

Title: Losing the child's voice and 'the captive mother'- an inevitable legacy of family-centred care?

EBN engages readers through a range of online social media activities to debate issues important to nurses and nursing. EBN Opinion papers highlight and expand on these debates.

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This month's opinion draws on an EBN Twitter chat that focused on child & family-centre care (FCC). Access the blog at <http://blogs.bmj.com/ebn/> and the Storify at <https://storify.com/josmith175/loosing-the-child-s-voice-and-the-captive-mother-a>

Background

A key role of the children's nurse includes supporting children, young people and their families to be involved in care, yet this involvement has not been embedded into every day practice. Parents want and expect to be involved in their child's care and to work in collaboration with health professionals but want to choose their level of involvement.^{1,2} The Twitter chat focused on a recent publication, '*Family-centred care: the captive mother revisited*',³ which revisited Roy Meadow's (Arch Dis Child 1969) acclaimed article '*The captive mother*'.⁴ The article is already generating debate and questioning the relevance of FCC, where some argue that the emphasis should be on treating the child as an individual, with rights and choices, and having a voice in their care.^{5,6}

Key messages from the Twitter Chat (#ebnjc)

A range of issues were debated during the chat but two key themes emerged:

The first related to the lack of evidence that FCC improves the care of the child, young person and their families (Figure 1). We all know and embrace FCC, in fact, children's health services have become so enamoured of it that management, executives and decision makers have ensured that their organisations advertise that they practice and value FCC. Hence websites, posters, leaflets, explanatory handouts and so forth espousing that 'we practice FCC here in our hospital or clinical

setting' are plentiful. It sounds good - parents are encouraged to work in partnership with health professionals to ensure they are involved in their child's care, and health professionals are expected to embrace the principles of family-centred care when delivering care. However, if asked what those principles are, few health professionals can articulate what FCC really is and how it operates in practice.^{1,7} This in itself is problematic, but even more concerning is the fact that there is no research that demonstrates whether FCC works, or makes a difference to the care of children, young people and families. A Cochrane systematic review, updated in 2012 with another update planned, found no randomised controlled trials (RCTs) have been undertaken that have evaluated FCC.⁸ Similarly, a Joanna Briggs Institute review of quasi-experimental studies confirmed a lack of evidence about the effectiveness of FCC as a model of care for children in hospital.⁹ Although a second Joanna Briggs Institute review that evaluated qualitative studies found a growing evidence base about FCC, most worrying, the review highlighted that FCC is often misunderstood, and is not implemented effectively.¹⁰

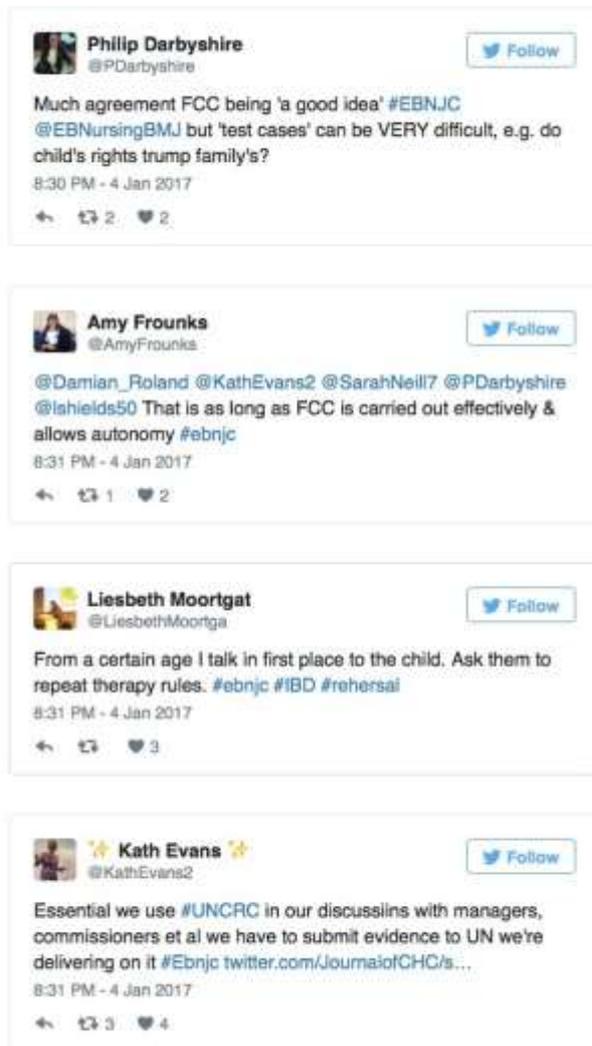
The Twitter chat mirrored questions raised in these reviews^{8,9,10} such as why FCC has become such a 'sacred cow' and questioned whether it is ethical to continue to push a model for which little evidence of effectiveness exists. Another issue raised was that while most nurses and organisations pledge allegiance to 'evidence-based practice (EBP)', at least in principle, it too is poorly understood, especially at clinical and organisational levels. Perhaps part of the challenge of FCC in relation to EBP is that undertaking an RCT seeking to compare FCC with another model of care would be almost impossible to undertake. What, for example would 'traditional care' look like in 2017? Is there a recognised and clearly understood model of 'treating the child as an individual' or 'respecting the child's voice' that could be compared? Probably not; in the absence of a clearly defined model to use as the comparator, the first step would seem to be the identification of models, which are working in practice. Identifying exemplars of excellent practice from which qualitative research can define or develop a model is a possible way forward. One of the fundamental problems with FCC has been that it was and is promulgated by professionals rather than children and their families. A grounded theory study found that partnership with parents was a professional ideology not shared by parents, and that '*parents felt compelled to be there and to be responsible for their children's welfare in hospital*'¹¹ reflecting the captive mother of Meadow's original article.

