International commentary on Phiri et al. ‘Registered nurses’ experiences pertaining to family involvement in the care of hospitalised children at a tertiary government hospital in Malawi’

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Introduction

This commentary has been written by academics who are part of an international network of nurses who study family-centred care (FCC), the model widely used in paediatrics and children’s nursing. Called ‘International Research Network for Child and Family Centred Care’, its members are drawn from across the world and their goal is to promote evidence-based FCC. Members share and discuss articles related to FCC and nursing practice, research and policy.

In 2017, an article about FCC in Malawi1 highlighted issues that generated debate in the group, initiating discussion around the low nurse–patient ratio of 1:84 in a children’s ward. We examine the article from several perspectives, and ask the question as to whether it is ethical to suggest that FCC should be implemented given the constraints on health priorities. Comments specifically address four important issues: a) lack of resources and the impact of this on FCC; b) lack of empowerment of family members in their child’s care; c) lack of policies to guide and support FCC; and d) the importance of nursing ethics in FCC.

This discourse presents commentary written by several authors. Each section contains the thoughts of each individual author, listed per country.

Fatch Kalembo, Maggie Zgambo, Linda Shields

USA

It is a long-established principle that parental involvement in the care of a hospitalised child is beneficial for child and family, and may reduce stress and anxiety.2 Thus, FCC encourages family participation at several levels – the very least, but vital, is sharing information. Reflecting as a mother and a nurse on personal family circumstances, the importance of family involvement during hospitalisation is crucial.

Family involvement for me involved much more than information sharing and delivering treatment. Ultimately, the attention given to me by staff translated into a powerful message: that my presence, insights, and ideas were valuable and to be respected. This, too, reduced anxiety.

Feeling valued further enhanced care, not only reducing stress but also reducing hospital stay. The involvement of family takes time, careful listening, honesty and negotiation. Ultimately, while parental involvement can be crucial in decision making, perhaps the most important contribution a family member can bring to a child, irrespective of age, is security and love. No treatment is as powerful as the knowledge that the people who love the child are there. The simple presence of that love can never be quantified, but its value for all concerned can likewise never be underestimated.

Ellen Ben-Sefer

Ireland

I read this report of a study carried out in Malawi1 and found it very thought provoking. The fact that the average nurse-to-patient ratio is 1:84 in the paediatric unit is a very striking statistic, as it illustrates the conditions under which the nurses have to work to deliver care to children and families. Clearly, parental presence and involvement is essential rather than just desirable, as otherwise the children may not receive the care they need (if any care at all). So it is quite understandable that parents do not have a choice about their involvement and contribution to the delivery of care. It indicates a pragmatic approach to the care needs of children when the paediatric unit is so under-staffed.

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The findings have parallels to the findings from studies in Ireland and Europe. Parents often feel they have to contribute a lot to the care of their child because nurses are busy or short-staffed, and this happens when the staffing ratio on an Irish paediatric unit could be 1 nurse to 4 children, a much better ratio compared to that in Malawi. But the difference is that parents in Ireland, for example, could decide that they cannot be there all the time to assist with their children's needs and care because of work or family obligations. However, they will often decide not to leave their child because they want to be present to provide love, care and comfort. They will then choose to stay in the hospital or nearby. Nonetheless, when parents are present consistently, they observe deficits in care, and this makes them feel that they have no option but to stay full time and meet their child's care needs.

The fact that nurses in Malawi are 'expected to involve families in care' and that this role should be regulated is of concern. Caring for large numbers of children undoubtedly means that nurses may lack time to focus on ways of involving families. So families are left to 'muddle through' and do their best. Phiri et al.'s study did not include parents as participants. If it had, perhaps the authors would have found that families were happy to be there and would not have been so critical of nurses' strategies to ameliorate their lack of involvement in the children's care. This brings us back to the fact that FCC is a concept that originated in resource-rich countries where it is seen as an ideal model of care. But if very well-off, developed countries, with high staffing numbers struggle to implement FCC, then it may not be realistic to expect countries such as Malawi to achieve optimum implementation.

There has been no research into the best nurse–patient ratio for the delivery of FCC, so most units operate at a range of ratios. When under-staffing occurs, nurses may prioritise children's care over any interactions with, or support for, parents. It is a pragmatic approach, as safety of the ill child is paramount, and the reason many nurses choose to work in paediatrics. So the fact that they have a 'child focus' may be appealing and desired by Malawian mothers/parents. To critique the level of care provided to parents seems an injustice when nurses operate under such reduced staffing levels. Ensuring that children remain safe during hospitalisation was always understood to be a key component of the nurse’s role.

