

The capacity of people with a ‘mental disability’ to make a health care decision

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ABSTRACT

Background. Based on the developing clinical and legal literature, and using the framework adopted in draft legislation, capacity to make a valid decision about a clinically required blood test was investigated in three groups of people with a ‘mental disability’ (i.e. mental illness (chronic schizophrenia), ‘learning disability’ (‘mental retardation’, or intellectual or developmental disability), or, dementia) and a fourth, comparison group.

Methods. The three ‘mental disability’ groups ($N = 20$ in the ‘learning disability’ group, $N = 21$ in each of the other two groups) were recruited through the relevant local clinical services; and through a phlebotomy clinic for the ‘general population’ comparison group ($N = 20$). The decision-making task was progressively simplified by presenting the relevant information as separate elements and modifying the assessment of capacity so that responding became gradually less dependent on expressive verbal ability.

Results. Compared with the ‘general population’ group, capacity to make the particular decision was significantly more impaired in the ‘learning disability’ and ‘dementia’ groups. Importantly, however, it was not more impaired among the ‘mental illness’ group. All the groups benefited as the decision-making task was simplified, but at different stages. In each of the ‘mental disability’ groups, one participant benefited only when responding did not require any expensive verbal ability.

Conclusions. Consistent with current views, capacity reflected an interaction between the decision-maker and the demands of the decision-making task. The findings have implications for the way in which decisions about health care interventions are sought from people with a ‘mental disability’. The methodology may be extended to assess capacity to make other legally-significant decisions.

INTRODUCTION

The ethical principle of respect for individuals and their right to self-determination is embodied in the requirement in common law jurisdictions for clinicians to obtain consent before undertaking any health care intervention (CARDOZO J in *Schloendorff v. Society of New York Hospital* 211 *New York Reports* 125 (1914); LORD GOFF in *Re F* [1990] 2 *Law Reports: Appeal Cases* 1; LORD DONALDSON MR in *Re T (adult: refusal of*

treatment) [1992] 4 *All England Law Reports* 649). However, an individual’s decision to give or withhold consent cannot be considered valid unless he or she has the capacity to make that decision.

In English law (i.e. the law in England and Wales), as in many other jurisdictions, there is a presumption that adults (that is, people aged 18 years or more) have capacity. Nevertheless, this presumption may be called into question, particularly if he or she has a ‘mental disability’ (the term used by the Law Commission (England and Wales) – hereafter, the Law Commission, 1995; see Fig. 1, and subsequently adopted in the draft Mental Incapacity Bill), and may

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prompt a clinical assessment. The traditional approaches to such assessments, based solely on the 'outcome' of the individual's decision-making or on his or her 'status' (or diagnosis), have been rejected on both empirical and conceptual grounds; instead, a 'functional' approach is now preferred (Hoggett, 1994; Arscott, 1997; Grisso & Appelbaum, 1998*a*). This focuses on the person's relevant abilities and the extent to which these match the demands of a particular decision-making task. Nevertheless, diagnosis remains important as a source of valuable information about the cause, prognosis and possible remediation of the individual's abilities (Grisso, 1986). A functional approach has been adopted by many common law jurisdictions (President's Commission, 1983; Weisstub, 1990; Creyke, 1995; Scottish Law Commission, 1995; Grisso & Appelbaum, 1998*a*), as well as within the English legal framework (*Re C (Refusal of Treatment)* [1994] 1 *Family Law Reports*, 31; Department of Health and Welsh Office, 1993; Law Commission, 1995; Lord Chancellor's Department, 1997, 1999).

Though a universally accepted standard for capacity to make health-care decisions remains elusive (Wong *et al.* 1999), there is a consensus that the following abilities are particularly important: retaining and understanding information about the procedure; appreciating that the information is of personal relevance; weighing up the information to reach a decision; and communicating that decision (Appelbaum & Grisso, 1988, 1995; Weisstub, 1990; Law Commission, 1995; British Medical Association/The Law Society, 1995; Berg *et al.* 1996; Grisso & Appelbaum, 1998*a*).

