

SUPPORTING FAMILIES WHEN TREATMENT IS WITHDRAWN FROM NEONATES: PARENTAL VIEWS ON THE ROLE OF THE CHAPLAIN

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Abstract: Recent in-depth interviews with 108 parents for whose babies there was discussion about treatment withholding/withdrawal, have revealed that whilst the decision itself is seen to be in the medical domain, chaplains can provide valuable support and confirmation. Their reassurance about the morality of what is being done and about the trustworthiness of the medical team is appreciated. They can help parents to gain a sense of control, and offer comfort and ongoing recognition of their loss and grief. Where he has known the child and shared the distress of the parents, the chaplain has a strong advantage when it comes to tailoring the christening/blessing and burial/cremation services to suit the family's beliefs and preferences. A powerful source of solace which influences parents' thinking about treatment withdrawal derives from a belief in an afterlife and/or a divine plan. However, many parents are grateful when chaplains avoid references to God.

Keywords: Neonatal care, withdrawal of treatment, decision making, support, chaplaincy, qualitative research

Background

Neonatal intensive care has changed out of all recognition over the past thirty years. The technology has become immensely sophisticated, medical knowledge has increased at a phenomenal rate, and parental expectation has risen as the media have publicised the stories of particular families or the intricacies of new treatments. But in some circumstances it is either not possible or not desirable to offer or to continue intensive invasive treatment. Sometimes aggressive efforts to save a life are simply not in the child's own best interests. In these circumstances it is an accepted part of medical practice to limit what is done (Royal College of Paediatrics and Child Health 1997, British Medical Association 1999).

Just when it is appropriate to make these decisions has been the subject of widespread debate. Detailed studies in the States have examined decision making practice there (Gustaitis and Young 1986, Guillemin and Holmstrom 1986, Anspach 1993). In this country a series of court cases has helped to establish legal boundaries and the limits of clinical judgement (Campbell and McHaffie 1995). More recently lengthy consultation processes and discussions have

resulted in professional guidelines being issued which help to define the parameters and guide clinicians (Royal College of Paediatrics and Child Health 1997, British Medical Association 1999). There are essentially three situations where limitation of treatment might be considered:

- The 'no chance' situation where life sustaining treatment is simply delaying death without significantly alleviating suffering.
- The 'no purpose' situation where the infant might be able to survive with appropriate treatment but "the degree of physical or mental impairment will be so great that it is unreasonable to expect them to bear it."
- The 'unbearable' situation where the illness is progressive and irreversible and further treatment is more than can be borne. (Royal College of Paediatrics and Child Health 1997)

This is the official position, but what about the reality? What do those people most intimately involved in these situations think and what do they do? A recent in depth research study investigated the opinions and practices of doctors and nurses working in Neonatal Intensive Care Units (NICUs) who have faced these difficult situations (McHaffie and Fowlie 1996). The dilemmas for them are practical as well as ethical. For example, what should they do if

a baby does not die when treatment is withdrawn and death is protracted? How should they manage a child with severe asphyxia who will never lead an independent life? Just when does a dose of opiates become an illegal dose? Where is the dividing line between palliative care and euthanasia?

The very latest insights come from a study of the parents' own experiences and opinions which has just been completed and it is the findings from this Scottish study which form the basis for this paper. The methods and procedures have been reported in detail elsewhere (McHaffie in press) but for our purposes here I limit such detail to that which sets a context for this essentially practical discussion of the issues which might influence a chaplain's role.

Method

In order to hear their full stories and explore these extremely sensitive issues I interviewed parents face to face, usually in their own homes. Families were eligible for inclusion if there had been any discussion about treatment limitation. They were recruited sequentially from three Regional Referral Units in Scotland and were representative of families in all NICUs on all factors except ethnic origin; Scotland has relatively few such families. Interviews were scheduled to take place at two points of enquiry, 3 months and 13 months after the babies had died. At the first stage 108 parents from 59 families participated, at the second stage 90 parents from 50 families.

The issues

When a baby is so critically ill or so severely damaged that treatment is of questionable value, there are two processes going on: that of determining what should be done and that of supporting parents through the decision making and the dying. The chaplain's role is essentially to support although as we shall see, part of that support may come from helping the parents to feel confident about the decision. For our purposes support is taken to mean whatever parents identified as supportive.

Decision making

When deciding whether or not to limit treatment, judgements have to be made. Opinions, beliefs,

values vary from individual to individual. Official advice for many years has been that parents should be involved. However, detailed analysis of the thinking of medical and nursing staff who are actually making these decisions and working with the families on a daily basis has revealed that a large majority have anxieties about giving parents responsibility for the decision itself (McHaffie and Fowlie 1996).

