

Assessing Children's Ability to Give Consent

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Abstract

This paper explores the important issue of children's ability to give consent, via the development of a focussed questionnaire relating to medical matters. A questionnaire in relation to common 'medical; issues' was developed from interviews with children and was then given to a sample of 201 children aged 11 and 12 years. The results were compared to those from a group of 245 university students. Of the three sections of the questionnaire, definitions and forced choices showed some ability to discriminate between adults and children, but using the method of ranking of choices did not. Selecting the elements with highest discriminatory power produced a scale that showed good effect size which would be worthy of further exploration and use. It is clear that determining a child's competence to consent is a challenging but necessary task. Whilst 'objective measures' cannot give a simple answer this study indicates that they have potential to assist in relation to the exercise of professional judgment in this area.

Key Words: consent, children, Gillick competence

Introduction

Recently in England the case of Hannah Jones, the 13 year old terminally ill teenager who has "won a battle against a hospital's attempt to force her to have a life saving heart transplant" (p. 1, The Guardian Society Section, 11.11.2008) illustrates the complexity and importance of issues that surround the age at which children can be seen to be able to make their 'own decisions' about matters that may previously have been seen to be the province of adults. The 13 year old's decision is in line with the prevailing position in medical practice in the United Kingdom that the age at which a child can consent to treatment has been reduced from this point by a landmark Court judgement (Gillick. v West Norfolk and Wisbech AHA, 1986), with the capacity to consent being:

"...when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed" (*per* Lord Scarman *at* 188).

However, to fulfil this criteria requires that the young person has an understanding and appreciation of the relevant information, and an ability to use the information to weigh the risks and benefits of different options while making a choice (Beyth-Marom et al., 1993). Studies of decision-making ability within research contexts have shown that children ages 7 to 12 have difficulty identifying and describing risks and benefits to research participation (Abramovitch et al., 1995). With increasing age, the early adolescent usually becomes able to understand the implications of information, and consider the future consequences of their decisions. In line with these findings, the long-standing legal wisdom has been that children under 12 years of age virtually never possess such capacity, and that it is rare to find the requisite capacity until the age of 14 years (Brazier, 1992). Hannah Jones's case calls this into question, indicating that children as young as 13 can sensibly and appropriately make literally life and death decisions. This article seeks to locate such decisions within a wider legal framework, and provides details of an exploratory study in relation to children, young adults and consent.

The introduction of the Mental Capacity Act 2005 sought to bring greater consistency to the issue of capacity to give consent in a wide variety of situations. However the Act specifically excludes children, though s5 does address issues for young people over the age of 16 years. Thus the problem of how to respond to a child within a clinical setting, and how to decide the appropriate level of consent that should be sought from them remains the judgement of the clinician present. There are few formal aids to carrying out this task, however, and in practice the decision as to whether a young person has the capacity to decide about treatment is based upon whether they understand:

- the purpose of the procedure
- its nature
- the potential risks
- the consequences of not proceeding

and can be seen to be making a voluntary choice.

These are very difficult elements to for which to offer objective measures. Underlying the notion of obtaining consent from children and Gillick competence" is the view that "pre-Gillick competent children's" responses with regard to medical choices are likely to be different from "adult" response simply because of the abilities and knowledge as they possess as "children". If this is the case then it should be open to exploration, understanding, and, use in practice. To explore the potential for this, we sought to investigate whether a questionnaire evaluation of ability to define medical terms and make judgments upon alternative choices would be able to distinguish a style of "child-like" responses from those of adults.

Method

The Development of the Instrument

The initial phase of the project consisted of a series of 16 open-ended interviews with children and young people waiting for routine procedures on a paediatric ward. Their thoughts about the procedure, their knowledge of terms used about the procedure, and the elements that prompted concern were noted, as was their understanding about wider issues of health.

The initial data was analysed and based on these results a pilot questionnaire consisting of three sections was devised. The first section sought to give a score for the young person's understanding of terms that might be used in explaining any procedure. Using the information from the survey six terms were chosen to be defined, namely operation, disability, anaesthetic, consent,

discomfort, paralysis. Ten senior anesthetists with significant clinical experience were asked to give definitions for the terms, the results of these were collated and analysed, and the definitions that were then constructed formed the definitions that would achieve the best scores. It was interesting to find that their definitions were quite consistent, so constructing the definitions proved to be relatively straightforward. In addition a group of 20 adult volunteers were asked to provide definitions for the six terms, and a scoring regime was then devised using these and the answers from a subset (5%) of the children who had taken part in the piloting phase of the project.

