

Palliative care for babies following a diagnosis of lethal fetal abnormality

For many clinicians working in obstetrics, fetal medicine and genetics, termination seems to be the rational, obvious, decisive “solution” when a diagnosis of a lethal or life-limiting malformation is made before birth.

Following a diagnosis of a life-limiting condition, many parents are shocked and confused. They find themselves in a painful and emotionally charged situation that they had never imagined. They ask themselves “How do responsible parents act in this situation”. As a result they are frequently open to implicit suggestion and manipulation from professionals, and many parents opt for an abortion, at least in part because of explicit or implicit pressure from health professionals.

However, over the last decade there has been a growing realisation amongst health professionals in the UK that termination of pregnancy is not the only viable option following the antenatal diagnosis of a life-limiting malformation. Continuing the pregnancy with the provision of high quality palliative care after birth is increasingly recognised as a compassionate and realistic response. The terminology of “perinatal hospice” is often used in the USA. I prefer the term neonatal palliative care as it demonstrates the connection with palliative care in children and adults. Also in the UK the term “hospice” implies a separate charitable institution whereas in reality neonatal palliative care is usually provided within established NHS facilities.

In my experience a neonatologist has an important role in counselling parents in the antenatal period. The neonatologist can provide parents with factual information about the nature of neonatal care and the care options which exist after delivery. The neonatologist can also offer practical experiences of palliative care in similarly affected infants and can reassure parents about the realities of the dying process. They may also be able to recount the experiences of other families and how they have come to view the experience in retrospect.

It is my experience that on the first mention of continuing the pregnancy followed by palliative care, some parents are troubled or even repelled by the concept. The idea of continuing a pregnancy when death is inevitable may at first appear macabre and strange, even medieval. Yet once the reality is discussed and the understandable concerns of parents are addressed, many will start to reconsider the option.

From my own practical clinical experience of caring for babies over more than 25 years I have become convinced that, when a lethal fetal malformation is identified, continuing the pregnancy and providing palliative care after birth may have many positive aspects.

One of the most important factors is that there is the opportunity for the parents to meet the child. Even if the baby only lives for a matter of days or hours the child has an identity and a name. Parents are able to spend precious minutes and hours meeting their child, experiences which are often vividly relived and remembered for the rest of their lives. Photographs are taken and mementos, such as footprints or a hospital name bracelet, are kept. Relatives including siblings and the extended family are involved and are able to meet the child, in addition to a range of health professionals attached to the neonatal unit. Religious and other ceremonies can be arranged. All of this means that the child becomes a social reality; not just a theoretical concept but a real tangible member of the community. As a result there are many opportunities to provide support for the parents, both from family and friends and from health professionals. Of course there is still sadness and loss, but these painful emotions are shared by others, who have seen and held the baby.

This is in marked contrast to the events surrounding a late termination of pregnancy for fetal malformation. With late termination there is usually a strong desire to maintain strict confidentiality; often the parents do not wish anybody to be informed about the termination and sometimes an obscure sense of shame is apparent. Only a very small number of trusted individuals are let into the secret. Parents may not wish to see the body of the aborted fetus and seem to be less likely to spend time with the baby after death. And as a result many opportunities for social support and comfort are lost.

There is no doubt that both the experience of termination of pregnancy for fetal abnormality medical reasons and the experience of neonatal bereavement are psychologically stressful and may have long-lasting consequences. But in my experience there are differences in the psychological responses to these two major life-events.

With termination there is often an initial sense of relief but with time there may be a sense of psychological ambivalence. "Did we make the right decision?", "Did I love my child too much or not enough?", "Was my decision

to terminate genuinely in the interests of my child or was I being selfish or perhaps, cowardly?”, “I wonder what my baby would have looked like if the pregnancy had continued”, “Perhaps the doctors were wrong and the condition was not as serious as was thought.”

It is not surprising that several studies have found high levels of long-term psychological distress following termination for fetal abnormality.

The psychological response to neonatal bereavement seems different. Although there is great sadness and a devastating sense of loss, in my experience there is rarely any psychological ambivalence or feelings of regret. Parents have a sense that they did everything they could for their baby. Most parents find great comfort and solace both from the short time they spent with their baby and from the degree of support from family, friends and staff. The sad memories may be tinged with glimpses of comfort, even joy in the midst of sorrow.

For health professionals, the goals and priorities of palliative care are very different from routine paediatric care. In routine care the primary goal is to extend life and to reverse pathological processes. But when we institute palliative care the aim is neither to prolong life nor to hasten death by medical intervention. The timing of death is seen as part of a natural process and outside the control of the health team. In principle death should be allowed to occur naturally and by natural processes.

So our first priority is to prevent or minimise pain and to treat any distressing symptoms, such as breathlessness, hunger, convulsions, vomiting and so on. Secondly the priority is to maximise the opportunity for private, loving interaction between the dying baby and his or her parents and the wider family.

At the same time we have a humanitarian duty to provide basic hydration (and nutrition with milk feeds unless there is a strong contra-indication). Finally we have a duty to provide psychological support for parents and family as they go through the profound and painful life experience of accompanying their baby to death.

The pioneers of adult palliative care in the UK developed the concept that the dying person suffered “total pain”. This is pain that encompasses every aspect of the individual - physical, cognitive, affective, relational, social, and spiritual

or existential. In palliative care of the newborn it might be conceived that this total pain is distributed between the baby and the parents. The baby may have physical pain and possibly a degree of mental distress, but the other aspects of pain are suffered by the parents. The challenge for health professionals is to address every aspect of this total pain. In contrast to the narrow technical skills which much of modern neonatology requires, palliative care requires a broad understanding of many different aspects of human experience and a sensitivity to the unique constellation of issues which every patient and every family bring.

