Journal of Pediatric Nursing (2015) **xx**, xxx–xxx

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

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Received 1 May 2015; revised 6 November 2015; accepted 7 November 2015

Key words:
Pediatric;
Interventions;
Models;
Family-centred care;
Families;
Parents

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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http://dx.doi.org/10.1016/j.pedn.2015.11.009
0882-5963/

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