among all health professionals and families (Bruce 1997; Bruce 2002; Coyne 2007a; MacKean 2005; Roden 2009). In addition, the hospitalisation of a child, whether planned or unplanned, is stressful for even the most well-organised and functional family (Melnyk 2000). The significant adjustments to both parent and healthcare provider roles when a child is hospitalised may result in understandable levels of stress (Callery 1997). Potential disadvantages of family-centred care may be that families feel that they are expected to provide input into the care of their child beyond their expectations or capabilities, or are given more information than either the child or the family is ready to hear. This may cause additional stress or anxiety for both the parents and child. In summary, in 1994, Darbyshire (Darbyshire 1994) suggested that family-centred care was a wonderful idea,

but difficult to implement effectively, and some authors are beginning to agree, questioning family-centred care as a model of care (MacKean 2005; Sarajarvi 2006). Also, questions are being raised as to the ethics of continuing to use a model for which no rigorous evidence of effectiveness exists (Shields 2010).

Other models of health care for children

Family-centred care, which involves participation of, or partnering with parents (or family-members) is described as different to the standard models of care used in paediatric health services. In these, often, the healthcare provider plays a major role in assessing and formulating a plan of care, based upon the perceived needs of the child and/or family. In the medical or standard model of health care, the healthcare worker plans care around the child’s illness and treatment needs, and the family is generally expected to comply with treatment recommendations (Ahmann 1998).

Implementation of family-centred care

It is expected that the development, implementation and outcomes of family-centred models of care may differ according to the population and setting in which the models are applied. For example, the needs and outcomes for families of a child with a chronic condition who experience long hospital stays may differ from those of families of a previously healthy young child who is admitted for a treatment procedure. Also, older children may have a greater awareness and understanding of the reasons for their hospitalisation. Therefore, models of care may reflect increased participation of the child in their hospital care.

However, even if the family-centred care models are seen as making a difference and are advantageous in their own right, reliable reassurance that they result in more good than harm should be sought. The previous Cochrane review (Shields 2007) of which this current review is an update found that no studies met the inclusion criteria for either family-centredness of the intervention under study, or were excluded because they did not meet key methodological quality criteria as pre-specified by the review authors. That said, there were 11 studies at that time which used qualitative methods to examine the implementation of family-centred care, and which met the criteria for family-centredness, and we published a review of these (Shields 2006).

OBJECTIVES

To assess the effects of family-centred models of care for hospitalised children aged birth to 12 years (but excluding premature neonates), when compared to standard models of care, on child, family and health service outcomes.

METHODS

Criteria for considering studies for this review

Types of studies

In this update, we have included only randomised controlled trials (RCTs) including cluster randomised trials in which family-centred care models are compared with standard models of care. In [Shields 2007](#), we took a broader approach, including quasi-RCTs and controlled before and after (CBA) studies. We decided that in the interest of rigour, and to try to definitively say whether or not family-centred care is effective in delivering care to children and families, we would seek the highest level of evidence possible for this update of the review.

However, we have assessed quasi-experimental studies e.g. quasi-RCTs and controlled before-and-after studies, in a separate review for the Joanna Briggs Institute ([Shields 2012](#)). Another and separate review for the Joanna Briggs Institute which will also be linked to this update will be a review of the qualitative studies which met the family-centredness score. In this way we will be able to provide a rounded, and highly rigorous statement about the effectiveness or otherwise of family-centred care for hospitalized children aged 0 to 12 years.

Types of participants

Child/children: throughout this review, the term 'child' or 'children' is used to include all newborn infants, babies and children up to the age of 12 years being cared for in hospital; and all parts of hospitals that provide a service to children. The definitions of childhood can vary, and age limits are arbitrary. For the purpose of this review the National Library of Medicine's medical subject headings ([NLM 2004](#)) were used to define the age cut-off of 12 years. However, we have excluded neonates born prematurely and who are patients in a neonatal intensive or special care nursery, as their requirements for family-centred care, and the ethics and philosophies of care around this particular group, are different to those in a ward/unit where full term infants and children are nursed ([Brophy 2006](#)).

Families: throughout the review the following definition of the family was applied:

The family is a basic social unit having as its nucleus two or more persons, irrespective of age, in which each of the following conditions are present:

1. the members are related by blood, or marriage, or adoption, or by a contract which is either explicit or implied;
2. the members communicate with each other in terms of defined social roles such as mother, father, wife, husband, daughter, son, brother, sister, grandfather, grandmother, uncle, aunt; and

3. they adopt or create and maintain common customs and traditions.

This definition has been modified from Nixon's original definition ([Nixon 1988](#)) to allow for inclusion of significant others who do not usually cohabit with the family.

Healthcare providers involved in caring for hospitalised children.

Types of interventions

We included any intervention that aimed to promote the family-centred model of care during a child's hospitalisation. Only studies that provide clear evidence that the family and/or child were actively involved in the planning and/or delivery of health care during the child's hospitalisation were considered for inclusion. For the purposes of the review, the minimum criteria for active involvement included evidence of collaboration between health carers and the family and/or child in the planning and/or delivery of care as soon as possible after admission or during the preadmission period. Included studies must also have compared family-centred models with standard models of care. In the original review, we included "professionally-centred" models of care, but it became apparent to us that these are the same as "standard models" so we deleted the words "professionally-centred" as redundant for this update.

For inclusion, an holistic family-centred care model, including interventions such as the those in the following list, had to be present. Single interventions (for example, parental presences during one-off procedures) do not represent a family-centred care model, and if the study was about a single intervention only it was not included because the family-centredness score ([Trivette 1993](#)) could not be applied. The list includes:

- Environmental interventions as evidenced by collaboration with the family and/or child in the design or redevelopment of facilities to provide an environment that maximises parental involvement and enhances child recovery and/or convalescence, care-by-parent units, privacy areas;
- Family-centred policies which may include open visiting hours for siblings or extended family, parent participation in their child's care to the extent they choose (for example, feeding, bathing);
- Communication interventions could include parental presence and participation at daily interdisciplinary ward rounds and family conferences to plan future care, developing collaborative care pathways where both parent and/or child and health carer document issues and progress, reorganisation of health care to provide continuity of care-giver (such as, primary nursing), shared medical records, local hospital based interpreters;
- Educational interventions could include structured educational sessions for parents of technologically dependant children, continuing education programs to equip staff to provide care within a family-centred framework, preadmission programs;

- Family support interventions such as flexible charging schemes for poor families, referrals to other hospital or community services (such as, social workers, chaplains, patient representatives, mental health professionals, home health care, rehabilitation services), facilitating parent-to-parent support.

In [Shields 2007](#), we tried to identify several interventions as family-centred. On reflection for this update, we viewed this as a deficiency in the original review, where, at times, it required a deal of discussion and deliberation about the possibility of inclusion of various studies. We have tried to avoid such problems in this update by taking a more direct and simple approach. Consequently, it is important, for this update, to describe what we considered did not constitute an holistic model of family-centred care. We excluded studies where there was no clear evidence of collaboration between the family and/or child and healthcare provider in the planning and/or delivery of care. Such studies could include parental presence during healthcare procedures such as routine examinations, anaesthetic induction, venipuncture and post-anaesthetic recovery, parental education packages, and bereavement team/protocols; because singular interventions such as parental presence without any collaboration or communication does not meet the holism of family-centredness. As an example, parental presence for anaesthesia induction might occur in the operating room, but this does not mean that the same hospital will allow parental involvement in any other aspect of the child's care. In other words, if one intervention was the focus of a study, without recourse to a total family-centred care model, it was excluded.

The assessment of family-centredness is described in detail later, but in brief, we used the same scoring system as we used in the original review ([Trivette 1993](#)), as it worked effectively in the first instance, and also provided us with a way of quantifying what family-centred care is about. It has been used in the assessment of research and literature before, and is well tested. See [Data collection and analysis](#) - 'Assessment of the family-centredness of the intervention', and [Appendix 1](#) for details.

Types of outcome measures

A number of processes and outcomes might be affected by models of care which aim to incorporate families in the decision making, planning, provision and evaluation of care when their child is hospitalised. Where possible, when assessing study quality we considered the use of validated research tools to measure satisfaction with care and psychological outcomes.

Child

- Psychosocial outcomes including psychological health (such as anxiety, confidence, sense of control, coping, adjustment, stress, upset, crying, insomnia, fears, behavioural regression), attitudes towards caregivers and attitudes towards rehospitalization.

- Behaviour (such as level of co-operation, compliance with care, and appetite).
- Physical health including physiological measures such as blood pressure and pulse rate; pain assessment or control such as use of medication or other means to reduce pain; length of hospital admission, readmission.
- Developmental outcomes including weight gain, developmental milestones.
- Knowledge and understanding including knowledge of condition, treatment, knowledge about personnel or procedure.
- Satisfaction: for example, with involvement in decision making, with level of communication.
- Attitudes: for example, views of cultural appropriateness, flexibility.

Parent

- Psychological health (for example, stress, anxiety, perceptions of coping, sense of control) and satisfaction (for example, involvement in decision making, level of communication).
- Attitudes (such as complaints, evaluations of cultural appropriateness, flexibility and responsiveness of the intervention).

Staff

- Psychological health (for example, stress, responsiveness to patient's needs, confidence) and satisfaction (for example with the intervention, with care provided, with the level of education provided about family-centred care).

Health services

- Health-service provision outcomes, such as staffing requirements, costs of the intervention, time needed for the intervention, use of other hospital department services, litigation claims

All adverse outcomes, such as an increase in anxiety after receiving the intervention, were also sought.

Search methods for identification of studies

Electronic searches

For the original review ([Shields 2007](#)) we conducted the following searches in February 2004:

- MEDLINE (PubMed) (1966 to February 2004);
- The Cochrane Central Register of Controlled Trials (CENTRAL), (*The Cochrane Library*, Issue 2, 2004);
- CINAHL (1982 to February 2004);

- PsycINFO (1972 to February 2004);
- ERIC (1982 to February 2004);
- Sociological Abstracts (1963 to February 2004);
- Social Work Abstracts (1977 to February 2004); and
- AMI Australian Medical Index (1966 to February 2004).

Search strategies for the 2004 searches are available from the authors upon request.

For this update, we identified relevant studies by electronically searching the following databases:

- MEDLINE (Ovid SP), 2004 to 10 December 2011 ([Appendix 2](#));
- The Cochrane Central Register of Controlled Trials (CENTRAL), *The Cochrane Library*, Issue 12, 2011 ([Appendix 3](#));
- EMBASE (Ovid SP), 2004 to 10 December 2011 ([Appendix 4](#));
- PsycINFO (Ovid SP) 2004 to 21 December 2011 ([Appendix 5](#));
- CINAHL (EBSCO Host) 2004 to 22 December 2011 ([Appendix 6](#)); and
- Sociological Abstracts (CSA) 2004 to 5 January 2011 ([Appendix 7](#)).

A search strategy was developed for MEDLINE (Ovid SP) ([Appendix 2](#)), using the search filter for RCTs, quasi-RCTs and CBA studies developed by the Cochrane Consumers and Communication Review Group. The search strategy was then adapted for the other databases, specified above. The updated search was limited to papers from 2004 onwards. We conducted searches in May-June 2009, and reran them in December 2011 (except for Sociological Abstracts which was updated in January 2011).

In this update, there were several changes to the databases searched. We searched EMBASE from 2004 onwards, and several which were included in the original review were not used: ERIC was not searched as it was not considered relevant, the Social Work Abstracts database was not available for searching at the range of libraries available to us. Any relevant articles that may have appeared in those databases we were confident we had identified from the other databases searched. Similarly, AMI was available but not searched as relevant references were indexed in other databases searched.

In this update, as in the original review, RCTs, quasi-RCTs and CBA studies were all included in the searches to ensure consistency with the original review, but we then screened them by hand, by which time we had decided, in the interests of rigour, to include only RCTs. The quasi-experimental studies are included in a separate review for the Joanna Briggs Institute ([Shields 2012](#)).