The strength of feeling of parents themselves on this matter has been eloquently demonstrated. Fathers have themselves disconnected life sustaining equipment (Paris and Schreiber 1996), even holding staff at gun point while they did so (Lantos et al 1989). Parents have taken their case to court (Dyer 1997). They have written harrowing accounts of the consequences of their exclusion (Stinson and Stinson 1983). But exceptional cases make bad exemplars and careful scientifically conducted research carries a different kind of weight. Our study has shown that the parents themselves do indeed want the *opportunity* to be actively involved in decision making seeing it as part of their overall parental responsibility. However, the fact that a substantial number preferred that the medical team decide or were relieved when "the baby decided," indicates that they should not be *obliged* to accept this responsibility. Amongst those who feel they have themselves accepted responsibility, we found no evidence of the subsequent guilt which some have feared (Rue 1985, Anspach 1993, McHaffie and Fowlie 1996), but where parents had not received sufficient concrete evidence of the poor prognosis, or where the death had been protracted and distressing, they did occasionally harbour lingering doubts.

Support for parents

Making such crucial decisions is a momentous task. It is evident from our programme of research that the decision is essentially made by the medical team and the parents. Nevertheless, six families we studied reported finding the chaplain supportive. What was it that he (taken to include she) could supply? The parents identified five factors.

Reassurance

The families clearly place great trust in the doctors' assessments and recommendations. However, some expressed their appreciation for the chaplain's reas-

assurance when he confirmed the authority, expertise and wisdom of the clinical team, and the seriousness with which they debated these decisions. His endorsement of the morality of what was being done carried particular weight coming as he did from a background which encompassed religion, philosophy and ethics: as one family put it, his statement that this was not deliberate killing but simply removing an extraordinary means of keeping an extremely ill baby alive temporarily, stilled their misgivings. It was clear though, that the families did not see the role of the chaplain as giving advice; this was in the province of the medical team. Indeed, one family were distressed when the chaplain gave his own opinion about the cost of intensive care and about what they should decide. Support came rather through confirmation that the medical team were trustworthy. For example, when a child died shortly after the removal of the machines and the chaplain pointed out that this reinforced the impossibility of independent survival, the parents were confirmed in their decision. Being non-medical with no position to defend, his reassurance was seen as an independent assessment that everything was being done as it should be. In reality the chaplain is perhaps not as independent as the parents perceive but his relationship with the medical team may allow him to convey with conviction his assurance that they are to be trusted.

Comfort

Parents drew considerable support from the chaplain being with them, respecting their grief and the importance of this infant's life. When there was little to confirm the reality of his existence, it was confirming to hear from the minister that their child was unique and infinitely precious. His life was valued. Some expressed their surprise that the chaplain had been supportive, he had not tried to moralise or preach to them but had been sensitive to their views and a comforting presence. Platitudes and pious thoughts were cited as unhelpful. As one mother put it: "No matter how much Jesus wanted him, we wanted him more!"

Sense of control

One set of parents found it most helpful when the chaplain steered them in the direction of regaining some control over a situation which seemed to be escalating beyond their reach. By breaking it down

into manageable parts and helping them to assess their own preferences and wishes, he enabled them to orchestrate an event which left them with few regrets. It was important in parents' experiences of treatment withdrawal and death for them to be able to do certain things with the baby, and to choose how each stage would be managed, and the extent of their own participation. But they sometimes needed assistance in identifying the different options and choosing the alternatives which best suited their values and preferences. To a large extent the nursing staff guided parents through this process, but some families found the chaplain appeared to have time to sit with them talking about whatever subject came to their minds. Furthermore they were not deflecting attention away from the baby when they asked him questions. He was seen as particularly helpful in explaining the consequences of choosing burial or cremation, in discussing the funeral service, and talking through the steps to be taken after death.

Officiating at ceremonial functions

Almost all families, irrespective of their religious beliefs, wanted their child to be christened or blessed, and most elected to have the hospital chaplain perform this function. In these situations the ceremony marked a recognition on the part of the parents of the gravity of the baby's condition. They derived comfort from the words and messages conveyed and the sensitivity with which the occasion was handled. They looked for a sense of the value of this child no matter how short his life and a recognition of the depth of the parents' love. Some singled out the fact that there was little or no reference to God as reassuring.

When it came to arranging the child's funeral the parents were warm in their praise of chaplains who steered them through the process. This was often the first funeral they had ever had to arrange. A third (20, 34%) asked the NICU chaplain to officiate, 3 others asked the chaplain from their own local hospital. A quarter (15, 25%) chose church officials whom they already knew to conduct the service, but it was a local minister not known to them who performed this service for twenty (34%) sets of parents. In two cases relatives led the mourners in the service. Those who had asked the chaplain commented that it had been good to have someone speaking of a child he had personally met and it was

comforting to have the same person present who had been with them through the whole experience. Knowing that the chaplain was himself touched by this tragedy confirmed for them that this baby had been of value and importance.

