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# Models of Care Delivery for Families of Critically Ill Children: An Integrative Review of International Literature

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**Problem:** Critical illness in children is a life changing event for the child, their parents, caregivers and wider family. There is a need to design and evaluate models of care that aim to implement family-centred care to support more positive outcomes for critically ill children and their families. Due to a gap in knowledge on the impact of such models, the present review was conducted.
**Eligibility criteria:** Primary research articles written in English that focused on children hospitalised for an acute, unexpected, sudden critical illness, such as that requiring an intensive care admission; and addressed the implementation of a model of care in a paediatric acute care hospital setting.
**Sample:** Thirteen studies met the inclusion criteria.
**Results:** The models of care implemented were associated with positive changes such as reduced parental anxiety and improved communication between parents/caregivers and health professionals. However, no model provided intervention throughout each phase of care to (or post) hospital discharge.
**Conclusions:** Models of care applying family-centred care principles targeting critically ill children and their families can create positive changes in care delivery for the family. However a model which provides continuity across the span of care is required.
**Implications:** There is need to describe how best to design, implement and sustain models of care for critically ill children and their families. The success of any intervention implementation will be dependent on the comprehensiveness of the strategy for implementation, the relevance to the context and setting, and engagement with key stakeholders.

## Background

Critical illness in children is a life changing event for the child, their parents, caregivers and wider family. Medical advances, such as the increasing availability and capacity of mechanical and artificial organ support systems, have resulted in increasing numbers of paediatric intensive care unit admissions and children surviving critical illnesses such as serious physical injury, cardiorespiratory disease and sepsis (Australian Institute of Health and Welfare, 2009; Warwick, 2012).

Whilst survival following paediatric critical illness has improved, it remains a significant life event that can cause residual physical and psychosocial morbidity for the child, but also the family (Cutler, Hayter, & Ryan, 2013; Rennick et al., 2014; Shudy et al., 2006). For example, on the day a

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child sustains a serious illness or injury, parents/caregivers are thrust into a new and threatening world (Shudy et al., 2006). Parents play a key role in their child's recovery, and parental ability to cope with the stress associated with injury affects the quality of life of all family members (Taylor et al., 2001). When a child is critically ill, there is an instant role change for the parent, from being the person responsible for the safety and care of their child, to being completely reliant on the medical team to save their child's life (Davidson et al., 2007). This role change is coupled with countless other stressors, including witnessing the pain, fear and often shocking physical changes in their child, seeing other injured children on the ward, being under constant pressure to make difficult decisions, being exposed to bright lights and machine alarms throughout the day and night and interacting with the numerous specialty clinicians involved in providing care (Balluffi et al., 2004; Board & Ryan-Wenger, 2003; Davidson et al., 2007). More than 60% of parents of children hospitalised after a serious injury are likely to meet the psychological criteria for acute stress disorder (Daviss et al., 2000).

After the initial crisis passes, parents must come to terms with the longer term implications of their child's illness and their care needs. During this time, parents experience emotions ranging from sadness and loneliness to feelings of shock, grief, guilt and helplessness (Carnevale, 1999; Leidy et al., 2005; Noyes, 1999). Caregivers without the skills or support to manage these emotions are at clear risk for psychological distress (Ostrowski et al., 2011). Around 10–30% of parents/caregivers of seriously injured children develop post-traumatic stress disorder (PTSD) after their child's injury (Daviss et al., 2000; Ostrowski et al., 2011; Rees, Gledhill, Garralda, & Nadel, 2004), and around 20–40% of parents are at risk for developing depression or anxiety (Wade et al., 2006). Further, serious injury in a child can have a negative impact on family dynamics (Montgomery, Oliver, Reisner, & Fallat, 2002) and can threaten the cohesiveness of the immediate family unit (Youngblut & Lauzon, 1995; Youngblut & Shiao, 1993).

A systematic review by Shudy et al. (2006) found that critical illness and injury are stressful for the entire family including parents/caregivers and siblings. Paediatric critical injury can have a negative impact on family dynamics, relationships, finances, and employment (Montgomery et al., 2002) with the impact on finances and family function greatest one month post injury (Winthrop et al., 2005). One study reported that some families experienced new health problems post discharge (Tomlinson, Harbaugh, Kotchevar, & Swanson, 1995) whilst another study reported that a decline in the family's health could last up to 60 days post discharge (Leidy et al., 2005). Siblings were often affected as parents devoted their time to the injured child putting all else aside (Carnevale, 1999). Siblings often felt neglect and rivalry (Sparacino et al., 1997), isolated, unimportant and resentful (Carnevale, 1999), with some suffering behavioural, school and peer difficulties, and exhibiting increased fears and withdrawal from their injured sibling (Montgomery et al., 2002).

