Family-centred care: the 'captive mother' revisited

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Introduction

At the end of his long career, Sir Roy Meadow was associated with a major scandal over incorrect evidence in child abuse cases. Nonetheless, at his peak, his scholarship and research were influential. In 1969, Meadow published a paper in which he described the “captive mother” as one who, admitted with her child, would be stuck in a hospital ward with a child with whom she would not normally spend much of her day. He argued that school-aged children would normally spend most of their time outside the home, under the influence of people other than their parents. A busy mother, whose job as housewife and carer of other children was jeopardized by having to stay away from the home, was caused great inconvenience and trouble, and it was unrealistic and put too much unnecessary pressure on the mother (and the family) to insist that she stay with the child.

While mothers’ roles have changed, the “captive mother” still resonates in relation to admission of children, and in particular in relation to family-centred care (FCC). It is time to rethink FCC.

Evolution of family-centred care

At first, models of paediatric care emerged in the United Kingdom (UK) and United States. Spitz coined the term “hospitalism” to define children whose psyche had been changed by long-term hospitalization. In the 1950s, a citizen’s committee in New York recommended admitting mothers with hospitalized children, while a British select parliamentary committee investigated children’s hospitals, and brought about monumental changes. They recommended admission of the mother and provision of accommodation for her (fathers were not mentioned). Facilitated by newly-formed consumer organizations, and pioneering theories of John Bowlby and James and Joyce Robertson, policies around the world changed so that parents became an accepted part of the child’s admission to hospital.
The care of children changed. Medicine focused on disease and cure; nursing, in particular, developed ways of caring for children and families. Models such as care-by-parent, partnership-in-care, negotiated care, and FCC\(^4\) became prominent.

With changes in societal roles of family members, health professionals have come to expect that parents stay with their admitted child, to give what is inappropriately termed “basic” care, and perceive that they may not be “good” parents if they do not stay. (“Basic” care such as bathing or toileting encompasses assessment, observation and clinical judgement and is rarely rudimentary).

**Evidence about family-centred care**

Today, most hospitals caring for children, in any country, have either a formal written policy, or an informal policy, of FCC, which means that care cannot be planned around the individual child, but around the whole family\(^6\). It sounds nice – inclusive, protective, gentle, etcetera, but despite its ubiquity, there is no good evidence to demonstrate whether or not FCC works\(^7\).

Some have tried to evaluate FCC using the *Measuring Processes of Care* questionnaire\(^8\) in a variety of medical specialities. However, it measures processes only, not attitudes to FCC, nor philosophies and perceptions surrounding it. Such examination is needed to test FCC’s effects, and a proper, rigorous, and well conducted randomized controlled trial of FCC is needed\(^7\). Unfortunately, this would be expensive - it is much cheaper for health services to pay lip service to FCC as this feels good.

It is time to debate the ethics of using a model for which minimal evidence exists. While there is strong evidence that small children need their parents\(^9\), perhaps it is too far to expect parents to stay with older children. In addition, parents may have things happening in
their lives that preclude their staying, and it is not right to pressure them to stay if they cannot. It is time to revisit Meadow’s\textsuperscript{1} argument – the “captive mother”.

No-one would argue that FCC is not the best option for very young children. A large literature exists about the importance of parental presence for young children\textsuperscript{9}, especially during frightening or stressful events. However, older children may not need parents to be present all the time. Reflective of Meadow\textsuperscript{1} it is no service to parents to insist that they stay, regardless of the age and needs of the child, and their life circumstances at the time. Family-centred care is premised on a) effective communication between family members and health professionals, and b) negotiation with family members to see what is best for them. Insisting that parents stay, and perceiving them as “bad” parents if they do not, is not FCC. Unless these conditions are met, sound care cannot be planned.

**Problems with family-centred care**

Parents and families assume that hospitals have their best interests at heart. After all, “family-centred care” sounds lovely. While there is a dearth of evidence about its effectiveness\textsuperscript{7}, there is a growing body of rigorous qualitative research which gives cause for concern\textsuperscript{10}. Consistent themes, seen repeatedly in different settings, in various countries, and across a range of health disciplines, include health professionals acting as gatekeepers for parents, ineffective communication between health professionals and parents and children, controlling parental access to children; needs of parents not being met, and parents having to use various strategies to have those needs met\textsuperscript{10}. Some have found that nurses punish parents, often in petty ways, when parents do not live up to nurses’ expectations of a “good” parent\textsuperscript{11}. Doctors have been high-handed in their communication with parents and children, often peremptory in the way they deliver information and expect parents to act upon it\textsuperscript{12}. Parents are resentful at being made to do what they consider nurses’ work\textsuperscript{11}, and some health
professionals expect parents to stay without any consideration of what else might be going on in the family's life. Qualitative research cannot prove or disprove anything, but it gives rich information about phenomena; in the case of FCC it demonstrates that all is not well with this model that has become a ‘sacred cow’.

