How should we understand family-centred care?

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Abstract
What is family-centred care of a hospitalized child? A critical understanding of the concept of family-centred care is necessary if this widely preferred model is to be differentiated from other health care ideals and properly evaluated as appropriate to the care of hospitalized children. The article identifies distinguishable interpretations of family-centred care that can pull health professionals in different, sometimes conflicting directions. Some of these interpretations are not qualitatively different from robust interpretations of the ideals of parental participation, care-by-parent and partnership in care that are said to be the precursors of family-centred care. A prominent interpretation that regards the child and his or her family collectively as the ‘unit of care’ arguably arises from ambiguity and is significantly problematic as a model for the care of hospitalized children. Clinical practice driven by this interpretation can include courses of action that do not aim to do what will best promote a hospitalized child’s welfare, and such cases will not be unusual. More broadly, this interpretation raises challenging questions about the responsibilities and authority of health professionals in relation to the interests of hospitalized children and their families.

Keywords
Children’s rights, critical thinking, ethics, family-centred care, parents

There is widespread commitment to family-centred care (FCC) as the most appropriate model for treating hospitalized children (Coyne, 2015; Kuo et al., 2012). Is this commitment justified? To address this question adequately, at the most basic level, we need to know what FCC is. However,
health care professionals take FCC to mean different things or are unclear about what it implies and requires (Coyne et al., 2016; Darbyshire, 2016). Scholarly publications offer varying conceptions of FCC (Bruce and Ritchie, 1997; Carmen et al., 2008; Jolley and Shields, 2009; Trajkovski et al., 2016).

An article of this length cannot comprehensively answer the question of how we should understand FCC. Nonetheless, the type of analysis the article provides is essential if FCC is to be clarified, differentiated from other health care ideals and properly evaluated as appropriate to the care of hospitalized children. This article argues that different interpretations of FCC currently available are either not clearly distinguishable from earlier healthcare ideals or significantly problematic. It begins by contrasting a range of prominent scholarly and institutional interpretations of FCC and discussing which of them might best represent a conception of FCC. It then explains why the interpretation of FCC that is most clearly distinguishable from earlier, more limited healthcare ideals arguably involves ambiguity. The latter, evaluative sections of the article argue that this interpretation of FCC is significantly problematic as a model for the care of hospitalized children. In practice, it can include courses of action that do not aim to do what will best promote a hospitalized child’s welfare, and such cases will not be unusual. This interpretation of FCC also raises challenging questions about the responsibilities and authority of health professionals in relation to the interests of hospitalized children and their families.

Examples used in this article to illustrate the different conceptions that FCC can imply in practical contexts do not describe actual people. They are derived from the scholarly literature on FCC (Shields, 2010: 2634–2635) or based on experience from clinical practice and describe relevantly similar situations that can arise in the hospital setting. While the article’s principal focus is FCC as applied to hospitalized children, its relevance extends to health clinics and institutions for children with disabilities and to the delivery of post-hospital treatment.

**What is FCC?**

FCC invokes a more robust notion of family inclusion in decisions about and provision of a child’s care than parental consent to treatment and allowing parents to stay with a hospitalized child (Shields, 2015). But what, in addition, is required for care to be family centred? There is no unitary definition of FCC, and it is instructive to identify distinguishable ways in which various authors understand FCC.

First, FCC is often understood as a commitment to involving family members, and particularly parents, in delivery of the child’s treatment, where appropriate (Kuo et al., 2012). This ‘family participation’ interpretation of FCC could be enacted by, for example, a parent’s active involvement in giving a hospitalized child’s medication, subject to regular monitoring by a ward nurse.

A family participation interpretation can be contrasted with a second understanding of FCC as a commitment to determining the most appropriate approach to providing a child’s treatment with reference to the child’s relationship to other family members, particularly to his or her parents (Bruce and Ritchie, 1997; Carmen et al., 2008). This ‘child-in-family-context’ interpretation could be enacted by, for example, clinicians actively involving a child’s parents in negotiations about their child’s treatment, to identify or facilitate the most appropriate course of treating the child or to minimize the child’s anxiety.

These two conceptions of FCC emphasize the child’s parents or family as actors, as co-providers of the child’s care or as (co-)decision makers or (co-)facilitators in relation to the child’s treatment. By contrast, in adopting promotion of the health and well-being of the individual
child patient and his or her family as a central goal (Institute for Patient- and Family-Centered Care, 2017), a third interpretation of FCC emphasizes the child’s parents or family as care recipients. This interpretation is said to regard the family, as opposed to the individual hospitalized child, as the ‘unit of care’ (Shields et al., 2006). This understanding of FCC could be enacted by, for example, a health professional taking a child’s family’s circumstances into account in deciding when to recommend the child’s hospital discharge.