During their child's hospitalisation, one study reported that more than 80% of mothers of children being cared for in one paediatric intensive care facility experienced low energy levels, poor appetite and trouble falling asleep (Board & Ryan-Wenger, 2003). In the early weeks after their child was discharged, mothers were still experiencing problems, with more than 80% reporting headaches experiencing significant fatigue, feeling easily irritated or annoyed, worrying too much and having regular headaches (Board & Ryan-Wenger, 2003). Six months after their child's discharge, 77% of mothers still felt fatigued (Board & Ryan-Wenger, 2003). A Swiss study of 287 critically ill children and their parents found that mothers were more vulnerable to PTSD symptoms and both children and parents were more likely to develop PTSD symptoms following injury than a new diagnosis of diabetes mellitus type 1 or cancer in the child. This study, along with the literature exploring the experiences of parents and families of critically ill children, recommended a family systems approach and early interventions in the treatment of paediatric patients (Landolt, Ystrom, Sennhauser, Gnehm, & Vollrath, 2012; Manning, Hemingway, & Redsell, 2014).

A key element of care delivery models, such as family-centred care (FCC), in paediatric settings is recognition of the importance of parent/caregiver participation. Family-centred care is a philosophy of health care that places the family rather than the hospital and medical staff at the centre of the health care delivery system (Hostler, 1991). Since the 1970s there has been increased parent participation in the care of their hospitalised child, and acknowledgement by health professionals of the key role parents play in providing support and continuing care. Although parental participation in care delivery is well recognised as a means of parental engagement, there remain problems with the current approaches to care delivery for critically ill children and their families. The lack of understanding of the family's needs when their child is hospitalised (Gill et al., 2014), the nature of the hospital admission, for example, non-accidental injury, and a high work nursing load can be barriers for nurses to commit to FCC (Keatinge & Gilmore, 1996; McCann et al., 2008). It is also true that models of care implemented in one hospital setting may not be automatically transferable to another hospital due to contextual differences in setting, processes and management. The present review was conducted to examine paediatric models of care delivery that have been applied and evaluated for critically ill children and their families.

## Aim

The aim of this paper is to examine the impact of models of care that have been implemented for families of critically ill children, to extend understandings of, and inform future care delivery for, this group. Specifically, the review sought to describe:

1. The models of care for families of critically ill children have been evaluated

2. The outcomes of models of care that have been implemented for families of critically ill children.

## Methods

An integrative review method was conducted. This method is inclusive of a broad range of literature, including empirical and non-empirical work. The integrative review method employs a systematic approach to searching for, reviewing, extracting and analysing literature, using the stages of problem identification, literature searching, and data evaluation, analysis, and presentation (Whittemore & Knafl, 2005). For the purpose of review, a model of care includes a framework for practice for patient care delivery through the application of a set of service principles across identified clinical streams such as paediatric illness and patient flow continuums (Wilson, Huntington, & Commission, 2009).

A search of the literature using electronic databases and key word search terms and combinations was used to locate articles relating to models of care delivery for critically ill children and their families. The search terms focused on treatment setting, care provider and models of care. Search terms such as ‘pediatric’, ‘hospital’, ‘parent’, ‘family’, ‘family-centered care’, ‘care coordination’, ‘case management’ and ‘partnership’ were used. The CINAHL, MEDLINE and PsycInfo electronic databases were systematically searched for abstracts for all available years until June 2015 (CINAHL from 1982, MEDLINE from 1946, PsychInfo from 1860). A hand search of the full text articles obtained was also conducted. Inclusion criteria included primary research articles (defined as articles that report on a new set of findings from original research), written in English. Articles were included if they focused on children hospitalised for an acute, unexpected, sudden critical illness, such as that requiring an intensive care admission; and addressed the implementation of a model of care in a paediatric acute care hospital setting. The model of care needed to be an intervention focused on improving the care for families of children who were critically ill, such as FCC, shared care, or partnered care. Although the majority of studies represent the ‘family’ as consisting of parents and the ill child, some studies also included non-parent caregivers and other family members. In recognition that family structures are increasingly heterogeneous (Shudy et al., 2006), we did not exclude any particular ‘type’ of family. Articles were excluded if they included the following cohorts: adult hospitalisations, mental illnesses, home care not associated with children, newborn or preterm babies, obstetrics, parental roles or training, family community support, day surgery, neonates, death of child, chronic illnesses, developmental disability, and disabilities from birth.

