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### **Neonatal ethics and the ANNP: providing high quality practical support for neonatal intensive care teams**

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## MANUSCRIPT

### *Contemporary issue*

#### **Neonatal ethics and the ANNP: providing high quality practical support for neonatal intensive care teams**

*Evolution of the ANNP role:* At its inception in the 1990s, the Advanced Neonatal Nurse Practitioners' (ANNP) role focussed on contributing to a stable neonatal workforce, and on reducing the degree of variation in the quality of neonatal care provided in the UK. This priority was recognised partly due to the shortages and rapid turnover of junior doctors, and partly out of a realisation that there was under-utility of existing neonatal nursing expertise<sup>1</sup>. ANNPs were trained to assume a leading role in the care of the sick neonate, and to master the practical skills associated with this. This evolved to include a significant teaching role for career paediatricians/neonatologists, and in-service training days for nursing teams, and further, to actively supporting the middle and junior grade medical rota<sup>2</sup>. Providing high quality clinical care to sick neonates has become the norm for the ANNP.

*What is changing?* It is our opinion that the ANNP role has exponentially evolved, especially around complex ethical cases, such as but not restricted to those born at the threshold of viability<sup>3,4</sup>. At the front line care of these critically ill neonates, ANNPs are a regular bedside point of contact for neonatal nurses who are managing (or observing others manage) such a baby, or seeking reassurance that they understand the issues accurately, asking questions and looking for bite-sized secondary discussions around key concepts utilised in consultant-led team-decision making. As permanent respected members of the team, and at the junction of medical-nursing interphase, ANNPs have strong insights into the quirks, strengths, fallibility of both the nursing and medical workforce. They are the most stable hands on deck, and the most visible workforce at the bedside. Therefore, they are not infrequently compelled to raise difficult questions, to challenge and to promote awareness of different perspectives held within the wider team, all in interest of cohesion in the care provided.

But ANNPs too, live through and absorb the ongoing individual moral dilemmas of those around them. For example, the 'moral injury'<sup>5</sup>, stemming from internal conflict when their individual beliefs differ from decisions of the parents and teams around the baby, or from seeing

the pain and experiences lived by their patients<sup>6</sup>. An example scenario can be seen in Table 1; these are no doubt added sources of stress.

*What is the challenge?* The value of ANNPs in promoting unit cohesion in times of complex ethical and moral discussions within teams appears to be more apparent and necessary now. However, as a group, enhanced training or support may be required to meet the challenges this evolving secondary role produces<sup>7</sup>.

*The way forward:* In striving towards delivery of high quality neonatal and family care the issues to tackle for the future include how best to a) harness the evolving ANNP role for the benefit of neonatal teams, b) to optimally equip ANNPs to recognise and manage this role, and c) to develop strategies to counter the stressors that this role may bring. The pressure of being in a continuous intensive care environment<sup>2</sup>, together with the ethical and moral challenges this brings, could be contributing to limited recruitment in the UK.

As a start, a reinforced focus for ANNPs around neonatal ethics may be of value, through bedside experience and ongoing reflection, teaching, multi-sourced continued professional development, and/or simulations that engage the learner through the eyes of a patient<sup>8</sup>. These may be useful tools going forward, in consciously empowering ANNPs to support their teams, and function comfortably in what has become an inevitable but highly valued role.

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**Table 1**

**Thoughts which a nurse/health care worker/clinician may be dealing with, around the care of the critically ill neonate**

*Scenario: A 22<sup>+4</sup> week gestation preterm baby is born and offered life-sustaining support. She continues to deteriorate, and after the first 48 hours of intensive care a discussion is being held about reorienting care away from provision of intensive care.*

- Has resuscitating baby caused more harm than benefit?
- Is it really in baby's best interest to continue life-sustaining/intensive care, or to re-orientate towards comfort care?
- Do I think parents and the team have the best interest of *baby* at heart by continuing life-sustaining/intensive care, or re-orientating towards comfort care?
- Why is the medical decision changing from what was said at the beginning?
- I believe all life is valuable – they shouldn't stop life-sustaining/intensive care.
- I know baby has a right to live, but what about the right to die/be left alone?
- I want to express my opinion, but it is different from the rest of the team – how do I do this?
- Is baby feeling pain or discomfort?
- What would I do if it were my baby?
- Am I causing more pain and suffering to baby by nursing/providing medical care to baby?
- Is it right to interfere with the course of life and nature?
- How will the family cope if we continue and baby is severely disabled?

*If baby is deteriorating during or soon after leaving the shift:*

- Was my care the best it could have been?
- Could I have done anything more?
- Did I miss any clinical warning signs?
- I am upset that I could not make baby better.
- I am sad that I could not help mother/father/family/carer.
- How will the mother/father/family/carer cope if we re-orientate care away from life-sustaining intensive care support to comfort care, and baby dies?