These distinguishable interpretations of FCC are not rigid categories. For instance, each of them can invoke the desirability of family members being appropriately involved in the provision of a child’s treatment. However, we cannot simply assume that these different understandings of FCC can be regarded as elements of a broader conception of FCC within which they can all compatibly coexist, as opposed to being different, possibly competing interpretations. A unit of care understanding of FCC affords the interests of members of the child’s family a different status (as themselves care recipients) than either a family participation or a child-in-family-context interpretation of FCC would indicate. In practice, these distinguishable interpretations of FCC will also be subject to different standards of compliance and expectation. To illustrate this, we might ask what FCC requires where, for example, a young teenage girl (Amy) suffering from anorexia is brought into hospital unwillingly by her very worried mother. Does a commitment to FCC require immediately hospitalizing Amy and then supporting both her and her mother during Amy’s treatment; or (merely) consulting Amy’s mother about her daughter’s psychology, as a means of informing the best course of Amy’s care; or trying to recruit Amy’s mother as an active participant in the process of treating Amy against her will? Here it would be unsatisfactory to respond that, from among these alternatives, FCC is best enacted by the course of action that is most appropriate in the circumstances. This begs the question of ‘most appropriate for whom?’: for Amy, or for both Amy and her mother regarded collectively as a unit of care? More importantly, as a model of care, the role of FCC is as a guide to the most appropriate course of action, not the other way around.

Those who are committed to FCC need to be clear about its scope and expectations and not shift uncritically between different interpretations. If the interpretations of FCC identified in this section can indeed operate alongside one another in practice, and if there is good reason for this to be so, then health practitioners would need to know which interpretation of FCC applies in which type of situation and why. Clarity about the nature of FCC is also essential for its proper assessment as a model for the care of hospitalized children. The assessment of FCC in practice (Trajkovski et al., 2016) might differ between different interpretations. Examination of the assumptions and principles on which FCC is based will need to consider different understandings of FCC.

A significant consideration for how we should understand FCC is its underlying rationale. This rationale will be the reason or set of reasons that provides the (purported) justification for FCC as the preferred model for the treatment of hospitalized children. The following sections of the article address distinguishable interpretations of FCC in terms of what FCC aims to achieve.

**FCC’s underlying rationale**

The development of and widespread commitment to FCC would appear to reflect the view that FCC best promotes a hospitalized child’s welfare, with a corresponding commitment on the part of health professionals to act (Coyne, 2015). This view does not claim that an individual child’s welfare is indistinguishable from that of his or her family. Rather, it typically maintains that appropriate inclusion of a child’s family in decisions about and provision of the child’s hospital
care can significantly aid the child’s treatment and recovery and can otherwise mitigate what is often an emotionally traumatic event for these vulnerable, immature and dependent patients.

This is not to say that FCC, or an interpretation of FCC, could not be given a different rationale. For instance, a ‘family unit’ interpretation might claim that the interests of a hospitalized child’s family ought to be considered in decisions about the child’s treatment, independently of what might best promote the individual child’s welfare. This alternative rationale would, presumably, differ significantly in its practical application from what would be indicated by a commitment to FCC as best promoting a hospitalized child’s welfare.

The remainder of the article will examine the interpretations of FCC distinguished earlier against a commitment to doing what will best promote a hospitalized child’s welfare. There are three important points to note. First, the claim that FCC best promotes a hospitalized child’s welfare is empirical and depends on evidence. Second, the claim is a generalization that rests upon more basic assumptions, such as that most children are members of families, that a child’s parents are usually responsible for the child’s well-being, and that parents or families are mostly willing and able to participate to some extent in their hospitalized child’s care. As a generalization, the claim must acknowledge possible exceptions. Third, the justificatory rationale that this claim would provide to FCC is instrumental. As applied to a family unit interpretation, the reason for regarding the family as the unit of care is the view that generally the child’s welfare will by this means be best served. This will also be the (purported) justificatory reason underlying family participation and child-in-family-context interpretations.

The next two sections argue that while the family participation and child-in-family-context interpretations are consistent with this underlying rationale, they fall short as understandings of FCC. In as much as a family unit interpretation best represents FCC, it diverges from FCC’s underlying rationale. The article’s final section outlines the implications of this analysis for how we should understand FCC.