The second section of the questionnaire sought to assess decision making by asking the respondents to make a forced choice between seven dichotomous illnesses or disabilities (see Table 2). The dichotomies were chosen to explore whether a child could recognize the longer term consequences of disability over its immediate impact. Finally, using the information from the survey, nine statements were generated which captured the issues which the children interviewed had raised. The respondents were asked to rank these in the order that seemed most important (score of 1) to least important (score of 9), to them.

Assessing the accuracy of the scale

As part of a wider project, the parents of the sixth and seventh year children attending a large senior school were asked to allow their children to take part in the survey. This age group was chosen because their academic development should allow them to complete the questionnaire, while their age (11-13 years of age) would place them below a presumed age of competence to give full consent. The questionnaires were presented within form time and 201 of the possible 217 were completed. For comparison purposes, adult students (all aged over 18) attending a University's Joint Honours courses in non-professional subjects were also asked to complete the questionnaire. 251 questionnaires were returned, with 245 included in the study sample, six being returned blank. The advantage of using this group of adult students was that they were nearest age to the children whilst being at the same time clearly adults. Although 40% plus of young people are now entering higher education, it is nevertheless true that students are not completely representative of the wider population. Thus, although it is suggested that for this exploratory study it was acceptable to use the groups sampled, in a further stage of the development of this research it would be helpful to sample from the wider adult population as well.

Results

The first section of the questionnaire was analysed using one-way analysis of variance (Table 1). This shows that most of the questions were able to distinguish the children from the adults using this scoring system to a high level of statistical significance. The dichotomous questions were somewhat less successful at distinguishing child from adult, though analysis showed that four of the questions were significantly effective (Table 2). Thus children tended to see losing a foot as worse than losing a hand, difficulties with swallowing as more problematic than troubles with walking, being bald as worse that losing teeth, and taking tablets as worse than having an operation.

The final section, the ranking of concerns, was not able to show clear differences between children and adults (Table 3), and analysis of the ranking pattern (Diaconis, 1989) revealed no significant difference in the scoring.

Using these findings, a formula was devised in which the definitions section was weighted towards the most discriminating definition (disability). The dichotomous questions were

scored for each of the four that were significant discriminators (hand vs foot; swallow vs walk; bald vs teeth; medicine vs operation) giving the lowest score to the children, and the resultant multiplied by two and added to the definitions score. This gave means of 21.8 (std dev = 4.9) for the children and 29.4 (std dev = 4.6) for the adults. A two sample t-test showed a significant difference between the samples t (df of 444) = 16.6; p < 0.0001. The 95% confidence interval on the difference (6.6, 8.5), with Cohen's d = 1.6, which is a high effect size.

In order to determine the best cut off for this scale, area under the curve (AUC) calculations were carried out on the scale data. The best score obtained was 0.6, when the cut off of 27 was chosen. This gives a sensitivity of 0.73 and specificity of 0.82 for the scale using this cut off.

Table 1

Comparison of scores between children and adults on definition of terms

	Children's	Adults	Test		
Term	Scores	Scores	Scores (F)		
Defined	Mean (std dev) n = 201	Mean (std dev) n = 245			
Operation	2.01 (1.05)	2.91 (0.91)	87.69***		
Disability	1.59 (1.07)	3.15 (1.17)	210.96***		
Anaesthetic	1.68 (0.97)	2.52 (0.94)	85.64***		
Consent	1.77 (1.0)	1.87 (1.11)	0.83		
Discomfort	1.55 (0.71)	2.32 (1.07)	71.26***		
Paralysis	2.59 (1.39)	3.50 (1.27)	51.69***		

* p > 0.05, ** p < 0.01, *** p < 0.001

Table 2

Chi Squared scores for children vs adults on dichotomous questions element (N = 446 and all having 1 degree of freedom)

	Value	Significance
Blind vs deaf	3.17	0.075
Lose hand vs foot	20.46	0.000
Headache vs itchy skin	0.93	0.336
Unable to swallow vs unable to walk	5,94	0.015
Unable to speak vs unable to eat	0.00	0.987
Being bald vs losing teeth	6.28	0.012
Having medicine vs having an operation	14.78	0.000

