Contradictions within concepts of children's competence

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Abstract

This paper discusses contradictions within concepts of children's competence or capacity to consent, with examples drawn from research on children's consent to surgery. Competence entails understanding and wisdom. Yet definitions of understanding as esoteric abstract professional expertise conflict with the kinds of profound understanding some sick children have, drawn from their experience, thought and feeling. `Wisdom' combines Kantian reason which discerns the correct decision with Millean maturity which accepts responsibility for freely made decisions, even if these are mistaken; concepts of a correct choice conflict with those of a best guess. Beliefs about children's inevitable immaturity are contradicted by the demonstrated maturity of certain young children. Children's rights to resources and to protection can contradict yet complement their autonomy rights. When children are assumed to be incompetent, `children's autonomy rights', which depend on demonstrable competence, is a contradiction in terms. Adults' interests and their notions of children's welfare and interests can conflict with children's views of their own interests. There is a tragic tension between informing and respecting sick children but also protecting them from avoidable stress. Yet protection can involve violence, as when treatment is enforced during efforts to protect children from disease. Rights entail responsibilities which can compromise yet enrich the child's autonomy.

Understanding these contradictions, realising when discussants are talking at cross purposes, resolving and overlapping over-sharp dichotomies are necessary early stages in furthering respect for children's rights. Respect for children's competence addresses the root cause of child abuse, through showing when reasoning can replace blind force.

Contradictions within concepts of children's competence

This paper discusses contradictions within concepts of children's competence or capacity to consent, with examples drawn from research on children's consent to surgery (Alderson 1993). The contradictions are found within the terms `competence', `children' and `rights'. Progress in greater respect for children's rights partly depends on wider acknowledgement of these contradictions.

Dilemmas about surgery

A recent sociological study of children's consent involved hundreds of interviews with children having surgery, and with their parents and health professionals caring for them. Many interviewees were troubled by conflicting beliefs about competence and rights whilst they struggled with dilemmas concerning young patients' best interests.

An example from a heart-lung transplant unit illustrates the difficulties. Children being considered for surgery spent four days in the unit with their parents, having intensive investigations and information. After seeing over one hundred children with cystic fibrosis, one member of the unit staff felt that they had profound knowledge of severe illness, intensive treatment, the meaning of death and the value of life. The family of 10-year-old `Sarah' had travelled hundreds of miles to the unit. Her father said angrily to Sarah, referring to one of the unit staff, `Tell her, tell her you don't want the bloody operation.' The staff member commented:

> Her brother had died of cystic fibrosis, so she knew she was very ill. Her father was angry, and her parents were so sad, because they wanted her to have the operation. She was their only other child. So I said, `Do you really not want this operation?' I wanted to know what she knew. She had a concept of death. She found it very strange that her parents had been positive about death, and now they weren't. Why was it all right to be sick and go to heaven, and now, because of this operation, it wasn't all right? She was also confused because she didn't want to go through this operation. However, she agreed to stay for the whole week and then perhaps compromise, and be put you on a provisional list, `Until you decide you want to be on the actual list'. The next day she asked to go on the actual list because, `You listened. I don't like physio but "sorry you have to have it", same with medication. I just wanted to see what would happen if I said no.'
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> These children are given that right of choice. It's not a question of whether they are capable of making a decision. If a child truly understands what is involved and the alternative outcome, then they are not forced into agreeing to a transplant. That causes a lot of problems for nursing staff when the age of consent is now what - 16? Certainly that is an age we are comfortable with. Because

> transplantation is a limited resource, it is important to select the children most likely to benefit from it, and we have time to do this... None of us knows whether transplantation is an appropriate treatment. There's only what is right or wrong for individuals. We don't have the right to assume we know what's appropriate for a particular family.
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> All the children we see have demonstrated an ability to make their own decisions. Whether they do it or not is another matter. Many aren't autonomous enough. One mother said to her son after his brother had died, `We owe it to your brother for you to have a transplant'. He was very distressed. I said to him, `If you didn't want that operation would you tell us?' He said, `No, because my mother would be so sad if I said that.'
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> I would say that often as young as four or five they can understand a lot about a transplant. Of course, it varies very much, and you can't generalise. I believe the child always has to be involved. We know that they literally have their life in their hands afterwards. If they stop taking their medications, for example, they will die.

