Personal practice

Management of perinatal bereavement

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'At first the full reaction may be delayed, or there may be a period of numbness or blunting in which the bereaved person acts as if nothing had happened for a few hours or days or up to two weeks. Thereafter attacks of yearning and distress with autonomic disturbance begins. These occur in waves and are aggravated by reminders of the deceased. Between the attacks the bereaved person is depressed and apathetic with a sense of futility. Associated symptoms are insomnia, anorexia, restlessness, irritability with occasional outbursts of anger directed against others or the self, and preoccupation with thoughts of the deceased.1

My study of perinatal bereavement stems from a prior interest in the emotional and psychological aspects that accompany illness in children and its impact on the family. To help me deal with these problems I sought help by joining a Balint Group on the doctor–patient relationship; and later we—a group of like minded paediatricians—started the Anna Freud Paediatric Study Group which lasted for some 20 years until her death. This led to the establishment of my ‘Tuesday’ clinic in Woolwich where every type of emotional problem associated with illness was tackled: chronic illness, handi-capped children, life threatening illnesses, and bereavement.

The bereavement clinic

In the late 1960s when Machin approached us to participate in the South East Metropolitan Region study of spontaneous aborted fetuses I invited parents who had suffered a perinatal bereavement at the British Hospital for Mothers and Babies to talk things over.2 There were at that time no guidelines from others experienced in the field and no literature that I could find on the subject. But interestingly enough this ‘experimental bereavement clinic’ coincided with publication of some papers on the subject, which demonstrated a new climate of thinking.3-5 This motivated me to try to engage others,6 and a small group of interested professionals and consumers came together to produce a pamphlet which the Health Education Council published in 1979 and has continued to publish, providing some 10 000 free copies a year.7 Concurrent initiatives led to the founding of the Stillbirth and Neonatal Death Society (28 Portland Place, London) and publications by the Royal College of Midwives8 and the Royal College of Obstetricians and Gynaecologists.9 A remarkable change has occurred in the last 15 years, as is evidenced by the perennial spate of articles in popular weeklies, newspapers, and especially the two excellent films produced by Esther Rantzen for the BBC called ‘The Lost Babies’.

To answer the particular needs of an ever increasing number of families whose malformed fetus is being diagnosed by ultrasound, the self help group, Support after Termination for Abnormal Pregnancy (SATFA) has been launched. Batcup has written on the management of 12 to 28 week fetal loss.10

What and how

What are the basic and fundamental lessons that I have learnt from all this experience in the management of perinatal bereavement? Essentially that it is a painful, difficult, and demanding task and calls for much patience and applied endeavour. I learned very quickly that the medical model of ‘pain relief’ and ‘tea and sympathy’ does not meet the needs of bereaved families. The pain of the death of a baby cannot be extinguished. It has to be lived through. Experience of those working in the field of bereave-ment has taught us that grief is the inevitable emotional reaction to loss and that mourning is the psychological process that gradually undoes the psychological bonds with the dead child and eventual freedom from the preoccupation with the dead baby. Adequate mourning enables the bereaved to readjust and to organise their lives successfully.
Unfortunately in the past, and sadly still in the present, bereaved parents are not helped as much as they could be by professionals who block the reality of the experience by misplaced kindness because they try to spare parents the pain of seeing and holding, for example, a malformed baby. We have now learnt, however, how to clothe such a baby to make it easier for the parents. The routine photography of all stillborns, and now even miscarriages, \(^{10,11}\) and practices such as giving parents the baby's name tag, lock of hair, or other momento shows how much progress has been made. While an experienced and interested midwife, paediatrician, obstetrician, or social worker can provide help, everyone who is in contact with the family needs to be aware of the loss and the need that bereaved parents have of empathy for their state of mind and feelings.

Right from the start, with the first suspicion that there may be something amiss, a recognised and identified professional should be immediately available and it should be someone who hopefully will be available subsequently. From a practical point of view each team should try to evolve a first, second, and third person to be 'on call' for such help. The skills required are an interest in such needs and the ability to share with parents their grief. We are not all made for this work, but much of it can be taught and learnt, and if for personal reasons and one's own life events, we are not comfortable or suited to undertake this onerous task, we should be honest and say so, otherwise it is neither fair to parents or to ourselves.

The acute intensity of the moment of realisation calls for special skills, as when an infant is unexpectedly stillborn, when the ultrasound shows an abnormal fetus, or the amniocentesis shows abnormal chromosomes. We should recognise the subjective anxiety and fear that such situations can engender in junior nursing or medical staff and a protocol established for help from a named and identified senior member of staff.

