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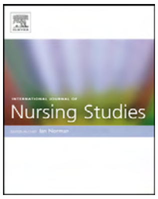

Review

Parents' and health professionals' perceptions of family centred care for children in hospital, in developed and developing countries: A review of the literature

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ABSTRACT

Background: In paediatrics family centred care (FCC) is a widely used model of care that is believed to help meet the emotional, psychological and developmental needs of the hospitalized child. However, perceptions of the effectiveness of the operationalization of FCC in terms of meeting family needs are varied.

Objectives: The aim of this review was to explore the attitudes towards and experiences of FCC by healthcare professionals and parents during the hospitalization of a child.

Design: A comprehensive search of the literature was undertaken drawing principally on key electronic databases of the health literature, augmented with reference list searching.

Data sources: : English language publications indexed in CINAHL, EMBASE, The Cochrane Database of Systematic Reviews, AMED, MEDLINE and PsycINFO published from 1997 to 2009.

Review methods: : Two review authors independently undertook the searches and two to three authors independently assessed trial quality, family centeredness, data extraction and thematic synthesis. Fifteen studies were reviewed.

Results: Four themes emerged from the literature on communication, healthcare professional and parent relationships, caring for parents and available resources. The differences, similarities and interpretation between healthcare professionals' and parents' perspectives on these themes are reported.

Conclusion: The effectiveness of FCC can often depend on individual demographic characteristics of the child, parent and healthcare professional. A broad spectrum of variability exists in the perceptions of healthcare professionals and parents on parental needs and FCC within a hospital context.

What is already known about this topic?

- Other terms of care that were precursors to the formalized model known as FCC include parental participation, care-by-parent and partnership-in-care.
- The debate continues to exist as to what FCC means for healthcare professionals, parents and children.
- Parents of hospitalized children have physical and psychosocial needs, which need to be met to enable them to effectively support their hospitalized child.

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What this paper adds

- This review demonstrates that regardless of country, culture, population or healthcare setting FCC continues to have a negative impact on communication, relationships, needs and personal, social or financial resources for some parents and healthcare professionals in the hospital setting.
- The needs of parents are not similar across all countries and cultures.
- No empirical evidence exists to say FCC works or that it makes a difference to family and child healthcare outcomes.

1. Introduction

The separation of the family from the hospitalized child has long been reported as detrimental to the physical, emotional and psychological wellbeing of the child and family (Bowlby, 1953; Robertson, 1962; Spitz, 1945). The concept of FCC was developed in Britain following the seminal research by Bowlby (1952) and the Platt Report (1959). FCC held the family as important in the emotional and psychological care of the hospitalized child (Alsop-Shields and Mohay, 2001; Jolley and Shields, 2009).

In 1992, the Institute for Family Centred Care (IFCC) was established in America whose primary role was to develop leadership strategies, resources and programmes for policy-makers, administrators, direct service providers, educators, design professionals, and patient and family leaders to facilitate a patient and family centred care approach (Institute for Family Centred Care, n.d.). This is in line with the United Nations Convention on the Rights of the Child (UNCRC) that clearly states every child has the right to self-determination, dignity, respect, non-interference and the right to make informed decisions (United Nations, 1989). The IFCC took over the role of the Association for the Care of Children's Health (ACCH). The IFCC and ACCH developed 9 elements that characterize FCC health services (Johnson, 1990; Shelton et al., 1987; Trivette et al., 1993). Trivette et al. (1993) further developed 13 evaluative items that describe the features of these 9 elements of FCC as set out in Table 1.

The first nursing research to explore FCC was conducted by Goodell (1979) and a plethora of international, national and local research has followed. Despite extensive research and literature reviews into FCC confusion continues to exist over the definition, benefits, burden, characteristics and realities of effectively operationalizing and measuring this care for policy-makers, organizations, healthcare professionals, parents and children (Ahmann and Johnson, 2000; Corlett and Twycross, 2006; Coyne, 2008; Shields, 2001; Shields et al., 2006, 2009). Despite this FCC has been formalized into many international, national and local government policies and embraced by healthcare professionals and families (Chenery, 2007; Coyne and Cowley, 2007; Crawford, 2000).

For the purposes of this review the following definition of FCC was used:

> Family centred care 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 recognized as care recipients (Shields et al., 2009; Shields et al., 2006, p. 1318).

The parent in this context includes the primary caregiver to the child being the child's natural or adoptive parents, step-parents or any other parent–child relationship that fits this context. This review differs from previous literature reviews as the set inclusion criteria, to include primary research studies published or unpublished in English between 1997 and 2009, that include data from both the healthcare professional and the parents' perspective, aim to increase the rigor of the results and reduce

Table 1
Association of the care of children's health elements and the 13 evaluative items.

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