Previous empirical studies, mainly from North America, have noted some impairments in capacity to consent to treatment among people with a 'mental disability'. These studies have included participants with a mental illness, such as schizophrenia or depression (Grossman & Sommers, 1980; Irwin *et al.* 1985; Grisso & Appelbaum, 1991, 1995*a*; Schachter *et al.* 1994; Grisso *et al.* 1995), or with dementia (Marson *et al.* 1995*a, b*). A small number of studies (Morris *et al.* 1993; Arscott *et al.* 1999) have included men and women with the diagnostic criteria for a 'learning disability' (Dorrell, 1991; known in other countries as 'mental retardation' (Luckason *et al.* 1992), or intellectual or developmental

disability). Across the different groups, it appears that there are particular problems in understanding and retaining information relating to the decision to be made, but impairments have been found in all the relevant abilities. Nevertheless, despite this general trend, impaired performance by participants with a 'mental disability' is by no means inevitable. In part, it is related to the nature and severity of the clinical condition. For example, among people with a mental disorder associated with psychosis, the ability to give consent has been found to be related to the degree of thought disorder, conceptual disorganization and unusual thought content (Irwin *et al.* 1985; Schachter *et al.* 1994; Grisso & Appelbaum, 1995*a*). In addition, the complexity for the person of the particular decision-making task (Grisso & Appelbaum, 1991) and the ability or combination of abilities used as the legal criterion of capacity (Grisso & Appelbaum, 1995*b*; Marson *et al.* 1995*b*) are important. Furthermore, as predicted from a functional approach, the way in which relevant information is presented to the decision-maker is crucial: regardless of whether or not the person has a 'mental disability', material seems easier to understand when it is presented in simple language and as separate elements rather than as uninterrupted text (Grisso & Appelbaum, 1995*a*).

Given the variety of clinical conditions encompassed by the term 'mental disability', and the range of aetiologies, psychological impairments, and social disadvantages associated with different diagnoses (see review by Murphy & Clare, 1995), it cannot be assumed that individuals with different clinical conditions respond similarly to the same decision-making task. However, this assumption has never been tested directly within a single study. Further information about the performance, and the pattern of responding, of people with different diagnoses may help in the development of specific remedial strategies. The aims of this exploratory study were two-fold: first, to investigate and compare the performance of three groups of participants with a 'mental disability' (mental illness, learning disability, or dementia) on the same decision-making task using the same assessment methodology. It was expected that the performance of each of the three groups would be significantly poorer than that of their counterparts in the

general population, but no specific hypotheses were made about the extent of the impairment or the pattern of responding. The second aim was to assess whether, by simplifying the presentation of information and modifying the response so that it became less dependent on verbal ability, capacity might be improved. It was expected that all the groups would benefit from this process.

METHOD

Ethical considerations

Approval for the study, which was carried out for research purposes and did not affect subsequent treatment, was obtained from the local research ethics committee. It was anticipated that some potential participants would not have the capacity to decide whether or not to participate in the study. As the involvement of these individuals was crucial, it was decided, following discussions with medical lawyers and the multi-disciplinary Advisory Board established to oversee the project, that they would not be excluded. The decision was consistent with current approaches to research (Medical Research Council, 1991, paras. 6.1.3, 6.3.2; Law Commission, 1995, para 6.34) that involves people who are not able to consent to participation, and subsequent publication (Doyal, 1997).

Consent was always sought, using simple written information about the study which was read out to every potential participant and supplemented by a verbal explanation. Wherever possible, the main carer of participants in the 'mental disability' groups was also involved. Men and women without capacity to consent were not asked to participate unless they could show that they agreed to take part. Great care was taken throughout to ensure that participants were assenting.

Participants

Potential participants were adults (18 years or older) who had been advised by their general practitioner or psychiatrist to have a blood test for general health reasons or to monitor blood levels of medication. Convenience samples of the three 'mental disability' groups were recruited through the relevant local clinical services. A fourth 'general population' group

was recruited from the outpatient phlebotomy clinic of the local district general hospital. Potential participants were excluded if they: (i) met inclusion criteria for more than one of the groups; (ii) had no verbal expressive communication; (iii) could not be assessed prior to their appointment for the blood test; and (iv) were having blood tests where the implications were potentially grave (for example, HIV tests) or required a complicated explanation (for example, haematological monitoring for clozapine therapy).

The three groups with a 'mental disability' comprised a 'mental illness' group ($N = 21$), who had at least a 5-year history of diagnosed schizophrenia or schizoaffective disorder, using ICD-10 criteria; a 'learning disability' group ($N = 20$); and a 'dementia' group ($N = 21$). The presence of a learning disability or dementia was confirmed from health records and by assessment using establishment instruments. Seven people were detained in hospital under the Mental Health Act 1983. Six of these were in the 'mental illness' group; the seventh was a man with a learning disability who was admitted for an affective disorder. At the time of participation, he was mentally well and was in hospital for a social reason. To exclude a 'mental disability', the 'general population' group ($N = 20$) were screened using medical and educational history and a brief mental state examination. Reflecting the local population, all except three persons (one each in the 'learning disability', 'mental illness', and the comparison groups) were native English speakers; all were fluent in English.