A two-step screening process was used to obtain the articles for review. The initial search generated 3296 records (see Figure 1). Preliminary screening of titles and abstracts against the inclusion/exclusion criteria were performed by two authors (KC and KF), resulting in 334 abstracts (including duplicates removed). Full texts of retained records were read, reference lists hand searched and secondary screening conducted. Thirteen papers were included for review. The constant comparison method was used to systematically extract and analyse data (Patton, 2015). Data relevant to the research question were extracted from each study and entered into a matrix. Data were then compared and contrasted within and across studies in an iterative process until consensus between the authors on final categories was reached. In the final step, results from the analysis were then synthesised into an integrated summary (Whittemore & Knafl, 2005).

## Results

The review included thirteen published studies evaluating models of care delivery from 1988 to 2015 in Australia, Ireland, Thailand and the United States. They comprised randomised controlled trial (n = 2), quasi-experimental (n = 3), prospective cohort (n = 1), pre/post evaluation (n = 1), cross-sectional survey (n = 1), mixed method (n = 1), ethnographic (n = 1) and qualitative (n = 3) design studies. Two studies included non-English speaking parents (Seltz et al., 2011; Walker-Vischer, Hill, & Mendez, 2015). The contexts of care included a: tertiary medical centre (n = 1), acute care referral centre (n = 1), regional general hospital (n = 1), trauma centre (n = 1), teaching hospital (n = 2), paediatric hospital (n = 6) and other general hospitals (n =1). The impact of the models of care was evaluated on different stakeholders; mothers (2/13), parents (7/13), families (3/13), and nurses (3/13). Sample size varied from 18 to 144. Most studies that implemented a model of care included some form of education or training for the nurses before or during the course of implementation.

### Models and Approaches of Care and Outcomes for Families of Critically ill Children

The models of care included in this review were based on various theories and approaches including: Lazarus Stress & Coping, Nursing Mutual Participation Model of Care (NMPMC), Partnership Model of Care, FCC, Shared Care, Family-Centered Rounds (FCR), Negotiated Care Tool, Creating Opportunities for Parent Empowerment (COPE), and Patient and Family-Centered Care (PFCC). Each model was implemented for a specific phase of care in hospitalisation, especially transitioning from the PICU to the ward. No model of care was identified that provided intervention throughout each phase of care to (or post) hospital discharge. Table 1 provides an overview of the range of methods for models of care implementation, for example providing written information on what to parents should expect post PICU discharge. Each model involved parents/family members in different ways (Table 2) and all models had the same intent — to improve paediatric patient care delivery. The majority of studies focused on parents.

The models of care evaluated all had a positive impact on enhancing families’ and parents’ experience in a paediatric setting. Depending on the focus of the model of care, the

