Differing views on quality of life

Alan Craft

Perspective on the paper by Knowles *et al* (see page 388)

The banner "The end of doctor knows best" was just one of the many eye-catching newspaper headlines which accompanied the publication of the Kennedy report¹ into the outcome following paediatric cardiac surgery in Bristol. Professor Kennedy highlighted the need for health care professionals to work closely with patients, and parents, in decision making relating to their health care. "Trust me I'm a doctor" was no longer good enough and the paternalism which had pervaded medical practice during much of the last century had to end. He, of course, had contributed hugely to opening up this debate in his Reith lectures ("Unmasking Medicine") some 20 years before the Bristol report.² He wrote "If illness is a judgement the practice of medicine can be understood in terms of power. He who makes the judgement wields the power". The Royal College of Physicians' recent report on professionalism in medicine has continued the same theme.³ The recent Nuffield Council on Bioethics report⁴ highlights the fact that over the past 20 years there has been a greater public desire for transparency, accountability and responsibility in all spheres of professional activity, perhaps with an increasing mistrust of professionals. So the basis for the practice of medicine in the 21st century has to be a partnership between professionals and patients, and in the case of children, parents. The Royal College of Paediatrics and Child Health as well as other major paediatric societies, including the American Academy of Pediatrics and the Canadian Pediatric Society, have issued guidance along these lines.⁵⁻⁷ Much of medicine is straightforward and the outcome of a particular intervention can be easily explained by health professionals and understood by the potential user of the intervention. However, there are interventions which are more complicated and where the outcome is uncertain. In the practice of paediatrics this is highlighted in the case

of the newborn and the Nuffield Council on Bioethics⁴ has just spent 2 years in considering how best to ensure that the right decisions are made about the care of very preterm babies. Their report emphasises the need for joint and shared decision making between parents and healthcare professionals.

If joint decisions are to be made, then a prerequisite is that both parties must have the same information and, more importantly, the same understanding of it, for, as Theodore Dalrymple so eloquently explains, "information without perspective is just a higher form of ignorance".⁸ The Nuffield Council report acknowledges that in the field of newborn care it was not always possible to provide an unequivocal answer as to what ought to be done in any particular circumstance as opposed to what could be done. All the more important, therefore, to understand the consequences of what could be done.

The current paper by Knowles *et al*⁹ is an important contribution, comparing the value that parents and professionals put on various hypothetical quality of life outcomes of interventions for congenital heart defects. They find that parents and professionals share similar values, both are more averse to poor neurological than poor cardiac outcome, and a small proportion recognise some outcomes being worse than death. Their findings are somewhat different to those of Saigal *et al*¹⁰ who looked at differences in preferences for neonatal outcomes among healthcare professionals, parents and adolescents. The latter two categories included those who had survived being born very small as well as those born at a normal gestational age. They found that healthcare professionals were more likely to rate health related quality of life lower than any of the other groups, that is, they were more pessimistic about a particular scenario than parents or adolescents. All groups recognised a state of life worse than death.

All studies like this are dependent on the respondent's prior knowledge and experience of the type of issues that are being considered. Parents of severely disabled children could well respond differently to those who have had little experience of disability. Where they are in the child's illness journey will also be important; those in the early years could well respond differently to those who have had many years to endure.

The recent Nuffield report makes it clear that difficult decisions must be made in partnership between parents and professionals. Informed choices can only be made with adequate information and it is important that all parties are interpreting this correctly. There is clearly much more research which could and should be done, but this present paper at least suggests that parents and professionals are on the same wavelength.

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