Searching other resources

For the updated review we also searched Web of Science Conference Proceedings, Australian Research Online, Clinical Trials

Registry, Current Controlled Trials, UK Clinical Research Network: Portfolio Database, Bandolier and Google, using keyword search “family centred care” or family centred care”. Of these, only Google produced any relevant results with links to two conference web sites. We searched the abstracts of the following conferences: The 4th International Conference on Patient- and Family Centered Care (2009); The 3rd International Conference on Patient- and Family-Centered Care (2007); Family Centred Care in Context Conference (2009).

We cross referenced relevant literature including identified trials, existing review articles, published conference and symposia proceedings, dissertations, hospital policy documents and other key informants. We searched reference lists of relevant articles.

There was no limitation by publication language, and we found no relevant papers in a language other than English. [Landry 2007](#) was published in English, and when we contacted the author for further clarification of the age group and intervention, we found that the data reports were in French. These were interpreted and we were able to ascertain that the study did not meet the required 50% cut-off in the score for family-centredness, and so was not included.

Data collection and analysis

Selection of studies

Two review authors (LS and MT) screened the outputs of the searches literature search independently and compared results. They screened the outputs from the database searches based on title and abstract, and assessed them according to the selection criteria. Four review authors (HZ, JP, JH and LS) independently screened the full texts of possible papers according to the inclusion criteria of the review, including an assessment of the intervention in terms of the degree of family-centredness, as described below (see also [Appendix 1](#)). We discarded those references which clearly did not fulfil inclusion criteria, and retrieved potentially relevant articles, and undertook full-text assessments using the specifically developed and piloted assessment form (see [Appendix 1](#)). Discrepancies were resolved through discussion with all review authors. The full-text studies that were excluded are listed in the [Characteristics of excluded studies](#) table, with reasons for exclusion.

Assessment of the family-centredness of the intervention

For this update, as in [Shields 2007](#), in order to assess relevant studies for the degree of family-centredness, we used a rating scale modified from the scale developed by Trivette and colleagues ([Trivette 1993](#)). These authors used the 9 elements of family-centred care, as described by the Association for the Care of Children’s Health (now the Institute for Patient- and Family-Centered Care), to develop 13 evaluation items that describe the features of family-

centred care. We present the 9 Association for the Care of Children's Health elements and the 13 corresponding sub-elements in [Table 1](#). These sub-elements are further grouped into three cluster groups (that is, Cluster 1: family as a constant; Cluster 2: culturally responsive; Cluster 3: supporting family individuality) derived from an original cluster analysis by Trivette and colleagues ([Trivette 1993](#)). The clusters were designed to be used to help describe the model of family-centred care in individual trials.

We applied a rating of 0 to 4 to each of the 13 sub-elements of family-centred care, from 0 indicating the article included no evidence that the intervention either implicitly or explicitly was based upon the elements of family-centred care, to 4 indicating the article included numerous instances of explicit evidence that the intervention was based upon the elements of family-centred care (see [Appendix 1](#)).

We considered that an element of family-centred care was implicitly addressed if it could be inferred that the author(s)' descriptions, arguments etc. were consistent with the intent of the elements of family-centred care, whereas if an element of family-centred care was clearly stated and distinctly expressed it ought to underscore health practice and we therefore considered it to have been explicitly addressed or endorsed ([Trivette 1993](#)).

Independently, each review author scored the evaluation items from 0 to 4 for each study, and final scores were resolved by consensus among authors. We added the scores together to give an overall rating of the intensity of family-centredness for each study. The maximum possible score was 52, and scores of 42 (or 80% of total score) (see below) or greater would have indicated a high degree of family-centredness. The results of the study rating were compared amongst review authors and also by an independent expert in the field. The reliability and validity of the scoring system had been tested by Trivette, Dunst and colleagues ([Trivette 1993](#)). Our scoring sheet, of which the scoring system was an integral part, was tested by the review authors, and others who were independent of the review, by repeatedly using the sheet, comparing answers and refining the document. The construction of the sheet prevented us using reliability statistics for each section, however Trivette's ([Trivette 1993](#)) scoring system for family-centred care had yielded a median Cohen's kappa score of 0.85 (range 0.65 to 1.0) for each element.

In the original review, we used an 80% cut-off point for inclusion, and called that "a high degree of family-centredness". A score of 42 from a possible total of 52 (80%) had been chosen, based on the Pareto distribution, which says that for many events, roughly 80% of the effects come from 20% of the causes ([Narula 2008](#)). No studies were included.

In [Shields 2007](#), we found no studies which could be included,

mainly because so few met the 80% cut-off. While our justification of implementation of the Pareto principle is sound, we decided that greater flexibility may have afforded us the opportunity to capture RCTs which tested family-centred models but which still provided a way of testing effectiveness. Hence, in this update, we lowered the cut-off point for inclusion to 50% (26 points from a total of 52). We rated a score of 50 to 80% as a 'moderate degree of family-centredness'; and below 50% as a 'low degree of family-centredness'. In the update, we excluded all those studies for which the intervention rated less than 50% for family-centredness, and planned to analyse separately those studies which fell into the high and moderate categories respectively.

Data extraction and management

Data were extracted from included studies by three review authors working independently (EP, LS, HZ). Any discrepancies were resolved by discussion to reach consensus. We collected descriptive data on the author, year of publication, setting, country, time span of the study, basis for calculated sample size, number of study participants, description of study participants, number of participants analysed, timing of data collection, and description of the intervention (particularly in terms of the nine elements of family-centred care as discussed earlier). We created a structured narrative presentation of the study, based on the categorisation of the interventions listed under '[Types of interventions](#)', i.e. family-centred models and standard models of care. Extracted data were entered into RevMan by one review author (LS) and checked for accuracy by a second review author (HZ).

Assessment of risk of bias in included studies

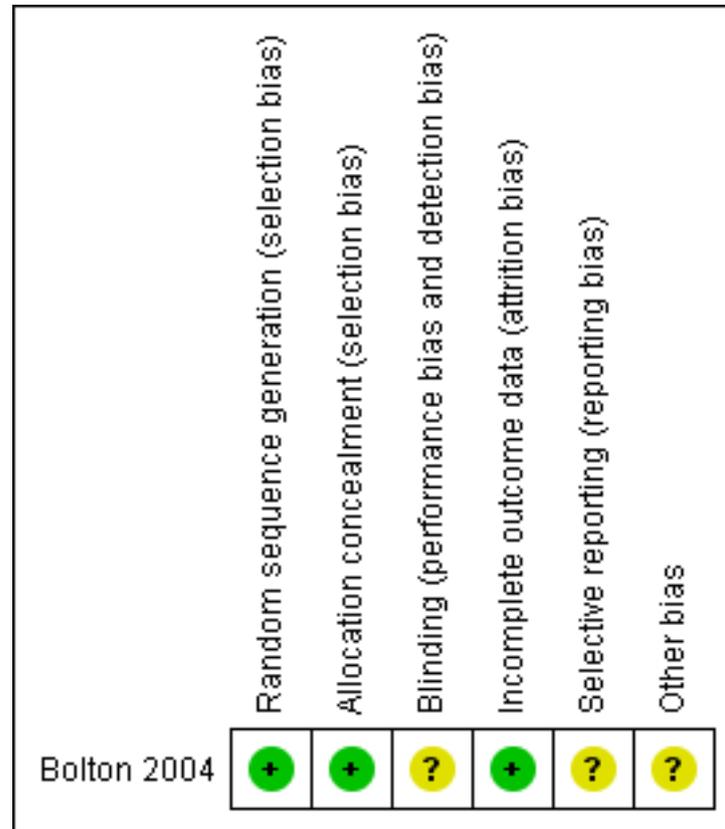
We assessed the methodological risk of bias in included studies using the Cochrane Collaboration's Risk of Bias tool ([Cochrane 2008](#)). We rated each of the following domains as 'yes (low risk) / unclear (unclear risk) / no (high risk)':

- random sequence generation
- allocation concealment
- blinding of participants, personnel and outcome assessors
- incomplete outcome data assessment
- selective outcome reporting
- other potential threats to validity.

Two authors (LS, HZ) assessed risk of bias, and discrepancies were resolved at first by discussion and consensus, or by recourse to two other authors (JP, JH).

The Risk of Bias tool is presented in [Appendix 8](#) and the results of the assessment are presented in the [Characteristics of included studies](#) table and [Figure 1](#).

Figure 1. Risk of bias summary: review authors' judgements about each risk of bias item for each included study.



Data synthesis

Meta-analysis was not possible, as we identified only one study (Bolton 2004) for inclusion. Had other studies been included, the following methods would have applied: Meta-analysis would have been conducted using the fixed-effects model. Heterogeneity would have been assessed using the Chi² test of heterogeneity along with visual inspection of the graph. A significance level less than 0.10 would have been interpreted as evidence of heterogeneity. Where heterogeneity was found, the authors would have looked for an explanation. If studies with heterogeneous results were found to be comparable, the statistical synthesis of the results would have been done using a random-effects model. Sensitivity analysis would have been conducted to determine the impact of risk of bias on outcomes, if studies of different risk of bias were identified. The risk of bias criteria used in this analysis would have been in accord with the method of allocation to treatment.

Consumer participation

There are several organisations worldwide which are advocates for children and families who use health services. A representative of the Australian Association for the Wellbeing of Children in Healthcare (AWCH) provided feedback on the 2007 version of the review (Shields 2007) via the Cochrane Consumers and Communication Review Group's standard editorial process for reviews.

RESULTS

Description of studies

See: [Characteristics of included studies](#); [Characteristics of excluded studies](#).

Results of the search

In the original review of family-centred care for children in hospital, of which this is an update (Shields 2007), of the 1688 records found through the searches, of which 103 were broadly relevant and thus assessed, none were found that met the inclusion criteria. For this update, from the 9271 records produced from the 2009 and 2011 searches, we identified approximately 122 papers as broadly relevant, and these were assessed in full text. Those excluded before obtaining full text papers included papers which were not research or were reports of quality improvement activities, were unrelated to family-centred care (for example, were about diseases or obesity), and were outside the age ranges of this review update. Those assessed in full text and excluded were, in the main, either ineligible study designs, mainly qualitative studies, or were about a single intervention rather than the family-centred care model as described above. After all searches were completed, we found one study (Bolton 2004) (through informal communication with a colleague), which was a chapter in a doctoral thesis, which met the inclusion criteria.

Included studies

We included one randomised controlled trial involving 288 participants (Bolton 2004). This trial was one part of a PhD thesis which examined the postoperative care of children post-tonsillectomy. It compared children who received standard inpatient care with children who were cared for in a care-by-parent unit (CBPU). The study was undertaken from 2002 to 2004. The CBPU met the description of family-centred care, as not only was it physically and environmentally family-centred, it was also an holistic approach which involved parents, children and family members, and met the FCC score (36/52 = 69%) (see Appendix 9).

One hundred and forty three of the participants were nursed with standard inpatient care, while 145 were admitted to the CBPU. Of these, 124 (87%) inpatients and 136 (94%) CBPU children were between 3 and 13 years of age. The study was conducted in two wards: one standard inpatient, the other a CBPU in an Australian metropolitan tertiary referral children's hospital. All public patients who were scheduled to undergo tonsillectomy with or without adenoidectomy were reviewed to assess their eligibility for inclusion. These were that the children were at least 3 years of age, had no evidence of obstructive sleep apnoea, no history of significant cardiac, respiratory or hepatic disease, and their parents did not require an interpreter or have trouble with written English.

Interventions

Bolton 2004 assessed the effects of admission to the care-by-parent unit (CBPU) compared with standard inpatient care post-tonsillectomy. The CBPU was a unit where parents were accommodated with their admitted children, where parents (and children as appropriate) were supported and encouraged to be part of the decision-making team, and were expected to provide as much of the care as they could appropriately undertake.

Outcomes

The primary outcome was a composite indicator of 'inadequate clinical care', which was recorded as 'yes' or 'no'. This outcome was considered to be met (i.e. care was considered to be 'inadequate') if there was one or more instances of inadequate care from five markers:

- less than good control of nausea and vomiting (assessed by parents as fair, poor, very poor),
- less than good pain control (assessed by parents as fair, poor, very poor),
- medical attention needed but not provided within 30 minutes,
- discharge delay beyond 1200h one day post-surgery, and
- unplanned medical consultation within seven days of surgery.