Clinical experience shows how difficult it is to predict how long a baby with a particular combination of clinical features may survive with palliative care. On many occasions I have predicted that a baby is likely to die shortly after birth, only to have my prognostications proved wildly inaccurate. A wide range of medical interventions are possible and these may have the effect of prolonging life by days, weeks or months.

Whether the process of dying last minutes, hours, days or months, however, the duty of the health team is to accompany the baby and the parents along the journey, and to reassure the parents that we will never abandon them.

Where a lethal or life-limiting malformation has been diagnosed antenatally, it is essential that a management plan for postnatal care is developed and put into practice. It is important to have a detailed discussion with the parents on the likely events after birth, including the possible responses which the neonatal team may make if the condition of the baby is unexpectedly good. It is important to consider the possibility that the diagnosis or prognosis may be in error and raise this possibility with the parents. I have had personal experience of several cases in which the confident diagnosis of a lethal abnormality had to be rapidly revised following delivery!

Wherever possible the aim should be to have an experienced neonatal team present at the delivery in order to rapidly assess the baby's condition and reassure the parents that appropriate decisions are being made. In my experience it is helpful for the baby to be admitted to the neonatal unit for assessment after birth. This facilitates careful clinical examination and assessment and allows appropriate psychological support to be provided for the parents. Wherever possible a private space for parents and baby should be provided to maximise the opportunity for the parents to spend uninterrupted time with their baby. If the parents will only have a few hours with their child

before death, it is important for those precious hours to be protected. Sometimes parents wish to be left alone with their baby. Sometimes they prefer to have the support of a nurse or doctor in the room with them.

It is important to try to individualise medical and nursing care for the baby and family and in this situation the staff should be prepared to improvise and to try unconventional approaches. It is also important to try to ensure continuity of care over nights and weekends, when staff changes may cause disruption and anxiety. In particular it is vitally important to avoid any psychological sense of “abandonment”.

In place of the traditional paternalistic model of the doctor-patient relationship, when discussing options with parents in the antenatal and neonatal period a more collaborative approach is appropriate.

I believe that the model of an “expert-expert” relationship can be helpful. The neonatologist has expertise in the diagnosis, prognosis and treatment options available to a newborn with a life-threatening illness or malformation. The neonatologist must bring not only technical expertise to the discussion, but also the essential virtues of the physician - compassion, empathy, wisdom, humanity and moral integrity. But parents have expertise too – in their family background, life history, values and philosophical beliefs and so on. The basis of expert-expert relationships must be one of mutual respect. I expect parents to respect my expertise as a neonatologist, but I too must respect the particular expertise of the parents. Together we try to find agreement on the way forward, a consensual decision which meets the concerns of both parties. This quest for consensus requires honesty, openness and transparency. Sometimes it may be necessary to negotiate in the attempt to reach a compromise solution which is acceptable to both parties.

If death does not occur rapidly it may be useful to consider the possibility of continuing palliative care at home or at specialist paediatric hospice. Again, it is essential to avoid “abandonment”. A care package involving skilled nursing and medical support is essential before a dying baby can be transferred home and detailed planning is essential. This is a growing trend in the UK and home palliative care has been provided very successfully in many cases.

I have concluded that one of the essential characteristics that neonatal staff should display to the dying baby is one of *respect* – respect for the essential dignity of the human person, however malformed and distorted by the

consequences of disease. Parents are very sensitive to the hidden attitudes of the staff and if they sense an attitude of contempt or indifference to their child this can be very hurtful. We communicate this attitude of respect by spending time with the baby, by the way we touch and handle the baby and parents, by our words and by our actions. In my experience parents often find it helpful if staff verbalise their own feelings; the expression of humanity and empathy is always appropriate.

A bereavement appointment after 3-4 weeks is very valuable. Firstly, to review the events that happened before and after birth and to explain the reason for any medical decisions. Rational understanding and cognitive processing is an important part of the grieving process and some weeks after death many parents have questions and issues that they wish to discuss. Secondly, the bereavement appointment is valuable for discussion of the implications for future pregnancies and the possible diagnostic procedures and referrals which may be required. Thirdly, the appointment allows discussion of the psychological elements of the unique grieving process which the parents are experiencing and the resources that are available for ongoing psychological support.

Parental intuitions about their dying baby

Here are some common parental intuitions about the malformed or terminally ill newborn which emerge from my own clinical experience.

“My baby is a unique individual to be named, loved and treated with respect - a person not a thing.”

“Although my baby may have very limited chance of life or development, he or she is not disposable and can never be replaced.”

“If my baby has no prospect of long-term survival, it is appropriate to ‘allow nature to take its course’, but this is intuitively different from killing or actively ending the life of my child.”

“If my baby dies, the physical reminders of his or her existence are of unique significance and importance.”

“Although I may have future babies, they can never replace the unique individual I have lost.”

Conclusion

Neonatal palliative care provides a realistic, compassionate, compelling and practical response to the diagnosis of a life-limiting fetal abnormality. I would argue that it should be promoted and celebrated as a life-enhancing development within modern medical care. Speaking personally, I must have cared for many thousands of babies who survived and went home to great celebration and relief. But it is the relatively small number of dying babies that I had the privilege of caring for that stand out in my memory.

However at present the provision of neonatal palliative care is patchy and it is sadly true that many parents given a diagnosis of a life-limiting fetal abnormality are not informed of the possibility of high-quality palliative care after delivery. There is a major task of education and we need to transform attitudes within the healthcare professions. To ensure that a baby dies at peace, pain-free and surrounded by his or her family who are in turn being supported by healthcare staff, should be seen as a triumph of modern neonatal care.

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