In the early 1990s, Philip Darbyshire raised debate around FCC. A qualitative researcher who studied the nursing care of children in hospitals, he postulated that FCC was a wonderful ideal, but extremely difficult to implement effectively. When a child was admitted to hospital with his or her parents, nurses had to deliver care in the presence of parents - Darbyshire called this “nursing in public”. Similarly, parents cared for their child in the presence of the nurses - “parenting in public”. He theorised that each side felt threatened, creating tensions that compromised successful implementation of FCC. Another notion under research at present, which may prove FCC untenable is that of who “owns” the child in hospital. Doctors talk about “my patient”; nurses say “she’s mine today”; or, perhaps, posters around hospitals discuss “our children”. This may seem innocuous, but language is powerful. Parents hearing this may think that they “own” their child (notwithstanding concepts of who owns another human being at all). If health staff think they “own” a child, and parents think that they “own” him or her, the potential tension could inhibit implementation of FCC.

Perhaps FCC as we know it cannot work, even in countries with the world’s best health services and conditions for families. Sweden has an excellent universal health service, free at point of delivery, supported by taxation and cultural mores around rights and accompaniment responsibilities. Family-centred care takes on a different perspective. As with other countries, it is the principle philosophy guiding paediatric care, and is so well supported, philosophically, bureaucratically, and financially, that it is intrinsic in any health care interaction with children and their families. Family-centred care underpins all health
care, not just for children, and is the driving philosophy behind Sweden’s characteristic “womb-to-tomb” health care. It is enshrined in policy, and is provided for by governments of all persuasions. Every Swedish parent is entitled to 60 days per year on 80% of their salary to care for children who are sick (http://www.sweden.se/eng/Home/Work/The-Swedish-system/Employment_based_benefits/Parental-leave/). As a consequence, Swedish health professionals expect parents to stay with their admitted child\(^{16}\). A converse argument arises – if an expectation that parents will stay with their children is part of the particular FCC philosophy, does this not compromise the negotiation which makes the model work, and thereby negate the family-centredness of the model? If parents should not be pressured to stay with their child, and their ability and willingness to stay should be negotiated according to their needs and life situation, arguably, despite the generous financial commitment given by the Swedish government, FCC is not being practiced.

**Children in family-centred care**

In Western societies today, children rarely play unsupervised, or walk to school by themselves; in fact few walk to school at all. Parents run a shuttle service between schools, sports, music lessons, acting classes, etcetera. A group of children playing football in the street could be considered to be acting dangerously. Parents who allow primary-school-aged children to travel unaccompanied on public transport are considered irresponsible\(^{17}\). A furore in Australia centred on a newspaper photograph showing a man teaching his nine-year-old daughter how to fish. It was lambasted because the child was sitting on the dinghy with her legs hanging over the side, and not wearing a life jacket. The journalist who wrote the piece, shocked by the reaction of many of the public, asked “in this day and age of television as the new drug of the nation and childhood obesity, an active, healthy child is surely a cause for celebration. Is this why kids stopped climbing trees and riding their bikes on the road?”\(^{18,p}\)
Inquirer 2. The columnist Frank Furedi asked “... 30-40 years ago it was still possible to read criticism of some parents for being over-protective towards their offspring. But how often do we hear parents criticised for being over-protective today?” 19, p Inquirer 2. Is this thinking why the FCC model is so widely (said to be) implemented, with little critical thought about its effectiveness, and the possibility that its imperfect implementation is putting pressure on parents who are being, at best, condemned, and in some cases castigated for not staying with their hospitalized children?

The over-protective attitudes illustrated by this public outcry must be hindering the independent development of children, and perhaps they also are affecting children's care in health services. Hence, expectations that parents have to stay to fit in with “good FCC” may just be a symptom of the over-protectiveness of children that is such an integral part of today’s (Western) world. Is it these attitudes which provide a modern day “captive mother”?

Conclusion

Meadow’s 1 1969 “captive mother” may be relevant today; the fashionable FCC model may be irrelevant to, at least, older children. Qualitative research demonstrates many problems with the implementation of FCC, and it is questionable practice to continue to implement a model for which no good evidence of effectiveness exists. As family structures have changed, parents in all countries are increasingly expected to stay with a child in hospital, with little consideration of the inconvenience or hardship that this may cause the parents and other family members. This is not FCC, and Darbyshire’s 14 suggestion that FCC is a wonderful ideal but very difficult to implement effectively has credibility.

The family is the centre of a child’s life, and so any new model must be built on that premise. However, children’s needs change as they become more independent, and coercing parents to stay with an admitted child may not be in the best interests of the child or family.
Perhaps Meadow was right. The “captive mother” is an alien being, who would not normally be with her school-aged child all day, and unless we take this into consideration when planning care, we are disadvantaging families in a system which purports to support them.