Assessment of decision-making capacity

Decision-making task

The decision about consent to having a blood test was chosen for the following reasons. First, since the intervention was clinically required, rather than hypothetical (Morris *et al.* 1993; Marson *et al.* 1995*a, b*), the decision-making task was of practical and emotional relevance to the participants. Secondly, it is legally significant. A blood test taken without the consent of a person with capacity is an assault. Where the person is without capacity, the decision whether it was necessary in his or her best interests must be made, and justified, by the clinician. Thirdly, it is a frequent health care decision for both

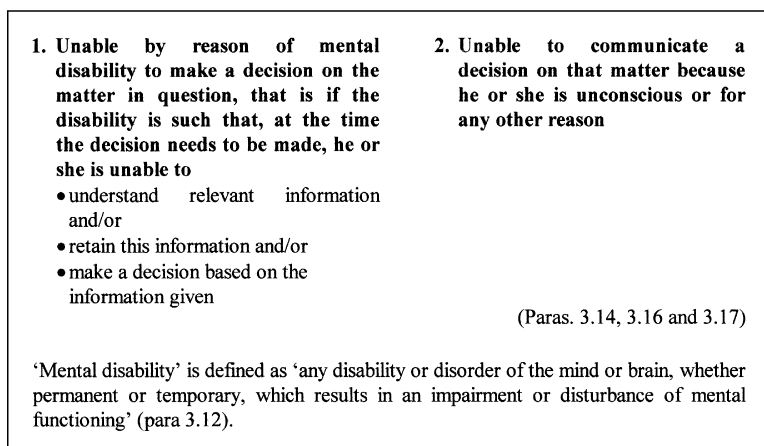


FIG. 1. Definition of incapacity (Law Commission, 1995).

people with, and those without, a ‘mental disability’, thereby allowing a direct comparison between groups.

Criteria for capacity

Following consultation with the Advisory Board and others, we used the criteria for the legal definition of ‘incapacity’ (see Fig. 1) suggested by the Law Commission for England and Wales (Law Commission, 1995) and adopted in the draft Mental Incapacity Bill (Lord Chancellor’s Department, 1997, 1999).

Decision-making assessment

Drawing on the methodology used in the MacArthur Treatment Competence Study (Grisso *et al.* 1995; Grisso & Appelbaum, 1998*a, b*), and in consultation with senior phlebotomists, medical practitioners and a medical lawyer, an information sheet and a standardized semi-structured interview were devised.¹

Information sheet

The sheet was designed to meet legal requirements for appropriate disclosure and provided the following five elements of information about a blood test: (i) the ‘purpose’ of the test; (ii) the nature of the ‘procedure’; (iii) the ‘risks’ of having the test; (iv) the ‘risks’ of not having the

test (‘risks’ of saying ‘no’); and (v) ‘voluntariness’ (the principle of a free choice in making a decision about the procedure).

The information sheet was prepared in two versions, relating either to general health screening (e.g. full blood count, thyroid function) or medication level monitoring (e.g. anti-convulsant or lithium levels). Both versions were written in simple language and printed in large font. The complexity of the information was analysed with an established formula (Flesch, 1948), previously used for medical and legal texts (Ley, 1977; Sherr, 1986; Clare & Gudjonsson, 1992). It was considerably less complex than the UK’s best-selling tabloid newspaper. The format was prepared as a continuous passage and as separate elements.

Decision assessment measure

The semi-structured interview schedule was based on the criteria for ‘mental incapacity’ proposed by the Law Commission (1995, see Fig. 1) and subsequently adopted in draft legislation (Lord Chancellor’s Department, 1997, 1999). It was designed to provide a framework to elicit information about participants’ skills in ‘understanding and retaining elements of information’, and ‘communicating a choice’. A staged approach, involving a maximum of four stages, was used (see Fig. 2). *Spontaneous account* Participants were asked what they knew about blood tests before any information disclosure was used to establish a baseline.

¹ A copy of the Decision Assessment Measure (including the information sheet) may be obtained, on request, from I. C. H. Clare.