This composite outcome incorporates aspects of the child's physical health outcomes (see Types of outcome measures). Additional serious physical outcomes were assessed, such as significant haemorrhage, readmission due to complications, and pain scores. Bolton 2004 also assessed:

- child behavioural outcomes measured using the Posthospital Behaviour Questionnaire (PHBQ) (Vernon 1966) for those under 13 years and the Child Behaviour Questionnaire for parents of adolescents (the latter measure was not included in our review) (Rutter 1970);
- parental satisfaction using the standard questionnaire used by the hospital; and
- costs of post-operative care.

Analysis

It was planned that all data would be analysed on an intention-to-treat (ITT) basis in the first instance, although some outcomes were only able to be analysed based on return questionnaire numbers. The authors provide ITT and as-treated data for the primary outcome 'inadequate clinical care'.

Excluded studies

Five studies (see Appendix 9) met all inclusion criteria except the requisite degree of family-centredness (Akinci 2008; Bauchner 1996; Landry 2007; Li 2007; Melnyk 2004). Most fell short on the family-centredness cluster 'Cluster 2: cultural', however, many studies were also deficient in 'Cluster 3: supporting families'. 'Cluster 1: family as a constant in the child's life' was the most consistently well scored.

In this update, we revisited the studies (Bauchner 1996; Curley 1988; Gray 2000; K-Hallstrom 1997b) which we had excluded from Shields 2007 due to lack of, or lack of clarity of, blinding of outcome assessment. They remained excluded as they did not meet the minimum family-centredness score (50%) for this update.

We have identified 26 qualitative studies, which again are scored as family-centred, but, because they are qualitative studies, are not included in this update (Aein 2007; Bsiri-Moghaddam 2011,

Cheung 2004; Coyne 2007a; Coyne 2007b; Diaz-Caneja 2005; Harbaugh 2004; Hummelinck 2006; Jackson 2007; Koller 2006; Lam 2006; LeGrow 2005; MacKean 2005; Martenson 2007; Meltzer 2009; O'Haire 2005; Paliadelis 2005; Pinto 2005; Roden 2005; Shin 2005; Silveira 2006; Stratton 2004; Teare 2004; Tsuruta 2005; Verwey 2008; Ygge 2007). They do, nonetheless, contribute importantly to the debate about the use of family-centred care, and more and more such studies are questioning its use. We are including these in a separate review of qualitative studies published since 2004, which will be published by the Joanna Briggs Institute, and which is expected to be available in 2012. This Joanna Briggs review of qualitative studies, along with its sister Joanna Briggs Institute review of quasi-experimental studies of family-centred care for hospitalized children aged 0 to 12 years (Shields 2012), will be linked and cross-referenced to this update.

Risk of bias in included studies

We report the risk of bias assessment for Bolton 2004 below, in a risk of bias table and at Figure 1. Overall, the risk of bias for this study is rated as unclear to low risk.

Allocation

Allocation to standard inpatient care or the CBPU was done by a computer generated block randomization method. The randomisation in Bolton 2004 was conducted by an independent epidemiology and statistics unit, and the group allocations were placed in sealed opaque envelopes. Following consent, participants were allocated to the next available study number and the corresponding envelope opened.

Blinding

Given that placing a child in either the inpatient ward or CBPU could not be hidden from either researchers, staff or parents, blinding was not possible.

Incomplete outcome data

Overall, response rates across all measures were high, for example only 1% of data were missing for the primary outcome, and the authors provided reasons. Missing data were equally distributed between groups.

Selective reporting

The protocol for this study was not available; however authors reported all outcomes stated in the study's methods section.

Other potential sources of bias

While use of validated questionnaires (Posthospital Behaviour Questionnaire (Vernon 1966) and Child Behaviour Questionnaire (Rutter 1970) helped minimize possible bias in reported answers, it is possible that respondents gave results which were subjective, for example, parents assessing the behaviour of their children. Recall bias may have occurred, but this was minimized by contacting the families several times post-discharge, and was thought not to have influenced the result. The possible impact of interviewer bias was minimised by use of the same research assistant and a script.

Effects of interventions

Child

Physical outcomes

The primary outcome of 'inadequate clinical care' was analysed using intention-to-treat (ITT) and as-treated (AT) approaches. According to the ITT analysis, the CBPU patients had significantly less inadequate care than children receiving standard inpatient care. The absolute risk difference in favour of CBPU was -12.4% (95% CI -23.8% to CI -0.03%; Analysis 1.1). This difference was not influenced by age, weight, sex or concurrent adenoidectomy. When applying an 'as treated' analysis to account for the failure of ten allocated patients to reach the CBPU, the absolute risk difference in favour of CBPU was slightly larger: -17.6% (95% CI -28.8% to -6.3%).

Of the five components of the 'inadequate clinical care' composite outcome measure, the component with the largest effect was that of delayed discharges in the inpatient group (25.2%) compared with the CBPU group (6.2%). We present the individual results for each component of this outcome measure at Table 2.

Other physical outcomes such as significant haemorrhage, readmission due to complications, and pain scores are also reported in Table 2. There were no significant differences between groups on any of these measures.

Behavioural outcomes

Behavioural changes in the children under 13 years measured by the Posthospital Behaviour Questionnaire (PHBQ) (Vernon 1966) showed no significant difference in behaviour change for inpatients compared to CBPU patients (mean difference (MD) -0.35 (95% CI -2.71 to 2.01; Analysis 1.2)).

Other child outcomes

None of the following child outcomes we sought were addressed in the included study:

- Psychosocial outcomes including psychological health (such as anxiety, confidence, sense of control, coping, adjustment, stress, upset, crying, insomnia, fears, behavioural regression),

attitudes towards caregivers and attitudes towards rehospitalization.

- Developmental outcomes including weight gain, developmental milestones.
- Knowledge and understanding including knowledge of condition, treatment, knowledge about personnel or procedure.
- Satisfaction: for example, with involvement in decision making, with level of communication.
- Attitudes: for example, views of cultural appropriateness, flexibility.

Parent

Satisfaction

Total parental satisfaction, measured before discharge on a 29-item scale, was significantly higher for parents of CBPU patients (MD 25 (95% CI 21.34 to 28.66; [Analysis 1.3](#)). Parental satisfaction measured via telephone one week after discharge (3 of 29 items reassessed) was also higher for parents whose children were in the CBPU (MD 1.3 (95% CI 0.64 to 1.96; [Analysis 1.3](#)). This result is derived from a sample that included some children over 12 years of age.

Other parent outcomes

The included study did not measure parents' stress, perceptions of coping, sense of control, or attitudes (such as complaints, evaluations of cultural appropriateness, flexibility and responsiveness of the intervention).

Staff

We looked for psychological and satisfaction outcomes for staff but these were not measured in the included study.

Health services

Costs

Total costs (to parents and hospital combined and for the entire stay) were calculated with a range of measures, including nursing care, accommodation for parents of inpatient children who had to stay outside the hospital, surgery, recovery room and hospital costs, post-discharge medical assistance, and others. Overall, the total cost of care per admission to CBPU was estimated to be AUD\$959 which was less than the total cost of care per inpatient admission, estimated to be AUD\$1185.

Other health service outcomes

No other health service outcomes were measured.

DISCUSSION

Summary of main results

The one included study was part of a composite project incorporating several sub-studies which examined the care of children following tonsillectomy, with or without adenoidectomy. Only one sub-study was an RCT that was eligible for inclusion in this review. The results show that children receiving care in a 'care by parent unit' (CBPU) were significantly less likely to receive inadequate care compared with standard inpatient admission, and there were no significant differences for their behavioural outcomes or other physical outcomes. Parents were significantly more satisfied with CBPU care than standard care, assessed both before discharge and at 7 days after discharge. Costs were lower for CPBU care compared with standard inpatient care. No other outcomes were reported.

Overall completeness and applicability of evidence

As some studies came close to meeting the inclusion criteria, we examined them in detail. Some studies met the criteria for study design and participants but did not fulfil the required degree of family-centredness, despite the fact that the threshold for inclusion using this scale was considerably relaxed (from 80% to 50% cut off) in this review update (see [Appendix 9](#)).

We could only include one study which provided limited evidence for some outcomes. The study did not measure the intervention's effects on: children's psychosocial or developmental outcomes, knowledge and understanding, satisfaction or attitudes; parents' stress, perceptions of coping, sense of control, or attitudes; staff outcomes, and health services outcomes other than costs. The study was conducted at a single tertiary-care hospital in Australia, involving patients undergoing a relatively minor procedure (tonsillectomy). Its applicability to other settings and patient groups may be limited.

Quality of the evidence

We included one study involving 288 participants. The included study was at low risk of bias for sequence generation, allocation concealment and attrition bias and at unclear risk of bias for other items.

The fact that some data pertained to children older than 12 years, and we were unable to contact the author to obtain results for children under 12 only, means that some of the data presented here relates to children slightly outside the age range specified for this review. Overall the evidence suggests some benefit for the family-centred care intervention but this is based on a small dataset and needs confirmation in larger RCTs.

Potential biases in the review process

The tool used for scoring family-centredness (Trivette 1993; Appendix 8) has been used for scoring existing literature (as well as our previous review, Shields 2007) and so was thought to be particularly relevant for this update. The fact that the scored studies consistently fell short in Cluster 2: cultural, may indicate a need for revision of the tool before further work is conducted in this area. However, it has not been possible to find other tools. Some studies investigating family-centred service delivery have developed tools, for example the MPOC (King 1995), but this instrument, which has been widely validated in many clinical areas, examines processes of care delivery rather than assessment of existing research. We have not included the studies using MPOC because while they suggest they are about family-centred care delivery, they examine relationships between parents and health professionals only, without the holistic approach that we see as an inherent part of a family-centred care model.

It is possible that the combination of the scoring system for family-centred care and the limitation to RCTs may have created a stringency that precluded inclusion of most studies in this field. The team discussed revising the scoring criteria, but decided to retain these as a way of establishing a baseline for further investigations of the effectiveness of family-centred care. Much of the very large literature on family-centred care is anecdotal, containing descriptions, stories and reports rather than research. We therefore wanted to ensure that this review was as rigorous as possible. Future reviews may consider it reasonable to revisit these inclusion criteria and scoring systems and to consider broadening the selection criteria to include other study designs. We will address this, in part, by undertaking two reviews for the Joanna Briggs Institute. The first will be of the qualitative research found, while a second review examines the quasi-RCTs which were excluded from this updated Cochrane review (Shields 2012).

Agreements and disagreements with other studies or reviews

Because of the difficulty of measuring the family-centredness of care, much of the published research in this area has used qualitative approaches. While useful in their own right, these studies do not answer questions of effectiveness. While we do not want to pre-empt the review of qualitative studies for the Joanna Briggs

Institute, early reading of the possible included studies reveal consistent themes about the delivery of family-centred care. For example, several papers (Darbyshire 1994; Coyne 1996; Coyne 2007a; O'Haire 2005) have described the resentment felt by parents when staff expect them to undertake some of the care of their hospitalised child, staff acting as gatekeepers for parents to access their own children (Coyne 2008), and parents having to negotiate with staff to have their needs met (K-Hallstrom 1999). These provide ideas for further qualitative research, which could subsequently form a basis for generating hypotheses for quantitative studies about both the acceptability and effectiveness of family-centred care.

As lifestyles continue to change over time, with the evolution of non-nuclear families, for example, parents have increasing expectations of their abilities to combine work and family life. As family structures and expectations of the healthcare experience change (often related to the development of innovative technologies in health care, and new models of care delivery) so such perspectives will affect the way care is given in hospitals. It is important that ways of measuring the effects of models such as family-centred care are developed, so that ultimately we can determine the best way to provide care for children and families in health services. Recent research has developed and validated tools to examine the family-centredness of care (Aggarwal 2009a; Aggarwal 2009b; Mitchell 2009; Shields 2004; Gill 2011; Shields 2011). These could be the basis for measurement within future quantitative studies.

