

What about brothers and sisters? Helping siblings cope with a new baby brother or sister in the NICU

The neonatal intensive care unit can be a distressing environment for both the parents and the sick infant, and equally so for a sibling. This article explores the effects on young siblings of having a new baby brother or sister admitted to the neonatal unit. Suggestions that may help the family understand and manage the situation more effectively are made.

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The neonatal intensive care unit can be a distressing environment for both the parents and the sick infant. However, the birth of a premature or sick baby into the NICU can be an equally distressing event for the sibling¹. With the introduction of the concept of family-centred and developmental care, parents on the NICU are encouraged to be involved with their infant's care and are given lots of advice and support both emotionally and financially². Nevertheless, the needs of the younger siblings of babies admitted to the NICU are very often forgotten. This became evident from clinical experience and having conducted a broad literature review, and contacting a number of charities who work specifically with siblings of sick children. There is a lot of research supporting siblings of chronically sick or disabled children tending to focus on older siblings who are able to communicate verbally³⁻⁵. However very little information is available to either the neonatal staff or indeed the families regarding the wellbeing of the younger NICU sibling.

Infants can be cared for in the NICU for several weeks, even months on end. The effect of the added stress on the family of the NICU infant can be considered to be similar to that of a family caring for a chronically sick child at home and having to pay regular visits to the hospital. In both cases this puts a strain on the family's financial, physical and emotional resources, and results in the family timetable being adjusted around the needs of the sick infant, and consequently minimising attention to the developmental needs of the sibling⁶. So why is it that siblings of children receiving palliative care

are considered, while very often the sibling of a NICU infant is forgotten? For some children this could be the beginning a lifetime of being the sibling of a sick child.

It is interesting to note that while advances in biomedical technology and improvements in care have led to a decrease in mortality rates in premature and extremely low birthweight neonates, there has not been a reported corresponding change in morbidity. This vulnerability of premature infants to medical and developmental complications has been demonstrated in the Epicure study⁷. The significance of these findings for the future health and development of these children, their siblings and the family unit will only become apparent after further assessment and research.

Arrival of a sibling

It can be very stressful for a child to accept the arrival of a sibling, regardless of the circumstances of the birth^{8,9}. However if this new brother or sister arrives suddenly and unexpectedly or is sick and has to stay in hospital, it is particularly confusing, tending to break the predictability of the sibling's world and family^{10,11}. Few parents anticipate complications of pregnancy or that their baby will be sick or premature, and so when this happens they are likely to become worried and traumatised, and may be worn out by the long hours, days and even months they spend with their baby in the NICU¹⁰. As well as the recognised trauma of preterm birth and having a sick infant on the NICU, one in ten women suffer from post traumatic stress disorder¹². To the sibling the short-term loss of the child's mother to the hospital may be as

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Key points

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1. The birth of a new baby can be a stressful time for a sibling, particularly if that baby is admitted to NICU.
2. The needs of younger siblings of babies who are not able to communicate verbally are often overlooked.
3. Separation from a parent for any length of time increases the distress of siblings.
4. Siblings need to be prepared before visiting the neonatal unit.
5. Parents need to take time to talk to their older children, explain what is happening and reassure them.

puzzling and upsetting as a more permanent loss would be, and they may worry the absent parent will not return¹³. Children can be enormously distressed by losses that adults regard as less important, and the birth of the new baby can be considered hugely distressing to the sibling, because it involves the loss of or lessening contact with someone treasured by them¹⁴.

Common feelings and behaviours

Children are quick to distinguish when all is not well with their parents. The effect is often triggered by the abrupt change in family routines and the subtle changes in their parents' behaviour towards them and each other¹⁴. It is quite natural for parents to have many changing emotions as they try to cope with the difficulties of a sick or premature baby, and this trauma may affect their parenting skills, thus making them, emotionally less resourceful and available to their other children¹⁴. This in turn may impact on the siblings' physical, psychosocial, behavioural and emotional wellbeing; affecting their school work and leading to feelings of anxiety, depression, resentment, jealousy, anger, fear and guilt³ (TABLE 1).