Į	3.8%	9.5%	2.6%	3.5%	17.0%	13%	15.2%	13.0%	31.9%
~ ∄	20%	14.2%	2.0%	3.0%	28.4%	1.5%	22.3%	13.3%	15.7%
a a a a a a a a a a a a a a a a a a a	2.6%	7.8%	5.6%	6.9%	22.6%	0.0%	16.5%	11.7%	18.5%
• 5	1.5%	14.2%	4.6%	13.2%	17.8%	2.0%	16.8%	9.2%	18.8%
1	3.0%	13.9%	1.3%	13.0%	23.9%	0.9%	14.3%	13.4%	15.5%
child	3.1%	13.2%	3.1%	15.2%	14.7%	3.0%	10.7%	11.7%	24.4%
ą	4.3%	15.2%	0.9%	21.2%	15.7%	3.4%	16.0%	8.2%	13.4%
le B	7.7%	10.7%	3.1%	14.2%	19.3%	4.5%	14.7%	9.2%	15.7%
add the second	7.7%	13.9%	3.0%	ු 23.8%	10.4%	1.7%	16.5%	11.3%	12.5%
child s	5.1%	17.3%	4.1%	28.9%	8.6%	1.5%	11.2%	12.2%	10.2%
Į	13.2%	17.7%	3.9%	19.9%	5.7%	6.0%	11.3%	18.2%	3.9%
- I	13.3%	13.7%	3.6%	13.2%	5.1%	6.1%	12.7%	22.4%	9.1%
1	26.9%	10.8%	18.5%	6.9%	0.9%	16.3%	5.6%	10.4%	3.0%
- 1	35.7%	6.6%	11.2%	7.1%	4.6%	112%	4.6%	12.2%	1.0%
1	17.1%	6:9%	25.8%	3.1%	3.0%	36.1%	4.8%	7.4%	0.4%
ch lik	13.3%	6.1%	28.6%	4.1%	1.5%	36.4%	4.1%	3.6%	3.6%
	21.4%	4.3%	38.6%	1.7%	0.9%	34.3%	1.3%	0.4%	0.9%
	18.4%	4.6%	39.8%	1.00%	0.0%	27.8%	3.0%	6.1%	1.5%
	lerm ranked what operation will involve	hów much will it hurt	what will happen without operation	how long will I take to recover	how long will I be in hospital	what are the dangers of the operation	will I be asleep	what will I be able to do afterwards	how long will it take

Table 3 Percentage Of Children And Adults Who Gave Ranking *i* For Response *j*.

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Discussion

The results of this exploratory study do show that there are some differences between adults and children. Since professional judgment about competence is 'looking for adult type responses' the ability to identify these types of responses in children would tend to support the assertion that the 'competent' child has an understanding of both health issues and their potential long term consequences. This exploratory study suggests that at least two of the approaches to assessing competence by this mechanism in children and young people could be helpful. The definitions of terms and dichotomous choice elements showed significant differences between children and adults, and by their nature offer information towards the respondent's ability to understand and make choices. Interestingly, the ranked items were ranked very similarly by both adults and children, offering little in the way of distinction, but the very similarity may suggest that these issues are more fundamental than might first appear, and the similarity is, in itself, an interesting finding that would merit further investigation.

An AUC of 0.6 is modest in its significance and stresses that such a scale can only be a guide rather than a determining element in deciding upon competence to give consent. It is perhaps not surprising that trying to find clear distinctions between adults and children has proved so elusive. Inspection of the responses from the children showed that 25 of the children scored more than the median score on one of the definitions, though interestingly none of the children had more than one "adult-type" definition.

It is a fundamental principle that we each have the right to decide what happens to us, and in medicine this finds expression in the need to obtain consent before any procedure is undertaken.

This principle is especially challenging when the patient is a child. The judgement in the Gillick case supported the view that capacity to give valid consent could exist below the age of 16 years, but subsequently courts have supported the view in children as young as 11 years of age, while acknowledging that this would be rare (Re T (Abduction: Child's Objections To Return), 2000). These judgments illustrate the difficulty of making any presumption that below a particular age competence was unlikely, and are likely to prejudice the health of adolescents and create barriers to care (Dickens & Cook, 2005).