Competence: understanding, knowledge and wisdom

Competence to consent to children's treatment has two main elements: understanding and wisdom. A competent child is one who `achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed' and also has `sufficient discretion to enable him or her to make a wise choice in his or her own interests' (Gillick 1985: 423). (Children's independence is recognised in later statute law; when children are capable of consenting to an application to see their health records, parents' may only apply with the consent of the child. Access to health records Act, S. 4 (2). (1990).) Interviewees in the consent study ranged from those who, like the health professional quoted above, thought that certain young children can understand, to a few people who believed that no child can understand, because of immaturity or because no lay person of any age can understand enough of the relevant medical information to make an informed decision.

Decisions about major surgery involve both medical and personal knowledge. Personal issues include the patient's felt need for treatment based on experience of disease or disability and of past treatment (if any), as well as on personal hopes, fears and values. Sarah had had rigorous daily treatment all her life. She had watched her brother die of the same disease and appeared to have come to terms with her own probable fate. Such acceptance involves profound experience and thought. She had unique knowledge of her own case.

Yet the literature on consent attends almost entirely to medical and legal information (such as Faden and Beauchamp 1986); professional, textbook knowledge is highly valued, personal experiential knowledge is discounted. This dismissal has several effects. Children are assumed to be ignorant, except in so far as they can recount medical information. The important contribution which they can, and often do, make to medical decision-making is rarely publicised. Academic theories of children's inabilities predominate (as when judges discuss whether an `intelligent 15 year old' is able to understand the meaning of contraception (Gillick 1985: 402, 409). The `non-competent child' who figures in the legal imagination is treated as arational rather then irrational. When children are credited, at least, with a misguided rationality (Perrin and Gerrity 1981), the importance of explaining and correcting misunderstandings is accepted. If children are implicitly treated as arational, then enforced treatment without regard for the child's views is endorsed by the courts (as when the views of a 17-year-old young women `were of no weight' in influencing the court's decision in re W [1992] Weekly Law Reports 3:758-82).

Severe or prolonged treatment can induce terror and despair in the child. Children who perceive treatment as worse than the disease risk having similar reactions to those of torture victims. Torture is defined as `breaking down a person's sense of identity'. It is exacerbated when people are in a strange culture, such as a hospital ward. It arouses feelings of utter helplessness, being out of control of events and one's own body, inability to sleep, or concentrate, irritability, confusion between feeling bad and being bad, the disintegration of mind and body. `A perfect way to cope with torture and prison is to disassociate your feelings from your experience; this is not the perfect way to cope with a love affair' or any intimate relationship. If it becomes a habit, children become emotionally crippled (Melzac 1992).

Children as young as 2-years suffer such stress after disasters. They know why they have come for therapy. `I was on the ferry and saw lots of dead bodies.' We formerly thought they did not understand, because we did not ask them. A 6-year old attempted suicide after a ferry disaster. `I couldn't stand the bad pictures of the ferry in my mind any more' (Yule 1992).

From early infancy, children begin to reason and to suffer mentally. Acceptance of a general licence to enforce treatment on `non-competent' children, as if they are unthinking or arational beings, is therefore misguided. It is extremely important to try to work with the child's informed agreement, or to defer any non-urgent treatment until the child can accept it.

Children's competence to make wise decisions is still more disputed than their understanding. Current definitions of competence as wisdom contain contradictions. Locke in 1690 (1959) and Kant in the 1780s (1972) argued that rational man, capable of pure reason and knowing the correct answer to moral questions, must be able to control his own life without interference. Women and children were denied this right as they were assumed to be irrational. In the 1850s, Mill (1982) acknowledged that not all moral questions have correct solutions, and advocated liberty as the greatest good: the individual's sovereign right `over his own body and mind' to make wise or foolish decisions. No adult should be compelled into any decision unless this would prevent harm to others. Children were again excluded.

These two meanings of competence, wisdom to know the correct decision, or else courage and maturity to make a best guess and to accept responsibility and blame for mistakes, contradict one another. Yet both are integral to modern meanings of competence, as shown during the research interviews. For example:

Interviewer: When do you think your daughter was or will be able to decide for herself about the proposed operation?

Mother: Well, now at twelve she is very sensible. I think she could decide now.

Interviewer: What would you do if you disagreed with her decision?

Mother: I don't think we would disagree, she's very sensible. But then, I suppose if it's life-threatening, I'd want to have the last say - just in case.

The mother's response could be guided by her beliefs about her daughter's ability, the ability and status of children generally, or her parental responsibilities. It is legitimate, indeed expected, for people to express such sentiments about their children and adolescents. Yet is the response necessarily age specific? If society approved of similar responsible concern being shown for adults, would not people make the same comments about adult relatives who go hang-gliding or feel suicidal?