**Family participation and child-in-family-context**

In considering family participation and child-in-family-context as interpretations of FCC, it is instructive to draw attention to ideals that are said to be FCC’s forerunners. These earlier ideals are parental participation, care-by-parent, and partnership-in-care, as applied to hospitalized children (Casey, 1988; Cleary, 1992; Coyne et al., 2016). Parental participation and care-by-parent acknowledge and utilize parental knowledge, skills and competence in the delivery of a child’s treatment and hospital care. Partnership-in-care implies mutual dependency and shared responsibility between parents and health professionals in caring for the child (Casey, 1988). FCC is conceived as and intended to be a significant development and progression from these more specific ideals that are said to be precursors of FCC (Jolley and Shields, 2009).

With these more specific ideals in focus, obvious questions arise about family participation and child-in-family-context as interpretations of FCC. How is family participation significantly different from parental participation or care-by-parent? How is the child-in-family-context interpretation of FCC not equivalent to partnership-in-care? Moreover, how could these interpretations, either individually or combined, be FCC, as opposed to ideals that are widely regarded as FCC’s more limited antecedents?

According to some authors, these more limited ideals are incorporated as elements of FCC. (Trajkovski et al., 2016 refer to development of respectful partnerships between parents and healthcare professionals as a core principle of FCC.) However, if ‘parental participation’ is indeed
an element of FCC and the appropriate element to apply in the case of delivering a hospitalized child’s medication, and if ‘partnership-in-care’ is an element of FCC and the right element to apply in making decisions about a child’s treatment, then what considerations determine this? On the one hand, a direct appeal to FCC’s underlying rationale might seem an obvious basis for selection between these different interpretations, regarded as elements of FCC. (What, among these options, is the best means of promoting the child’s welfare in this situation?) On the other hand, the family unit interpretation seems to come closest to what FCC is often taken to be as a distinctive progression from earlier ideals of parental participation, care-by-parent and partnership-in-care.

Family as a unit of care

The emergence of recent literature that emphasizes child-centred care (Carter et al., 2014) strongly suggests that FCC is commonly taken to regard the family, as opposed to the individual hospitalized child, as the focus of care. The following definition goes further in claiming that FCC encompasses other family members as care recipients:

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 recognised as care recipients. (Shields et al., 2006: 1318)

However, while statements of FCC by prominent exponents clearly regard the family as central to the child’s care, the extent to which they also regard family members other than the child as care recipients is debatable. In 2007, the Institute for Family-Centered Care in the United States and quoted by Jolley and Shields (2009: 165) stated that FCC is committed to:

- recognizing the family as a constant in the child’s life;
- facilitating parent–professional collaboration at all levels of healthcare;
- honouring the racial, ethnic, cultural and socio-economic diversity of families;
- recognizing 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 healthcare that is flexible, culturally competent and responsive to family needs.

Arguably, the Institute’s commitment to ‘adopting policies and practices that provide families with emotional and financial support’ is both based upon, and confined to the provision of support that is part of, or has a significant impact upon the care of the child patient. If, for example, a child’s hospital treatment will go much better with direct parental participation, then the hospital could have some responsibility to assist parents with accommodation or transport if necessary and feasible. This does not make the child’s parents care recipients. Rather, here the child’s hospital care is partly facilitated indirectly by assisting the parents’ participation. Similarly, a commitment to ‘designing healthcare that is . . . responsive to family needs’ might be intended to concern itself with such needs only to the extent that they have a significant impact on the child’s care.

By 2017, the statement by the Institute for Patient- and Family-Centered Care had changed somewhat to make the promotion of the health and well-being of individuals and their families a key goal. Nonetheless, its explanatory content refers to family participation and collaboration with
health professionals in the provision of a patient’s care and in decision-making. While the statement speaks of improved ‘family experience of care’, this could refer to the family’s experience of the patient’s care.

The idea that FCC includes all family members as care recipients is arguably due to a shift between two distinguishable notions. Trajkovski et al., for instance, say that FCC arises from ‘policies that place parents and the family at the centre of care’, and that ‘the underlying philosophy of FCC recognises and embraces the whole family when planning care for the individual/child/infant’ (Trajkovski et al., 2016: 266). Neither statement explicitly says that other family members are care recipients or that the family itself is the unit of care. On a plausible reading of the claim that FCC arises from ‘policies that place parents and the family at the centre of care’, this claim is elliptical and carries the implicit qualification ‘of the child’ after the word ‘care’: the claim is that FCC arises from policies that place parents and the family at the centre of care of the child. Whether the statement that FCC ‘recognises and embraces the whole family when planning the child’s care’ means that other family members are themselves care recipients depends on how the family is ‘recognised and embraced’. To recognize and embrace the whole family when planning the child’s care is different from recognizing and embracing the whole family as a care recipient.