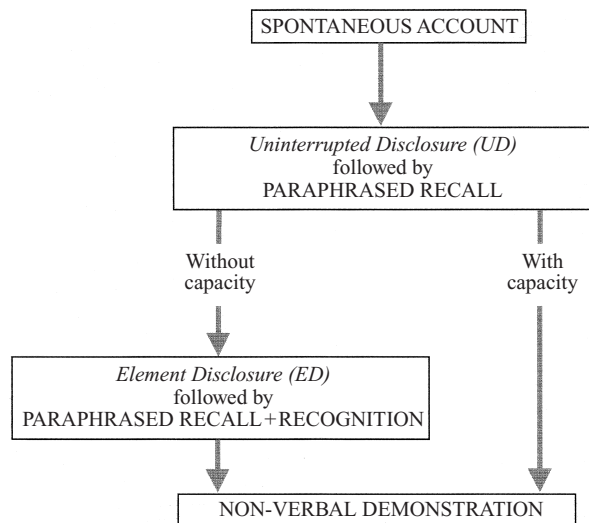


Fig. 2. Summary of procedure for assessment of decision-making capacity.

Uninterrupted disclosure (UD) The entire information sheet was given to participants to follow while it was also read aloud (to avoid the confounding effects of sensory impairments or literacy problems). They were then asked for 'paraphrased recall', an account of the information in their own words. This is an established psychological method (Grisso *et al.* 1995; Grisso & Appelbaum, 1998*a, b*) for assessing understanding of material relevant to decision-making.

Element disclosure (ED) This again involved 'paraphrased recall', but after presentation of each element of the information sheet.

Recognition In a much less verbally demanding task, participants were asked to identify each of a series of statements as the 'same as' or 'different from' the information on the sheet.

Non-verbal demonstration Participants were asked to show the procedure of the blood test, using materials chosen from a selection that included irrelevant medical 'distractor' items. This enabled understanding of the procedure to be examined independently of verbal skills.

All participants undertook the 'spontaneous account', 'paraphrased recall after UD', and 'non-verbal demonstration' stages. However, following piloting, participants whose capacity was evident did not undertake the 'ED' (see Fig. 2).

The participants' responses were written verbatim so that they were available for exam-

ination by others. Using operationalized criteria, they were then scored by the interviewer (J.G.W.), an experienced practising psychiatrist, against a threshold of minimal requirements established by clinical and legal consensus. Scoring of understanding and retention of the five elements of information in the information sheet used a 3-point system derived from Appelbaum *et al.* (1981). A 2-point score indicated a response that was totally acceptable, factually correct, and clearly relevant; a 1-point score, a response which was partially acceptable, factually correct or relevant; a zero score was a response that was unacceptable, factually incorrect or irrelevant. Recognition tasks were also scored on a 3-point scale: where four statements were presented, a score of 2 was given for four correct answers; 1 for three correct; 0 for two or fewer correct answers. Where two statements were presented (in the 'voluntariness' section), a score of 2 was given for two correct answers; 0 for one or fewer. It should be emphasized that these scores were used for the statistical analysis and to support the interviewer's clinical judgement of each participant's capacity overall and at each stage. However, they were not translated directly into determinations of capacity.

Other assessments

The severity of the participants' 'mental disability' was assessed, as follows: 'Mental illness', the Brief Psychiatric Rating Scale (BPRS)

(Overall, 1988); 'Learning disability', Verbal IQ (VIQ) prorated from the Vocabulary, Comprehension, Similarities and Digit Span subtests of the Wechsler Adult Intelligence Scale-Revised (WAIS-R) (Wechsler, 1981) (the first three subtests correlate highly with VIQ, while the Digit Span is a good measure of short-term memory retention (Shum *et al.* 1990)); 'Dementia', Mini-Mental State Examination (MMSE) (Folstein *et al.* 1975); 'General population', to exclude a 'mental disability' the participants completed the BPRS, the four WAIS-R subtests and the MMSE.

In addition, all participants or their carers (as appropriate) were asked for information about their employment and educational histories, and their previous experience of blood tests.

Procedure

Each person was seen individually: participants in the 'mental disability' groups were seen in their hospital ward, community residence, or day-service; for general population participants, at the phlebotomy clinic. First, relevant demographic and background information was obtained from the participants themselves; where necessary, this was supplemented by interviewing carers or drawn from health records. Before the date on which the blood test was due to be performed, capacity to consent to this procedure was assessed through an audio-taped interview using the Decision Assessment Measure. Finally, the relevant psychological assessment(s) was carried out.

