



Parent experience of shared decision making in Family Integrated Care

Learning from questionnaire responses and implications for future practice.

H. Apperley, S. Sakonidou, H. Meechan, F. Carey, M. Mendoza, E. Wood, P. Cawley
on behalf of the Evelina Children's Hospital Neonatal Family Integrated Care group
Neonatal Unit, Evelina London Children's Hospital



Background

Shared Decision Making (SDM) is an integral pillar of Family Intergrated Care (FICare). There is limited literature specifically relating to SDM in neonatal care and how parents experience this.

Understanding how effective our current SDM practice is through parental perceptions and feedback, is vital to improving both our service and that of similar tertiary NICU's looking to rollout or enhance SDM.

Methodology

Feedback from a SDM parent focus group informed the design of a questionnaire, which was then rolled out to gather mixed quantitative and qualitative data.

The 12-point questionnaire focused upon the six domains identified by informal consensus from a range of work around SDM, including the CO-PARTNER tool (1).

Over the period of one month in January 2023 there were 19 anonymised participants, including parents with babies previously and currently on the unit.

1) van Veenendaal NR, Auxier JN, van der Schoor SRD, Franck LS, Stelwagen MA, de Groof F, et al. (2021) Development and psychometric evaluation of the CO-PARTNER tool for collaboration and parent participation in neonatal care. PLoS ONE 16(6): e0252074.

Results

- A divergence of parent experience was observed:
- > 71% (81/114) of responses were positive (strongly agree/agree) to 6 core questions.
 - > 11% (2/19) did not feel included in clinical decisions with doctors and nurses
 - > 11% (2/19) did not feel able to contribute to decision making during ward rounds.

Concerns related to:

- 1) Consistency in ward round timing
- 2) Not being medically trained as a barrier to parental contributions
- 3) Parents trusting the medical team and feeling no need to contribute

74% (14/19) were supportive of the concept of parent led rounds. Whilst 26% (5/19) were against or ambivalent to the concept; reporting concern of being in the incorrect state of mind, confusing medical terms or worries that doctors would not have time for this.

Number of days per week parents attend ward-round

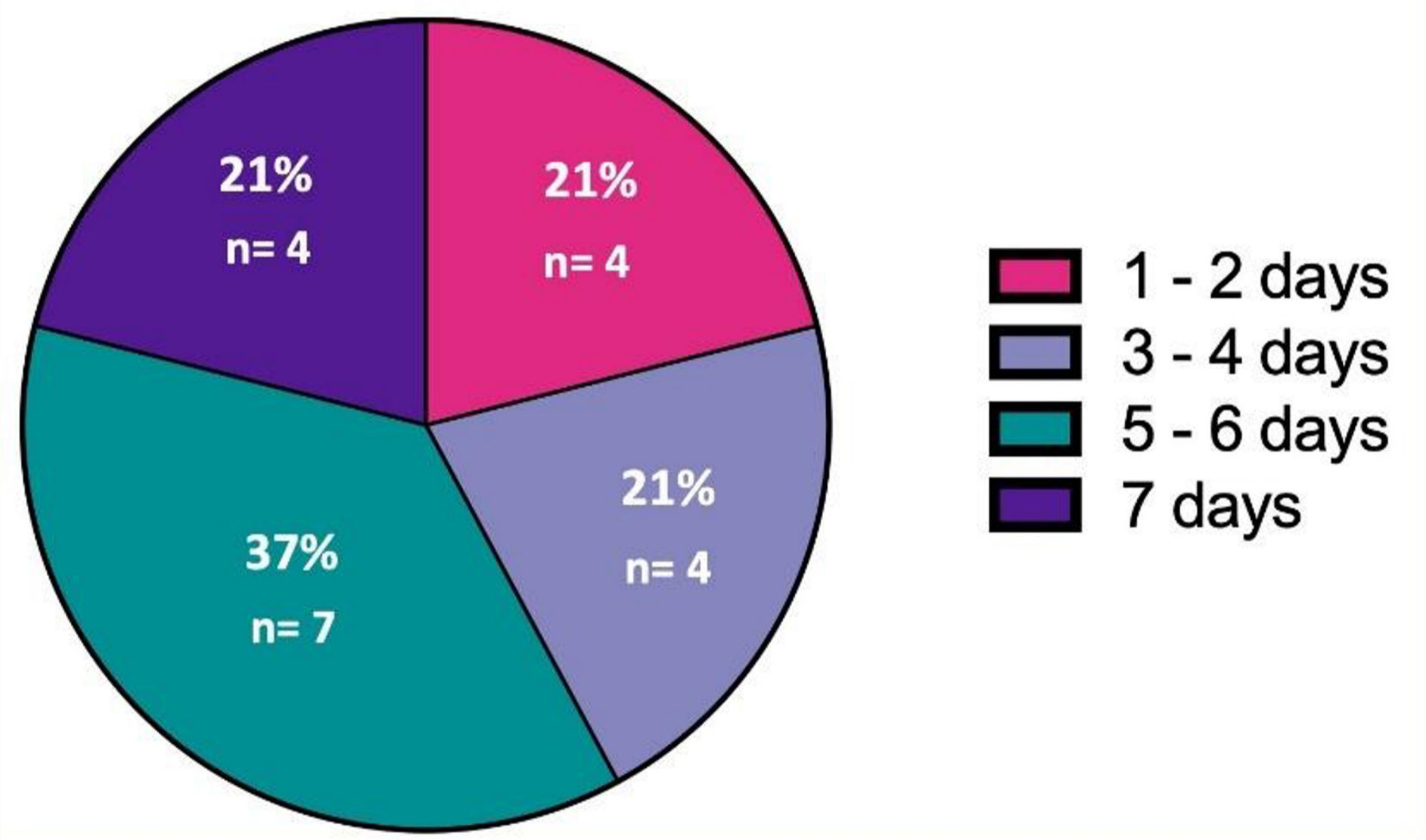


Figure 1. Number of days per week parents attend ward-round; as reported by parents.

Conclusions

Embedded practices can be at odds with proposed FICare delivery. There are cultural challenges to overcome for both staff and parents.

Staff training, redefining ward round practice and clarification of parental roles are areas for particular development. Early, active involvement sets a precedent for contribution and for improved understanding. Balancing the emotional aspects of care and support for new parents with focus on clinical care.