So how is a decision about capacity to consent to be made? Firstly, the capacity to understand fully needs to be made at the time that consent is being sought. Thus in practice the determination of Gillick competence must be rapidly followed by a decision as to whether the child has the capacity to give informed consent. The elements to be considered in determining this capacity were first outlined by Thorpe (Re C. (Adult: Refusal of Medical Treatment), 1993) – namely being able to comprehend and retain the necessary information, believe it, and weigh the information in order to reach a decision. These elements have continued to evolve (Gunn et al., 1999), with a growing emphasis upon recognizing that "the more serious the decision, the greater the capacity required..." (Re T. (Adult: Refusal of Treatment), 1992).

It is important to realise that the concept here is one of understanding and being able to make a decision, agreement with the doctor's view of what's best forms no part of deciding if the child is competent indeed, as Thorpe said (Re C (Adult: Refusal of Medical Treatment), 1993) *it does not matter if the decision reached is plainly wrong*.

If the child is able to demonstrate an understanding of the issues they can be asked if they consent to the procedure, and their decision can be relied upon. It is important to realize that the fundamental aim here is to try to ensure that the child makes the decision they genuinely wish to make, and not simply to find some way to obtain consent for treatment to proceed. There are however three situations where, as with an adult, the decision of a child who could be assumed to be competent can be set aside.

Comatosed or Confused. Understanding is closely linked with thinking clearly, and so any illness process which results in semi-consciousness, or a state of severe intoxication, prevents the child being competent to decide about their treatment. In such situations if the intervention is urgently needed to secure the child's safety then it can proceed without consent because if any legal case should arise the clinician's defense would be that of necessity. This does not mean that any procedure can be undertaken, intervention must be limited to those elements that reduce the life-threatening nature of the situation.

Mentally Ill. The powers of intervention available through the Mental Health Act 1983 are as applicable to children as they are to adults. However there is a great reluctance on the part of clinicians to use the Act's provisions when caring for children, a position which has been acknowledged by the courts (Re C. (Detention: Medical Treatment), 1997:180), although this is probably the most appropriate route when significant mental illness is present (Re W (Medical Treatment: Court's Jurisdiction), 1993:1). However these powers cannot be used to force medical treatment on an unwilling child, because the fundamental principle laid out in s 63 of the Act is that the treatment must be for "the mental disorder from which he is suffering". Case law has determined that s 63 includes nursing and care which is a pre-requisite of such treatment, which prevents the patient causing harm to himself or which alleviates the consequences of the mental disorder (ReB. v Croydon Health Authority 1995:683). It cannot be used to treat unrelated medical conditions.

Excessively Influenced by Someone. Powerful figures in a child's life can exert strong influence upon the decisions that a child makes. If such influence is clearly evident then the child's decision cannot be relied upon to be their unfettered view. One of the more familiar examples of this is where a child from a family of Jehovah's Witnesses refuses a blood transfusion. However it must be remembered that there are other sources of powerful influence, not least of which is the clinical team itself. In the desire to do what is clinically best for the child, it is important not to place what is therapeutically indicated over the clear and genuine wishes of a competent child.

If any of these confounding elements are present then the child's ability to make a valid decision is compromised. Even if the child appears competent to make the decision about their treatment, there have been a series of cases that have confirmed that any refusal can still be overruled by a person exercising parental responsibility, or by a court (e.g. ReT. (Adult: Refusal of Treatment), 1992; Re W (Medical Treatment: Court's Jurisdiction), 1993).

If the parents are also refusing to authorize treatment, then the situation may require the undertaking of proceedings under the Children Act 1989 so that parental responsibility can be invested in the local authority. Parental consent or court judgment are viewed as adequate defense against any subsequent claims of assault or battery, but the clinicians can still decide not to go ahead if ethically they do not feel able to proceed in the face of a child's continuing refusal. Figure 1 summarizes these stages of decision making.

Conclusions

The determining of a child or young person's capacity to give consent continues to be a challenging task for practitioners. As society's views on what constitutes maturity changes so the



judgements that will need to be applied to determine competence are under pressure to change. However the legal framework in which such judgements sit are not as quick to change and so will require the practitioner to continue to carry out a delicate, and at times challenging, balancing act. This study has sought to explore how children's views on health issues and their implications might differ from adults views. There are some areas of difference between adults and children – in relation to understanding of questions and (some) dichotomous questions – but also, some areas of similarity. This illustrates the complexity of this issue, and underlines the need for skill and the exercise of caution and informed judgement in working with children in this area. Mechanisms which might help to clarify this are worthy of development. If the voices of children are to be appropriately and effectively heard in the future with regard to this difficult and demanding area, further research and consideration of the issues involved is necessary and appropriate.

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