Reflections on thirty years of neonatal care

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As a retired neonatal nurse with more than 30 years' experience, I have seen great changes taking place and enormous improvements in the technology used to keep preterm babies not only alive, but with the promise of a good quality of life. From 1968 until my retirement, I worked as a neonatal nurse in Greece, in Switzerland, and in Plymouth, England. My particular interests include the effects of pain on the newborn baby, which influenced me to create a pain scoring system for the newborn, and the great difficulty parents experience in coping with the loss of a baby who dies without ever having lived.

The early years: Aghia Sophia Children's Hospital, Athens, 1968-74

From 1968-74, I worked as a staff nurse in the preterm baby unit of Aghia (Saint) Sophia Children's Hospital in Goudi, a suburb of Athens. To my knowledge, the only other special care baby unit (SCBU) in Greece at that time was in Thessaloniki in the north. The hospital was a handsome modern building set in well-tended walled gardens, with a separate nursing school in the same grounds. Medical care and nursing were of a high standard, but equipment was basic – there was no money to spare. There were no sophisticated life support systems but the staff improvised and made best use of the facilities they had, such as creating continuous positive airway pressure (CPAP) to support immature lungs using rubber tubing, glass containers and nasal prongs.

Top: Holding one of our infants on the premature baby unit, Athens. *Above:* Nursing colleagues at Athens.

Outside the Aghia Sophia Children's Hospital, Goudi, Athens.

Babies came to our SCBU from all over Greece, in baskets or boxes, usually wrapped in rags, sheep's wool or straw. There was an ever-present risk of infection, mainly from *E. coli*. On one tragic occasion every baby in the unit died, even those who were almost ready to be sent home. Babies with diarrhoea were given cold sweetened tchai (tea), which was usually very effective. Visiting was restricted; the maternity hospital was in another part of Athens and often it was weeks, if not months, before parents could set eyes on their children.

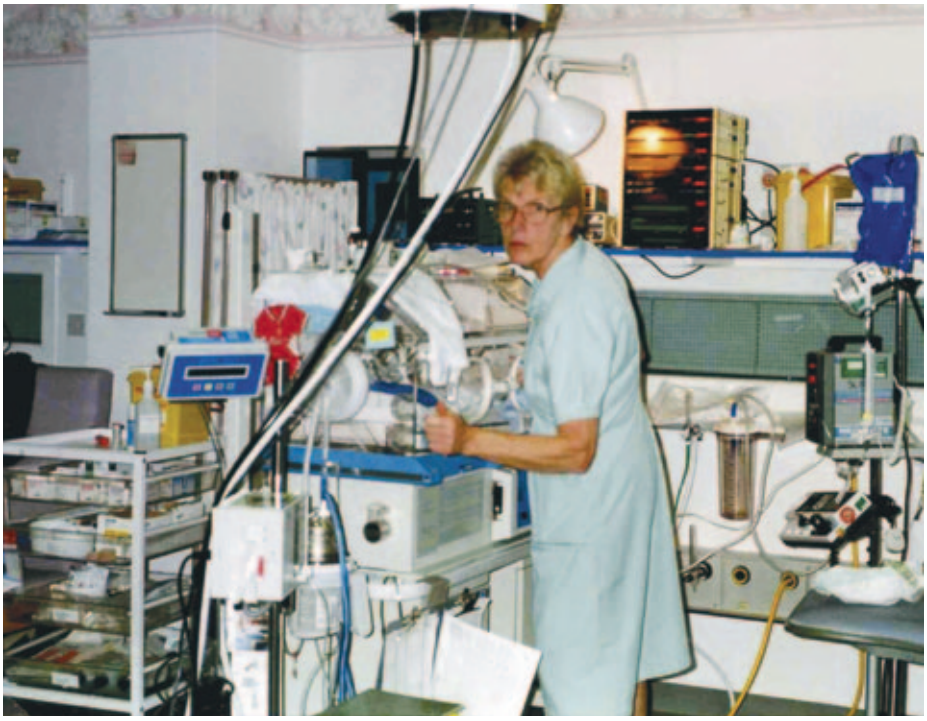
Neonatal jaundice requiring exchange transfusion was common at that time. The babies were bound, papoose-like, to a cruciform splint and usually slept calmly through the whole procedure in spite of the hours it took to complete – perhaps demonstrating how comforting swaddling is for the newborn. The house officer on call performed the procedure with an attendant nurse, using a 20mL syringe and discarding the used blood into an enamel bowl. This procedure was extremely tedious for the doctor and on one occasion the doctor complained of feeling dizzy and shaken. It wasn't until we noticed the blood swilling in the bowl that we realised we were in the middle of an earthquake.