Some children may^{2,3,9,14}:

- play up to get attention, while others may become quiet and withdrawn
- have trouble eating or sleeping
- return to common behaviours from when they were young, such as thumb sucking, bed wetting, carrying a security blanket, or toy. These behaviours may be comforting and familiar
- have trouble in school.

TABLE 1 Common behaviours exhibited by siblings of sick infants.

Building on Fanos et al's³ work regarding a child's psychological well being, Camhi suggests the birth of a sick, tiny baby, who may not even look human in appearance, might make the sibling feel guilty and think that it is their fault the baby appears damaged and is not able to come home¹⁰. Davis and Stein¹¹ qualify this by suggesting children often believe their thoughts or actions are powerful enough to make things happen, for example a sibling might have wished for the baby to hurry up and be born, and therefore feels responsible for the premature birth. The brother or sister may have had feelings of envy and jealousy

and think these thoughts have caused the baby to be sick^{10,15} or could feel dissatisfied and angry not to get a playmate¹⁶. In addition, the siblings may even feel the parent's stress is linked to their bad behaviour or worry they might also get sick, making them feel scared and confused^{15,16} (TABLE 2).

Needs of the sibling

A lot of emphasis is put on the worry and stress the parents must endure by having a premature or sick baby in the NICU¹¹ and very often the well sibling can be forgotten while the family's attention is focused on the sick infant³. The siblings of infants born to the NICU are faced with influential and upsetting images as they are often hurled into this alien world without warning. In the midst of the chaos, turmoil, and disorganisation, there is often little time or energy for parents and caregivers to focus on what is happening in the daily lives of siblings¹⁶.

Siblings often experience strong emotions and reactions in response to this situation, as Camhi¹⁰ reports on two years of work observing sibling's (5 girls and 5 boys aged 20 months to 6 years) play and behaviour in the NICU. The children were supervised by a child psychotherapist, focusing on the often unnoticed needs of the siblings of premature and sick babies. This report however, only studied 10 infants, and serves as a record of observation qualified to selected psychological and play theories. Although much of what was observed were snapshots of these children's experiences during the very early days after the birth of the sick infant, it is an attempt to explore the behaviours of very young children exposed to an experience that is becoming more common. These observations are reflected in the author's clinical practice and the theories highlighted within the report serve to quantify these behaviours.

In addition to Camhi's¹⁰ report, Levick et al²¹ have found through observing siblings of NICU babies at an evening club, that while most of the family's energy is focused on the sick infant, the siblings are experiencing strong emotions and requiring support in response to the many adjustments to the family routine. For example, one child expressed how the tooth fairy had not been, even though they had left their tooth under the pillow – an event obviously important to the child that had been missed by the parents. While

Some children may feel^{10,14}:

- left out of their new brother or sister's life or feel that nobody is paying them any attention, which may make them feel jealous
- anger towards their parents for not protecting their brother or sister, or perhaps scared their parents will not be able to stop them from getting sick
- guilty they are healthy and happy not to be in hospital
- angry with their new brother or sister for arriving too early and for getting sick.

TABLE 2 Common feelings described by siblings of sick infants.

another expressed how although her brother was soon to be discharged she feared he was going to die. Understandably in the chaos of NICU the parents had become so burdened by their own experience that it was difficult for them to notice the effect on their other children. It demonstrates there is a great need for the sibling to spend quantity – not just quality – time with their parents¹¹ and that it is essential to keep in touch with the sibling's thoughts and feelings¹³. However, parents of premature and sick babies on the NICU have special worries about juggling the complex needs of the new baby and being there for the other children – an acknowledgement that has implications for the nurse of the NICU infant, that of recognising the need for, and providing, holistic support to the whole family unit.

Understanding the needs of siblings is vital in any effort to help them process the whole experience. Newman and McSweeney¹⁷ consider organisation to be an essential element of any successful sibling involvement programme, and a key role in implementing and accepting sibling participation.