A child's mature independent judgement which happens to agree with the adults' views can seem like dependent compliance. It is only when the child and adults disagree that competence becomes a live issue, and then children can be dismissed as foolish simply because they disagree with adults.

Competence is very hard to define positively; it is easier to define negatively, when it is obviously missing in bizarrely self-destructive decisions. The literature and law on consent to children's treatment tend to assume that almost any life-extending treatment is better than none, and that refusal of proposed medical treatment is inevitably incompetent, though the suffering this causes has been critically documented (Frohock 1986).

The reservations about transplantations discussed in the opening quotations are shared by many health professionals, but are seldom publicised. Sarah died while still on the waiting list. Arguably, the end of her life was more distressing and painful because of the vain hope of transplantation. (In some cases, there has been delay in giving morphine if there is hope of a last-minute transplantation, because it reduces the patient's eligibility for surgery.) Uncertainty about high-risk treatment accentuates the tragic tension between making a correct decision or a best guess. The tension is further complicated by assumptions about the nature of childhood.

Children and childhood

What characteristics distinguish children from adults? Many children exceed many adults in size, strength, intelligence and in certain types of experience, such as very serious illness. Variations within and between societies as to whether 12-year-olds are treated as young adults or as dependent infants illustrate how children's and adults' assessments of a child's competence are influenced by cultural beliefs, at least as much as by the child's ability. The variations also show how children's infantile or adult speech, behaviour and independence are largely constructed through their social context (Solberg 1990). Yet the psychological literature on defining and assessing competence tends to take the child as the unit of analysis and unfolding competence as a biological fact, and to ignore the social context including the child's own experiences and the cultural beliefs about the nature of childhood (Melton et al 1983; Gaylin and Macklin 1982; Kopelman and Moskop 1989).

Twentieth century Western notions of childhood are dominated by developmental theories which implicity perceive children as partly formed human-becomings rather than as human-beings capable of full experiences and relationships as critically reviewed by the Stainton Rogers (1992). Beyond associating childhood with incompetent ignorance and folly, such notions take incompetence as the definitive and essential nature of childhood, the distinguishing feature from adulthood. A few interviewees in the consent study accepted this dichotomy, assuming that `children can't possibly decide for themselves until they grow up/ leave home/ have done A-level biology'. They dismissed the possibility of the competent child, or felt troubled or threatened by it. Most interviewees did not identify competence with age and believed that children could be competent. Yet influential ethicists (Buchanan and Brock 1989) and lawyers continue to accept simplistic status definitions of competence, and assert that most minors do not have the cognitive and moral maturity to evaluate complex decisions.

Anthropologists argue that the vague concept of the competent person is mainly defined negatively, by classifying certain groups as `incompetents' (Young 1990). Then adults, for example, do not need to question their own abilities, and can rest assured that they fit comfortably within the status of competent adulthood. Children's rights are far more than an intellectual matter; the unease and anger aroused during talk of children's autonomy indicate that such discussion deeply threatens adults' convenience, power and beliefs about the moral order. As discussed in the next section, if children are defined by their incompetence, ignorance and folly, then `children's rights' is essentially a contradictory term.

Rights

Relationships between differing rights to resources, to protection and to self-determination or autonomy have been thoroughly considered (Freeman 1983; Franklin 1986; Alderson 1992). These rights reinforce and enrich one another, yet also conflict. When asked whether child patients should have autonomy rights, many interviewees replied, `Oh no, they'll only refuse surgery, they'll be too frightened.' Autonomy was assumed to jeopardise the child's rights to health care resources, and to protection or relief from untreated disease or disability. The importance of protection and resources in developing autonomy is frequently expounded. Yet this reverses the historical order of the development of rights.

Rights to autonomy and non-interference were the first rights to be propounded (Kant 1972), and they are epitomized in the right to consent. Consent has an impact on all other rights. It is about selecting options, negotiating and accepting or rejecting them. Beyond making a decision in the narrower legal sense, consent is about making an informed choice and becoming emotionally committed to it (Alderson 1990). Consent can only happen when there is no force or coercion. Children's consent is about children being right-holders, deciding their own best interests and preferences, instead of adults deciding for them.