Phototherapy was in use and the lamps were very similar to those used today. We would place babies with jaundice close to the windows to benefit from the light, while taking care to protect them from the hot sun of Greece. There was a curious custom at that time among the remote villages; babies with jaundice would arrive with shallow cuts in a cruciform pattern on their backs. These were made, usually by superstitious grandmothers brandishing knives, in order to 'let the devil out' with the blood.

Antibiotics were given intramuscularly, with the result that injection sites became as hard as chunks of wood. Intravenous fluids could be given but scalp veins were frequently used with needles fixed into place by plaster of Paris. Extravasation and consequent scarring was commonplace.

Geneva, Switzerland 1976-87

In 1976, following a brief spell at the Simpson Memorial Hospital in Edinburgh, I moved to the neonatal unit in Geneva, which was attached to the maternity hospital, making life much easier for



The NICU Plymouth.

parents than it had been in Athens. Switzerland, being a much wealthier country, had more sophisticated equipment than Greece. There were monitoring systems, syringe pumps and ventilators – although ventilation was hazardous as the ventilators were very basic and could not be set to different breathing rhythms.

Antibiotics were given intravenously; the neonatal nurses were experts in placing intravenous needles so there was less tissue damage but babies were pricked many times during their stay and frequently showed many scars. In Switzerland at that time, nurses were authorised to perform venepuncture, which relieved the pressure on junior doctors and, since the nurses became very adept, saved the babies some discomfort.

Parents were given strict instruction on visiting times but they were shown how to help care for their baby and a room was provided for the mothers whose babies were able to breastfeed. The parents were also shown nursing techniques, such as nappy changing, bathing and tube feeding.

Derriford Hospital, Plymouth, England, 1987-99

The last part of my career was spent as a staff nurse in the NICU of Derriford Hospital in Plymouth. By this time visiting hours had become much more flexible and parents were encouraged to help with the care of their baby at the earliest opportunity. The more stable ventilated babies were permitted to leave their incubators and were placed against their mother's bare skin – 'kangaroo' care. The presence of parents and siblings was now seen as crucial to the long-term well-being of the family.

Innovators such as Heidelise Als, with her synactive model of neonatal behavioural organisation[1] and T.B. Brazelton with his neonatal behavioural assessment scale[2], were beginning to encourage perception of the newborn baby as a person who, though incapable of speech, had emotions which could be read and understood.

Around this time neonatal units were becoming 'user-friendly'. As part of the ENB405 Neonatal Nursing course, I researched environmental problems for the sick newborn baby in hospital; stress caused by pain and other factors such as light, noise, day and night routines, and separation from parents[3].

By the time I retired in 1999, ventilators had become so sophisticated that the slightest chest movement could trigger ventilation. Life support systems had become very complex; this was and is very daunting to parents, who feel their baby is concealed by tubes and wires.

Changes over so many years could cause difficulty for a nurse who began work in a neonatal unit 30 years earlier! Hands-on nursing skills must be accompanied by expertise with technical apparatus and an understanding of abundant monitoring systems. When I started nursing, we were not trained to understand ventilators, machines and monitors. I learnt to adapt but some failed; one sister about my age worked all her nursing life on neonatal units but could not cope with these complexities and would hide herself in the store cupboard whenever there was an emergency admission.

After I retired, I recorded some of my experiences with bereaved parents and in 2009 I published 'Holy innocents: grieving for the death of a baby'[4]. I explored the different forms of grief experienced when losing a baby before, during and after birth and the needs of all family members; mothers, fathers, siblings, grandparents, etc. The book addresses the experiences of parents left angry and frustrated by staff insensitive to their needs and the spiritual needs of parents with different religious beliefs. I feel it is important to help parents 'move on' after they have endured the first grieving period, and later remember and mourn their baby as a member of the family; someone who did live, if only for a short time.

Life in an NICU is not a normal one for very small babies but we can try to make it as loving as possible. There are some things that are never out of date and never too late to learn: how to keep our babies comfortable and free from pain and how to reassure and comfort parents who are in great distress.

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