The crucial difference is between, on the one hand, placing a child’s family at the centre of that child’s care, and on the other hand, regarding the child and his or her family as care recipients. The former is consistent with family participation and child-in-family context interpretations of FCC, and it may be generally defensible as a means of doing what will best promote a hospitalized child’s welfare. But it is not qualitatively different from robust ideals of parental participation, care-by-parent and partnership-in-care. There might be a pragmatic, strategic reason for adopting the language of care that is ‘family centred’ to pursue these more specific ideals, to remind health professionals to enact the negotiations and consultations necessary for appropriate parental and family involvement and shared responsibility for the child’s care. At the same time, the term ‘family-centred care’ has fostered ambiguity and an interpretation that, for reasons outlined in the next section, is significantly problematic as a model for treatment of hospitalized children.

Is the family as a unit of care interpretation defensible?

This section of the article argues that we should reject an interpretation of FCC that regards the family as collectively a unit of care if indeed FCC aims to do what will best promote a hospitalized child’s welfare. The discussion also questions what this interpretation of FCC implies and requires concerning the responsibilities of health professionals towards hospitalized children and their families.

It follows from FCC’s instrumentalist rationale, that even a family unit interpretation will regard a health professional’s responsibility of care towards a child’s family as confined to matters that relate to the treatment and care of the child himself or herself. (For instance, in our earlier example, FCC does not require that a clinician treating Amy’s anorexia also arrange for treatment of Amy’s brother’s acne.) In this regard, the relationship between the provision of a child’s care and the child’s family can go in two directions. One direction concerns way(s) in which a child’s family’s circumstances might positively or negatively affect the child’s care. This raises the issue of what responsibilities health professionals would have on this account. To illustrate these two directions, we can revisit the example in which the effect that a sick child’s family’s circumstances could have on the quality of her continuing treatment at home makes this a relevant concern for a
clinician in recommending the timing of the child’s hospital discharge. In this case, the primary concern of the clinician (Jes) might be to do what will best promote the welfare of the sick child (Sally). Importantly, this consideration does not make Sally’s parents and siblings care recipients. However, in the other direction, a child’s illness can have a negative impact on his or her family in various ways. And in this direction, a family unit interpretation of FCC suggests that Jes would also be required to consider the disruptive effect on Sally’s family as itself a reason for delaying her hospital discharge since other family members are themselves care recipients.

The family unit interpretation raises wide-ranging questions about what health professionals who are responsible for a child’s hospital care need to consider in enacting FCC. Even if their responsibilities to a child’s family are confined to purely health-related matters, for example, would FCC include (arranging for) care for family members for health conditions (such as anxiety) that flow from the child’s illness, or provision of treatment of a parent’s own medical condition if this is necessary for that parent adequately to care for her child at home? (The treatment of parental anxiety or illness is not an issue. Rather, the question is whether this is part of FCC and thus something for which the child’s health carers are responsible.) A broader question concerns what types of care would be within a health professional’s responsibility under a family unit interpretation. Does FCC extend, for example, to help with negotiating employment leave or securing welfare and other benefits that might be necessary for a family to care for a child at home?

As a model for the care of hospitalized children, FCC needs to be a general presumption that is open to exceptions, since it is based on assumptions that do not invariably hold. When these assumptions are clearly inapplicable in a specific set of circumstances, the practice of FCC will lack justification in those circumstances. Moreover, since FCC is a general presumption, the circumstances in which its underlying assumptions do not hold need to be unusual and not represent a significant percentage of cases. The family participation and child-in-family-context interpretations of FCC can acknowledge and accommodate this important point. However, the family unit interpretation needs squarely to face the fact that a child’s illness can and often does negatively affect the interests of other family members or the whole family. This raises significant problems when it comes to identifying the professional responsibilities of the child’s health carers if FCC includes other family members as care recipients.