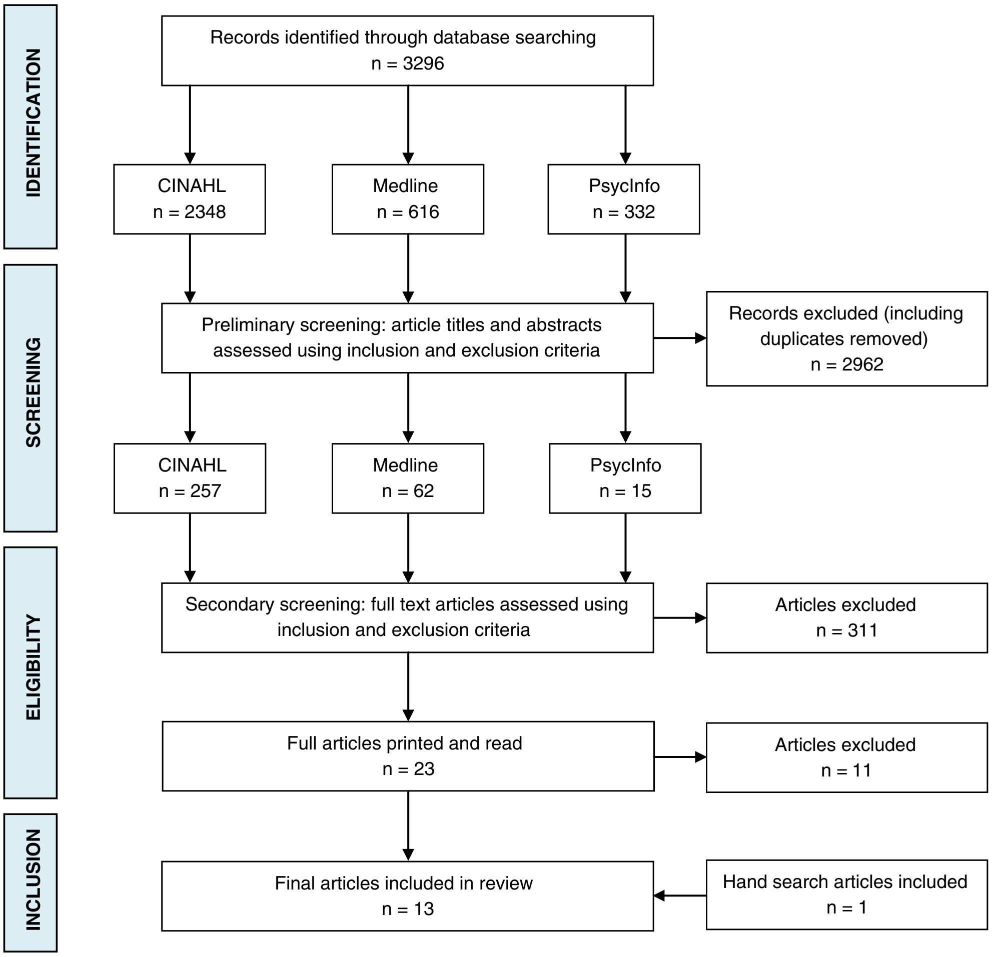

**Figure 1** Search and screening.

most common outcomes were associated with reduction in anxiety levels for parents (Bouve, Rozmus, & Giordano, 1999; Keatinge & Gilmore, 1996; Melnyk, Crean, Feinstein, Fairbanks, & Alpert-Gillis, 2007), and improved open communication between parents and healthcare professionals (Keatinge & Gilmore, 1996; Kuo et al., 2012; Landolt et al., 2012; Melnyk et al., 2007; Subramony, Hametz, & Balmer, 2014; Uhl, Fisher, Docherty, & Brandon, 2013; Walker-Vischer et al., 2015). The studies reported few negative outcomes associated with the implementation of a model of care from the parent's perspective. Some parents felt there were occasions where they did not need to be included in the discussion (Seltz et al., 2011; Uhl et al., 2013) and others reported feeling confused by medical jargon (Seltz et al., 2011; Subramony et al., 2014) which limited their understanding of their child's condition. Further, some healthcare professionals found shared care to be a problem, as although some parents agreed to share patient care activities, parents were not capable of performing some of these activities (Keatinge & Gilmore, 1996).

## Reduced Parental Anxiety

Four studies assessed parents' trait and state anxiety associated with model of care using the state-trait anxiety inventory scale (Bouve et al., 1999; Curley & Wallace, 1992; Keatinge & Gilmore, 1996; Melnyk et al., 2007). Trait anxiety reflects stress and feelings of worry that individuals can experience in the general day-to-day whilst state anxiety reflects feelings of nervousness, fear and discomfort that an individual can experience in response to perceived dangerous situations. High trait anxiety was associated with negative parental beliefs and negative moods during hospitalisation. Melnyk et al. (2007), found the Creating Opportunities for Parent Empowerment (COPE) program, which is a parent-focused educational behavioural intervention, supported mothers and prepared them for their time during their hospital stay and resulted in lower trait anxiety, a decrease in negative moods and an increase in confidence in parenting. Similarly Bouve et al. (1999), Curley and Wallace (1992) and Keatinge and Gilmore (1996) demonstrated that their parental education, shared care and mutual participation interventions were associated with reduction in parent and family anxiety levels. Parents who were exposed to these models showed a significantly lower trait and state anxiety than parents who had usual care during their child's hospitalisation stay. This reduction in anxiety was attributed to increased parental confidence, engagement and awareness in the care plans for their child (Bouve et al., 1999; Curley & Wallace, 1992; Keatinge & Gilmore, 1996).

