ARCHIVES OF DISEASE IN CHILDHOOD

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Annotations

Withdrawing and withholding treatment: comments on new guidelines

A new practice framework for clinicians has recently been issued by the Royal College of Paediatrics and Child Health through their Ethics Advisory Committee.[1] It deals with babies and children for whom intensive treatment may not be in their best interest. These are difficult cases. Absolute certainty is rarely possible; there are inevitably issues of conscience and conflict, which add to the burden individuals carry. Do the RCPCH guidelines address the concerns of doctors and nurses at the cotside? Will they be of practical help?

The guidelines are based on evidence from experts, and discussion by carefully selected focus groups, both useful ways to further thinking on a subject. But these methods lack the rigour of empirical data collected by scientific research. Does research evidence confirm expert opinion? If it does, the guidelines will carry greater weight.

We looked at the RCPCH document in relation to the expressed concerns and stresses of staff who work in neonatal intensive care units. In a recent survey[2] we carried out in depth interviews with 57 doctors and 119 nurses currently employed in six neonatal intensive care units in Scotland. The units were selected to reflect different geographical, cultural, and social factors; the sample was stratified to represent all grades and levels of experience.

In principle, the RCPCH guidelines do address most of the issues that concern clinicians, but we highlight five areas that warrant further discussion.

Team involvement

Time and again the RCPCH document refers to the need to listen carefully to all those participating in the care of the child. The committee calls for "open and timely communication", "reasoning together", a "corporate moral responsibility". Specifically they advise that "all members of the clinical team should have an opportunity to voice their feelings". This is timely reinforcement. In five of the six units we surveyed there was one group—the nurses—who felt they were insufficiently involved in discussions. In two of the units only one of the consultants ever consulted the nurses—by the consultants' admission as well as in the nurses' perceptions. This caused considerable tension within the team. In all the six units, when our respondents considered specific cases where treatment withdrawal was being considered, over half (55%) of the nurses (in contrast to only 21% of the doctors) cited doctor–nurse conflict as a cause of tension. The nurses repeatedly commented that their views were underrepresented. While there was rarely disagreement about the final decision, more than a third (38%) of the nurses and 30% of the doctors singled out the timing of events as a major area of tension within the team. In addition, 22% of the nurses, but only 9% of the doctors, identified the way the case was managed as the factor causing unease. Team effort has to be real, not just a paper exercise, and this new document comes as welcome reiteration of the message.

The role of junior doctors

In the RCPCH document, emphasis is rightly placed on the necessity not to hurry any decision. Facts have to be accumulated and options explored. Junior doctors, the RCPCH states, should administer life sustaining treatment until senior more experienced doctors take over. This is wise counsel and the policy in most units; however, the implications should not be underestimated. In our interviews, junior doctors eloquently described a number of emergency situations they had experienced and the stress of carrying out such instructions in the face of overwhelming evidence that starting intensive treatment was ill advised. Their consciences were greatly troubled; defence of their actions to parents sounded lame; and senior nurses sometimes compounded their stress by making it very plain that the doctor had made a mistake. Perhaps this is an area for particular attention.

Withdrawal of procedures designed to alleviate pain or promote comfort

"Where treatment aimed at alleviation or cure of a condition has been withdrawn, the clinical team has a duty always to offer palliative care," states the RCPCH. One of the findings of our inquiry was that practices and procedures vary considerably both between and within units. One area of major difference relates to the use of drugs. Opinions differ regarding the giving of opiates and paralysing agents. Some teams carry out a series of tests to confirm a bleak prognosis but first they withdraw all medication to be sure that no symptoms are masked. Others orchestrate deaths to be sensitive to parents' needs, using drugs in various doses and combinations. Strong opinions were voiced to us by staff who construed these things very differently. The distinction between the means and the intention made in these guidelines appears helpful

and should reassure both clinicians and parents. Giving a medicine for the purpose of relieving pain or distress and not to cause or hasten death is legal and can be appropriate management. It is not necessary to withdraw paralysing agents before withdrawing respiratory support in a baby being managed with paralytics, but it would be considered euthanasia to induce muscle paralysis deliberately to avoid the terminal gasping that sometimes follows withdrawal of ventilation.