Suppose that in our earlier example, it would best promote Sally’s welfare that she is discharged from hospital as soon as possible and that her parents manage her home-based treatment and their own responses to this situation in a suitable way. If, as the health professional directly responsible, Jes regards her principal duty as to do what best promotes Sally’s welfare, this suggests that Jes should recommend that Sally be discharged from hospital promptly and her continuing treatment delivered at home. If in Jes’ negotiations with Sally’s parents about this, they press the difficulty for them of making the necessary adjustments in relation to their other commitments and the home environment, then Jes is being asked to ‘trade-off’ what in her professional judgement would, on balance, be best for Sally, against what would ‘work best’ for her whole family. And if in negotiating with Sally’s parents, Jes seeks to persuade them of the desirability for Sally of continuing her treatment at home, and of their making the necessary adjustments as soon as possible, then this invokes a different conception of FCC in which the health professional sees his or her responsibility as one of educating and encouraging parents to accept a treatment plan that best promotes their child’s welfare. In encouraging Sally’s parents to accept increased involvement and responsibility for her care, Jes would be endeavouring to advance what, in her professional judgement, best promotes Sally’s welfare, contrary to what might be better overall for her family regarded collectively as a unit of care.
The foregoing discussion highlights an important general point. Often, enacting the more specific ideals of parental participation and partnership-in-care will require significant sacrifice of some type by a hospitalized child’s parents and family. (The fact that many parents and families are (more than) willing to make such sacrifices for a sick child’s benefit does not negate the sacrifice.) Thus, enacting these more specific ideals can come into tension with enacting a family unit interpretation of the FCC. Moreover, if the rationale for the widespread commitment to FCC is indeed a concern to do what best promotes the hospitalized child’s welfare, then it is crucial to recognize how and why a family unit interpretation of FCC can undermine this rationale. Once care of the whole family becomes the goal of FCC, then FCC can persist in cases in which its implementation clearly does not best promote the hospitalized child’s welfare. And such cases will not necessarily be, as they should be within an instrumentalist rationale, relatively unusual exceptions to which FCC is inappropriately applied. For this reason, a family unit interpretation is not defensible against the rationale of the more specific ideals that are said to be FCC’s precursors. Whatever FCC’s underlying rationale is taken to be, a family unit interpretation raises the question of whether it is reasonable to expect health professionals to consider the interests of other family members when caring for a hospitalized child, and how far this extends. Even if the health professional’s care towards other family members is restricted to matters that relate to the child’s hospital care, much of what transpires in a family can be directly or indirectly related to the provision of a child’s treatment and care and in varying degrees. Understanding and navigating what may be conflicting interests and dynamics within a family, and between a hospitalized child and his or her family, arguably exceeds a health professional’s responsibility and authority. In some circumstances, it may well be appropriate and beneficial for a health professional to raise some of the implications that the child’s treatment may have for other family members, for instance. But in many circumstances, it will be the responsibility of the child’s family, and not the health professional, to decide how to manage those issues.

**Conclusion**

The foregoing analysis has significant implications for clinical practice. It identifies distinguishable interpretations of FCC, which can pull in different directions. The current ambiguity surrounding FCC is unhelpful for health professionals or the children for whom they care. If FCC is to direct health professionals in how to approach the care of hospitalized children, then FCC’s underlying rationale, as well as what FCC implies and requires, must be clear. Health professionals who care for children and their families, and their managers who make decisions for clinicians to implement may, with justification, be unclear about what FCC requires and about the clinical practice implications of decisions based upon FCC. The language of FCC as expressed in hospital posters, leaflets and on websites, is appealing in its sentiment and its rationale, in as much as it represents the idea that the family is very often a crucial support for an immature and vulnerable child while he or she is undergoing a potentially emotionally traumatic event. However, as this article shows, the language of FCC has also fostered confusion.

A prominent understanding of FCC that regards the family as collectively the unit of care can imply courses of action that do not aim to do what will best promote a hospitalized child’s welfare and such cases will not be unusual. In as much as a family unit interpretation of FCC stems from ambiguity and involves a shift between two importantly different notions, those whose commitment to FCC as a model of care rests on the view that FCC best serves a hospitalized child’s welfare should reject a family unit interpretation. At the same time, they need satisfactorily to
explain how FCC is a distinctive progression from robust interpretations of earlier, more specific ideals of parental participation, care-by-parent and partnership-in-care.

Others who, upon reflection, endorse FCC as committed to enacting whatever best promotes the health and welfare of everyone in a hospitalized child’s family, cannot represent FCC as a progression from precursors of parental participation, care-by-parent and care-by-parent, since enacting these earlier ideals will often require significant sacrifice on the part of parents and families in promoting a hospitalized child’s welfare. Rather, on this interpretation, FCC is a redirection, away from those earlier ideals towards a different goal that requires a different justificatory rationale.

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