**Table 1** Overview of studies evaluating models of care for critically ill children and their families.

| Author, year, country | Study design | Participants, sample size | Study aim | Model | Overview of model | Outcome |
|---|---|---|---|---|---|---|
| Bouve et al., 1999, United States | Randomised control trial | Parents. n = 31 in experimental group and n = 19 in control group | Examine a nursing intervention intended to diminish the anxiety level of parents of children being transferred from a Paediatric Intensive Care Unit (PICU) to a ward | Lazarus Stress & Coping | Information sheet and verbal explanation provided to parents to reduce anxiety when child transferred from PICU to ward | Effective transfer preparation significantly reduces anxiety experienced by parents facing the imminent transfer of their child out of PICU |
| Curley, 1988, United States | Quasi-experimental | Parents. n = 16 in experimental group and n = 17 in control group | Determine effects of care model on perceived environmental stress of parent | Nursing mutual participation model of care (NMPMC) | Nurse negotiation with parent to foster active parental involvement in the care of their ill child | The NMPMC is helpful in alleviating parental stress, specifically the stress related to interruption in the parent-child relationship |
| Hughes, 2007, Ireland | Cross-sectional survey | Parents and nurses. n = 100 parents and n = 44 nurses | Examine the attitudes of parents and nurses to the model of care delivery on an in-patient children's unit | Partnership model of care/ family-centred care (FCC) | Involving parents as partners in care via an open-visiting policy allowing parents to stay with their child on the unit overnight | Both parents and nurses viewed FCC as appropriate, however there were differences between what parents and nurses saw as their roles |
| Keatinge & Gilmore, 1996, Australia | Pre/post evaluation | Parents and nurses. n = 39 parents and n = 20 nurses | Evaluate the implementation of shared care in a paediatric unit | Shared Care | Increased engagement with parents and shared bedside documentation for planning, negotiation, sharing of responsibilities and education of child's illness | Implementation of shared care was associated with a reduction in the anxiety levels of most parents who participated in shared care |
| Kuntaros et al., 2007, Thailand | Quasi-experimental | Mothers. n = 16 in experimental group and n = 17 in control group | Examine the effects of FCC on mothers' self-efficacy in participatory involvement in child care and satisfaction with nursing care | FCC (using NMPMC) | NMPMC implemented (e.g. information regarding treatment provided, parent's expectations assessed, discussion of child's care with clinicians encouraged) to foster parent participation in child's care | Mothers' self-efficacy in participatory involvement in child care and satisfaction with nursing care in the experimental group were significantly higher than that in the control group |
| Kuo et al., 2012, | Prospective cohort | Families. n = 70 families in | Compare families of children | FCR | Family participation in | FCR are associated with |

**Table 1** (*continued*)

| Author, year, country | Study design | Participants, sample size | Study aim | Model | Overview of model | Outcome |
|---|---|---|---|---|---|---|
| United States | | the family-centred rounds (FCR) team, n = 69 families in the non-FCR teams | admitted to a general paediatric unit-based ward team with FCR versus 2 teams without formal FCR training | | ward rounds allowing family members to participate in discussions with the team and ask questions about the child's care plan | higher parent satisfaction, consistent medical information, and care plan discussion, with no additional burden to health service use |
| Latta et al., 2008, United States | Qualitative | Parents.<br>n = 18 | Identify how parents responded to participation in interdisciplinary teaching rounds | FCR | Families included in ward rounds. Nurses prepared parents by: providing information regarding the purpose/structure of the rounds, content for discussion, roles of team members, questions parents may want to ask | Parents' experience of being included on ward rounds was positive. Being able to communicate, understand the plan, and participate in decision making about their child's care were important to parents |
| McCann et al., 2008, Australia | Quasi-experimental pre/post-evaluation | Nurses.<br>n = 69 | Evaluate the effectiveness of a documentary tool designed to formalise role negotiation and improve communication between parents and nurses | Negotiated Care Tool | Nurses negotiated and recorded care plan with parents. Parents given the opportunity to negotiate full or partial responsibility for undertaking care of their child or allow the nurse to assume full responsibility | The Negotiated Care Tool raised staff awareness of the importance of effective communication and negotiation of care with parents in busy clinical practice areas |
| Melynk et al., 2007, United States | Randomised control trial | Mothers.<br>n = 78 in experimental group and n = 65 in control group | Test a theoretical model examining processes through which a parent-focused educational behavioural intervention (Creating Opportunities for Parent Empowerment (COPE)) relates to children's post-hospital adjustment problems | COPE | Audiotaped and matched written information provided to parents post discharge followed by a telephone call to increase parents' knowledge and participation in child's emotional and physical care post discharge | COPE participation was associated with more maternal support for the child, which was associated with less internalising and externalising behaviours 3 months post discharge |
| Seltz et al., 2011, | Qualitative | Families<br>n = 28 | To characterise Latino families' | FCR | Resident physician invites | Spanish-speaking Latino families are |

(*continued on next page*)

