Balancing protection and respect in paediatrics

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The clinical care of children can pose dramatic ethical and legal challenges for clinicians and parents. Some of these difficulties can best be summed up by a phrase familiar to every mischievous child and exasperated adult: "Grow up!" We want children to be as adult as they can and yet we do not want them to be more adult than they should. In their clinical contact with children, doctors are no different. They want children to cooperate as fully as possible in their care and support. Sometimes, however, children may be reluctant to do so, posing perplexing dilemmas for everyone concerned.

To see why, consider one of the things that makes the unexpected death of any child so tragic: the thought of the lost potential that this represents. For this young person there will be no challenges posed and met, no formation of lasting adult relationships and, most importantly, no chance of the emergence and exploration of a unique and evolving identity. They go to the grave, in the words of the American author Henry Thoreau, "with their song still in them".[1] Such tragedy underlines the moral importance of providing children with such opportunities to flourish and doing our best to respect their evolving autonomy. While parents can play the most important role in achieving this, the responsibility extends to all those whose contact with children may influence the formation of their future character. Paediatricians obviously fit this bill.

Yet we may face a paradox when providing such encouragement. With greater freedom to explore and experiment comes greater risks of harm and distress. Such exploration entails seeking new experiences in unfamiliar circumstances—through adventure, success and failure—and potentially harmful mistakes and misjudgements are an ever-present possibility. The trick is to minimise the harm without pretending that it can be entirely avoided.[2] To overly protect children from harm is to deny them the opportunity to learn how to protect themselves, including the importance of balancing courage with prudence, trust with suspicion.

Paediatricians on a daily basis try to find their own appropriate balance between protecting the life and health of children and respecting their evolving autonomy. This delicate balancing act does not occur in a vacuum, free from outside influences, but in a context often charged with different sorts of distress, ambiguity and incomprehension on the part of everyone involved. Thankfully, most ordinary paediatric encounters are unproblematic in this regard. The child understands that medical care is required, that the doctor and medical team are there to provide it, and that their parents agree. While fear and apprehension may be hard to quell, all will hopefully be well in the end. Yet, even if not in the full "maturity of their faculties" (to quote J S Mill), we believe children should be encouraged to participate in the decision-making process as much as the circumstances permit—their voice should be heard—both as regards their desire for treatment or their reluctance to undertake it.[3] To force a child to have medical treatment may compromise their best interests through alienating them from both clinicians and the medical environment generally.[4] The difficulty arises when a child's refusal of treatment may lead to catastrophic consequences. Is the risk of alienation then outweighed by the prevention of serious medical harm?

Young children in particular are susceptible to undue medical coercion. Depending on their age and maturity, there are huge variations in the risks that they are competent to take (eg, to walk close to a burning log in a fire place) and those they are not (eg, to stoke the log to increase its flame). From a very early age, they will express their evolving autonomy through making their desires known. For example, it will at times be clear that they do not want to be clinically examined or to have drugs of whatever kind administered, particularly by injection. Perhaps readers may remember the distress of being forced—often physically—to comply with such coercion and in ways that, at the time at least, were as incomprehensible as they were infuriating. (We do!) Such frustration, which may not easily be forgotten by the child, should only be risked when treatment is necessary rather than elective. If there are good reasons for the intervention, then it is important for doctors or parents to communicate them to children in appropriate ways, depending on the level of autonomy of the child concerned. This is now increasingly recognised within medical education and is taught in communication skills courses.

The law also recognises the importance of respect for the autonomy of children and young people. Those under the age of 16 can consent to medical treatment—even without parental involvement—provided that, among other things, the doctor responsible for their care believes that they have the capacity to do so and that the decision is in their best interests.[5] For example, a mature adolescent woman may request a termination without parental knowledge on the grounds of her sustained distress and depression: she is unable to look after a baby on her own and her parents would never tolerate her remaining at home with the child. Indeed, if the pregnancy is discovered, she may face violence within the family. However, in England—though not Scotland—young people are not legally able to refuse treatment deemed to be in their best interests until they are 18. For example, a protesting young child may be given no option but to have a ruptured appendix removed, just as a sensible and mature adolescent may be forced to have a life-saving blood transfusion, despite the fact that both patient and parents are devout Jehovah's witnesses. In both cases, the moral issue will again turn on whether the likely adverse consequences of non-provision of treatment can trump the prima facie obligation to respect patient autonomy.

These cases can be especially difficult for clinicians. They may on occasion agree with the young person's refusal. For example, a competent adolescent with advanced cystic fibrosis may understandably refuse cardiopulmonary resuscitation on the grounds of poor quality of life and lack of overall benefit. Yet parents may be unwilling to accept this, leaving the

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doctor in the middle. At other times, there will be no option but to ignore the child's refusal, no matter how understandable. For example, a mature child suspected of having been physically abused by a parent may be unwilling to implicate them, despite compelling evidence. Because of their fear of separation from their parents, they may refuse to discuss the origins of their injuries (or provide unconvincing explanations) and may not consent to related diagnostic examinations. Despite this unwillingness, the clinical team may still believe it necessary to contact the relevant authorities to discuss how the child can best be protected through further investigation. This could entail breaching the confidentiality of the child as well as the parents if they too refuse to cooperate. The trust that we emphasised earlier may be lost as a consequence, with the same potential damaging consequences for the child's perception of doctors and healthcare generally, as well as their relationship with their parents. Yet not to proceed with an investigation may put the child at severe risk of injury or worse.

What to do? There is considerable controversy about these issues. Some commentators, sometimes triumphantly called "child liberationists", argue that existing levels of respect for the autonomy of children in medical practice is far from acceptable and should be increased.[6] Others, sometimes called "child protectionists", argue that too much emphasis has been placed on the concept of autonomy to the potential detriment of children.[7] To provide a guide through such potentially troubled waters, Richard Beach and Rosalyn Props, consultant paediatricians at Norfolk and Norwich NHS Trust, have written an engaging paper ***(see page 181)*** based on their personal experiences and provide practical advice on how best to proceed, especially in the face of morally and legally indeterminate "hard cases".[8] Few things can be more upsetting for doctors than feeling that they have failed a sick child. Doctors Beach and Proops have a longstanding interest in ethical and legal issues and are members of the clinical ethics committee within their Trust hospital. We hope that the following paper will help prevent some of the difficulties we discussed above and that, if thorny dilemmas do arise, that the authors' advice will help readers find a morally acceptable resolution.

We welcome responses to the views and arguments developed by these authors. Some clinicians may wish to question the fact that depending on the circumstances, they appear both to accept and reject the exercise of quite strong medical authority. Where should the line be drawn between acceptable "soft" paternalism and unacceptable "hard" paternalism in the treatment of child patients? How much say should parents have about the medical management of their children? Is the concept of "best interests" robust enough to make such decisions or is it too vague to be of any real use? We look forward to further debate and discussion from readers on these and other related matters.

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