Capacity & Consent Issues in Older People With Stage 5 CKD: More Than Just Doing an MMSE

Renal Supportive Care Symposium
St George Hospital

Dr John Obeid
Consultant Geriatrician
Norwest and The Hills Private Hospitals

Outline

- What is capacity
- Causes of incapacity
  - Mental illness
  - Dementia
  - Delirium & acute medical illness
- Testing Capacity
- Substitute and Supported Decision Making and the law

What is “capacity”?

- Capacity = An individual’s ability to make and communicate a decision
- Capacity is domain-specific (e.g. Testamentary, health care, financial, POA, guardianship etc)
- Capacity is situation-specific (i.e. Might differ for individual decisions within a particular domain)
- Presumed to be present unless proven otherwise.

What is “capacity”?

- A diagnosis of a psychiatric disorder or dementia of itself does not preclude capacity
- The ‘quantum’ of required capacity (cognitive function) is partly determined by the complexity of the issue at hand
- Capacity in any given individual can vary from time to time (depending on their condition at the time). This is especially important in significant medical conditions such as renal failure, delirium, liver failure etc where fluctuations occur

Capacity

- Don't assume a person lacks capacity based on appearances
- Assess the person's decision-making ability not the decisions they make
- Substitute decision-making is a last resort

Capacity

- A person has the capacity to make a specific decision if they can:
  - understand the facts and the choices involved
  - weigh up the consequences
  - communicate the decision

Impact of Dementia

- Dementia and renal disease are both age-associated illnesses, therefore commonly occur together.
- A diagnosis of dementia on its own does not equate to incapacity.
- A low MMSE score neither equates to incapacity nor even dementia

Impact of Dementia

- The MMSE
  - Only a screening test for dementia. Validated for otherwise well, community dwelling older people.
  - Low MMSE does not = dementia
  - Confounders are the 5 D's: depression, deafness, delirium, drugs, developmental delay
  - So a good clinician would never say:
    - "MMSE 15/30 = severe dementia" or
    - "Lacks capacity because RUDAS score is 12"

How Severe is the Dementia?

- Pitfalls in just relying on cognitive scores:
  - Educational level
  - English not first language
  - Depression
  - Deafness
  - Visual impairment
  - Reliability of tester
  - Medications
  - Predominant dysphasia (cognitive tests affected out of proportion to actual cognitive impairment)
  - Frontal lobe impairment with reasonable scores on MMSE and other tests

Impact of Dementia on Capacity

- Issues to consider:
  - Is there a diagnosis of a cognitive disorder/dementia (or is it one of the 5D confounders)?
  - Length of the history of cognitive decline
  - Are there functional impairments (ADLs, IADLs)?
  - What are the questions we are asking the patient to answer about their medical treatments?

Impact of Dementia

- Medical assessment of capacity in a person with dementia should focus on whether they:
  - Understand what the issue is – do they understand dialysis (and the commitments involved on their part), non-dialysis supported care, symptom management etc.
  - Understand the effect that their decisions will have – do they understand the impact on family members/carers, do they understand the impact of their decisions on life expectancy?
  - Are consistent in their requests from day to day

Impact of Dementia

- The simpler the issue to be resolved, the less cognitive function required to possess capacity to make a decision or consent to treatment.
  - Basically: Capacity $=$ $\frac{\text{brain function}}{\text{complexity of decision}}$
  - i.e. “tiny” amount of cognition may still have capacity if only a “tiny” decision is required
  - And: the more complex the decision, the greater the cognitive function required to possess capacity to make that decision

Health Care Decision Making in NSW

- Hierarchy of decision-making

1. Patient (presumed to have capacity unless proven otherwise)

2. Enduring guardian with function of health care

3. Person responsible:
   a. Spouse or intimate partner
   b. Close personal relationship
   c. Unpaid carer

(Note: children not officially recognised in hierarchy of decision making in NSW)

Supported Decision Making

- Process whereby a person with a disability is enabled to make and communicate decisions (UN Rights of Persons with Disabilities 2006)
- Aims to maintain person's decision-making ability and create enabling contexts to allow supported decision-making
- Victoria already has provision for a 'supportive attorney' and 'medical support person'
- Aim is to assist the person to understand, weigh options and communicate choices

Managing a Person With Suspected Cog Impairment in Setting of Stage 5 CKD?

- Ascertain the diagnosis: does the person have cognitive deficits/dementia? Is there a reversible component that might improve with treatment (e.g. deafness, depression, drugs etc).

- Use a range of cognitive tests across a number of domains. Include frontal tasks (e.g. problem solving, mental flexibility) as well as perceptual, memory and visuospatial tests. OK to do tests like MMSE, RUDAS, MOCA, but don't rely on them dogmatically.

Managing a Person With Suspected Cog Impairment in Setting of Stage 5 CKD?

- People with S5 CKD may have subcortical disease (e.g. vascular cognitive impairment or dementia) rather than Alzheimer's disease. VCI tends to affect frontal-type functions such as problem solving, mental flexibility, planning, executive tasks, whereas AD might affect speech, memory, praxis etc.

Managing a Person With Suspected Cog Impairment in Setting of Stage 5 CKD?

- Discuss options with the person with CKD re RRT or RSC or both. Make sure YOU know what is medically-feasible or likely to be effective!
- Ascertain person's understanding of the options by checking back with them
- Can they weigh up the alternatives?
- Do they understand the implications of the decision on themselves and on others?
- Can they communicate their decision?
- Are they consistent in their wishes for the type of treatment?

What NOT to do in a Person With Suspected Cog Impairment in Setting of Stage 5 CKD

- Assume they don't have capacity to make decisions
- Speak to "the family" instead of the person
- Make the decision yourself without reference to the person
- Explain the options then ask the person "so, what do you want to do"?
- Assess capacity solely by doing a MMSE or neuropsychology assessment

Managing a Person With Suspected Cog Impairment in Setting of Stage 5 CKD?

- If person lacks capacity to make decision re RSC/RRT, consider supported decision making or substitute decision making (based on hierarchy in NSW).
- It is worthwhile involving a geriatrician as part of the assessment process (not just to assess capacity but to assess and manage comorbidities)
- Is treatment urgent and life saving? – no consent required.
- Is there a legally—appointed guardian (either enduring guardian or public guardian appointed by NCAT)? – that person makes decision
- Otherwise, it is the "person responsible" who can legally make decisions

Powers of Attorney (POA)

- POA in NSW relates to decisions regarding property and financial affairs – NOT Healthcare decisions.

- General POA (GPOA): operates immediately or at a date specified in POA document, BUT it ceases to operate when the person loses capacity

- Enduring POA (EPOA): operate when the person loses capacity AND endures thereafter (until they regain capacity or in the event that they possess enough capacity to make a specific decision)

Enduring Guardianship (EG)

- Allows another person to make life decisions (including some medical and end of life decisions) on their behalf if they lack capacity

- i.e. only begins to operate after the person loses capacity (or does not have capaity at the time a decision is required)

Questions