For the three groups of participants with a 'mental disability', at least two separate sessions were used to complete all parts of the assessment. Four participants (three with dementia and one with a mental illness) appeared distressed. The session was ended immediately. Two of these individuals later completed the entire assessment. No participant subsequently did not consent or assent to a blood test.

Statistical analysis

To establish inter-rater reliability, four audiotapes were selected at random from each group. Independent ratings were carried out by a second psychiatrist (A.J.H.), who had no prior information about the group membership of the 16 participants. Judgements about the participants' capacity overall, and at each stage, and

scores for each of the decision-making abilities and elements of the information were compared to produce a reliability measure using kappa coefficients. Where the table is asymmetric, the kappa coefficient is undefined, so Spearman correlations were used instead.

Using the SSPS for Windows statistical package (SPSS-Inc, 1995), comparisons between the four participant groups were performed by ANOVA for continuous variables and by chi-squared or Fisher exact tests for categorical variables. To assess participants' progress through the stages of assessment, the McNemar test was used to compare participants across two stages, and Cochran's Q test for comparisons across four stages (as applicable). The Friedman test, comparing the averages of item score ranks for each participant, was used to establish which items of information were most difficult to understand.

RESULTS

Participant characteristics

Table 1 shows the age range, gender balance, and mean scores of the four groups on the assessments of 'mental disability'. In the 'mental illness' group, 19 (90.5%) participants had a diagnosis of schizophrenia, while two (9.5%) had received a diagnosis of schizoaffective disorder.

Since the mean BPRS score (42.5; s.d. 9.3) was > 40, the score usually associated with a need for in-patient treatment (Grisso & Appelbaum, 1995*a*), this indicated significant psychopathology. The mean prorated Verbal IQ score (60.2; s.d. 8.8) of the 'learning disability' group suggested that their intellectual functioning lay towards the lower end of the mild learning disability range. Of the 'dementia' group, 11 (52%) people had a diagnosis of Alzheimer's disease, with eight (38%) having a diagnosis of vascular dementia and two (10%) of unspecified dementia with mixed symptoms. The mean MMSE score (11.9; s.d. 5.2) indicated at least moderate dementia. In contrast, for the 'general population' group, the mean scores on all three assessments were within the normal or average range; this suggested that none of them was a person with a 'mental disability'.

There were no statistically significant differences between the three 'mental disability'

Table 1. *Characteristics of participant groups*

	Participant group			
	Mental illness (<i>N</i> = 21)	Learning disability (<i>N</i> = 20)	Dementia (<i>N</i> = 21)	General population (<i>N</i> = 20)
Mean age	40.1 (s.d. 10.6)	36.8 (s.d. 12.1)	82.2 (s.d. 8.3)	53.4 (s.d. 17.5)
Gender (% male)	76%	70%	48%	55%
Severity of 'mental disability' (mean scores)*	BPRS: 42.5 (s.d. 9.3)	WAIS-R prorated Verbal IQ: 60.2 (s.d. 8.8)	MMSE: 11.9 (s.d. 5.2)	BPRS: 19 (s.d. 2); WAIS-R: 95 (s.d. 12); MMSE: 29 (s.d. 1)†

* BPRS, Brief Psychiatric Rating Scale; WAIS-R, Weschler Adult Intelligence Scale-Revised; MMSE, Mini-Mental State Examination.

† All scores within the 'normal'/'average' range.

groups combined and the 'general population' group in the mean chronological ages or proportions of men. Self-report and interviews with carers indicated that the 'mental illness', 'dementia' and 'general population' groups were similar in terms of their most prestigious employment and academic qualifications. All but one participant (in the 'learning disability' group) had previous experience of a blood test.

Inter-rater reliability

The level of agreement on overall capacity was satisfactory ($\kappa = 0.87$). The only disagreement related to a participant whom both raters regarded as of borderline capacity. At each stage, there was complete agreement about the participants' capacity. The overall inter-rater agreement for each of the decision-making abilities and elements of the information was satisfactory, as follows: understanding and retaining elements of information, (i) purpose $\kappa = 0.77$, (ii) procedure $r = 0.99$, (iii) risks $\kappa = 0.43$, (iv) risks of saying 'no' $\kappa = 0.66$ and (v) voluntariness $\kappa = 1.0$; making a decision based on information given, $\kappa = 0.60$; and communicating a choice, $\kappa = 1.0$.