AUTHORS' CONCLUSIONS

Implications for practice

This update has found limited evidence, in the form of a single moderate-quality RCT, to guide practice. The study suggests there may be some positive effects of family-centre care on outcomes such as adequacy of clinical care, parental satisfaction and costs. There is no evidence of harm; nor is there evidence for a range of other relevant outcomes. While awaiting further definitive evidence of the effects of family-centred care models, health services can continue to explore the application of these models as an option for children's care in hospital.

Current arrangements in some hospital settings, whereby children and their families receive care using a model that incorporates some aspects of family-centred care, but which militate against truly regarding the family as the central unit of care, and in which ineffective negotiation about roles of both family members and staff are common, can cause resentment and inappropriate communication between families and hospital staff (Coyne 2008; Coyne 1996; Coyne 2007a; Darbyshire 1994). Future research will hopefully identify effective models of care which may ameliorate such communication breakdown between staff and families.

Implications for research

This updated review has shown that more high-quality research is needed. We found only one randomised trial providing limited evidence for the benefits of family-centred care for particular outcomes.

The included study (Bolton 2004) considered a narrow, discrete category of children having a single type of surgery (tonsillectomy), in one hospital, where contamination across groups would have been possible, and blinding difficult. Also, family-centred care is influenced by a range of factors, including the diagnosis for which the child is admitted, and the length or frequency of their hospital stay. The included study did not consider the influence of culture and ethnicity (and notably, the cultural component of the family-centredness score was given a 0 result for this study). Future research should examine the effects of family-centred care for children with a range of diagnoses, and length and frequency of hospital stays, as well as for children from different ethnic and cultural groups. This updated review has also highlighted the need for a review to examine the effects of family-centred care on adolescents and their families/carers.

We have identified clearly the elements of family-centredness that should be addressed by future intervention research. Any family-centred care intervention (model) should include the family as the centre point of the child's life, and therefore the family should be integral to care delivery. The intervention should also include structural and environmental factors, such as accommodation for parents (which would be more than a chair beside the child's bed) and should include bathrooms, laundries, eating places, parking and other facilities for parents and family members. A family-centred care model should take cultural differences of families into consideration, perhaps including separate spaces for prayer and reflection, culture-specific foods, and awareness of the needs of family members. Education and effective communication are important parts of a family-centred care model, and these need to be in place for both health professionals, and children and family members. Support of all kinds, for example parent to parent, or consumer groups and information services are available in a true family-centred care model. Specific interventions (venipuncture, dressings, injections, for example) in a family-centred context require the presence of parents and family members.

To minimise the risk of contamination between intervention and control groups, and to ensure a sufficiently large sample size, cluster RCTs may be the preferred model for future research. These would require the cooperation of several hospitals which were run on similar lines. Future single site studies may be at risk of contamination between groups and find blinding difficult to implement. In some situations, for example, in a town where there is only one children's hospital/ward/unit, allocation to an experimental or control hospital/ward/unit would not be possible. Random allocation may also not be feasible when a child is admitted to a

particular hospital/ward/unit for specific specialist care available only at that hospital. Further, parents' choices may dictate where a child is admitted. If the difficulties in conducting RCTs of family-centred care prove insurmountable, before and after studies in one or two sites may be a feasible way of ascertaining the effects of family-centred care, though this would not provide the same level of evidence as a randomised trial.

Models of care are changing with differing methods of running hospitals. A family-centred care model could contain, for example, a learning package for staff and families about family-centred care, and a period of implementation of the principles learned. This becomes problematic in an era of short stays in hospital, with models of day admission and treatment the norm for many conditions. Such models could suggest that family-centred care is irrelevant, as the child stays in hospital for less than a day. However, family-centred care may be important whatever the health setting may be, and for any length of stay and involvement, including the pre-hospitalisation and follow-up phases, and so should be investigated in all healthcare settings: acute hospital, community services, and long-term facilities.

Future research should measure a range of important outcomes that have not been addressed to date, including children's knowledge and understanding, satisfaction, parental stress, coping and sense of control, and outcomes for staff including satisfaction. Comprehensive cost measures as well as staffing and time outcomes are also needed (Shields 2006).

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* Indicates the major publication for the study

CHARACTERISTICS OF STUDIES

Characteristics of included studies [ordered by study ID]

Bolton 2004

Methods	<p>RCT (this was sub-study of a larger project which examined the postoperative care of children having tonsillectomy)</p> <p>The RCT compared routine inpatient care with care in a Care-by-Parent Unit (CBPU) in a tertiary referral paediatric hospital in Australia. Other investigations included various types of pain control, control of postoperative nausea and vomiting, and costs of admission</p>
Participants	<p>All public patients who were scheduled to undergo tonsillectomy with or without adenoidectomy were reviewed to assess their eligibility for inclusion (at least 3 years of age, no evidence of obstructive sleep apnoea, no history of significant cardiac, respiratory or hepatic disease, and parents did not require an interpreter or have trouble with written English)</p> <p>A total of 153 (inpatient) and 148 (CBPU) participants were enrolled. Of these 3 inpatients refused written consent and 7 cancelled surgery or had it performed elsewhere prior to informed consent being obtained. A further 3 CBPU participants withdrew prior to consent being obtained.</p> <p>A total of 288 participants consented to the trial and were randomly allocated to routine inpatient care (n=143) or CBPU (n=145). Some of these were over 13 years, but it was found that 260 of these children were aged between 3 and 13 years, and were analysed separately, hence were able to be included in this review (124 inpatient, 136 CBPU)</p> <p>The sample size was adjusted incrementally throughout the study as the original sample size calculation was not able to be met through the recruitment strategies employed. The author stated that initial calculations indicated that a two-group, large sample normal approximation test of proportions with a one sided 0.05 significance level of 207 participants in each group would provide an 80% power to reject the non-equivalence null hypothesis that the CBPU intervention (though it must be remembered that this part of the study constituted only a small component of the overall study) offered a lesser quality of treatment than routine inpatient care. The prespecified zone of equivalence was stated to be 0.12 (an absolute difference in the proportion of each study group reaching the primary outcome of 0.12 or more). The assumptions underpinning these sample size and zone of equivalence calculations were that the expected differences in proportions between CBPU and routine inpatient care groups was zero, and that the proportion of participants registering at least one marker of inadequate care in each study group was equal to 0.4</p> <p>Revision of the sample size was accepted by the Human Research Ethics Committee at the end of 2002 when it was apparent that the sample size would not be reached. A larger pre-specified zone of equivalence of 0.14 (the absolute difference in the proportion of each study group reaching the primary outcome was 0.14 or more) was therefore accepted. The assumptions were that the incidence of the primary outcome was unchanged at 0.4 (routine care group), that the study's power also remained stable at 80% and so that a total of 300 subjects would be needed. In addition, the age range was enlarged to allow children over 13 years to be included</p>

Interventions	Admission to care-by-parent unit (CBPU) versus standard inpatient care post-tonsillectomy. The CBPU was a unit where parents were accommodated with their admitted children, where parents (and children as appropriate) were supported and encouraged to be part of the decision-making team, and to give as much of the care as they could appropriately undertake	
Outcomes	<p>Primary outcome: 'Inadequate clinical care', which was recorded as yes or no based on a single instance of inadequate care from 5 markers:</p> <ul style="list-style-type: none"> • less than good control of nausea and vomiting (assessed by parents), • less than good pain control (assessed by parents), • medical attention needed but not provided within 30 minutes, • discharge delay beyond 1200h one day post-surgery, and • unplanned medical consultation within seven days of surgery <p>Secondary outcomes:</p> <ul style="list-style-type: none"> • Physical outcomes including primary haemorrhage, readmission, pain. • Behavioural outcomes measured using the Posthospital Behaviour Questionnaire (Vernon 1966) and the Child Behaviour Questionnaire for parents (Rutter 1970). • Parental satisfaction (using the standard questionnaire used by the hospital). • Costs of post-operative care. • Financial impact on the family, measured as need for additional (paid and unpaid) childcare (during the admission), and number of days taken off work by the main adults involved in the child's care. 	
Notes	The study was undertaken from 2002 to 2004.	
Risk of bias		
Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Computer generated block randomization. Random blocks of 2, 4, 6 and 8 were used
Allocation concealment (selection bias)	Low risk	Procedure prepared by an independent epidemiology and statistics unit, and the group allocations were placed in sealed opaque envelopes. Following consent, participants were allocated to the next available study number and the corresponding envelope opened
Blinding (performance bias and detection bias) All outcomes	Unclear risk	Once the participants were in the ward or CBPU, it would have been impossible to blind them, researchers, staff or parents as to the type of care they were receiving
Incomplete outcome data (attrition bias) All outcomes	Low risk	Overall, response rates across all measures were high, for example only 1% of data

Bolton 2004 (Continued)

		were missing for the primary outcome, and the authors provided reasons. Missing data were equally distributed between groups
Selective reporting (reporting bias)	Unclear risk	The protocol for this study was not available; however authors reported all outcomes stated in the methods section
Other bias	Unclear risk	While use of validated questionnaires (Posthospital Behaviour Questionnaire (Vernon 1966) and Child Behaviour Questionnaire (Rutter 1970) helped minimize possible bias in reported answers, it is possible that respondents gave results which were somewhat subjective, for example, parents assessing the behaviour of their children. Recall bias may have occurred, but this was minimized by contacting the families several times post-discharge, and was thought not to have influenced the result. The possible impact of interviewer bias was minimised by use of the same research assistant and a script

Characteristics of excluded studies [ordered by study ID]

Study	Reason for exclusion
Abu-Hasheesh 2011	Intervention did not meet FCC criteria
Aein 2007	Ineligible study design
Aggarwal 2007	Intervention did not meet FCC criteria
Ainbinder 1998	Ineligible study design
Akinci 2008	Less than 50% of family-centredness score
Aksornsri 2011	Intervention did not meet FCC criteria
Almquist 1986	Ineligible study design
Baker 1995	Ineligible study design
Bauchner 1991	Ineligible study design

(Continued)

Bauchner 1996	Excluded from Shields 2007 due to inadequate or unclear blinding of outcome assessment. Revisited for the update: less than 50% of family-centredness score
Bernaix 2008	Intervention did not meet FCC criteria
Bevan 1990	Intervention did not meet FCC criteria
Blank 2011	Intervention did not meet FCC criteria
Blesch 1996	Ineligible study design
Bloch 2008	Intervention did not meet FCC criteria
Borghini 2006	Intervention did not meet FCC criteria
Bouve 1999	Intervention did not meet FCC criteria
Braude 1990	Intervention did not meet FCC criteria
Brewer 2006	Intervention did not meet FCC criteria
Brown 1999	Intervention did not meet FCC criteria
Bruce 1997	Ineligible study design
Bruce 2002	Ineligible study design
Bsiri-Moghaddam 2011	ineligible study design
Burke 1997	Intervention did not meet FCC criteria
Burke 2001	Ineligible population
Byers 2006	Ineligible study design
Callery 1991	Ineligible study design
Callery 1996	Ineligible study design
Callery 1997	Ineligible study design
Cameron 1996	Intervention did not meet FCC criteria
Cassady 1999	Intervention did not meet FCC criteria
Cevasco 2008	Intervention did not meet FCC criteria
Cheung 2004	Ineligible study design

(Continued)