Distressing news

It is only natural for parents to try and protect their child from hearing bad news or from seeing unfamiliar or unpleasant sights. However the sibling's point of view and the effect of change of the family routine on the child must be considered¹⁷. If a child's mother is in hospital either because she has had to stay in for her own health or to stay with the sick baby, the sibling will be missing her and needing to know where she is, who is looking after her and the new baby and when they will be coming home^{17,18}. If not given answers,

children will begin to make up their own reasons which are likely to be untrue¹⁷. Helping a child to cope with the death of a sibling can be equally as challenging if not more so¹⁹. Parents understandably become preoccupied with their own feelings of bereavement. Lindsay and MacCarthy (1974), cited in Walker²⁰ found that siblings of ten years and under perceived the absence or preoccupation of their parents as rejection of themselves. Young siblings often find themselves disconnected from the family unit and the normal grieving process, as there is a tendency of families to want to protect them¹⁹. Bowen (1978), cited in Walker²⁰ suggests children are hurt more by the closed communication than by the death of a sibling.

As Lindsay and Elsegood¹⁴ suggest, distressing news should be disclosed in such a way as to lessen the intensity of a child's anguish, reducing the sense of disbelief, sadness, anger, guilt, shame, inadequacy, vulnerability and hopelessness. Clinical experience has demonstrated it is useful to start by checking what the child already knows and their level of understanding before telling them more, thus making sure their understanding is correct before they become confused by additional information, which may not make sense. Children need to be told the truth or at least not told lies^{17,18}. As suggested by Falkenberg²¹, the whole experience could be made easier for the siblings of sick infants if they understand what is going on and the purpose of all the activity around their new brother or sister.

Visiting the unit

In the unit where the author is based, an open visiting policy is operated which appears to be similar in many other NICUs, promoting the concept of family-centred care and allowing parents, siblings, and grandparents the opportunity to support each other. However younger children should not be exposed in an unprepared way to some of what they may experience in the NICU environment²². Siblings who visit the NICU for the first time without being prepared are suddenly exposed to a noisy, hurried, stressful environment and surrounded by parents with high anxiety levels and the staff concerned about the preterm or sick infant. Both parent and staff efforts are primarily focused on the NICU baby who needs their attention and care. The siblings, who also desperately need attention and care, may be overlooked, not



Siblings need a chance to meet their baby brother or sister, no matter how sick they are. Photograph taken from 'A Photographic Memory: Guidance for Professionals' produced by the Child Bereavement Charity (formerly The Child Bereavement Trust). www.childbereavement.org.uk

deliberately, but because of the very nature of the crisis¹⁶. Preparing siblings to visit their sick baby brother or sister will help them to deal with the NICU environment and what is happening in their family life. Siblings need lots of reassurance through activities and experiences that display a parents' love for them too, an argument supported by Taylor et al²³. It should, however, be recognised that a properly organised visit to the NICU, allowing time for preparation of the sibling and for the emotional experience of the sibling, can be a positive one – enhancing sibling bonding and strengthening the family unit.

Siblings club

Having performed a broad internet search the author has found that a number of units worldwide facilitate some of the needs of the sibling. A unit in New Zealand has a designated play area either supervised or unsupervised near to the neonatal unit¹⁶. Family functioning and bonding can be strengthened through play by slowly involving siblings in the family experience of the hospitalisation and care of a premature or ill infant. Play is always important for children for fun, developing social skills, discovering and communicating – and can be a great aid to promoting normality, reducing anxiety, facilitating communication and preparing the sibling for a visit to the NICU for the first time¹⁶.