The notion of cultural safety is relevant in countries such as Malawi. Its core premise in nursing is that nurses provide care within the cultural values and norms of every family and treat every family with dignity and respect. So that could have been the focus of Phiri et al.’s study rather than a focus on FCC, benchmarking against Western practice so different from cultural contexts of Africa.

Healthcare professionals in USA, Australia and Turkey preferred working with children rather than the parents, and now nurse academics call for a reframing of FCC to a child-centred focus. This will still incorporate the family, but the emphasis is on the child’s needs and the child’s perspective. Others have suggested that child-centred care is embedded within an FCC model but that the family should be the first focus as parents have the legal responsibility for the child. A question arises. Is FCC about being family-centred or child-centred? Or is it about support and involvement strategies that nurses use with parents? Or about communication and relationships? Or all of these issues? Students often see FCC as being practiced more in non-Western countries where parents deliver all the physical care and nurses contribute a small amount of nursing care procedures. However, in some poor countries, when parents have to give care because of a lack of nursing staff, then that is not FCC, which has at its core, choice. In such situations, parents have no choice.

Phiri et al. compared their findings with current evidence from other countries and found the practice of FCC lacking. This is concerning, as the cultural context is so different, the FCC model of care may not be applicable at all in such settings. Although the staff–patient ratio was not mentioned by Feeg et al., nurses in Turkey mostly leave the physical care of children to mothers because of inadequate numbers of healthcare personnel.

Imelda Coyne

**Malawi and Australia**

As Malawian registered nurses, we have both worked in paediatric wards in Malawi for several years and we share the issues raised by Phiri et al. regarding the challenges faced in implementing FCC there. Phiri and colleagues raised an important point regarding lack of policies and resources affecting the involvement of healthcare workers. The Malawian healthcare system is negatively affected by lack of human and physical resources. The ratio of professional healthcare workers to the population is 0.2 per 10,000 and 3.4 per 10,000 for doctors and nurses respectively. The nurse-to-population ratio is only a third of what the World Health Organization recommends. Because of the workloads, healthcare workers report feeling exhausted and failing to discharge their duties professionally, resulting in an increase of workload for healthcare workers, including nurses, who consequently delegate some of their work to patients so that they can focus on more critical roles.

In addition, the provision of quality FCC requires the availability of accommodation for the family to use, especially when they are staying overnight. The physical structure of hospitals in Malawi does not support FCC. There are no beds or accommodation facilities for families to use when they are caring for their sick child. Family members sleep on the floor beside their child’s bed. In some cases, especially during peak malaria season, two or three sick children share one bed, and their parents are expected to share the limited space on the floor. They have no choice of finding accommodation outside the hospital as they are expected to care for the child during the day and night. Family members are, therefore, exhausted, due to lack of adequate sleep and the demanding caring role, which may put them at a greater risk of emotional and physical health problems.

Also, important principles of FCC such as collaboration and sharing of information are rarely practiced because of
the lack of equal power between healthcare workers and parents. For example, in Malawi, parents of children admitted to hospital did not understand the importance of oxygen therapy to their critically ill child, but they still accepted the treatment because it was prescribed by doctors. In Malawi, healthcare workers have more power than most people seeking healthcare because of their level of education, and this constrains the parental level of engagement in the care of their children. The unequal power between healthcare workers and the people they serve is illustrated by patients being shouted at, disrespected, ordered not to complain, slapped and sworn at by healthcare workers. This state is reversed when socially prominent figures or educated people seek medical attention. They are cared for differently because they are aware of their rights and/or hold the power to jeopardise one’s employment.

In Malawi, social circles of patients and their families are usually large, and sick children are often supported by extended families, friends and acquaintances. People from these social circles are willingly available to support the sick child with hospital visits, general care and monitoring of the patient. It is culturally acceptable for affected members even to excuse themselves from business activities to be available throughout the hospitalisation. Although general care such as personal hygiene and patient monitoring are theoretically nurses’ obligations, it is practically impossible to provide all the required nursing care due to the shortage of nursing staff. As highlighted in Phiri et al., nurses delegate some tasks to family members who are always available and willing to take care of their sick child. At least one family member is required at the bedside of the sick child all the time. While this practice brings to question the quality of care provided by family members, who are often inadequately trained and supervised, both family members and nurses seem to benefit. To the family members, this practice means the opportunity to love and care for their sick child, while nurses and other health workers benefit from the reduced workload.