**Table 1** (*continued*)

| Author, year, country | Study design | Participants, sample size | Study aim | Model | Overview of model | Outcome |
|---|---|---|---|---|---|---|
| United States | | | experiences with family-centred rounds at an academic children's hospital to identify areas for improvement | | families to participate in rounds; parents are asked whether they prefer the discussion take place at the bedside or outside the patient's room. For Spanish-speaking families, a bilingual provider, if present, would update the family at the conclusion of rounds for the patient. | not consistently receiving optimal family-centred rounds. Different strategies are needed to fully engage and empower Latino families. |
| Subramony et al., 2014, United States | Qualitative ethnographic | Families. n = 140 patients, their families and medical team were observed, n = 6 family members were interviewed | Understand the alignment between the principles of FCC and FCR in practice | FCR | Medical teams: 1) give families a choice to participate in rounds; 2) introduce themselves to family members; 3) form a circle inclusive of the patient and family; 4) verbally invite families to participate in discussion; 5) avoid the use of medical jargon | FCR practices may set the stage for FCC but they do not necessarily ensure that the principles of FCC are upheld. Contextual factors may mediate how FCC principles are translated in practice |
| Uhl et al., 2013, United States | Mixed-method descriptive | Parents. n = 9 completed focus group, n = 134 completed surveys | Describe parents' care experiences during hospitalisation of their children to identify strategies that could improve the provision of patient and family-centred care (PFCC) | PFCC | Twenty-four hour parental presence and participation during daily medical rounds, changes in the length of physician clinical rotations and assignment of an attending physician of record | PFCC provides the opportunity to ameliorate parental stress however there were both positive and negative experiences in relation to the PFCC concepts of dignity and respect, information sharing, participation in care and collaboration |
| Walker-Vischer et al., 2015, United States | Qualitative | Parents. n = 20 | Describe the experiences of Latino parents of hospitalised | FCR | Families included in ward rounds to promote the exchange of | FCR helped parents understand the plan and facilitated |

**Table 1** (*continued*)

| Author, year, country | Study design | Participants, sample size | Study aim | Model | Overview of model | Outcome |
|---|---|---|---|---|---|---|
| | | | children during FCR | | information between parents, the child, and the healthcare team to create and support a partnership | communication when done in Spanish. Parents felt their participation and input were valued and that these positively impacted care. |

### Improved Communication Between Parents and Health Professionals

Parents experienced an increase in open communication with health professionals during the implementation of shared care (Keatinge & Gilmore, 1996; Walker-Vischer et al., 2015) and mutual participation (Kuo et al., 2012; Latta, Dick, Parry, & Tamura, 2008; McCann et al., 2008) models of care delivery. The models of care, in particular those with shared care and mutual participation frameworks, challenged nurses to encourage parents to ask questions and to allocate time to respond to questions. Parents still, however, experienced difficulty in understanding complex medical terminology when they were included in ward rounds (Latta et al., 2008; Uhl et al., 2013). In particular, parents preferred any questions they had of health professionals to be answered in lay terminology, where possible. Kuo et al. (2012) who compared parents involved in FCC rounds to parents who received usual care, found that parents felt by being involved in FCC rounds they had a better understanding of the medical team's perspective of their child's condition. In addition, parents felt that their expectations were met when the rounds team engaged them in decision making and this also reduced misunderstanding between healthcare professionals and parents, although parents did feel uncomfortable if there was conflict between rounding medical staff (Uhl et al., 2013) or information was given in front of other family members or the child (Seltz et al., 2011). Parents who were included in ward rounds felt more comfortable when asked their opinion, permission or in asking questions of health professionals than parents not included in ward rounds. Parents who were included on FCC rounds felt listened to, respected, and treated as an important member of the care team. This ultimately resulted in improved communication between the parent and health professionals (Kuo et al., 2012; Subramony et al., 2014; Uhl et al., 2013), particularly when FCC rounds were conducted in the parent's primary language if they had limited English proficiency (Seltz et al., 2011; Walker-Vischer et al., 2015).

### Challenges for Implementation

Although the implementation of the different models of care delivery reviewed was associated with positive experiences for families and parents, only three studies (Keatinge & Gilmore, 1996; Kuo et al., 2012; McCann et al., 2008) reported in detail the local implementation of the change in practice. Although referring to implementation considerations, no studies described or evaluated the wider implementation considerations such as gaining organisational support, economic impact or wider workforce administrative implications. Three studies however examined the effects of the model on the nursing staff (Hughes, 2007; Keatinge & Gilmore, 1996; McCann et al., 2008). Nurses felt the models of care that involved shared care between parents, increased their workload and took them away from their other clinical duties that are deemed equally if not more important (Keatinge & Gilmore, 1996; McCann et al., 2008). Nurses also reported assessing parental capabilities and dealing with parents' inability to carry out tasks to be challenging (Keatinge & Gilmore, 1996). Two studies demonstrated the need for increased training in communication skills for nurses when implementing shared or FCC models. Keatinge and Gilmore (1996) found that there was a lack of confidence from nurses in communicating with parents, and Hughes (2007) demonstrated that nurses believed they were better at teaching parents new skills than the parents perceived the nurses teaching skills. However, none of the models of care reviewed addressed the child's recovery journey and phases of care from hospital admission through to post-discharge.