Another unit in America promotes a family-centred care approach by offering a

programme and intervention designed to meet the unique needs faced by siblings. One evening a week the parents and siblings meet. The parents are encouraged not to sit with their children, but to join other parents of NICU siblings on the other side of the room, separated by a curtain. The siblings are supervised by a play therapist giving them the opportunity to express their feelings either through play or by talking to other siblings of their age group or a child specialist¹⁶. Finally another unit in America has been funded and supplied with 200 hand decorated boxes with messages of love and encouragement and an assortment of activities such as colouring books, crayons, felt tips, cards and small games²². A simple but very effective idea allowing the parents to focus more on the care of the sick infant, while the sibling is occupied.

Suggestions for parents

One of the most important things parents can do for their other children is to talk with them. They need to be honest about what is happening, and let the sibling know they are willing to listen to them, assuring the sibling they are still special and loved. The whole experience can be made easier for the sibling when they can understand what is going on and the purpose of the activity around their new brother or sister. Suggestions the nurse may make to the family to encourage sibling involvement include^{1,10,15,21}:

- Involving them in the baby's progress,

- giving simple and honest updates, marking days off on a calendar.
- Giving reassurance that their baby brother or sister's illness is not the sibling's fault and being alert to behavioural changes.
- If planning a visit with siblings, helping them to prepare by making a video tape of one of their own visits, or taking photos, showing the sibling the NICU environment. Equally, the parents can describe how it looks, sounds and how the equipment is helping their brother or sister.
- Before visiting, helping the sibling to choose a toy, a family photo or photo of themselves to put in the baby's cot.
- Encouraging the sibling to draw a postcard size picture to go into the cot for their brother or sister.
- Where possible allowing the sibling to determine the length of stay.
- Surprising the sibling with a toy their baby brother or sister has 'chosen' – by putting it into the cot for them to find when they visit.
- Leaving messages on the cot from the baby brother or sister to the sibling.
- If possible encouraging the sibling to talk to and touch their baby brother or sister, reinforcing the family unit and enhancing bonding.
- Advising the family to discuss the visit with their child after they leave, and if they have time to take them to a park or other similar recreational ground.
- Making a scrap book for the sibling to take to school with photos of their first cuddle with the baby, footprints, a nappy, and hospital information booklet.
- Involving the sibling in the creation of a baby's journey box. (A small cardboard box given to parents on the author's NICU, to store photographs, name tags, the first size nappy, first feeding syringe etc).
- Setting aside a special time for reading books at bedtime, (maybe to tell a special story about a baby on NICU), singing songs, visiting the park, going to a movie, taking them out in the pushchair.
- Spending time looking through photos of the sibling as a baby – talking about what is the same and what is different.
- As much as possible, maintaining the familiar routines such as going to playgroup and visiting friends.
- Borrowing different toys, books, etc from their local library to keep the sibling occupied while they are resting or expressing milk for the baby.

- Seeking support from other family members and friends.

Advice pamphlet

Having identified and discussed the emotional needs of the siblings of premature infants in the NICU, the author has designed and produced an advice pamphlet to raise awareness of these issues in the parents and staff based on the author's NICU. Parents with siblings of the infants on the NICU were invited to be involved in the publication of the pamphlet providing constructive feedback on the pamphlet's design, wording and on what information they found useful and the information they would like to see included. The pamphlet offers simple, practical information and advice on some common behaviours and feelings that may be experienced by siblings within the NICU. Support for production of the pamphlet was gained from the unit counsellor, manager, consultants and sisters. The advice pamphlet was designed, published and is currently available on the author's unit.

Recommendations

- Production of information leaflets for both families and healthcare staff
- Continued professional development of healthcare staff in recognising the importance and scope of holistic, family-centred care within the NICU.
- Development of a designated play area for visiting siblings on the unit away from the cot side, run by nursery nurses with the involvement of a child development/play specialist.
- Links with the hospital crèche.
- Improved links and referrals between the paediatric intensive care unit play specialist resources, hospital family counsellor and NICU.
- Introduction of small play objects, such as colouring books to entertain siblings on the NICU if a play area is not available.
- Evening clubs for both parents and siblings, promoting play and discussion between similar family groups.
- Inclusion of the sibling topic as part of medical and nurse teaching programmes.

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