Second opinion

The guidelines suggest that obtaining a second opinion for legal reasons as well as clinical assurance might be adopted in the same way as for termination of pregnancy and brain stem death. Although for all other grades we took a stratified sample, all consultants in the study units were given the opportunity to be interviewed; 21 of the 22 agreed. Half of the doctors who accepted responsibility for the decision making admitted, in the privacy of a confidential interview, that they found it burdensome, and almost all recognised that it could be emotionally draining. Over the years they tended to develop ways of dealing with the stress that cushioned them from the full effects of each case. One avenue that most acknowledged as supportive was discussion with colleagues. Reassurance and peace of mind came from other competent consultants with expert knowledge of neonatology similarly concluding that treatment should be withdrawn. Some consultants working in district general hospital units indicated that they consulted experienced colleagues from regional university based centres with established reputations to gain backing for their decisions. To some extent the doctors have already built in a legal defence as well as a personal support system.[3]

Withholding feeds

One area barely mentioned in the guidelines is the withholding of feeds. The role of assisted feeding, the RCPCH says, "should be considered very carefully and discussed fully with the family." Although withholding artificial feeds in situations where oral feeding is not possible or cannot be tolerated (for example, severely birth asphyxiated babies who are profoundly damaged) is practised in only a minority of units, it is a source of acute stress, particularly for nurses. The consultants explain logically and persuasively that this course of action demonstrates conclusively to the family that the outlook is bleak, but to nurses it feels like withholding basic comfort and dignity. This is an area of practice that must be given detailed consideration in the future. From our discussions with all those involved it appears that implementing the instruction can feel very different from giving it. Many clinicians we interviewed were unaware that such a practice is still adopted, and this could account for its scant attention in the RCPCH framework.

Conclusion

The RCPCH framework does address the concerns of clinicians. Empirical evidence supports its conclusions in general. The guidelines will provide reassurance as well as a source of reference. But consideration of the recommendations should prompt neonatal teams everywhere to examine their actual practices honestly to see whether an infrastructure is available to support all levels of staff engaged in these crucial decisions.

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1 Royal College of Paediatrics and Child Health. *Withholding or withdrawing life saving treatment in children. A framework for practice*. London: RCPCH, 1997.
2 McHaffie HE, Fowlie PW. *Life, death and decisions: doctors and nurses reflect on neonatal practice*. Cheshire: Hochland and Hochland, 1996.
3 Bolam v Friern Hospital Management Committee. QBD (1957) 2 ALL ER 118.

Toddler diarrhoea: more a nutritional disorder than a disease

For the practising paediatrician toddler diarrhoea or chronic non-specific diarrhoea is a frequently encountered disorder. Every paediatrician knows the tableau vivant of extremely worried parents around a sparkling, healthy looking child who appears to be unaware of all the commotion. After a thorough clinical history and a simple physical examination, the diagnosis is often obvious. Both defecation frequency and stool consistency are very different from other children. The stools are foul smelling, watery, and contain mucus with undigested vegetable material. The parents are likely to report a short mouth to anus transit time. Usually, the children have no failure to thrive and they present in a good nutritional state. Abdominal pain may be present in a minority. In the developed, Western countries, toddler diarrhoea is by far the most frequent cause of chronic diarrhoea in children between 1 and 5 years of age. Since the first description in 1966, research on this common condition has mainly concerned its nutritional aspects.[1–4]

What is a normal stool?

The defecation pattern of healthy young children is extremely variable in consistency and frequency. Important variations in bowel habits exist between different populations. Normal values for daily frequency and total bowel transit time have been reported for children in industrialised countries.[5] For a toddler it may not be abnormal to have more than three soft and occasionally loose stools each day with visible food remnants. In this respect, colonic water absorption and colonic transit are extremely important for faecal consistency. Of all water entering the proximal colon, more than 80% will be retrieved. On a body weight base, young children need to handle more fluid, and they have less effective colonic water absorption and higher faecal water losses as a consequence.[6] In general, it is not well recognised that the water content of normally formed stools is as high as 70–75%.[7] In a runny, watery stool this will be 90%.[7] Therefore, a relatively small increase in water can make all the difference in the parental perception of