Decision-making capacity

Decision-making capacity among different groups

Table 2 shows the proportions of each group judged overall to have capacity to make a decision about a blood test. As expected, compared with the 'general population' group, significantly smaller proportions of the 'learning disability' and the 'dementia' groups were

judged as having capacity. However, statistical analysis indicated no significant difference between the proportions of participants with capacity in the 'mental illness' and 'general population' groups. Neither did it reveal any significant difference between the proportions of participants with capacity among those detained under the Mental Health Act 1983 and their counterparts.

Patterns of decision-making abilities

To identify which of the relevant abilities were most difficult for each of the three 'mental disability' groups, within-group comparisons were carried out between participants with and without capacity. Within the 'mental illness' group, the only significant difference lay in the ability to 'make a decision based on information given' ($P < 0.05$). Similarly, this ability differentiated those with and without capacity in the 'learning disability' and 'dementia' groups ($P < 0.001$ for both groups). However, in addition, participants with capacity in these two groups were also significantly better able to 'Understand and retain' the relevant information ($P < 0.05$).

Understanding and retaining different elements of information

To identify whether some items of the relevant information were more difficult than others, the performance of participants within each group was compared, regardless of their response to the decision-making assessment. The same pattern was displayed by the 'mental illness' ($\chi^2 = 37.9$, $df = 4$, $P < 0.001$) and 'learning disability' groups ($\chi^2 = 31.5$, $df = 4$, $P < 0.001$). In order,

Table 2. Outcome of the assessment of capacity to make a decision about a blood test

Participant group	Number with capacity N (%)	Comparison with 'general population' group
Mental illness (N = 21)	19 (90)	Fisher's exact test, not significant
Learning disability (N = 20)	13 (65)	Fisher's exact test, $P < 0.01$
Dementia (N = 21)	7 (33)	$\chi^2 = 20.25$ (df = 1), $P < 0.001$
General population (N = 20)	20 (100)	

from best to least well understood, the pattern was: procedure > purpose > voluntariness > risks of procedure > risks of saying 'no'. While, among the participants with dementia, the pattern differed slightly ($\chi^2 = 27.0$, df = 4, $P < 0.001$): procedure > voluntariness > purpose > risks of procedure > risks of saying 'no', again, 'procedure' was the easiest item, while 'risks' and 'risks of saying 'no'' were the most difficult. No significant trend was evident in the 'general population' group.

Impact of simplifying the decision-making task

Fig. 3 shows, in the form of cumulative percentages, the proportion of each group judged as with capacity as the decision-making task was simplified (the non-verbal demonstration stage is not included as it assessed only understanding of a single element, 'procedure').

Overall, as expected, capacity improved as the decision-making task was simplified. The provision of information (UD) was the most effective strategy ($\chi^2 = 9$, df = 1, 1-tailed $P < 0.01$) accounting for a shift to capacity for nine people (five from the 'mental illness' group, three from the 'learning disability' group and one from the 'general population' group). As the task was simplified, capacity improved significantly for the 'mental illness' group (Cochran's $Q = 14.4$, df = 3, $P < 0.01$), but not for the participants with a learning disability or dementia. Qualitatively, though, they responded very differently. In the 'dementia' group, neither UD nor the two procedures following ED increased the proportion of participants with capacity. In contrast, while UD benefited some of the 'learning disability' group, the effects of

