Assessing capacity to make decisions (DMC)

Andrew Rock
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Batemans Bay, 2012
– “I did it my way”
– Why DMC is sometimes called into question, and even curtailed
– How it’s assessed
– The need for capacity assessments in the future
Assessment of DMC

• A wise saying…
Assessment of DMC is all about the conflict between two principles

**Autonomy**

- “An ordinary part of being an adult is having the authority and responsibility to make our own decisions. Our decisions help to define us as individuals. They not only shape the practical course of our lives, they also illustrate to others how we see ourselves and what our hopes and dreams are. When our power to make our own decisions is taken away from us, our sense of self is also at risk.” *Queensland Law Reform Commission, 2008*

- “part of being an adult is the right to make decisions independently” *Law Reform Consultation paper, 2005*
Beneficence

- Need to act in the best interests of our patients
- Responsibility to protect vulnerable people from their own choices
  - Likely consequences and inconsistency
Reconciling the conflict

• If capacity intact, autonomy takes precedence over beneficence

• `Even when a patient’s own life depends on receiving medical treatment, an adult of sound mind is entitled to refuse it. This reflects the autonomy of each individual and the right of self-determination.` Airedale NHS Trust v Bland

• When capacity is impaired, beneficence takes precedence over autonomy e.g. Re MB and the caesarian

• Capacity the gatekeeper to right of self-determination. Incapacity legitimizes removing right of choice
What is DMC?

- Capacity issues in NSW resolved by the Guardianship Tribunal under the Guardianship Act, the Supreme Court of NSW and the Mental Health Review Tribunal (under the Trustee and Guardian Act 2009)
- No universal definition of capacity
- Not defined or defined differently in case law, legislation, and health
No consensus but convergence: DMC involves the ability to...

**US: Appelbaum and Grisso, 1988**
understand the relevant information, e.g. about proposed
diagnostic tests or treatment; appreciate their position in
terms of their values and medical situation); use reason to
make a decision; and communicate their choice

**MC Act, UK 2005.** Someone who lacks capacity cannot:
Understand information given to them re: a particular
decision; retain it long enough to make the decision; use or
weigh up the info provided to make the decision;
communicate their decision

**Capacity toolkit, NSW AG’s Dept 2008**
understand the facts involved; understand the main choices;
weigh up the consequences of the choices; understand how
the consequences affect them; communicate their decision
Capacity is domain-specific

• Global impairment is rare
• Can “have a little bit of DMC;” can lack capacity in some areas but not in others.
• can’t infer lack of capacity in one area from lack of capacity in another area
Domains of DMC

1. Independent living
2. Financial management
3. Treatment consent
4. Testamentary capacity
5. Research consent
6. Sexual consent
7. Voting
8. Driving

1. personal and lifestyle decisions, e.g. accommodation
2. health
3. Financial decisions re: money and property
How do we know if someone has DMC?

conceptual approach 1: Status model

• Incapacity can be inferred from diagnosis or group membership
• Still in operation
• Problems
  – Global not capacity specific
  – Doesn’t allow for borderline cases, or change
  – Undermines individual rights
  – Can obscure impairment, e.g. alert and responsive but impaired
Psychiatric diagnosis

Acquired brain injury

Progressive conditions (e.g. dementia)

Intellectual disability

Severe neurological events – e.g. stroke

Impaired

DMC
conceptual approach 2: outcomes

- Empirical; seems evidence based
- Problems
  - Retrospective
  - Punishes non-conformity; “If you agree with me you’re ok”
  - “a decision which is inconsistent with the views and values of the assessor, or which rejects conventional wisdom, is by definition incompetently made...this penalises individuality and demands conformity at the expense of personal autonomy” Law Commission 1995
conceptual approach 3: functional model

- What matters isn’t diagnostic status, or outcome of decision, but integrity of decision making processes
- Understanding risk and consequences
- Sliding threshold: greater understanding needed for greater risk or complexity
practical assessment

- Competence = legal issue,
capacity = clinical issue

Presumption of capacity in law. To establish need for substitute decision maker, need evidence ...
- a disabling condition exists
- the disabling condition is impacting the ability to make decisions or manage affairs independently
- there is a trigger situation
Translating legal guidelines into practice

- Historically done by GPS, psychiatrists, medical specialists
- Traditional approach:
  - Diagnosis, interviews, general mental status reviews
- Often ok e.g. severe cognitive impairment
- Not always effective –
  - group vs. individual level
  - Ambiguity
  - Conflict within families, or patient vs. team
Limitations of traditional assessments

• Hill et al 2006 asked psychiatrists: ‘What are the key elements in the assessment of a patient’s capacity?’
  – Can the patient... 1 understand the info relating to treatment? 2 retain the information? 3 weigh it up to make a decision? 4 ‘believe the information’? 5 communicate the decision?