## Discussion

Family-centred care models typically try to ensure that care delivery is planned around the whole family, not only the injured child, and that all family members are recognised as care recipients (Jolley & Shields, 2009). Optimally, FCC of severely injured children should include: 'parental participation' which involves parent/carer involvement in care delivery, 'care-by-parent' where the parent/carer is onsite, and 'partnerships-in-care' where parents/carers work together with healthcare providers in providing care (Jolley & Shields, 2009). The current review identified a relatively small number of studies with small sample sizes that had evaluated different models of care for critically injured children published in the peer-reviewed literature. One of the

**Table 2** Parent/family member involvement in studies evaluating models of care for critically ill children and their families.

| Author (year) | Parent/family member provided with written information | Parent/family member provided with verbal information | Parent/family member involved in shared care | Parent/family member participation in ward rounds | Parent/family member staying overnight with child |
|---|---|---|---|---|---|
| Bouve et al. (1999) | ✓ | ✓ | | | |
| Curley, 1988 | | | ✓ | | |
| Hughes, 2007 | | | ✓ | | ✓ |
| Keatinge & Gilmore, 1996 | ✓ | ✓ | ✓ | | |
| Kuntaros et al., 2007 | | ✓ | ✓ | | |
| Kuo et al. (2012) | | ✓ | | ✓ | |
| Latta et al. (2008) | | ✓ | | ✓ | |
| McCann et al. (2008) | | ✓ | ✓ | | |
| Melynk et al. (2007) | ✓ | ✓ | ✓ | | |
| Seltz et al. (2011) | | ✓ | | ✓ | |
| Subramony et al. (2014) | | ✓ | | ✓ | |
| Uhl et al. (2013) | | ✓ | | ✓ | |
| Walker-Vischer et al. (2015) | | ✓ | | ✓ | |

✓ = yes.

study designs may have encouraged subjects to alter their behaviour due to the knowledge of being observed (also known as the Hawthorne effect) (Curley, 1988). Other limitations included the exclusion of non-English speakers in all but two studies, which may have resulted in the exclusion of caregivers that needed the most support/assistance. Future research in the use of the FCC should include this group of parents.

Each model of care only involved one or two aspects of FCC, which ranged from involving the parent in care decision making for their child (four studies), including the parent in ward rounds (six studies), letting a parent undertake some of the care for their child (one study), providing parents with an information sheet and verbal information when their child was transferred from PICU to a paediatric ward (one study), and providing mothers with written information on discharge of their child relating to their physical and emotional care, including a 3-month follow-up (one study). No studies described a holistic FCC model, that is, a model that considered the whole critical illness trajectory for the child and their family.

This review, however, did identify that models of care applying only one or two aspects of approaches such as FCC, shared care, partnered care and increased caregiver involvement in care provision of critically ill children were associated with reduced parental anxiety, increased parental

**Table 3** Principles for implementing a care delivery model.

| Principle[a] | Description |
|---|---|
| Consider the setting | Consider the hospital context/setting and engage the health care professionals who are at the front line of care for critically ill children and their families |
| Illustrate the reason for implementation | Illustrate through quantitative or qualitative data the reason the hospital is implementing the model. Clinicians are more engaged in changes to practice when they understand the evidence base of the practice |
| Invest in tools and skills | Education in the implementation of the model of care is not enough, hospitals need to invest in the tools and skills needed to create a culture that embraces the model of care, where questions are encouraged and systems are put in place to make it easy to follow the model of care |
| Engage stakeholders | Identify clinician champions who can lead by example and engage stakeholders (other clinicians as well as families). Stakeholder acceptance of the model is critical to its success |
| Pilot the model | Piloting the model is essential to determine the best fit for the hospital context and the setting of care delivery. There is no uniform way to implement a care delivery model and the hospital may need to modify to fit the hospital's culture and context |
| Evaluate outcomes and processes | Evaluate the outcomes and processes of implementation. Stakeholders need to know that the efforts to improve care delivery have a positive impact on quality of care through provision of feedback on performance |
| Ensure sustainability | Once in place, ongoing monitoring will ensure the model is embedded in routine practice and working in the way it was planned. It will also provide information needed to adapt and change the model to optimise effectiveness if required |

[a] Adapted from Agency for Clinical Innovation (2015) and Titler (2008).

satisfaction in care provided and improved communication between parents and health care providers. However the design of these different models of care was restricted to specific locations or phases of care which precluded continuity of care, and the implementation of interventions was not clearly considered or described.

