Deciding for incompetent patients: whose best interests are we talking about?

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1. Decision-making capacity
2. Surrogate decision makers
3. Criteria for decision making
4. Incompetent patients’ behavior
5. Interests of patient and others
Societal Divide

- Competent (Capacity)
  - Right to self-determination
- Incompetent (Incapacity)
  - Infringements on right to self-determination permissible
- 40% of acutely hospitalized patients
  Raymont V et al, Lancet 2004

- 70% of older adults for whom treatment decisions are required

- 95% of critically ill patients
  Prendergast TJ et al, Am J Respir Crit Care Med 1998
Ethical Relevance

Capacity to decide for yourself

Existential weight of the decisions

Rise of guardianship cases per year in Germany

Guardianship cases 1995-2009 (official statistics)
Elements of capacity:
- Understand and retain information
- Deliberate benefit and harm
- Make a stable decision
- Communicate the decision

Rules of capacity determination:
- Individual & just-in-time determination
- Based on process, not result of decision making
- Requirements depend on complexity and gravity of decision
Is decisional capacity purely cognitive? Emotions play key role in decisions!

*Damasio A 2003, Northoff G, J Med Ethics 2006*

- Can we determine capacity by measuring brain function? fMRI

- Can we determine capacity by brain-computer-interface?
  - for *locked-in syndrome*
  - for *minimally conscious syndrome*
Open Questions

- How should we deal with fluctuating capacity?
- Can we treat dysfunctional decision making, thus allowing otherwise incompetent patients to give informed consent?
- Can we enhance decisional capacity?
1. Decision-making capacity

2. Surrogate decision makers

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Candidates

- Family proxies
- Relatives via durable powers of attorney
- Legal guardian (court-appointed)
- Physician as quasi-proxy
- Court
### Who should speak for the patient?

<table>
<thead>
<tr>
<th>Familiar surrogates</th>
<th>Unfamiliar surrogates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of patient (common narrative, whole person)</td>
<td>Legal and medical knowledge/training</td>
</tr>
<tr>
<td>Existentially affected</td>
<td>Emotionally detached</td>
</tr>
<tr>
<td>More time and availability</td>
<td>More experience</td>
</tr>
<tr>
<td>Subsidiary solution, less costs</td>
<td>Execution of social control</td>
</tr>
</tbody>
</table>

→ Does it matter? Do they come to different decisions?
Social science experimental study

Family caregivers and professional guardians (deciding for dementia patients), n=32

2 case vignettes (end-stage dementia)

Think aloud method
Results

No consent to treatment

Consent to treatment

Both vignettes

Vignette pacemaker

Vignette PEG tube

n = 25 20 15 10 5 0 5 10 15 20

Family caregivers

Professional guardians

### Results

<table>
<thead>
<tr>
<th>Professional guardians</th>
<th>Family caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Take time to decide</td>
<td>Decide quickly and intuitively</td>
</tr>
<tr>
<td>Try to disregard own values</td>
<td>Consider own values, interests</td>
</tr>
<tr>
<td>Focus on patient autonomy</td>
<td>Focus on patient wellbeing</td>
</tr>
<tr>
<td>Consult with clinicians</td>
<td>Consult with relatives</td>
</tr>
<tr>
<td>Request court decisions</td>
<td>Do not ask the court</td>
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</table>

**Professional role**

**Emotional role**

*Jox RJ et al. (2012) Int J Geriatr Psychiatr 27:1045*
The choice of surrogate decision maker critically affects life-and-death decisions.

Surrogate decision making may vary according to emotional attachment.

Yet, legally & ethically, decisions should uniformly be based on the same criteria.
Outline

1. Decision-making capacity
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Rationale
Ethical Criteria

- Patient wellbeing
- Patient autonomy

- Criterion of best interests
- Criterion of substituted judgment
- Criterion of precedent autonomy

Situation / Evidence for autonomy

Best interests

Precedent autonomy

Substitutive autonomy

Jox RJ, Ethik Med 2004
1. Are these criteria currently realized in practice and if not how could this be improved?

2. How should incompetent patients’ behavior inform decision making?

3. Are these patient-centered criteria sufficient – Are the interests of others ethically relevant?
Advance directives – practical problems:

- Barriers for the less well-educated
- Often not available when needed
- Often no informed decisions (questioning autonomy)
- Often not applicable (too vague, too narrow)

Best possible solution:

Structured Advance Care Planning programs
Randomized study, n = 309 patients > 80 years

After 6 months 56 have died: Patient preferences respected in 86% (ACP) vs. 30% (no ACP)

Relatives (ACP): ↓ distress, anxiety, depression
Practical problems:

- Only 68% accuracy (even by closest relatives)
  
  Shalowitz et al, Arch Int Med 2006

- Choosing your own surrogate and discussion treatment preferences in advance do not increase accuracy
  
  Ditto PH et al, Arch Int Med 2001, Shalowitz et al. 2006

- Predicting decisions is problematic due to situational factors
  

- Relatives consider own values and interests (psychological biases like projection)
  
Idea:

1. Preferences are correlated with personal and health characteristics (age, gender, ethnicity, marital status, place of residency, income, education, religion, disease, prognosis…)