Cohen 2005	Intervention did not meet FCC criteria
Conniff 2011	Intervention did not meet FCC criteria
Cooper 2007	Ineligible study design
Cousino 2011	Intervention did not meet FCC criteria
Coyne 2003	Ineligible study design
Coyne 2007a	Ineligible study design
Coyne 2007b	Ineligible study design
Coyne 2010	Intervention did not meet FCC criteria
Curley 1988	Excluded from Shields 2007 due to inadequate or unclear blinding of outcome assessment. Revisited for the update: less than 50% of family-centredness score
Curley 2011	Intervention did not meet FCC criteria
Daeyoung 2006	Ineligible study design - single intervention only
Darbyshire 1994	Ineligible study design
Dave 2011	Intervention did not meet FCC criteria
de Groot 2007	Intervention not directed at children in hospital
De Lima 2001	Ineligible study design
DeLemos 2010	ineligible study design
Diaz-Caneja 2005	Ineligible study design
Diniaco 1983	Ineligible study design
Dordevic 2008	Intervention did not meet FCC criteria
Dreimane 2007	Intervention not directed at children in hospital
Drew 2012	Intervention did not meet FCC criteria
Eckle 2001	Ineligible study design
Erdeve 2008	Intervention did not meet FCC criteria
Espezel 2003	Ineligible study design

(Continued)

Evans 1994	Ineligible study design
Farrell 2008	Intervention did not meet FCC criteria
Feaster 2011	Intervention did not meet FCC criteria
Felder-Puig 2003	Intervention did not meet FCC criteria
Ferguson 1979	Intervention did not meet FCC criteria
Festini 2009	Intervention did not meet FCC criteria
Fina 1997	Ineligible study design
Finley 1996	Intervention did not meet FCC criteria
Fiorentini 1993	Intervention did not meet FCC criteria
Fisher 2009	Intervention did not meet FCC criteria
Flanigan 2012	Intervention did not meet FCC criteria
Forcada-Guex 2006	Ineligible study design
Fortier 2011	Intervention did not meet FCC criteria
Forward 1996	Intervention did not meet FCC criteria
Fung 2011	Intervention did not meet FCC criteria
Futamura 2010	Intervention did not meet FCC criteria
Galvin 2000	Ineligible study design
Gamell 2010	Intervention did not meet FCC criteria
Gamell 2011	Intervention did not meet FCC criteria
Gardner 2002	Ineligible study design
Gathwala 2008	Intervention did not meet FCC criteria
Gauderer 1989	Intervention did not meet FCC criteria
Gedaly-Duff 1994	Intervention did not meet FCC criteria
George 1993	Ineligible study design

(Continued)

Giannini 2011	Intervention did not meet FCC criteria
Giarelli 2005	Intervention not directed at children in hospital
Gielen 2007	Intervention did not meet FCC criteria
Gillette 1990	Intervention did not meet FCC criteria
Gill 2011a	ineligible study design
Gillerman 1996	Intervention did not meet FCC criteria
Glazebrook 2007	Intervention did not meet FCC criteria
Gonzalez 1989	Intervention did not meet FCC criteria
Gonzalez 1993	Intervention did not meet FCC criteria
Gray 2000	Excluded from Shields 2007 due to inadequate or unclear blinding of outcome assessment. Revisited for the update: less than 50% of family-centredness score
Greenberg 1999	Intervention did not meet FCC criteria
Hannallah 1983	Intervention did not meet FCC criteria
Harbaugh 2004	Ineligible study design
Hart 2006	Ineligible study design
Hauptert 2004	Intervention did not meet FCC criteria
Hemmelgarn 2001	Intervention did not meet FCC criteria
Henderson 1993	Intervention did not meet FCC criteria
Himes 2003	Ineligible study design
Hinds 2007	Intervention did not meet FCC criteria
Holm 2008	Intervention did not meet FCC criteria
Hong 2008	Intervention did not meet FCC criteria
Hsieh 2010	Intervention did not meet FCC criteria
Hummelinck 2006	Ineligible study design
Huth 2003	Intervention did not meet FCC criteria

(Continued)

Iacovidou 2010	Intervention did not meet FCC criteria
Jackson 2007	Ineligible study design
Johnston 1988	Intervention did not meet FCC criteria
Jotzo 2005	Ineligible study design
Junge 1987	Ineligible study design
K-Hallstrom 1997a	Ineligible study design
K-Hallstrom 1997b	Excluded from Shields 2007 due to inadequate or unclear blinding of outcome assessment. Revisited for the update: less than 50% of family-centredness score
Kable 2011	Intervention did not meet FCC criteria
Kain 1996	Intervention did not meet FCC criteria
Kain 1997	Intervention did not meet FCC criteria
Kain 1998a	Intervention did not meet FCC criteria
Kain 1998b	Intervention did not meet FCC criteria
Karabudak 2010	Intervention did not meet FCC criteria
Karl 1990	Intervention did not meet FCC criteria
Kaufmann 1998	Ineligible study design
Kawik 1996	Ineligible study design
Kilicarslan 2011	Intervention did not meet FCC criteria
Kim 2007	Ineligible study design
King 2006	Age group outside defined parameters
Koller 2006	Ineligible study design
Kuntaros 2007	Ineligible study design
Lai 2006	Intervention did not meet FCC criteria
Laine 1989	Intervention did not meet FCC criteria
Lam 2006	Ineligible study design

(Continued)

Landry 2007	Less than 50% of family-centredness score
Lardner 2010	Intervention did not meet FCC criteria
Larosa-Nash 1995	Intervention did not meet FCC criteria
Larsen 2011	Intervention did not meet FCC criteria
Latour 2011	ineligible study design
LeGrow 2005	Ineligible study design
Li 2007	Less than 50% of family-centredness score
Li 2010	Intervention did not meet FCC criteria
Mack 2011	Intervention did not meet FCC criteria
MacKean 2005	Ineligible study design
MacNab 2000	Ineligible study design
Madrigal 2010	Intervention did not meet FCC criteria
Martenson 2007	Ineligible study design
Martinez 2007	Intervention did not meet FCC criteria
Maxton 1997	Intervention did not meet FCC criteria
McCann 2009	Ineligible study design
McLoone 2011	Intervention did not meet FCC criteria
McPherson 2011	Intervention did not meet FCC criteria
Melamed 1988	Ineligible study design
Mello 2004	Ineligible study design
Melnyk 1994	Intervention did not meet FCC criteria
Melnyk 1997	Intervention did not meet FCC criteria
Melnyk 2001	Intervention did not meet FCC criteria
Melnyk 2004	Less than 50% of family-centredness score

(Continued)

Melnyk 2007	Intervention did not meet FCC criteria
Meltzer 2009	Ineligible study design
Meng 1982	Intervention did not meet FCC criteria
Neill 1996a	Ineligible study design
Neill 1996b	Ineligible study design
Newnham 2009	Intervention did not meet FCC criteria
Nowicka 2010	Intervention did not meet FCC criteria
O'Haire 2005	Ineligible study design
Oliveira 2011	ineligible study design
Ozcerin 2011	Intervention did not meet FCC criteria
Page 1990	Ineligible study design
Paliadelis 2005	Ineligible study design
Parker 1992	Intervention did not meet FCC criteria
Parsons 2011	Intervention did not meet FCC criteria
Patel 2010	Intervention did not meet FCC criteria
Penticuff 2005	Ineligible study design
Phipps 2007	Ineligible study design
Pinto 1989	Intervention did not meet FCC criteria
Pinto 2005	Ineligible study design
Polkki 2008	Intervention did not meet FCC criteria
Powers 1999	Ineligible population
Proctor 1987	Intervention did not meet FCC criteria
Reid 1995	Ineligible study design
Rennick 2011	Intervention did not meet FCC criteria

(Continued)

Robinson 1991	Intervention did not meet FCC criteria
Roden 2005	Ineligible study design
Roman 1995	Ineligible study design
Rosen 2009	Ineligible study design
Roskies 1978	Intervention did not meet FCC criteria
Ryder 1991	Ineligible study design
Sacchetti 1996	Ineligible study design
Saenz 2009	Intervention did not meet FCC criteria
Sarisoy 2011	Intervention did not meet FCC criteria
Scholten 2011	Intervention did not meet FCC criteria
Schroeder 2006	Intervention did not meet FCC criteria
Schulman 1967	Intervention did not meet FCC criteria
Shaw 1982	Intervention did not meet FCC criteria
Shields 2001a	Ineligible study design
Shields 2001b	Ineligible study design
Shin 2005	Ineligible study design
Shirley 1998	Ineligible study design
Silveira 2006	Ineligible study design
Simons 2001	Intervention did not meet FCC criteria
Skipper 1968	Intervention did not meet FCC criteria
Skuladottir 2003	Intervention did not meet FCC criteria
Smith 2011	Intervention did not meet FCC criteria
So 2011	ineligible study design
Spence 2006	Ineligible study design

(Continued)

Stratton 2004	Ineligible study design
Stratton 2010	Intervention did not meet FCC criteria
Teare 2004	Ineligible study design
Tsuruta 2005	Ineligible study design
Vagnoli 2010	Intervention did not meet FCC criteria
van der Pal 2007	Intervention did not meet FCC criteria
Vavarouta 2011	Intervention did not meet FCC criteria
Verwey 2008	Ineligible study design
Vessey 1994	Intervention did not meet FCC criteria
Voos 2010	Intervention did not meet FCC criteria
Vulcan 1988	Intervention not directed at children in hospital
Wakefield 2011	Intervention did not meet FCC criteria
Wang 2008	Intervention did not meet FCC criteria
Weinstein 1991	Intervention did not meet FCC criteria
Westrup 2000	Intervention did not meet FCC criteria
Widrick 1991	Intervention did not meet FCC criteria
Wolfer 1975	Age group outside defined parameters
Wolfer 1979	Intervention did not meet FCC criteria
Wolfram 1996	Ineligible population
Yager 2010	Intervention did not meet FCC criteria
Ygge 2007	Ineligible study design
Zelkowitz 2008	Intervention did not meet FCC criteria

DATA AND ANALYSES

Comparison 1. CBPU v usual care

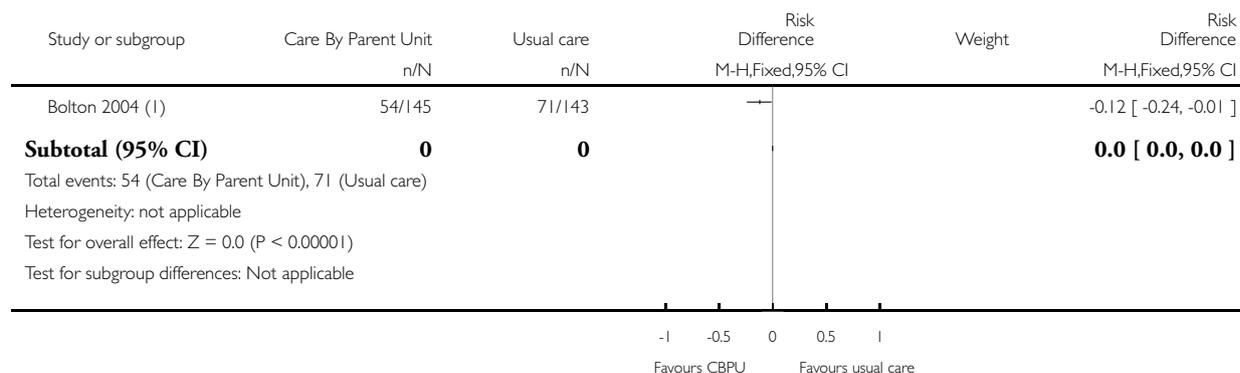
Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
1 Physical outcomes	1		Risk Difference (M-H, Fixed, 95% CI)	Subtotals only
2 Behavioural outcomes (mean change in PHBQ)	1		Mean Difference (IV, Fixed, 95% CI)	Subtotals only
3 Parental satisfaction	1		Mean Difference (IV, Fixed, 95% CI)	Subtotals only

Analysis 1.1. Comparison 1 CBPU v usual care, Outcome 1 Physical outcomes.