• Over a third identified two or less of the five points in testing decision-making capacity
Sessums’ 2011 review: 43 studies

- Found high average rates of incapacity in particular groups: impaired DMC in 68% of LD; 54% of AD; 44% of NH residents; 25% of medical inpatients
- Non-specialist medicos accurate but...
- In patients independently verified as lacking capacity, only recognised impaired medical DMC 43% of the time
The role of Ψ in DMC

To recap: to establish impaired DMC, need to establish... a disabling condition exists; impairing the ability to make decisions in the relevant area; presence of a trigger situation

1. is there a trigger situation?
   - Clinical: refusing treatment; difficulties uncovered by admission; refusing placement
   - Forensic and legal: finances and testamentary capacity; professional capacity; capacity to stand trial
2. Is there a disabling cognitive condition?

– Assess the domains
– Compare performance with peers
– Other uses of general cognitive assessment
  • Establish whether the impairment is likely enduring or transient
  • Identify strengths and weaknesses to compensate
3. Is the disabling condition impacting on ability to make decisions in the area of concern?

- est. intellectual disability necessary but not sufficient – are the deficits relevant to the specific situation? Answer with tests, capacity tools, and interviews
- A) Specific capacity tools – limitations, esp. among older adults, and those with Ψ illnesses
- B) detailed tests of particularly relevant skills
- Conceptually relevant areas
  - WM theoretically important in comparing potential outcomes of different treatments
  - memory
  - reasoning, comprehension, judgement linked with choosing between potential outcomes

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• **Empirically relevant areas**
  – understanding → conceptualisation, ability to name shown items, memory, and comprehension
  – appreciation → verbal fluency, attention and conceptualisation
  – reasoning → verbal fluency, executive functioning, cognitive flexibility, attention and memory
  – expressing a choice → comprehension, attention and executive functioning.

• Identifies areas to explore in targeted interviews, and highlights potential compensations

• C) Semi-structured interviews and collateral interviews
Putting it into practice: DMC is not unitary

- Pat was 69, with history including type II diabetes, hypertension, frequent significant DV
- trigger: being financially exploited, police involved. ? Accommodation ? Finances
- pat believed her memory was poor, but she was otherwise ok: thought she could “trade her way out of trouble”
- Family: generally ok functionally, but declining memory and judgement
General intellectual disability?
• Mild to moderate impairment

Test results in relevant areas
• Executive functioning, functional problem solving mildly reduced
• Numerical skills and memory moderately to severely impaired
Conclusions

Accommodation:
- Problem-solving skills somewhat reduced
- Realistic re: risks of living independently
- Ok re supported living vs. independent living
- Ok functional problem solving
- Clear and consistent wanted to live at home

Finances
- Poor numerical skills
- Poor understanding of her situation
- Clearly a need for intervention. Findings suggested DMC ok re accommodation at this stage, but need for financial management
Putting it into practice 2: DMC fluctuates

- Ability to make decisions is dynamic
- Psychiatric conditions; D and A abuse; medical conditions like head injury and stroke; dementia
• Pat was 64.
• Multiple MH admissions to multiple facilities over at least 5 years. Guardianship been recommended in past; admitted wandering naked and disoriented
• BPD; depression; small stroke; type II diabetes; poor compliance with medications; DA abuse***
• Previous findings: extremely poor performance on cognitive tests, functional tests: diagnosed with VaD
• But... did better than expected on Ψ review. Do results indicate a need for substitute decision making re accommodation?
Findings and conclusions

General intellectual disability?
• Mild to moderate impairment

Test results in relevant areas
• Executive functioning, memory, only mildly to moderately impaired

Interview: Awareness of deficits good; willing to accept help; reasonable solutions to hypothetical problems
• Need for substitute decision making re accommodation not compelling at this stage
What the future holds: need for capacity assessments will increase dramatically

- Changes in medical care
- Changes in the economy: new choices
- Changes in society
The greying of society

EU: 21% of the population over 65.
by 2050 this will rise to 34%.
elderly people living alone

- UK 2011:
  - 43% of 60+ live alone
  - 75+: ½ see family less than monthly; ¼ have no living relatives
- Singapore:
  - 35,000 in 2012 to 83,000 by 2030
- Japan
  - Single-person households the fastest growing and largest household group in Japan.
- Why living alone more? Choice and circumstance
Aging and disability

• Aging ≠ loss of capacity
• risk factor for conditions leading to it
# Projected increase in dementia

**Access Economics, 2011**

## Table 1: Dementia prevalence estimates and projections by state and territory and nationally, 2011-2050

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## Table 2.11: Total New South Wales dementia prevalence projections, by Federal Electoral Division

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Effect of these changes

Guardianship Tribunal report 2009-2010:
- 9% growth in workload as compared to the previous financial year
- Applications to review Enduring Guardianship appointments increased by 5.2%
- Reviews of Financial Management orders increased by 10.3%
- Need for assessments of DMC seems set to rise