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Confidence, not competence: Reframing roles to embed FICare

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ABSTRACT

This paper summarises and critically discusses the successful implementation of Family Integrated Care (FICare) at two Swedish tertiary neonatal intensive care units (Karolinska and Uppsala). The paper is the culmination of a three-day information-finding trip where we observed Swedish neonatal practice on the units and interviewed a range of key staff members regarding their approaches and values to neonatal care. The key findings were that parents are viewed as knowing their babies best and all neonatal staff work towards the ethos of zero separation. This is achieved through promoting confidence in parents to care for their own babies and the concept that neonatal nurses are there to facilitate instead of 'do'. We propose recommendations for how we can emulate the resource-independent aspects of this model in the UK.

1. Introduction

Family integrated care (FICare) is "a collaborative model of neonatal care which aims to address the negative impacts of the neonatal intensive care unit (NICU) … by involving parents as equal partners, minimizing separation, and supporting parent-infant closeness." (Waddington et al., 2021, p.148). A wealth of research has provided evidence that FICare is beneficial both to the prognosis of the baby (Chen & Dong, 2022), to the mental health of parents (Shin et al., 2018) and to attachments between parents and baby (Flacking et al., 2012). It is therefore becoming increasingly accepted amongst neonatal professionals in the United Kingdom (UK) that we should be striving to embed the FICare model in neonatal units alongside medical interventions (Bhojnagarwala et al., 2022) as outlined in the recent BAPM framework (BAPM, 2021). However, there is inconsistency across the UK as to how this should be done, with common barriers focusing on resources and policies, parental uptake, parental anxiety and professional perspectives (Janvier et al., 2022; van Veenendaal et al., 2022).

To better understand what successful implementation of FICare looks like, we conducted an information-finding trip to two tertiary neonatal units in Sweden: NICU Karolinska University Hospital (32 beds) and NICU Uppsala, University Hospital (20 beds) Fig. 1, Fig. 2:

We were struck by the calm and nurturing environment afforded by the NICU spaces, primarily due to the private areas that were available to families and reduced monitor activity. Flacking et al. (2012) have noted the multiple benefits on a baby's stability as a consequence of having unlimited skin-to-skin, and this was evident on the units, where kangaroo-care was actively promoted as a need of each baby from the moment parents were introduced to the NICU.

Creating an environment as described above is integral to the 'feeling' of FICare on the Swedish units; however, we were acutely aware that the resources and approach to parental leave that enables such 24/7 contact with babies is significantly lacking in the UK. As an example, in Sweden parents are offered up to 480 days paid shared parental leave (https://tinyurl.com/3map7bc9) and the neonatal facilities mean that they have somewhere to sleep, wash and eat without needing to leave the unit. This is driven by the premise that parents should be with their babies rather than any geographical need where families might be far from home: In Sweden, each of the 7 'health regions' has at least one tertiary NICU and the units work together to form 'transfer agreements' where babies can be moved or supported closer to home, either due to a medical need or parent preferences.

Given that the mortality rates in neonatal deaths in Sweden are 1.78 deaths per 1000, compared to 3.42 deaths per 1000 in the UK (https://www.macrotrends.net/countries/G-BR/united-kingdom/infant-mortality-rate); (https://www.macrotrends.net/countries/GBR/sweden/infant-mortality-rate), looking to the Swedish model may improve outcomes here in the UK. This paper will

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discuss the implementable aspects of the Swedish model and our recommendations for neonatal nursing practice.

2. Commentary

2.1. Facilitators, not 'do-ers'

From speaking with a range of different health professionals in the Swedish NICUs, we were struck by the consistent perception that a nurse's role was not as someone who 'does' things for the parent or baby, but as someone who shows and facilitates. Nurses were seen as coaches, empowering and enabling parents to gradually take on an increasing caring role, effectively becoming a member of the care team. Parents were integral members at ward rounds and their views and opinions were considered as equally expert and important as the rest of the medical team. Underlying this relationship was an ethos of *trust*: Parents were considered to know their babies best. As one professional at the Uppsala unit noted*: "Parents are a resource for knowledge-They know babies best"*.