Review: Family-centred care for hospitalised children aged 0-12 years

Comparison: 1 CBPU v usual care

Outcome: 1 Physical outcomes



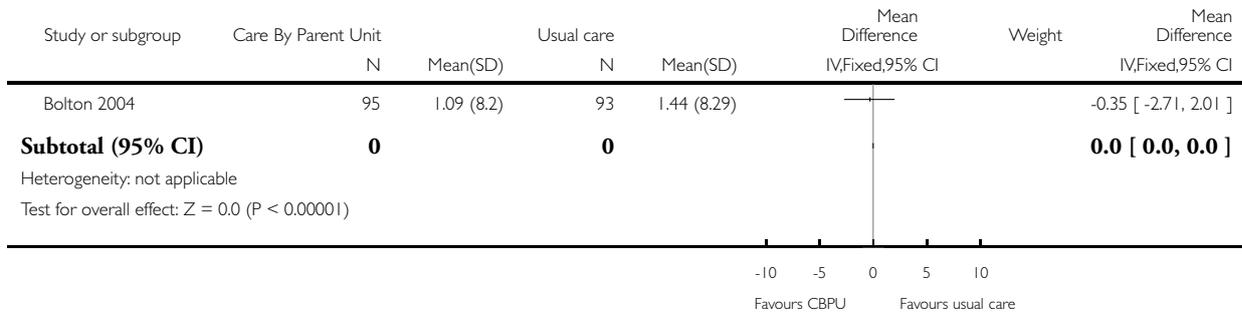
(1) 'Inadequate clinical care' (composite outcome)

Analysis 1.2. Comparison 1 CBPU v usual care, Outcome 2 Behavioural outcomes (mean change in PHBQ).

Review: Family-centred care for hospitalised children aged 0-12 years

Comparison: 1 CBPU v usual care

Outcome: 2 Behavioural outcomes (mean change in PHBQ)

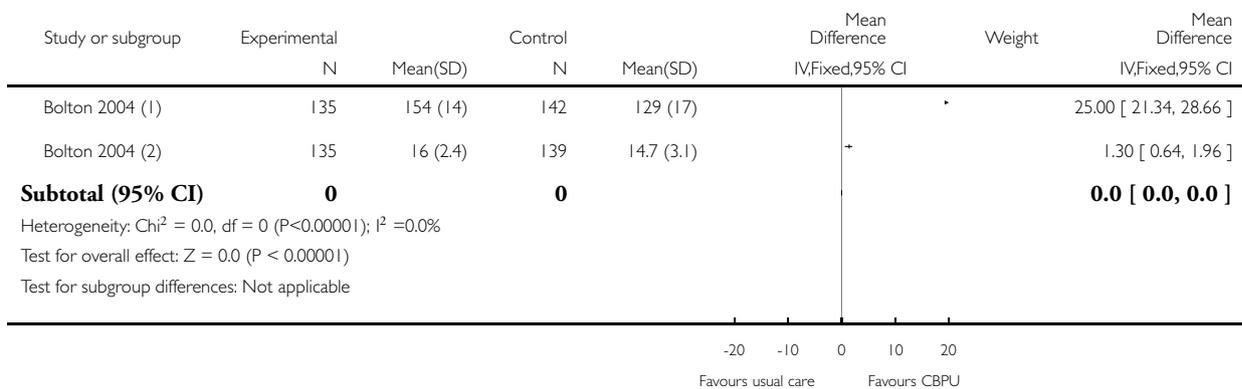


Analysis 1.3. Comparison 1 CBPU v usual care, Outcome 3 Parental satisfaction.

Review: Family-centred care for hospitalised children aged 0-12 years

Comparison: 1 CBPU v usual care

Outcome: 3 Parental satisfaction



(1) Before discharge (29 item measure)

(2) One week after discharge (3 of 29 items reassessed)

ADDITIONAL TABLES

Table 1. Association for the Care of Children's Health: Elements of Family-Centered Care

Elements of Family-centred Care	Evaluative Items
Recognising the family as a constant in the child's life	1. Family as the principle context for the provision of a child's health care
Facilitating parent-professional collaboration at all levels of health care	2. Promoting and utilizing parent-professional collaboration and partnerships
Honouring the racial, ethnic, cultural, and socioeconomic diversity of families	3. Respect for family diversity
Recognizing family strengths and individuality and respecting different methods of coping	4. Recognising the strengths and capabilities of families
	5. Recognising different methods of family coping
Sharing complete and unbiased information with families on a continuous basis	6. Complete sharing of all relevant information with families
Encouraging and facilitating family-to-family support and networking	7. Promoting parent-to-parent and family-to-family support
Responding to child and family developmental needs as part of health care practices	8. Attention to the developmental needs of children and families as part of health care delivery
Adopting policies and practices that provide families with emotional and financial support	9. Recognising and responding to family emotional needs
	10. Recognising and responding to family financial needs
Designing health care that is flexible, culturally competent, and responsive to family needs	11. Flexible delivery of health care to children and their families
	12. Culturally-competent delivery of health care
	13. Recognising and responding to family-identified needs

Table 2. Additional results from included study

Outcome category	Data
Components of primary outcome 'inadequate clinical care' (Table 45 of Bolton 2004) Inpatient n =143, CBPU n = 145	<i>Inadequate control of nausea and vomiting</i> Inpatient 13 (9.4%); CBPU 6 (4.4%); OR 0.5 (95%CI 0.3 to 1.4) <i>Inadequate pain control</i> Inpatient 21 (14.8%); CBPU 13 (9.6%); OR 0.61 (95% CI 0.3 to 1.4) <i>Medical attention not received within 30 mins</i> Inpatient 1 (0.7%); CBPU 0; absolute difference 0.7%

Table 2. Additional results from included study (Continued)

	<p><i>Delayed discharge</i> Inpatient 36 (25.2%); CBPU 9 (6.2%); OR 0.2 (95% CI 0.1 to 0.4)</p> <p><i>Unplanned consultation within 7 days</i> Inpatient 52 (36.4%); CBPU 49 (33.8%); OR 0.9 (95% CI 0.5 to 1.5)</p>
<p>Secondary clinical outcomes results (no significant differences) (Table 46 of Bolton 2004) Inpatient n =143, CBPU n = 145</p>	<p><i>Incidence of significant haemorrhage</i> Inpatient 1 (0.7%), CBPU 0</p> <p><i>Incidence of respiratory events</i> Inpatient 1 (0.7%), CBPU 0</p> <p><i>Incidence of readmission within 7 days</i> Inpatient 5 (3.5%), CBPU 7 (4.8%)</p> <p><i>Admission to ICU</i> Inpatient 1 (0.7%), CBPU 0</p> <p><i>Deaths due to complications</i> Inpatient 0, CBPU 0</p> <p><i>Severe vomiting</i> Inpatient 10 (7%); CBPU 8 (5.5%)</p> <p><i>Pain score greater than that acceptable by parents</i> Inpatient 45 (31.5%), CBPU 51 (32.5%)</p>

APPENDICES

Appendix I. Inclusion Criteria

Form version: 1.4 11 NOV 2009

Review title: Family Centred Care for Hospitalised Children Aged 0-12 Years

Study ID (Author Surname Year):

Name of review author completing this form:

Date form completed:

Notes (Unpublished for own use) Eg. Reference to be followed up, source of information (especially if multiple reports of same trial, or unpublished data/personal communication included).

IN - OUT- QUERY

Q1 Is the study an RCT? (YES/NO)

Q2 Are the children aged 0-12 years? (YES/NO)

Q3 Does this study implement a family-centred care intervention? (YES/NO)

Q4 Does the model of family-centred care in this study score >26 based on criteria below? (YES/NO)

Instructions for Applying Inclusion Criteria

Q1: Include studies that are cluster randomised trials; Include studies where the sequence generation is 'adequate' according to the Cochrane Handbook;

Simple/unrestricted randomisation, including repeated coin-tossing, throwing dice, dealing previously shuffled cards, a published list of random numbers, a list of random assignments generated by a computer;

Restricted randomisation, including blocked randomisation, stratified randomisation, minimisation, biased coin or urn randomisation, replacement randomisation, mixed randomisation and maximal randomisation.

Include studies which state they are an RCT but don't state the randomisation method (the trial authors will be contacted for information about the sequence generation method).

Exclude studies where the sequence generation is 'inadequate' according to the Handbook; exclude studies which state they are RCTs but turn out to be a quasi-randomized trial.

Systematic methods such as alternation, assignment based on date of birth, case record number and data of presentation are sometimes referred to as 'quasi-random'.

Q2: Include studies if the data for children 0-12 years can be extracted and analysed. If a study mostly contains children 0-12 years of age, with a few outliers, it will be included, but no subset analysis will be undertaken.

EXCLUDE studies examined premature neonates as infants born prematurely and who are patients in a neonatal intensive or special care nursery, as their requirements for family-centred care, and the ethics and philosophies of care around this particular group, are different to those in a ward/unit where full term infants and children are nursed.

Q3: Include any healthcare intervention that aims to promote the family-centred model of care during a child's hospitalisation. Only studies which provide clear evidence that the family and/or child were actively involved in the planning and/or delivery of healthcare during the child's hospitalisation will be considered for inclusion in this review.

For the purposes of the review, the minimum criteria for active involvement will include evidence of collaboration between health carers and the family and/or child in the planning and/or delivery of care as soon as possible after admission, or during the preadmission period. Included studies must also compare family-centred models with standard model of care.

Types of interventions could include:

- Environmental interventions as evidenced by collaboration with the family and/or child in the design or redevelopment of facilities to provide an environment that maximises parental involvement and enhances child recovery and/or convalescence, care-by-parent units, privacy areas;

- Family-centred policies which may include open visiting hours for siblings or extended family, parent participation in their child's care to the extent they choose (for example, feeding, bathing);

- Communication interventions could include parental presence and participation at daily interdisciplinary ward rounds and family conferences to plan future care, developing collaborative care pathways where both parent and/or child and health carer document issues and progress, reorganisation of health care to provide continuity of care-giver (such as, primary nursing), shared medical records, local hospital based interpreters;

- Educational interventions could include structured educational sessions for parents of technologically dependant children, continuing education programs to equip staff to provide care within a family-centred framework, preadmission programs;

- Family support interventions such as flexible charging schemes for poor families, referrals to other hospital or community services (such as, social workers, chaplains, patient representatives, mental health professionals, home health care, rehabilitation services), facilitating parent-to-parent support.

EXCLUDE Studies where there is no clear evidence of collaboration between the family and/or child and health care provider in the planning and/or delivery of care. Such studies could include parental presence during health care procedures such as routine examinations, anaesthetic induction, venipuncture and post-anaesthetic recovery, bereavement team/protocols, because singular interventions such as parental presence without any collaboration, communication etc does not meet the holism of FCC.

Studies which examine parental presence for a singular procedure, for the same reason. As an example, parental presence for anaesthesia induction might occur in the OR, but there's nothing to say that the same hospital will let parents be involved in any other aspect of the child's care. Similarly, a study that examines parental presence for venepuncture is not studying FCC, rather it is only parental presence for a specific reason.