Most discussion of children's rights is confined to protection and resources. Rights language benefits children when their interests are enshrined in international conventions (United Nations 1989), and in legal entitlements. Yet most of this discourse could be as fully developed under the headings of welfare, best interests or needs which are determined by adults. Autonomy rights and consent can only be understood in the context of human and legal rights, and not of welfare. Willing consent is likely to increase therapeutic benefit from health care and to protect patients from treatment they consider unnecessary, useless or harmful. Yet the purpose of consent is to defend the patient's physical and mental integrity. With adults and children, as Sarah shows, there may be conflict between rights to refuse unwanted treatment, and rights to possibly beneficial treatment.

However, children interviewed in the consent study took their health very seriously. As an 11-year-old succinctly said, `If I didn't want the operation, my parents wouldn't make me have it. If I was going to die they'd make me. It would be the only sensible thing to do, but I'd agree.' It is very rare for children to refuse life-saving treatment, and in the view of a senior clinical psychologist their response should then be taken very seriously. Such refusal can be deeply perturbing with competent adult patients yet is respected in law. Why should not informed, wise children receive the same respect in cases when health professionals are uncertain what is the correct choice? A 13-year-old said, `I would like to see the age limits completely scrapped, and maturity brought in. As you grow up, your age has a stereotype. I'm trying to escape from that stereotype.'

Numerous meetings supposedly devoted to children's rights actually promote adults' rights. An analogy would be 100 years ago, when men gathered to discuss `the women's rights problem'. Women would be absent as children are today. The men would discuss women's amusing foibles, weaknesses and need for protection. They would resolve to care for women still more considerately, and congratulate one another on their generous concern, mutually reinforcing their sexism. The same often happens today when adults discuss children; childism is so endemic and accepted that we do not yet have a word for it.

Emphasising vulnerability and protection does benefit those in need but can also increase and enforce vulnerable dependence (Kitzinger 1990). In the past, a prudent woman ensured her rights to resources and protection by sacrificing her autonomy, and obeying her father or husband. In effect, she had no rights, only privileges dependent on men's whim or goodwill. Women acquired legal rights to resources (such as equal pay) and to protection (such as from rape within marriage) only after they had gained autonomy rights. The key to respect for women's rights is respect for their competence, accepting women as no less rational than men. The key to competent children's rights is acceptance that they can be as rational as adults. When their rights are grounded, as far as possible, in their rationality, they have a greater share in rights which adults take for granted. For example, `a competent patient has a fundamental right to grant or withhold consent prior to examination or treatment .. refusal must be respected' (Department of Health 1990). (The final phrase was echoed in Children Act 1989 though later challenged in the Court of Appeal (Re R 1991; re W 1992). As long as childhood is identified with irrationality, the main grounds for children's rights (as opposed to their welfare or interests) is missing. The ideal of `pure reason' which justified the first autonomy rights was supposed to be `free from all contingencies' (Kant 1975: 95-6). It is too narrow; `if rational was what nineteenth century gentlemen were, children no less than women will come to grief in the rationality stakes' (Hughes 1989). Meanings of wisdom itself are set in opposition, abstract academic theory versus personal experience. Yet people's knowledge about their needs and rights often stems from contingencies, their weakness and suffering. If children are to be respected as rational, their experiences must be seen as profound sources of knowledge.

Ultimately, all treatment decisions are either reasoned with patients or forced on them. Reason (impartial discussion, negotiation, informed choice) and force (ulterior constraint, duress, violence) are at opposite ends of a spectrum, with persuasion (ranging into over-optimism, deceit, fraud) in the centre. (These terms are taken from the crucible of concepts about patient consent, the Nuremberg Code 1947.) Impartial discussion is inevitably qualified by medical uncertainty, choice of words, pressures of the illness or disability being treated, and attempts to respect but also protect anxious children. So persuasion overlaps broadly with reason at one end and force at the other. Yet at some point persuasion moves from informed optimism to deliberate distortion. Interviewees who gave high ages for consent tended to dismiss coercion as necessary firmness: `Kids only play up'; `They're only frightened', as if fear is irrational and therefore unimportant; `They've got to learn to put up with it for their own good'; `There isn't time to hang about until they're ready'. The most powerful way to justify coercion is to deny that children can reason, and to align adult reason with necessary force; children's resistance is then seen as mindless `self-destruction', to be overridden by rational adults.

Adults who respected consent at a younger age worried about the reason-force divide. A sister said, `I would always try to get a compromise.' A surgeon said, `I don't try and persuade people. If someone isn't happy with the idea of surgery, we'll talk again in a few months time, or a few years, and very often they've changed their mind.'