In the UK, (Bhojnagarwala et al., 2022)have emulated this educational model with parents, whereby building skills acquisition and inclusion in ward rounds has led to increased shared decision making and positive collaborations between parents and staff, observing increases in understanding of neonatal charts and knowing when to get help, in addition to self-reported improvements in confidence caring for their babies.

When asked about initial barriers to the notion of the nurse as a coach, professionals in Sweden articulated a feeling that some nurses feared a *"loss of control"* and also felt that this *"wasn't what we'd trained for"* However, there was a shift in the 1990s as nurses began to appreciate that, if parents could take on most of the caring responsibilities such as nappy changes, baths, administering oral medicines, etc., then this could provide valuable time and resources for nurses to focus on the medical skills and procedures they *had* been trained for. As one professional at Karolinska commented *"Parents take care of the baby, and we take care of everything else."*

2.2. "Parents can hold a baby better than an incubator"

Thernström Blomqvist et al. (2022) acknowledge that neonatal nursing in Sweden is structured around three premises: "… timely expression and provision of mother's own breastmilk, early and prolonged skin-to-skin contact and close collaboration with the family." (p.151542) Several professionals spoke to us about how the incubator is not seen as a critical part of the medical equipment but is just there as a "last resort" for the most complex babies with skin-to-skin being the best source of temperature regulation. When parents first enter the NICU, they are informed that their contact, closeness and breast milk are the three equally important things that they can provide for their babies and all routines and practices on the NICU revolve around enabling parents to make this happen.