2. Collect large data sets via surveys

3. Calculate individually predicted preferences by way of matching patient with data pool

→ Result: Accuracy of preference prediction is the same or higher than that of closest relatives

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Incompetent patients’ behavior

Variables with highest impact on substitute decisions (guardians and relatives):

- Current behavior
- Prior statements
- Nurses’ view
- Physician’s view
- Family’s view
- Life attitude

Relative decisional weight (0-1)

Jox RJ et al. (2012) Int J Geriatr Psychiatr
Survey among nurses in German dementia care homes:

- Patients' behavior
- Patients' wellbeing
- Advance directives

- Medical indication
- Law
- Relatives
- Guilt
- Own values

- Resources
- Guidelines
- Authority

Kuhelmeyer K et al (in preparation)
Common examples

Dementia patients:

- Refusal of nutrition (turning head, closing mouth)
- Physical defence against nurses, pulling PEG tube
- Smiling, laughing, crying, moaning

  Kuehlmeyer K et al. (in preparation)

Vegetative patients or neonates:

- Complex reflex movements
- Autonomic reactions (sweating, tachycardia…)
- Survival of critical situation
Interviews with family surrogates of patients in the persistent vegetative state:

• Many surrogates know patient preferences *against* life support, but don’t act accordingly

• Justified by (unrealistic) hopes for recovery and their own emotional attachment

• Reflex behavior of PVS patients was interpreted as expressions of a will to live

*Kuehlmeyer K et al. J Med Ethics 2012*
Case interviews with a pediatric palliative care doctor
Case: Neonate, progressive CNS disorder, septicaemia

That’s a statement you often hear by parents: „My child has to decide this.“ (…) I think, parents have to develop a sense for the right time, the feeling „Now my child doesn’t want any more, the vital force is gone (…)“. You also often hear: „He still wants to live. He is at home now and he survived that last crisis on intensive care, so he wants to live.“

Jox RJ in: Simon/Wiesemann, Springer 2013
How should behaviour of incompetent patients be interpreted and what role should it play in treatment decision making?
Examples of involuntary motor behaviour:

- Plantar reflex
- Grasp reflex
- Pathological crying/laughing
- Tremor

+ epileptic seizures, dystonia, tics...
Classification

Behavior of incompetent patient

Intentional behavior
- Embedded in a situational context, targeted at an object, accompanied by a bodily movement ("act")

- Aversive acts

- Appetitive acts

Non-intentional behavior
- Present in different contexts, often not targeted at an object, no specific bodily movement

- Expression of being well

- Expression of being unwell

Indication for the patient's best interests
Criteria for assessment:

- Situational and non-intentional behavior should not be taken as autonomous decision about treatment

- **Reliability**: Does the behavior occur reliably?

- **Consensus**: Do different caregivers interpret the behavior in the same way?

- **Consistency**: Is the behavior consistent with the person’s values and previous expressions?
Conflict with advance decisions:

- *No general priority* of previous autonomous expressions or current non-autonomous expressions

- Advance decisions depend on (tacit) assumptions about the future wellbeing, which may not be realized → advance directive not applicable

- People may specify in advance which weight they want to give to their behaviour when incompetent
It seems that the patient’s behaviour is often used to “rationalize” moral decisions based on the caregivers’ own best interests. – Should their best interests be considered and what if they conflict with the patient’s best interests?
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Paradigmatic case A

Miriam is a 61-year-old teacher who has been caring for her demented 85-year-old mother for the last seven years. Her mother still seems to enjoy the simple pleasures of life, but she now acquired severe pneumonia and Miriam has to decide whether to consent to intensive care treatment and ventilation. The two always had a loving relationship and the mother always wanted the best for her daughter. Miriam, however, is so exhausted by caring for her mother that she cannot cope with the situation any more (even her marriage is at risk). She therefore wants to let her mother die.
Paradigmatic case B

Paul is a 49-year-old part-time taxi driver. His 77-year-old mother Lydia has fallen into a vegetative state due to a brain hemorrhage. In her advance directive, she specified that she does not want to be kept alive in a state of irreversible unconsciousness. She also conferred durable powers of attorney to her only son Paul who now cares for her at home. The doctors are inclined to forego life-sustaining treatment, but Paul wants everything to be done because caring for his mother has become the meaning of his life and he would suffer tremendously by losing her.
How do you judge these cases?

Is it ethically justifiable to administer or withhold treatment in the interests of the relative?
Ethical considerations

- From a utilitarian view the wellbeing of caregivers (even the professionals) might count the same as that of the patient.

- Do health care professionals have a special obligation towards the patient (and not on the relatives)...
  - depending on the size of benefit?
  - depending on the health care needs of the patient?
  - depending on a specific contract?

- According to Kant it would be wrong to instrumentalize the patient for the sake of caregivers.
Ethical considerations

- Would it change the ethical judgement if the patient explicitly – or presumably – prioritizes the best interests of his caregivers over his/her own?

- What if the patient explicitly or presumably prioritizes his/her own best interests?

- Do the obligations towards family caregivers depend upon the closeness of the caregiver to the patient?
Thank you for the attention!

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