Consent to surgery entails consent to bodily invasion and loss of control. Sometimes urgent force was required, and parents could help children towards accepting this. A surgeon commented,

> I regard the issue of consent as a partnership between parents, the patient and the doctor - none of these can work independently. The success of this depends on a lot of things, including the age and understanding of the child. Because of the risk that children will refuse necessary treatment, it is so important that the atmosphere is right, so that the child can voice their fears.

Forcing information onto patients who would rather not know can be a form of coercion, but was usually seen as the lesser evil to forcing treatment on unprepared, resisting children. Sarah's initial resistance showed the crucial importance, whenever possible, of respecting and not coercing children. Treatment willingly undertaken is likely to have more therapeutic and placebo effect; not least because patients then understand the need to cooperate with taking drugs or doing physiotherapy. As quoted earlier, `they have their life in their hands'.

Another conflict about rights which troubled interviewees is shown in the earlier example of the boy who agreed to have a heart-lung transplant for his mother's sake. Rights are linked to responsibilities and personal autonomy is complicated yet enriched by concern for other people's interests. Rights language helpfully elucidates crucial issues, but only partially addresses the complex interdependence between child patients, parents, siblings and health professionals.

Addressing contradictions

So far, gaps and contradictions have been reviewed between: children's actual abilities versus their presumed inabilities; infant or adult; intellectual or experiential knowledge; a correct decision or a best guess; adults' versus children's status; uncritical acceptance of medical proposals versus knowledge of clinical risk and uncertainty; emotional or rational understanding; children's competence as a social construction or an unfolding biological fact; the social context or the abstracted individual; rights to resources and protection versus autonomy rights; protection or abandonment; welfare, interest and need discourse versus rights discourse; reason or force; partnership or coercion; autonomy or interdependence; control over the treatment decision and/or over the treatment process; deciding for or with children.

This final section considers the main effects of these contradictions and some means of partially resolving them. When contradictions are seen as conflicting dichotomies, there are four main effects. First, in hierarchical pairs, the higher part is ascribed to adults (understanding, reason, wisdom) and the lower to children (ignorance, emotion, folly). Second, if a child exhibits one weaker characteristic, such as ignorance, all other weaker attributes tend to be loaded onto the child. Third, where there are conflicts and gaps, vital matters get lost between them. One example is the reason/emotion split, the myth that we can think without feeling and feel without thinking. This prevents reflexive thought through which adults learn how their own anxiety and anger prevent them from accepting the justice of children's rights. Another example is the loss of the competent child in the gap between infant and adult, so that 15-year-olds are grouped with babies. Fourth, people talk at cross-purposes, not realising that they are defining, say, `rights' in opposite ways - as adult-defined interests or as children's choices.

Respecting and listening to children enables adults to learn from children how to provide the information and support they need, also to discover which children want to defer decisions to adults, or to share in making decisions, and the minority who want to take the main responsibility for deciding about proposed surgery. Adults can work with the child towards the best possible decision. Most importantly, health professionals then set highly influential examples of reasoning and non-coercion, which challenge the assumption that adult might is right, and so address the root cause of child abuse (Violence against children study group 1990).

On a practical level, these measures would be encouraged by more empirical research with children faced with choices in hospitals, schools and homes. Ways of clearly informing children and respecting their decision-making need to be developed. However, the main contribution to increasing respect for children's rights is to question all the underlying contradictions. The advantages of thinking, instead, in overlapping pairs need to be advanced: children are often like adults and adults like children in their rationality, maturity and interdependence; reason and emotion, intellect and experience are integral to one another; all patients, adult and children, have relative and partial rights, and are constrained and protected by medicolegal and economic systems. (For example no patient can have treatment unless a doctor chooses to provide it, (Re J [1991] 3 All ER 930 934) and competence to children's treatment involves making a wise decision in the child's best interests as Eekelaar (1986) admits despite his misgivings about children's autonomy.) Obviously there is a wide area for compromise between the extremes of either coercing children or abandoning them. The approach which draws together contradictions and combines respect with care (Gilligan 1982) was described by a chaplain and former headmaster during the consent study:

> But are you going to lay on children the weight of their future? Perhaps let them make a decision that could lead to their death? These are impossible questions, but hospital staff have to find the answers. Am I big enough to say, `Whatever you choose will be valued, even if you decide against the tide; okay, you've made that decision, I'll do all I can to support you, and we'll go forward together'? It's such a big step for the adult to surrender power to the child.

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