Q4: Scoring Criteria for Family Centredness

13 Elements of FCC	RATING				
	0	1	2	3	4
<i>Cluster 1: Family as a constant</i>					
Family as a constant in child's life					
Recognising family strengths					
Parent/professional collaboration					
Needs-based family support					
Flexible provision of health care					
Sharing information with families					
<i>Cluster 2: Culturally responsive</i>					
Culturally competent health care					
Respecting family diversity					
Providing financial support					
<i>Cluster 3: Supporting family individuality & need for different types of family support</i>					
Respecting family coping methods					
Providing emotional support					
Family-to-family support					
Attending to the developmental needs of children and fam-					

22. or/1-21
23. (animals not (humans and animals)).sh.
24. 22 not 23
25. exp child/ or exp infant/
26. child*.tw.
27. exp pediatrics/ or exp pediatric nursing/
28. p?ediatric*.tw.
29. (perinat* or neonat* or newborn* or infant* or baby or babies or toddler*).tw.
30. (preterm or prematur*).tw.
31. (school age or schoolage).tw.
32. or/25-31
33. exp hospitalization/
34. exp hospitals/ or hospital units/
35. hospital*.tw.
36. child, hospitalized.sh.
37. or/33-35
38. 37 and 32
39. 36 or 38
40. patient-centered care.sh.
41. family cent?red.tw.
42. patient cent?red.tw.
43. (famil* adj5 support*).tw.
44. professional-family relations/
45. family/ or family health/ or maternal behavior/ or paternal behavior/
46. exp parents/ or exp parent-child relations/
47. caregivers/
48. ((child* or famil*) adj focus*).tw.
49. family nursing/
50. exp maternal child nursing/
51. models, nursing/
52. (shar* adj3 care).tw.
53. ((care or cared or caring) adj3 (parent* or mother* or father* or famil*)).tw.
54. or/40-53
55. ((famil* or parent* or mother* or father* or care* or mutual) adj4 (partner* or participat* or presence or involv* or decision* or communicat* or negotiat* or collaborat* or visit*)).tw.
56. 54 or 55
57. 56 and 39
58. 57 and 24
59. limit 58 to yr="2004-2011"

Appendix 3. Cochrane Central Register of Controlled Trials (CENTRAL) search strategy

2004 - 2011

- #1 MeSH descriptor Child explode all trees
- #2 MeSH descriptor Infant explode all trees
- #3 MeSH descriptor Pediatrics explode all trees
- #4 MeSH descriptor Pediatric Nursing explode all trees
- #5 (child* or Infant* or pediatric* or paediatric* or perinat* or neonat* or newborn* or baby or babies or toddler* or preterm or prematur*):ti,ab,kw
- #6 ("school age" or schoolage):ti,ab,kw
- #7 (#1 OR #2 OR #3 OR #4 OR #5 OR #6)
- #8 MeSH descriptor Hospitalization, this term only

- #9 MeSH descriptor Hospitals explode all trees
- #10 MeSH descriptor Hospital Units explode all trees
- #11 hospital*:ti,ab,kw
- #12 (#8 OR #9 OR #10 OR #11)
- #13 (#7 AND #12)
- #14 MeSH descriptor Child, Hospitalized, this term only
- #15 (#13 OR #14)
- #16 MeSH descriptor Patient-Centered Care, this term only
- #17 ("patient centred" or "patient-centred" or "family centred" or family-centred):ti,ab,kw
- #18 MeSH descriptor Caregivers, this term only
- #19 (caregiver or parent* or mother* or father* or family or parental behavior or maternal care):kw
- #20 (famil* near/5 support):ti,ab,kw
- #21 ((child or famil*) next focus*):ti,ab,kw
- #22 MeSH descriptor Parents explode all trees
- #23 MeSH descriptor Parent-Child Relations explode all trees
- #24 MeSH descriptor Maternal-Child Nursing, this term only
- #25 MeSH descriptor Family Nursing, this term only
- #26 MeSH descriptor Professional-Family Relations, this term only
- #27 (share* near/3 care):ti,ab,kw
- #28 ((care or cared or caring) near/3 (parent* or mother* or father* or famil*)):ti,ab,kw
- #29 ((famil* or parent* or mother* or father* or care* or mutual) near/4 (partner* or participat* or presence or involv* or decision or communicat* or negotiat* or collaborat* or visit*)):ti,ab,kw
- #30 (#16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29)
- #31 (#30 AND #15)
- #32 ((child* or infant or pediatric* or newborn or neonat* or baby or babies) and hospital* and (family or mother or father or carer or caregiver or (care next giver) or parent* or participat* or shar* or involv* or partner* or collaborat*)):ti,kw
- #33 (#31 OR #32), from 2004 to 2011

Appendix 4. EMBASE (OvidSP) search strategy

2004 - December Week 50 2011 (3582)

1. randomized controlled trial/
2. single blind procedure/ or double blind procedure/
3. crossover procedure/
4. random*.tw.
5. trial.tw.
6. placebo*.tw.
7. ((singl* or doubl*) adj (blind* or mask*)):tw.
8. (experiment* or intervention*).tw.
9. (pre test or pretest or post test or posttest).tw.
10. (preintervention or postintervention).tw.
11. (cross over or crossover or factorial* or latin square).tw.
12. (assign* or allocat* or volunteer*).tw.
13. (control* or compar* or prospectiv*).tw.
14. (impact* or effect? or chang* or evaluat*).tw.
15. or/1-14
16. nonhuman/
17. 15 not 16
18. exp child/
19. child*.tw.
20. exp pediatrics/
21. p?ediatric*.tw.

22. (perinat* or neonat* or newborn* or infant* or baby or babies or toddler*).tw.
23. (preterm or prematur*).tw.
24. (school age or school age).tw.
25. or/18-24
26. exp hospital/ or hospitalization/
27. hospital*.tw.
28. child hospitalization/ or hospitalized child/ or hospitalized infant/
29. 26 or 27
30. (29 and 25) or 28
31. family centred care/
32. family cent:red.tw.
33. patient cent:red.tw.
34. caregiver/ or caregiver*.tw.
35. (famil* adj5 support*).tw.
36. exp parent/ or exp child parent relation/ or parental behavior/
37. family health/ or family/
38. family nursing/ or maternal care/
39. family coping/ or family interaction/
40. ((child or famil*) adj focus*).tw.
41. (share* adj3 care).tw.
42. ((care or cared or caring) adj3 (parent* or mother* or father* or famil*)).tw.
43. or/31-42
44. ((famil* or parent* or mother* or father* or care* or mutual) adj4 (partner* or participat* or presence or involv* or decision* or communicat* or negotiat* or collaborat* or visit*)).tw.
45. 43 or 44
46. 30 and 45
47. 17 and 46
48. limit 47 to yr="2004-2011"

Appendix 5. PsycINFO (OvidSP) search strategy

2004 December 21 2011 (1042)

1. random*.ti,ab,hw,id.
2. (experiment* or intervention*).ti,ab,hw,id.
3. trial*.ti,ab,hw,id.
4. placebo*.ti,ab,hw,id.
5. groups.ab.
6. ((singl* or doubl* or tripl*) and (blind* or mask*)).ti,ab,hw,id.
7. (pre test or pretest or post test or posttest).ti,ab,hw,id.
8. (preintervention or postintervention).ti,ab,hw,id.
9. (cross over or crossover or factorial* or latin square).ti,ab,hw,id.
10. (assign* or allocat* or volunteer*).ti,ab,hw,id.
11. (control* or compar* or prospectiv*).ti,ab,hw,id.
12. (impact* or effect? or change* or evaluat*).ti,ab,hw,id.
13. exp experimental design/
14. ("0430" or "0450" or "0451" or "1800" or "2000").md.
15. or/1-14
16. limit 15 to human
17. (child* or infant*).ti,ab,hw,id.
18. p?ediatric*.ti,ab,hw,id.
19. (perinat* or neonat* or newborn* or infant* or baby or babies or toddler*).ti,ab,hw,id.
20. (preterm or prematur*).ti,ab,hw,id.

21. (school age or schoolage).ti,ab,hw,id.
22. or/17-21
23. (hospitals or hospitalization or hospitalized patients or hospital admission).sh.
24. hospital*.ti,ab,id.
25. 22 and (23 or 24)
26. patient cent?ered.ti,ab,id.
27. family cent?ered.ti,ab,id.
28. ((child* or famil*) adj focus*).ti,ab,id.
29. (famil* adj5 support*).ti,ab,id.
30. caregivers/
31. (mother child relations or father child relations or parent child relations).sh.
32. parental involvement/
33. exp parents/ or exp family/ or family members/
34. (shar* adj3 care).ti,ab,id.
35. ((care or cared or caring) adj3 (parent* or mother* or father* or famil*)).ti,ab,id.
36. ((famil* or parent* or mother* or father* or care* or mutual) adj4 (partner* or participat* or presence or involv* or decision* or communicat* or negotiat* or collaborat* or visit*)).ti,ab,id.
37. or/26-36
38. 25 and 37
39. 38 and 16
40. limit 39 to yr="2004-2011"

Appendix 6. CINAHL (EbscoHOST) search strategy

2004 December 22, 2011 (1113)

- S1. randomi?ed controlled trial*
- S2. (MH "Experimental Studies+")
- S3. MH Random assignment
- S4. MH comparative studies
- S5. MH crossover design
- S6. MH placebos
- S7. MH quantitative studies
- S8. MH quasi-experimental studies+
- S9. PT clinical trial
- S10. AB (random* or trial or groups or placebo* or assign* or allocat* or volunteer* or factorial* or crossover or cross over or experiment* or control* or compar* or intervention* or chang* or evaluat* or impact* or effect?) or TI (random* or trial or groups or placebo* or assign* or allocat* or volunteer* or factorial* or crossover or cross over or experiment* or control* or compar* or intervention* or chang* or evaluat* or impact* or effect?)
- S11. AB (singl* or doubl* or tripl* or trebl*) and AB(blind* or mask*)
- S12. TI (singl* or doubl* or tripl* or trebl*) and TI (blind* or mask*)
- S13. AB (pre test or pretest or post test or posttest or preintervention or postintervention) or TI (pre test or pretest or post test or posttest or preintervention or postintervention)
- S14. s1 or s2 or s3 or s4 or s5 or s6 or s7 or s8 or s9 or s10 or s11 or s12 or s13
- S15. MH child+
- S16. AB child* or TI child*
- S17. MH pediatrics+ or MH pediatric nursing+ or MH perinatal nursing
- S18. ti (pediatric* or paediatric*) or ab (pediatric* or paediatric*)
- S19. ti (perinat* or neonat* or newborn* or infant* or baby or babies or toddler*) or ab (perinat* or neonat* or newborn* or infant* or baby or babies or toddler*)
- S20. ti (preterm or prematur*) or ab (preterm or prematur*)
- S21. ti (school age or schoolage) or ab (school age or schoolage)
- S22. s15 or s16 or s17 or s18 or s 19 or s20 or s21

- S23. MH hospitalization+ or MH hospitals+ or MH hospital units+
- S24. ti hospital* or ab hospital*
- S25. MH child, hospitalized or MH adolescent, hospitalized or MH infant, hospitalized
- S26. s22 and (s23 or s24)
- S27. s25 or s26
- S28. MH patient centred care or MH family centred care+
- S29. TI (family centred or family centred) or ab (family centred or family centred)
- S30. TI (patient centred or patient centred) or ab (patient centred or patient centred)
- S31. famil* N5 support
- S32. MH professional-family relations
- S33. MH family or MH family health or MH maternal behavior or MH paternal behavior or MH parents+ or MH parent-child relations+ or MH caregivers
- S34. (child N2 focus*) or (famil* N2 focus*)
- S35. MH family nursing or MH maternal-child nursing
- S36. MH nursing models, theoretical+
- S37. shar* N3 care
- S38. (car* N2 parent*) or (car* N2 mother*) or (car* N2 father*) or (car* N2 famil*)
- S39. s28 or s29 or s30 or s31 or s32 or s33 or s34 or s35 or s36 or s37 or s38
- S40. (famil* N4 presence) or (mother* N4 presence) or (father* N4 presence) or (parent* N4 presence) or (care* N4 presence)
- S41. (famil* N4 collaborat*) or (mother* N4 collaborat*) or (father* N4 collaborat*) or (parent* N4 collaborat*) or (care* N4 collaborat*)
- S42. (famil* N4 visit*) or (mother* N4 visit*) or (father* N4 visit*) or (parent* N4 visit*) or (care* N4 visit*)
- S43. (famil* N4 partner*) or (mother* N4 partner*) or (father* N4 partner*) or (parent* N4 partner*) or (care* N4 partner*)
- S44. (famil* N4 participat*) or (mother* N4 participat*) or (father* N4 participat*) or (parent* N4 participat*) or (care* N4 participat*)
- S45. (famil* N4 involve*) or (mother* N4 involve*) or (father* N4 involve*) or (parent* N4 involve*) or (care* N4 involve*)
- S46. (famil* N4 decision*) or (mother* N4 decision*) or (father* N4 decision*) or (parent* N4 decision*) or (care* N4 decision*)
- S47. (famil* N4 communicat*) or (mother* N4 communicat*) or (father* N4 communicat*) or (parent* N4 communicat*) or (care* N4 communicat*)
- S48. s40 or s41 or s42 or s43 or s44 or s45 or s46 or s47
- S49. s39 or s48
- S50. s27 and s49
- S51. s50 and s14
- S52. PY 200401-201112
- S53. S51 and S52

Appendix 7. Sociological Abstracts (CSA) search strategy

2004 - 5 January 2011 (53)

(KW=(random* or trial* or placebo* or assign* or allocat* or volunteer* or crossover or cross over or factorial* or singl* blind* or doubl* blind* or clinical stud* or longitudinal stud* or control* or compar* or intervention* or preintervention or postintervention or pre test or pretest or post test or posttest or experiment* or prospectiv* or chang* or evaluat* or impact* or effect*)) and (((DE=(children or preschool children or infants+ or pediatrics)) or (KW=(child* or p*diatric or perinat* or neonat* or newborn* or infant* or baby or babies or toddler* or preterm or prematur*)) or (KW=(schoolage or school age))) and ((DE=(hospitalization or hospitals) or (KW=hospital*))) and ((KW=(patient cent*ed) or KW=(family cent*ed)) or (DE=(family or parents+ or caregivers)) or (KW=(child or famil*) within 2 focus) or (KW=(child or famil*) within 2 focus*) or (KW=shar* within 3 care) or (KW=famil* within 5 support*) or (KW=((care or cared or caring) within 3 (parent* or mother* or father* or famil*))) or (KW=((parent* or mother* or father* or famil* or care*) within 4 (partner* or participat* or presence or involve* or decision or communicat* or negotiate* or collaborat* or visit*)))) Limited to 2004+

Appendix 8. Data Extraction Form

Adapted from the Cochrane Consumers and Communication Review Group Data Extraction Template, available at http://www.latrobe.edu.au/chcp/assets/downloads/DET_2009update.doc.