## Continuity of Care

This synthesis of the evaluations of paediatric models of care demonstrates the positive outcomes for parents of critically ill children at specific phases of care, such as in the PICU or following the transfer of their child from the PICU to the ward. However, children who have suffered critical illness are often transferred several times during their hospitalisation. The transfer of a patient to a different care setting should be accompanied by prompt, relevant and accurate communication about the episode, including details of active clinical problems and plans for ongoing management (Cummings et al., 2010). Care coordination helps ensure that the patient's needs and preferences are met over time with respect to health services and information sharing across people, functions, and sites (Finnie et al., 2012), and it is possible that a nurse or social work case manager role could facilitate this coordination (Curtis, Zou, Morris, & Black, 2006). Such a role for children who have suffered critical illness and their families would meet the need for increased communication and understanding of participation in care provision across the trajectory of care, and establish a strong partnership between the nurse and parents initiating at their child's admission and ideally continuing to post-discharge follow-up (Avis & Reardon, 2008; Coyne & Cowley, 2007; Galvin et al., 2000; Sousa, Antunes, Carvalho, & Casey, 2013).

Strategies that encourage and collaborate with parents across the phases of care transition are required as miscommunication can lead to risk of prolonged stay, lack of continuity of care, suboptimal patient flow, readmissions, patient dissatisfaction and increased parental stress and anxiety (Häggström & Bäckström, 2014). This is significant as parental anxiety can directly impact on the anxiety of the injured child (Landolt et al., 2012). These concepts are also important once the child has been discharged from hospital (Toscan, Manderson, Santi, & Stolee, 2013). The paediatric literature in the area of discharge planning and transitioning care for children following acute critical illness is scarce, however research involving adults has shown that after discharge the responsibility for an adult's care is often returned to their regular community doctor, where transfer of health information can be poor and this has been associated with hospital readmission rates and morbidity (McAlister et al., 2013; van Walraven, Mamdani, Fang, & Austin, 2004). Further, a discharge summary that contains a clear care plan for a child after critical illness is often lacking, which can affect the quality of follow-up care and, ultimately, can impact family stress (Kripalani et al., 2007).

### Implementation of Models of Care

Both health professionals and families of critically ill children acknowledge the challenge to develop the delivery of care that supports the family and child's needs and that treating clinicians need to comprehend and support the complex physical and psychosocial trajectory of survival (Landolt et al., 2012; Manning et al., 2014; Shields et al., 2012). Principles of the FCC model are used widely in paediatric settings and are thought to be the most effective way to deliver care for children however as this integrative review and a Cochrane review (Shields et al., 2012) has demonstrated, there is limited evaluation evidence of the impact of the model on parent and child outcomes when children are critically ill. Key principles of FCC include recognition that all family members are affected when a child is critically ill, and that in providing care, health professionals need to consider the effect of the child's illness and hospitalisation on the family (Shields, Mamun, Pereira, O'Nions, & Chaney, 2011). There is a need to implement and rigorously evaluate models of care delivery to support more positive outcomes for the critically ill child and their family (Gill et al., 2014), including reducing parents' anxiety and stress when their child is critically ill (Siffleet, Munns, & Shields, 2010), improving communication between parents and health professionals, facilitating a smoother transition from hospital to home for families (Armstrong & Kerns, 2002; Wade et al., 2006), empowering families so that they are able to make family health care decisions (Melnyk et al., 2004) and communicating with parents the influence they have in shaping and supporting their child's psychological and social well-being (Manning et al., 2014; Shields et al., 2011).

The opinions of clinicians around FCC and shared care models evaluated in this review were mixed. Implementation of new models of care can be especially challenging in the context of competing priorities and wider hospital environments, including lack of time, lack of resources, poor access to guidelines, complex guidelines, capacity for interdisciplinary teamwork, a lack of continuing education, limited finance for interpreter services (Seltz et al., 2011) and an unsupportive organisational culture (Haynes & Haines, 1998; Subramony et al., 2014; Wallis, 2012). Subramony et al. (2014) concluded that whilst FCC based clinical rounds are a starting point for collaboration around plan making, they do not guarantee that collaboration between clinicians and families always occurs. To maximise sustainable success, the implementation of any model of care or intervention should consider the principles outlined in Table 3 and develop strategies to address potential barriers to implementation. Care models should also be designed to change clinical practice behaviour and improve the uptake of evidence into practice (French et al., 2012). Strategies should include a validated method for theoretically assessing implementation problems as well as enablers, such as the theoretical domains framework, which considers professional and other health-related behaviours as a basis for intervention development (Cane, O'Connor, & Michie, 2012).

## Conclusion

Models of care applying FCC principles targeting critically ill children and their families can create positive changes in care delivery for the family. However a model which provides continuity across the span of care is required, and there is need to describe how best to design, implement and sustain such models. The success of any intervention implementation will be dependent on the comprehensiveness of the strategy for implementation, the relevance to the context and setting, and engagement with key stakeholders.

## Competing Interests

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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