The parents particularly valued those acts which demonstrated an understanding of their profound pain: ringing an undertaker to spare the parents having to tell their story, arranging for the transfer of the body. They appreciated the commitment of chaplains who put time and effort into designing a service to include personal touches and special requests. Parents variously chose to include poems or songs or pieces of music, some elected to sing or recite themselves. Orders of service were often stored in their box of treasured mementoes and many parents shared them with me months after the event alongside photographs of the child, namebands and locks of hair. A few parents specifically asked for certain things to be said by the officiating minister at the service, for example asking the congregation not to walk by the parents but to stop and speak, or reminding them that this was something which would always be with the parents and they should not be expected to "get over it" in a few weeks. The main messages they wanted conveyed were the importance of this child's short life, and the enormity of the parents' love and loss. When the chaplain incorporated all these elements tastefully and in line with their preferences they assessed the whole event as meaningful and poignant for them, and a measure of his own valuing of this baby's life.

Ongoing support and concern in bereavement

Although only two families (3%) cited ministers of religion as supportive in the early weeks following the death, as many as seven (14%) did so during the first year of bereavement. The things they found comforting were receiving cards or visits. It helped them to know their ongoing sorrow was recognised. Where the minister was the hospital chaplain there were special dimensions to the support. Knowing that he remembered them and the baby, and cared enough to act on those thoughts increased their sense of self esteem and worth as well as the importance of the baby. One couple were deeply grateful when the chaplain dropped in on them at home on the anniversary of their baby's death; a number of others spoke appreciatively of anniversary cards

they had received. Because he had shared their early experience the chaplain could reminisce with them in a meaningful way, his words carried conviction and were not hollow platitudes. They were unmoved by cards which seemed to them "routine" or which came from unknown staff. As support from others diminished and contact with the hospital medical staff was lost, having someone to talk to who had known the child was a significant opportunity greatly appreciated but the parents.

Opinions and beliefs

Knowing what parents believe and think is important in being sensitive to their needs. It was very clear from our study that almost all the parents supported the practice of not intensively and invasively treating a baby in certain circumstances. The cost to the child is sometimes too high. Overall they believed that decisions should be made individually for each case and some parents went further: they themselves could not be sure how they would respond were they ever to be faced with this decision again.

A clear message was conveyed that the child's interests are paramount. The factors which they identified as weighing heavily for them fitted with this priority: if death was inevitable it was inappropriate to prolong the child's suffering; if life might be possible, quality of life and suffering were important elements to take into account. Setting parameters around what constituted an unacceptable quality of life proved more elusive but related most closely to dependence and suffering. Only two families specifically said that future disability should not be brought into the equation; for them if there was a chance of life the child should be treated.

Assessments of the influence of religious beliefs are inevitably difficult but we did make attempts to find out if parents held any such beliefs relevant to treatment limitation. The results would appear to be of particular interest to chaplains. Parents from over half of the families (54%) could identify one of more such influence. In two cases these were staunch Roman Catholic parents who believed that babies should always be treated until their time came to die, one saying the switching off of life-sustaining machines amounted to murder. For the remainder the influence came in the form of solace relating to contemplation of death following treatment withdrawal. This arose from two basic beliefs:

in an afterlife - involving concepts of freedom from pain or disability, opportunities to be reunited with loved ones, and being taken care of - and/or in a divine plan which held a reason for the death of the child.

The effect on their faith of this experience of losing a child was mixed. This was unsurprising in that for many it was the first real tragedy in their lives. Three parents felt they now had a stronger conviction, two had moderated their views and felt they were now more rationally defensible, and one couple had now become church goers. On the other hand, seven now seriously questioned their beliefs, finding it inexplicable that a loving God should allow babies to suffer and die. Two fathers and one mother temporarily lost their faith but now felt it had been restored. A number commented that they were conscious that a lack of any conviction eliminated them from a source of comfort and one atheist father said that he encouraged a belief in his children which he did not himself support because he did not want to deprive them of this benefit. Some parents actively searched for spiritual reassurance that something of their child lived on, going to churches or ministers or spiritualists. Those who found what they were looking for were comforted.

Conclusion

The numbers of parents who analysed the chaplains' input are small and it would be unwise to generalise from their data. Nevertheless they convey important messages. Furthermore the views of these men and women carry the full weight of profound personal experience - these are not idle words or theoretical opinions.

Whilst determinations about if and when to limit treatment lie clearly in the medical domain, parents value the reassurance of the clergy that what is being done is ethical and appropriate. Coming from outside the life-saving team the chaplain seems to them to bring an independent assessment as well as the authority of his cloth. His role is principally one of support, and the sensitivity with which he comforts and steers parents through the rituals and processes reflects for them the level of his respect for both the baby and the depth of the family's grief. When they are often struggling to obtain adequate recognition of the existence of their child, it is especially heartening to know the baby has touched the lives and emotions of others. Their own personal religious

convictions serve more to comfort than to direct their decision making, and in the ceremonial events of christening/blessing and burial/cremation they look for words and messages which are in tune with their own values and beliefs.

Rarely do any of us get the chance to see ourselves as others see us. These parents have given us glimpses into how everyone concerned - doctors, nurses, chaplains, researcher - appeared to them. We can all learn from what they experienced and our greatest tribute to their courage is to take heed of their messages and improve our sensitivity in the future.

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