In practical terms every member of the hospital staff should know that a bereavement counselling service is available, where it is held, and how appointments are made. It has always been my practice to arrange for the parents to see the consultant obstetrician who was in charge of them in the first instance and to see themselves soon after they have seen him whenever possible. The fact that both parents are invited together recognises how much they are both involved; so often I find fathers are left out. I find that a minimum of 45 minutes is almost always needed: at this initial interview time is necessary for the weeping and comforting that take place. A lot of the time may be spent in silence, as an acceptance of the poignancy of their feelings which makes talking difficult. I learnt by experience, after many mistakes, when to try to break the silence with an open ended remark such as 'many parents have ideas about why their baby died, which they think might sound foolish—a parent once asked me if it could have anything to do with the dog next door having been ill?' I find it easier at such interviews when I sit alongside them and not behind a desk. I was puzzled how best to make notes. I even tried taping the interview, but the secretarial time in transcribing such tapes proved prohibitive, as did the editing of them. Eventually I found that jotting down the main features of the interview immediately after they had left proved best and most useful when discussing this at the perinatal meeting and in the confidential letters to their general practitioner and the appropriate local health authority (with the parent's permission).

When bereaved parents talk things over with a counsellor—who may be any member of the hospital staff, chaplain, psychiatric social worker, or midwife as well as the obstetrician or paediatrician—it may not be easy for them as they will be burdened with painful emotions. What they choose to talk about is obviously what they are thinking about and what matters to them. Over the years I developed an operative check list of items I found of importance to them in their day to day living as well as in the future, and I bring up these subjects when the parents appear to have finished their choice of conversation. These items include for example: what siblings think and feel and how best to include them in the experience as their needs are unfortunately too often overlooked or underestimated and they can suffer in their bewilderment immediately and, most importantly, for a long time afterwards. There is the ubiquitous embarrassment and discomfort that parents, relatives, friends, neighbours, and shopkeepers often experience; the impact of anniversaries; information about local support groups; and the time needed for adequate mourning before the next pregnancy and, above all, access for further counselling. The skill required for such counselling is not easily acquired and the lessons learnt from mistakes prove invaluable for the future, albeit very uncomfortable at the time. It requires more than just the ability to listen, for one has to learn to hear what is being said and not being said, and what may possibly lay behind what they are saying and asking. More comes up for discussion than just the event and the quality of the marriage, and the parent's relationship has a considerable bearing on the support they can give and receive from each other.

The reason for the baby's death and the informa-
tion parents require is important, but in practice not as much as I thought when I started. At first I thought that this would be a priority and I arranged for the first appointment to be six weeks after the baby's death in order to have the report of the postmortem examination to hand. Wiglesworth has pointed out succinctly how opportunities for pathological examination are still missed in the present day, and what needs to be done to improve the situation.11

To see, to hold, and to name the baby, and to discuss funeral arrangements have become part of everyday practice in an ever increasing number of maternity units.

There is a natural inclination on everybody's part to try to wipe out the past and its pain and advise the parents to try for another baby as quickly as possible. Understandable as this reaction is, we have now learnt that such a 'replacement' does not achieve the desired aim. Without a period of adequate mourning, which should be at least six to nine months, the mother's unresolved grief can resurge and with even greater force when the new baby is born. It is not easy to know when the mourning process is sufficiently over to embark on the next pregnancy as the apparent recovery may, in fact, be a state of denial. Pregnancy prevents adequate mourning and apart from the mother's resurgent grief the effect on the new baby of being a replacement can seriously affect the child's gender and identity.12 There are those who fail to respond to the help we offer them. Despite frequent counselling sessions they may not show progress and this 'pathological grief' may need more expert help, perhaps from a psychiatrist with a special interest in perinatal death.

Like so much in this new field further study and enquiry are needed. Past life events may render parents more susceptible and vulnerable than others to a perinatal bereavement. The identification of these events, which may include perinatal bereavements in previous generations, could alert us to be more prepared to pay special attention to such families rather than be taken by surprise at the otherwise inexplicable 'over reaction' to this loss.

What has happened up to date is most heartening and encouraging. The help parents and families are now receiving is very worthwhile on humanitarian grounds and by its mental health preventive influence. The benefits of research in this challenging field will add greatly to the wellbeing of such families in the future.

References

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