In the UK, professionals are very adept at educating mothers about

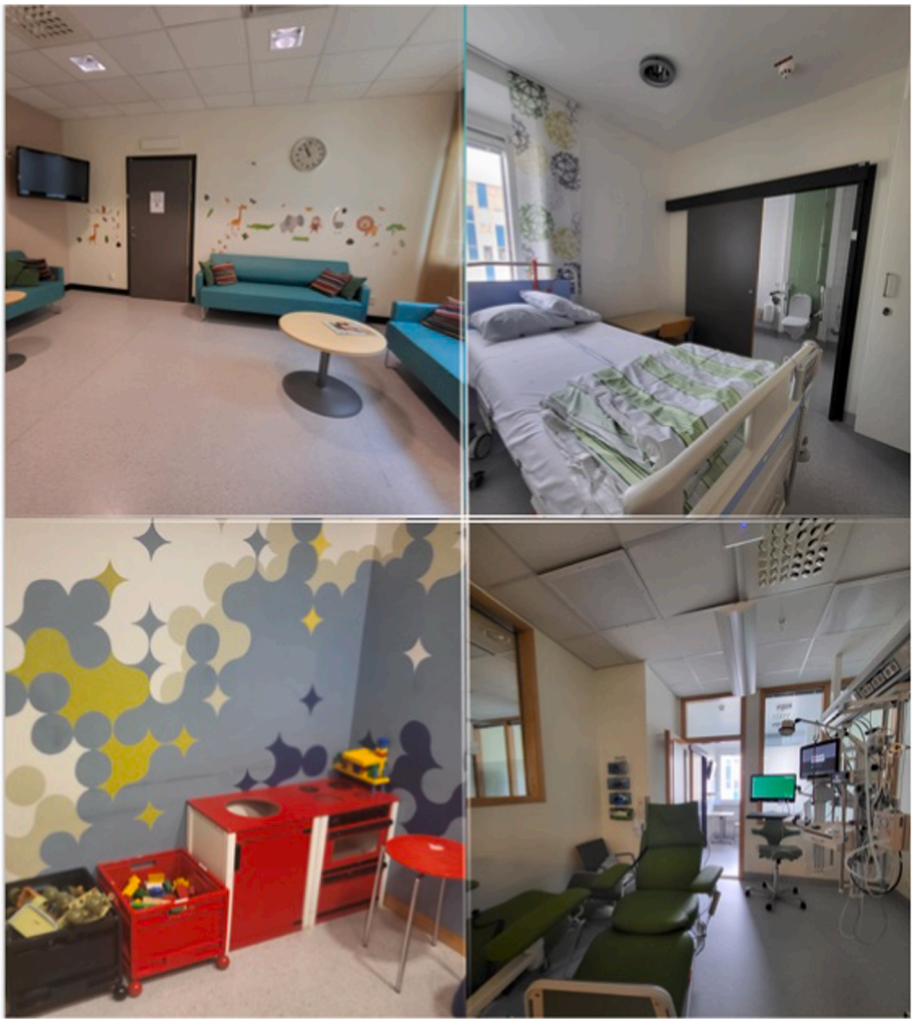

Fig. 1. Clockwise from top left: Family area, private family bedroom and on-ward family bay at Karolinska NICU; sibling play space at Uppsala NICU.

the importance of breast milk and many units have the facilities and support to promote expressing and breastfeeding. Interestingly, one professional noted in their interview with us that there is an inverse relationship between FICare practices and breastfeeding rates in Sweden because, in an embedded FICare environment, breastfeeding "is not the *only* thing that they [parents] can do." This could be viewed as one of the sacrifices of FICare and it would be pertinent to conduct comparative research investigating the impacts of this 'trade-off' on outcomes for babies and their parents in terms of physiological aspects, mental health and attachment in the UK and elsewhere. The question remains, however, why do we not promote skin-to-skin and closeness as highly as we do breastfeeding in the UK, when the evidence base clearly indicates a multitude of benefits for babies and their parents (Flacking et al., 2012)? It is possible that there's a reluctance to do so because nursing staff know that it is not always possible to support parents to have skin-to-skin on units that have space, resource and logistical constrains. But this is where the reframing of the role and importance of skin-to-skin becomes essential: If it is viewed as critical as the medicine and devices on the NICU, then our prioritization of how we enable it will need to change.

2.3. Confidence not competence

One of the striking things to come out of speaking with professionals was the language they used when discussing the parental role. Professionals didn't use terms such as 'skills, abilities or competencies' but instead talked about how *confident* or *empowered* parents felt. This terminology was reflected in the resources provided to parents as part of their initial induction onto the NICU and throughout the ongoing support they received when transitioning to home. This continuity of care and graded approach to building confidence was viewed very positively by parents and was cited by staff as one of the primary reasons for why babies in Sweden are discharged, on average, at around 35 weeks gestation (Compared to 38 weeks gestation at all units in the North East of England).

In the UK we have a mixed approach to parent education and many units still utilize 'going home checklists' that revolve around a parent's competencies rather than how *confident* they feel in carrying out tasks unsupported. Janvier et al. (2022) have acknowledged the delicate ethical balance of implementing FICare and how it can sometimes tip over into what they call "Family imposed care". They note the importance of considering the family's priorities when setting the pace and nature of 'training' and suggest that the most successful FICare practices will take a tailored approach to each family rather than following generic principles of what FICare *should* look like. One professional also spoke with us of "the maverick parent" and how powerful one 'trail-blazer' on the NICU can be. Whilst this might not initially sit well with most professionals, it was highlighted that often one loud parent voice can be a really informative window into some of the perceptions and difficulties parents face that staff might not immediately be aware of. Capturing the voices of these parents can be facilitated through establishing parent advisory groups; this is something happening across the country alongside the new Care Coordinator role and has proven to be an incredibly effective forum for improvement in the North East and other areas. The 'maverick parent' can also be a useful peer support for other parents who haven't felt confident enough to challenge or enquire.