Form version: 1.4 11 NOV 2009

Review title: Family Centred Care for Hospitalised Children Aged 0-12 Years

Study ID (Author Surname Year):

Name of review author completing this form:

Date form completed:

Notes for Review Author

Please record the source of each piece of information, including the precise location within a document (e.g. Page, Paragraph, line); Please highlight any missing information as unclear or not described; It may be reasonable to make assumptions about how the study was conducted, but these assumptions must be reported by the review author for transparency

Methods

Aim of intervention (As stated in the trial report/s. What was the problem that this intervention was designed to address?)

Aim of study (As stated in the trial report/s. What was the trial designed to assess?)

Study design (Include number of arms involved)

Methods of recruitment of participants (How were potential participants approached and invited to participate?)

Inclusion/exclusion criteria for participation in study

Informed consent obtained? (Yes/No/Unclear)

Ethical approval (Yes/No/Unclear)

Funding (including source, amount, if stated).

Statistical methods and their appropriateness (if relevant)

Consumer involvement(e.g. In design of study and/or intervention; in delivery of intervention; in evaluation of intervention; in interpretation of study findings)

Risk of bias assessment:

Domain	Review Author's Judgment	Description (Quote or Comment)
Adequate sequence generation?	Yes/No/ Unclear*	
Allocation concealment?	Yes/No/ Unclear	
Blinding for each outcome?	Yes/No/ Unclear	
Incomplete outcome data addressed?	Yes/No/ Unclear	
Free of selective reporting?	Yes/No/ Unclear	
Free of other bias?	Yes/No/ Unclear	

***Note:** 'Yes' indicates a 'low risk of bias'; 'No' indicates a 'high risk of bias'; 'Unclear' indicates an 'uncertain risk of bias'.

Review author please refer to Table 8.5.d: Criteria for judging risk of bias in the 'Risk of bias' assessment tool in the Cochrane Handbook for Systematic Reviews of Interventions (Higgins 2009).

Participants

Description (e.g. children/patients; carers/parents of patients; health professionals)

Geographic location (e.g. City/State/Country)

Setting (e.g. acute care hospital)

Number

- (Eligible, excluded, refused to take part, randomised to intervention, randomised to control, excluded post randomisation, withdrawn, lost to follow up, died, included in analysis, included for each outcome)
- Note reasons for attrition, and if attrition is different in control or intervention group, as this may be an indication of the acceptability of the intervention to the participants (e.g. people voting with their feet)

Age range, mean (standard deviation)

Gender

Ethnicity

Principal health problem or diagnosis

Treatment received/receiving

Other social/demographic details

Interventions

Details of intervention, including theoretical basis (with key references) and content (Capture this information for each arm of the study, e.g.. Intervention A, Intervention B)

Details of control/usual or routine care

Details of co-interventions in all groups (co-interventions may be separate to the intervention of interest for this review, or they may be other similar elements in a suite of interventions having a common purpose. Record all relevant information).

Delivery of intervention (e.g.. stages, timing, frequency, duration) (for each intervention included in the study, e.g.. Intervention A; Intervention B)

Details of providers (Who delivers the intervention? number of providers; training of providers in delivery of intervention).

Intervention quality (Record any information on the quality of the intervention - assessed by study authors, others, or by you - such as the evidence base of the intervention, or the quality of staff training for intervention delivery)

Family Centeredness Score /52 (%) (See [Appendix 1](#))

Fidelity/integrity (Was the intervention delivered as intended? Record any assessment of this)

Outcomes

Principal and secondary outcome measures (as identified by the study authors)

Methods of assessing outcome measures (e.g., phone survey, questionnaire, physical measurements (for each outcome)

Potential sources of imprecision

- Where outcome measurement tools validated
- Are outcome measures reliable

Methods of follow-up for non-respondents

Timing of outcome assessment (Including frequency, length of follow up (for each outcome)

Adverse events(e.g. complaints, levels of dissatisfaction, adverse incidents, side effects)

Notes

- Contact with author (No /Yes (information obtained))
- Power calculation? (No / Yes)
- Record if the study was translated from a language other than English (No /Yes)
- Record if the study was a duplicate publication (No /Yes)
- Any changes in trial protocol? (No/Yes, record details)
- Record any limitations explicitly noted by the study authors

Results

Dichotomous Outcomes

OUTCOME (Specify timing of measurement e. g. Days/Months)		Intervention Group Total Randomised N=		Control Group Total Randomised N=		Other reported dichotomous statistical results		
		Outcome N	Assessed N	Outcome N	Assessed N	Effect measure (e. g. RR)	Variance (e. g. Confi- dence inter- vals)	Statis- tical signifi- cance (e.g. P value)
Time	Family							
	Stress							
	Anxiety							
	Depression							
	Other							
	Child							
	Stress							
	Anxiety							
	Length of hospital stay							
	Other							
	Healthcare providers							
	Stress							
	Anxiety							
	Work satis- faction							
	Other							
	Health Services							

(Continued)

	Rehospitalization								
	Other								

Continuous Outcomes

OUTCOMES		Intervention Group			Control Group			Other reported statistical results
		Mean	SD	N	Mean	SD	N	
Time (eg days/months)	Family							
	Stress							
	Anxiety							
	Depression							
	Other							
	Child							
	Stress							
	Anxiety							
	Length of hospital stay							
	Other							
	Healthcare providers							
	Stress							
	Anxiety							
	Work Satisfaction							
	Other							

(Continued)

Health Services						
Rehospitalization						
Other						

Appendix 9. Summary of 6 studies with family-centredness score assessments

Study ID	Review Author	Family Centredness Score				Mean Score
		Cluster 1	Cluster 2	Cluster 3	Total Score	
Bauchner 1996	#1	12	1	4	17	11.5
	#2	4	1	1	6	
Bolton 2004	#1	24	0	12	36	36
	#2	24	0	12	36	
Melnyk 2004	#1	16	0	11	27	16.5
	#2	3	0	3	6	
Landry 2007	#1	20	0	5	25	14.5
	#2	3	0	1	4	
Li 2007	#1	17	0	6	23	13
	#2	3	0	0	3	
Akinci 2008	#1	9	0	3	12	7.5
	#2	2	0	1	3	

WHAT'S NEW

Last assessed as up-to-date: 10 December 2011.

Date	Event	Description
19 October 2012	Amended	Reference added to 2012 review of quasi-randomised trials of family-centred care for children in hospital, conducted for Joanna Briggs Institute (Shields 2012).

HISTORY

Protocol first published: Issue 2, 2004

Review first published: Issue 1, 2007

Date	Event	Description
6 July 2012	New citation required and conclusions have changed	<p>The newly-included study provides limited evidence for the effects of a family-centred care model on some outcomes for children and parents, and on costs</p> <p>We changed the following criteria for the update of this review:</p> <ul style="list-style-type: none">• included RCTs only (previously RCTs, quasi-RCTs and CBAs);• lowered the threshold for inclusion in the FCC score from 80% in the original review to 50%;• excluded single interventions that did not reflect a FCC model of care;• excluded premature neonates from the eligible participants;• removed the selection criterion whereby studies with inadequate or unclear blinding of outcome assessment were excluded from the review; and• adopted the Cochrane Collaboration's Risk of Bias tool to assess included studies. <p>We have also changed terminology to describe the control comparison group: in the previous version of the review we described 'professionally-centred models of care' but as these are the same as standard models of care we have now adopted 'standard models' to describe the control group</p>
10 December 2011	New search has been performed	Updated searches run, 9271 new studies assessed for inclusion, one study included
9 December 2011	Amended	The title for this review has been changed to ensure that the age range of birth to 12 years is clearly identified

CONTRIBUTIONS OF AUTHORS

Linda Shields, Jan Pratt and Judith Hunter: conceived the review and were content experts, providing input into the development of the background and objectives of the review.

Huaqiong Zhou: undertook review and assessment of studies, and helped with writing of completed review

Marjory Taylor: devised search strategy, undertook searches and helped with writing completed review.

Linda Shields: helped with searches and review and assessment of studies and writing of completed review.

Elaine Pascoe: helped with the assessment of studies and data extraction and writing of completed review, and would have undertaken statistical analysis.

Jan Pratt: undertook review and assessment of studies, and assisted with writing.

Judith Hunter: undertook review and assessment of studies.

Linda Shields will be responsible for future updates.

DECLARATIONS OF INTEREST

LS, JP, HZ, and MT work for paediatric health facilities which have stated policies of family-centred care. LS is an author of potentially relevant studies and was not involved in the assessment of these studies for inclusion in the review.

DIFFERENCES BETWEEN PROTOCOL AND REVIEW

In the original protocol and review ([Shields 2007](#)), we included a range of study designs (RCTs, quasi-RCTs and CBAs). For this update, we included only RCTs in an attempt to improve the methodological rigour of studies eligible for inclusion in the review. However, as a way of potentially including studies on family-centred care, we decreased the threshold for inclusion in the family-centred care intervention score from the 80% of the original review to 50%.

We have also excluded single interventions that did not reflect a FCC model of care from the review, and excluded premature neonates from the eligible participant group. Finally, we have removed the selection criterion whereby studies with inadequate or unclear blinding of outcome assessment were excluded from the review. We have also adopted the Cochrane Collaboration's Risk of Bias tool to assess included studies.

Another important difference between the original protocol and review and this update relates to screening of studies and interventions. Initial assessment in the original protocol and review was, at times, confusing, as we had to have many deliberations over whether or not to move studies of varying interventions forward for scoring of the family-centredness of interventions and quality assessment. In this update, we corrected this to ensure that only studies of a family-centred model of care, as opposed to studies of a single intervention, for example, venipuncture or parental present anaesthesia induction, became potential inclusions. This ensured a greater degree of precision within the methods of the update.

We have also changed terminology to describe the control comparison group: in the previous version of the review we described 'professionally-centred models of care' but as these are the same as standard models of care we have now adopted 'standard models' to describe the control group.

In the original review, our population of interest included premature neonates. This update has removed these from the eligible participant group because premature neonates' requirements for family-centred care, and the ethics and philosophies of care around this particular group, are different to those in a ward/unit where full term infants and children are nursed.

In the original review we excluded studies based on blinding of outcome assessment. This update has removed this exclusion criterion.

INDEX TERMS

Medical Subject Headings (MeSH)

*Child, Hospitalized; *Family; Comprehensive Health Care [*methods]; Family Health; Infant, Newborn; Patient-Centered Care [methods]; Randomized Controlled Trials as Topic

MeSH check words

Child; Child, Preschool; Humans; Infant