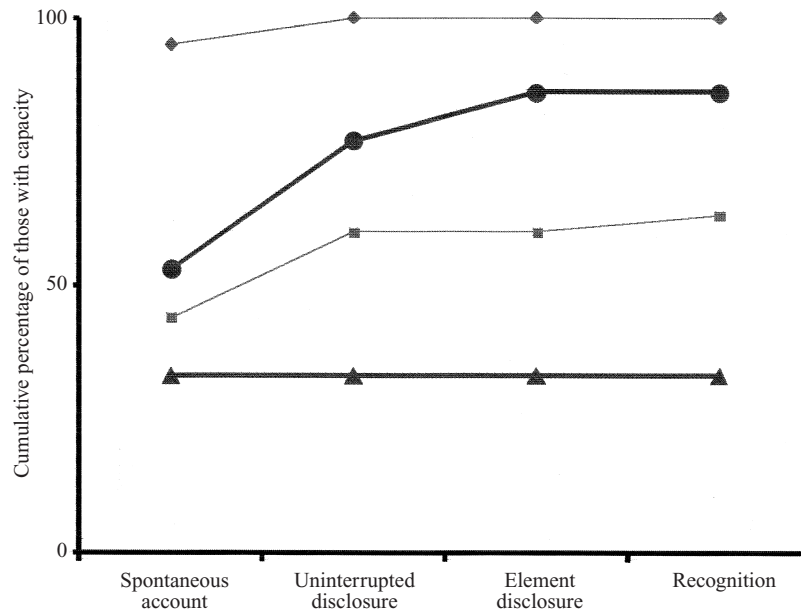


Fig. 3. Progression through 'verbal' stages of decision-making assessment. (●, Mental illness; ■, learning disability; ▲, dementia; and, ◆, general population.)

the two procedures following ED were mixed: on each, one participant improved and one deteriorated.

Importantly, three participants (one from each of the 'mental disability' groups) were only able to demonstrate understanding of the procedural element through the non-verbal demonstration. Without this, they would have been judged as without capacity because their verbal skills were so severely impaired.

DISCUSSION

In this study, capacity to make a decision about the same health care intervention among men and women with one of the three different clinical conditions associated with a 'mental disability' and a 'general population' group was compared on the same measure. The measure is systematic, and would be legally and ethically defensible since it both provides a framework for assessing all the abilities and elements of information believed, in England & Wales, to be relevant to the particular health care decision (Law Commission, 1995) and is consistent with current guidance to clinicians (BMA/The Law Society, 1995). It is, however, important to emphasize that, contrary to the concerns sometimes expressed (Kapp & Mossman, 1996), any assessment measure can only be an aid to clinical judgement. The court is the ultimate arbiter of capacity.

As expected from previous studies of people with a 'learning disability' (Morris *et al.* 1993) or 'dementia' (Marson *et al.* 1995a), the performance of these two groups on the measure was more impaired than that of their 'general population' counterparts. Nevertheless, in both groups, some participants had capacity to make a decision about having a blood test even at the initial (Spontaneous Account) stage. Moreover, importantly, and in contrast with previous studies (e.g. Grisso & Appelbaum, 1991, 1995a), there were no significant differences between the performance of the 'mental illness' group and that of their peers in the general population. These findings are particularly striking given that the 'mental disability' of our participants with either dementia or schizophrenia/schizoaffective disorder was more significantly more severe than in some important previous studies (e.g. Grisso & Appelbaum, 1991 (though not

Grisso & Appelbaum, 1995a); Marson *et al.* 1995; no relevant comparison data available for people with a learning disability in Morris *et al.* 1993; Arscott *et al.* 1999). It is most likely that the explanation lies in the limited demands of the decision-making task we used and its familiarity to all but one of the participants. Nevertheless, the results add to the empirical evidence for a rejection of a 'status' approach, whether based on participants' diagnoses or their legal position under mental health legislation, and support a 'functional approach'.

There were some similarities across the three 'mental disability' groups. Regardless of diagnosis, the main difference between individuals with and without capacity lay in their ability to 'Make a Decision Based on the Information Given'. However, it cannot be assumed that a lack of ability reflected the same difficulties in all the groups. Compared with other conceptualizations (Appelbaum & Grisso, 1988, 1995; Weisstub, 1990; Berg *et al.* 1996; Grisso & Appelbaum, 1998), which specifically refer to 'appreciation' and the 'ability to manipulate the information', the Law Commission's definition of this complex aspect of decision-making is very broad, requiring only that the choice seems to reflect the person's understanding of the five key elements of a legally acceptable disclosure, including the likely consequences, and is not divorced from it by the impact of the 'mental disability' (Law Commission, 1995, para. 3.17). The clinical implication of such a definition is that it may be hard to identify, and therefore to alleviate, the difficulties underlying any apparent impairments in this ability; further investigation is needed.

Across the three 'mental disability' groups, there was also a broadly similar pattern of difficulties in understanding and retaining particular elements of the information sheet. Understanding of the 'procedure' was easiest to understand, perhaps reflecting its purely 'factual' nature. In contrast, the 'risks of the procedure' and 'risks of saying no' appeared particularly problematical. Given that these 'risks' were reported by the 'general population' group, it is unlikely that they were too trivial to mention. From previous studies (e.g. Grisso & Appelbaum, 1991; Morris *et al.* 1993; Marson *et al.* 1996a), it seems most likely that these more complex and abstract elements were too cog-

nitively demanding. An intervention strategy which makes these elements more 'concrete' (for example, by using pictures) may be helpful; we are currently investigating this possibility.