3. Conclusions and reccommendations

The Swedish approach to FICare is deeply embedded into their systems and practices and, by the admission of the professionals we spoke to, did not happen overnight: Worries about nurses being 'de-skilled'; fears around litigation and what we can feasibly 'allow' parents to do safely; and worries about how this could look on the ground. For ethical reasons, we were unfortunately unable to speak with any parents during our visit and this might have enhanced our understanding of some of the barriers from a parent perspective. Nonetheless, Sweden has been a positive testbed for proving that the reticence around FICare was outweighed by the multiple benefits for babies, parents and staff alike (van Veenendaal et al., 2022) and is now so endemic to neonatal nursing practice that Swedish professionals gave us a slightly strange look when

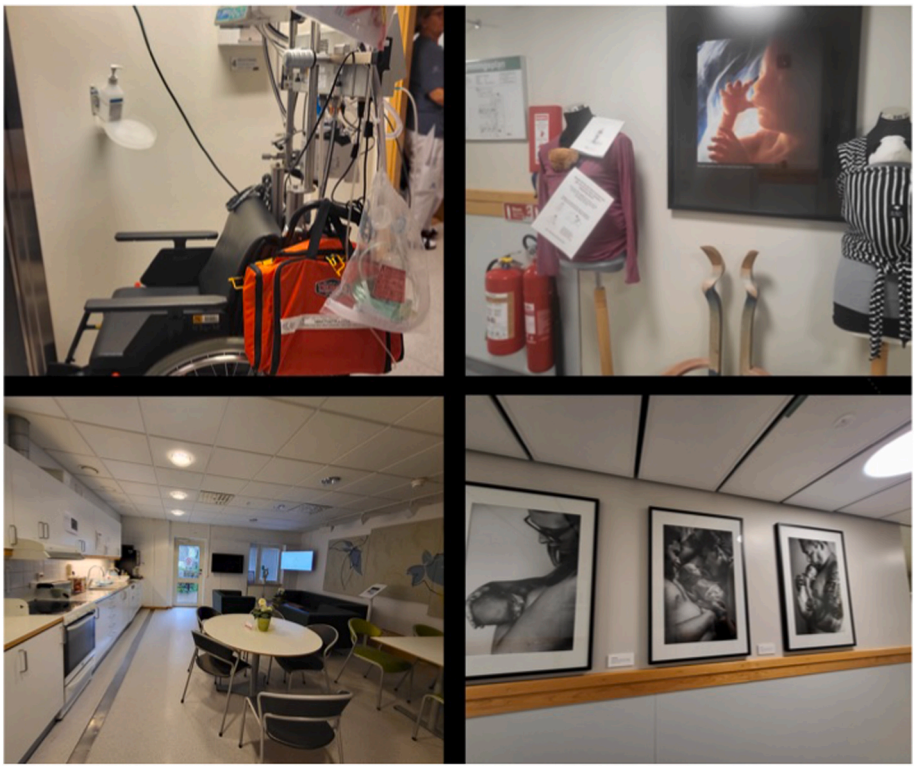

Fig. 2. Clockwise from top left: An adapted wheelchair at Karolinska NICU; adapted slings, family kitchen area and corridors at Uppsala NICU.

we asked why it's important. "Parents should be with their babies" is simply the core principle that sits at the centre of the NICUs.

So how can we begin to shift nursing culture in the UK towards this mentality of FICare just being the obvious best way forward? van Veenendaal et al. (2022) suggest utilizing the 'four Cs' of culture (values), collaboration, capacities and coaching. These may sit in parallel with the NHS '6Cs' but take a more focused approach on collaboration with families, leading us to develop 4 main recommendations from our trip.

1) We need to reframe the role of the parent and nurse to consider who is the expert in which aspects of the babies' care (Culture).
2) We need to work in partnership with parents, built on trust that they know their babies best (Collaboration).
3) In the absence of well-resourced NICUs and systemic parental well-being, we need to monopolize on the resources we have by setting the premise of closeness and contact from parents: "Parents can hold a baby better than an incubator" (Capacities).
4) We need to move away from 'competencies' and instead use education to build *confidence* in parents. (Coaching).

In following these recommendations, we can begin to make small, resource-free changes that will move us towards an ethos of 'parents not visitors' and the many positive outcomes that FICare can bring.

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Ethical statement

Ethical approval was not required due to this being an information-gathering exercise. All professionals interviewed gave their verbal consent for their anonymized quotations to be included in publications. No conflicts of interest to declare.

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