Figure 1: Is there an evidence base supporting FCC?



The second theme related to whether FCC marginalises the voice of the child. This was a fascinating discussion thread that for some seemed to exemplify the kind of Cartesian dualism that so much of nursing and health care falls into. Why, for example, would care that has a family and their wishes, needs and interests at the centre automatically preclude or ignore the child's 'voice'? Is it assumed that the child is somehow not part of this family or is it assumed that FCC involves a hierarchy with parents at the top and the child at the bottom? Where, in this hierarchy would young people sit? A collaborative action research involving children, their families and health professionals, might provide a route to the development of 'best practice' models, grounded in the United Nations (1989) Rights of the Child (Figure 2). Taking a collaborative approach provides an opportunity to shape future care models from the perspectives of those receiving care, not just those providing care.

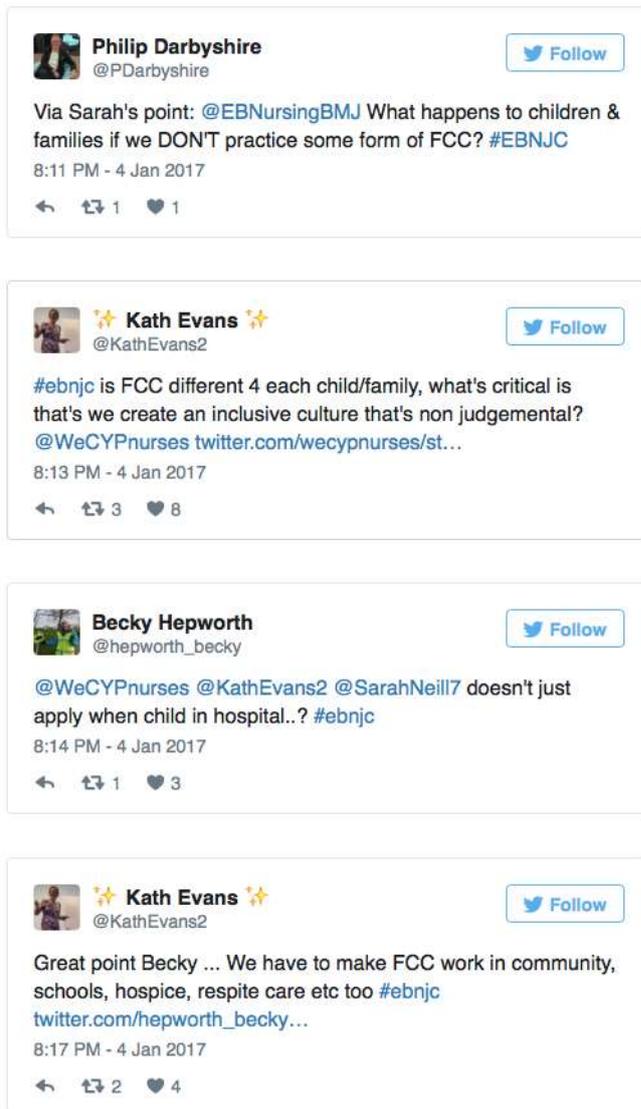
Figure 2: Does FCC marginalise the voice of the child?



Where next?

A new model for the care of children in health services is emerging. Carter and colleagues⁶ suggest that FCC has lost sight of the child, who, after all, is the focus of our care. While the family is vital for the support it provides to the child, unless we recognise that the individual child is the centre of the care delivery, we run the risk of losing the child in favour of the family, and so no one's needs will be effectively met. Re-focussing on the child also provides the flexibility to develop a model fit for any setting - not just the traditional hospital settings where FCC originated (Figure 3).

Figure 3: Can FCC be applied across care contexts?



It has been argued that the child's rights as an individual are being overlooked and a child-centred care model will ensure the child becomes central in the delivery of care.¹² Some words of caution, first, colleagues in countries like the United States of America, where health care delivery is tied to episodes of funding, express concern that child-centred models could result in parents being excluded from a child's admission because there would be no way to fund their care. Second, the world of nursing is littered with models and frameworks that have promised much but delivered little. It would be worth exploring the flexibility within FCC to determine if the question of the child's voice and the prominence of the child is a focus issue rather than an 'either/or' dichotomy that requires the creation of yet another model of care. However, we must be rigorous about ensuring a new model of care is tested for efficacy or there is the risk of it being another 'sacred cow' similar to FCC. Central to any future development, as previously highlighted, is the need to

work collaboratively with children, young people and their families, and in doing so put an end to professional paternalistic development of models of care.

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