Fatch Kalembo, Maggie Zgambo

UK

The problem with FCC, along with many other models and philosophies of practice, is that they are often misunderstood by clinicians, kidnapped by well-meaning academics, abused by researchers and under-resourced by budget holders. For years, pretty much anyone implementing FCC and/or researching FCC has identified the challenges to getting FCC right. Based on the numerous research articles, we know it does not always work as well as we hope it will, and these problems in implementation seem to be global. Years ago, in a commentary on a review of qualitative studies on FCC, I raised a warning note about the assumption that FCC was the best underpinning approach to our practice. Nearly 10 years on, the same arguments and worries abound, we are still not getting it right. Typically, we blame pretty much everything apart from the darned theory. Shields confirms my concerns when she states: ‘there is no solid evidence that family-centred care works or if it makes a difference’. Too often we fail to empower the child, and too often decision making is less about what the family wants and more about what we think families need. We have a naïve assumption that something that we like, but we know is problematic, can and should be implemented everywhere, regardless of the local conditions. And the conditions in which we nurse, teach and research are very diverse.

We have yet to even agree a consensus on FCC. If we are to move FCC forward from the monstrous mishmash it has become, we need to have some sort of consensus on what it is or should be. Perhaps the clearest or most authentic version of FCC is that practiced everyday by the parents of technologically dependent children with very complex needs. If you observe and/or talk to a mother or father about what she or he does in terms of weaning a child’s care into the fabric of their family, we can get a genuine inking of what FCC can be. Family-centred care in this instance is a compassionate and conscientious consideration of the needs of every member of the family and a determination to protect their wellbeing, sustain health, and promote happiness. Parents work in partnership with each other. This is done whilst planning, delivering, and evaluating complex techno-clinical care they are providing, sometimes despite the lack of support from professional services. If we need to (re-)learn how to nurse, we need to look no further than the parents of children with complex healthcare needs.

Bernie Carter

Australia

There is growing consensus that care for ill children in developing countries rests on surviving illnesses rather than meeting social or emotional needs. This implies significant challenges in delivering comprehensive and coordinated FCC services to children and families within practice. For instance, while parents are able to negotiate the nature of their participation in care of their hospitalised child, families in Malawi, Thailand, and Jordan are often forced to participate in care based on cultural expectations. These studies emphasised contextual factors that need to be outlined and understood before initiating new health policies for these settings. Failure to take into account relevant factors affecting the successful implementation of FCC in these settings will result in inadequate fulfilling of FCC’s mission and standards. It remains critical to take into account the impact of nurse–patient ratio, as well as issues of financial constraints, and/or poor coordination of care across settings before adapting the FCC model for developing countries.

Diana Arabiat

Australia

The delivery of healthcare under a FCC philosophy in Malawi is similar to the reported variables that act as barriers or facilitators to FCC delivery within developed countries, albeit to different degrees. It is difficult to
In Malawi, absence of guidelines, infrastructure, education, knowledge and resources to develop and sustain an FCC context that is orchestrated through globalisation without involvement from all countries is a significant barrier.1,16

As a paediatric lecturer and research scholar in Australia, I have travelled with nursing students to developing countries for international clinical practicums. In Africa, we worked with healthcare professionals in tertiary, secondary and primary healthcare settings that included remote villages, orphanages, schools and large public hospitals. The aim of the placement was to gain knowledge translational to that clinical context, whilst honouring a universal code of ethics. As an academic, I also wanted to initiate future collaborative educational and research relationships with industry to build on FCC globalisation. However, despite reports of FCC practice, health outcomes, paternalism and the degree of preventable diseases being notably different between developed and developing countries, the inherent characteristics of FCC were covertly evident within clinical practice, relationships and engagement between staff, parents and children in Africa.22 The international experience made me question how refugees, international students and consumers of healthcare perceive healthcare services when living in a country that is different to their own. In addition, the lived experiences and therapeutic relationships we built with African people, whilst immersed within their culture, were truly inspirational, and have enriched my knowledge and being as a person, nurse and academic living within a multicultural society.

Despite discourse on FCC,23 a current theme in the literature and lived experience was the universal importance placed on family as a valued and needed constant in the child’s life.7 How this is operationalised as being enforced, regulated, supported or consumer-led requires further development where cultural sensitivity and safety need to be contextually relevant and honoured.24 Family-centred care concepts require further understanding to provide contextually relevant direction and support to facilitate FCC delivery relative to each country’s needs.16

Mandie Foster

Summary

In summary, Phiri et al.’s article1 shows that FCC is not practiced in Malawi, as family members are not empowered with the knowledge and skills to effectively participate in the care of their child. Is it ethically sound to suggest that FCC could be appropriate there? It would need health funding, government commitment, time and resources to achieve. If other health problems need attention, is it right to press for FCC, given its problems, or should countries with tightly stretched resources such as Malawi prioritise other issues?

Linda Shields

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Conflict of interest

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