Nevertheless, there were some differences in the pattern of responses of the three groups of persons with a 'mental disability'. In terms of their understanding and retention of the different elements of information relevant to the decision, in reverse of the other groups, the participants with dementia found the 'purpose' of a blood test more problematical than 'voluntariness'. One possibility is that, since the purpose of a blood test may be different on different occasions, it requires new learning – a task likely to be particularly difficult for this group (Brandt & Rich, 1995). The most striking difference in the pattern of responses lay in the response to the simplification of the task. With the exception of the individual who benefited from the non-verbal demonstration stage, participants with dementia who were without capacity initially were not assisted by any part of this process. In contrast, for both the other two groups with a 'mental disability' and the comparison group, the proportion with capacity increased as the decision-making task was simplified progressively (see Fig. 3). Again, these findings support a 'functional approach', with capacity reflecting an interaction between the individual's relevant abilities and the demands of the particular decision-making task (Grisso, 1986), implying that capacity may be maximized by assisting the person to develop his or her relevant abilities and/or by simplifying the task. We attempted to simplify the task in two ways: by presenting information about the decision, first, in uninterrupted form, and then as constituent elements; and by limiting the verbal demands of the response by including recognition and non-verbal demonstration. The most effective part of this process was the provision of simple, clear, information about a blood test. The implication is that, in everyday practice, clinicians might use this basic strategy to maximize capacity to make decisions about health care interventions. Our finding that three people were only able to demonstrate capacity when they were provided with an opportunity for non-verbal demonstration of the procedure involved in a blood test suggests, however, that it may be flawed to rely on assessments requiring sophisticated verbal ex-

pressive skills. Contrary to the presumption of capacity in English law, and the intentions of the Law Commission (1995), such assessments provide too many 'false negatives' and may disempower people with a 'mental disability'. A challenge for the future is to explore further the development of non-verbal techniques for demonstrating a broader range of the abilities and skills relevant to capacity. It may be helpful to draw on some of the methodologies for assessing choice-making by people with severe or profound learning disabilities (Lancioni *et al.* 1996).

The findings of this study need to be considered in the context of the several methodological limitations. The groups were small and, since they were recruited as convenience samples, it is uncertain how far they were representative of the underlying populations of people with a 'mental disability'. No attempt was made to match the severity of the 'mental disability' between groups. In addition, the limitations of the Decision Assessment Measure need to be considered. Developing the pioneering work of Grisso and Appelbaum and their colleagues in the USA (Grisso *et al.* 1995; Grisso & Appelbaum, 1995*a*, 1998*a*), we have devised a systematic measure that provides a framework for assessing capacity to consent to a blood test. So far, it appears, overall, to have satisfactory inter-rater reliability. The limited agreement on some of the elements may reflect the second rater's difficulties in making assessments from audiotapes; ideally, videotapes should be used for inter-rater agreement. While the content of the assessment was developed through extensive consultation with clinicians and medical lawyers and therefore examines the relevant decision-making abilities, it is difficult to address validity fully because of the lack of a universally accepted legal definition of incapacity and uncertainty about the abilities required and the relative importance which they should be accorded. However, the measure has good face validity. Importantly, participants with a 'mental disability' did not find it either demeaning or distressing. Some individuals in the 'learning disability' group became confused by the repetition as the stages progressed but it is not clear whether this reflected their cognitive limitations or the impact of the questioning on their confidence in their original responses. Further investigation of this phenomenon is needed in

developing the measure further and assessing its use in clinical practice.

For those jurisdictions in which capacity is a crucial determinant of individuals' rights to autonomy and respect, the findings are of relevance to the important public policy goal that people with a 'mental disability' should be encouraged and enabled, as far as possible, to make decisions or themselves. In the United Kingdom, bills relating to decision-making by adults without capacity have been drafted (Law Commission, 1995; Scottish Law Commission, 1995; Lord Chancellor's Department, 1997, 1999), and are being considered for introduction into our legislation. As a result of these developments, it is likely to become increasingly important for clinicians to consider the capacity of people with a diagnosis associated with a 'mental disability' to make decisions about health care interventions. While capacity is task-specific, the knowledge gained through the development of the measure used in this study may be applicable to other areas of decision-making.

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