Transformative experience and adolescent capacity to refuse life prolonging treatment

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Children's capacity regimes (E&W)
≥ 16 years of age

- Family Law Reform Act 1969, s 8(1) →
  - Mental Capacity Act 2005:

    s 2(1): For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.

    S 3(1): For the purposes of section 2, a person is unable to make a decision for himself if he is unable–

    (a) to understand the information relevant to the decision,

    (b) to retain that information,

    (c) to use or weigh that information as part of the process of making the decision…

Children’s capacity regimes (E&W): <16 years of age

- *Gillick v West Norfolk and Wisbech AHA* [1986] AC 112 (HL) 189 (Lord Scarman):

  > I would hold that as a matter of law the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed…

- The *Gillick* test consists in similar components to the MCA 2005, s 3(1) *functional test*:
  - *Re JA (A Minor) (Medical Treatment: Child Diagnosed with HIV)* [2014] EWHC 1135 (Fam) [68] (Baker J).

Consent but not refusal of treatment?

- Two ways to undermine minor refusals of treatment:
  - ~~Concurrent consents doctrine;~~
  - M does not possess capacity commensurate w/decision.

- Cases:
  - *Re E (A Minor) (Wardship: Medical Treatment)* [1992] 2 FCR 219
  - *Re S (A Minor) (Consent to Medical Treatment)* [1994] 2 FLR 1065 (Fam)
  - *Re L (Medical Treatment: Gillick Competency)* [1998] 2 FCR 524 (Fam) *(Sir Stephen Brown P)*

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Minor capacity to refuse LPT: outcome *and* process understanding

- *Re E* 223-224, 226 (Ward J):
  - ‘obvious intelligence… calm discussion of the implications...’.
  - ‘[E] is of an age and understanding at least to appreciate the consequences if not the process of his decision.
  - E did not possess ‘full understanding of the whole implication’ of his refusal, *viz,* ‘the pain he has yet to suffer, of the fear that he will be undergoing, of the distress not only occasioned by that fear but also - and importantly - the distress he will inevitably suffer as he, a loving son, helplessly watches his parents' and his family's distress … He may have some concept of the fact that he will die, but [not] as to the manner of his death and to the extent of his and his family's suffering’

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Minor capacity to refuse LPT: outcome *and* process understanding (cont)

- *Re S* 1075-1076 (Johnson J):
  - 'She does not understand the full implications of what will happen … her capacity is [not] commensurate with the gravity of the decision which she has made … an understanding that she will die is not enough. For the decision to carry weight she should have a greater understanding of the manner of the death and pain and the distress'.
- *Re L 526-527* (Sir Stephen Brown P):
  - L's surgeon had explained that 'the blood transfusion would be essential in order to save her life', to she expressed a 'clearly spoken… true wish' to refuse.
  - L possessed a limited 'understanding of matters which are as grave as her own situation'.

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Adult capacity to refuse LPT: outcome understanding *only*?

- MCA 2005, s 3(4): relevant information includes reasonably foreseeable consequences…
- *Ms B* [2002] EWHC 429 (Fam) [63] (Butler-Sloss LJ):
    - Mr G (witness) concluded that '[B] was unable to give informed consent, not because of a lack of capacity in general but her specific lack of knowledge and experience of exposure to a spinal rehabilitation unit [etc]… On that aspect of his evidence, I have the gravest doubts as to its legal validity and indeed its practicality. Even in issues of the utmost significance and gravity people, including patients, have to make decisions without experience of the consequences and his requirement is unrealistic.

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Minor and adult capacity to refuse LPT: reconstructing different treatment

- Option 1: Lack of relevant *life experience* explains inclusion of process understanding in minor capacity test?
    - *Re E* 226 (Ward J): 'teenagers often express views with vehemence and conviction... Those of us who have passed beyond callow youth can all remember the convictions we have loudly proclaimed which we now find somewhat embarrassing'.
    - *Re S* 1072 (Johnson J): 'of necessity she has had a sheltered upbringing'.
    - *Re L 527* (Sir Stephen Brown P): 'she has led… a sheltered life... It is, therefore, a limited experience of life which she has…'.
- Adults possess sufficient life experience to justify an assumption of process understanding; adults are assumed to know *what dying is like*.

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Minor and adult capacity to refuse LPT: reconstructing different treatment (cont)

- Option 2: No assumption that adults possess sufficient life experience; adolescents are held to a *higher standard* of capacity. (b/c process understanding is important?)
- The problem: transformative experience.
  - re *life experience*: adults assumed to possess process understanding, adolescents assumed to lack; transformative experience unacknowledged.
  - re *higher standard*: transformative experiences supplies justification for higher adolescent standard; but calls into question lower adult standard.

Refusing LPT: capacity and decision-theory

- Normative decision theory:
  - *P* has options {x, *y*};
  - *P* assigns subjective utility to each of x and *y* and a probability;
  - *P* chooses (instrumentally) rationally iff she chooses whichever of x and *y* fits decision rule, eg MEU.
- Capacity tests (*Gillick*, MCA 2005) seem decision-theoretic:
  - ***Understanding***, ***retaining***, relevant information relates to grasping descriptively what {x, y} entail.
  - ***Using, weighing*** relevant information ***as part of decision-making process*** relates to assigning utilities and probabilities and choosing rationally in light of decision rule.
  - In principle agnostic as to value and decision rule.

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Transformative experience: a problem for decision theory

- L A Paul on transformative experience:
  - standard decision-theory breaks down re transformative choice: ‘experience that is both radically new to the agent and changes her in a deep and fundamental way’;
  - epistemic premise: ‘we lack epistemic access to the subjective values [attached to] possible outcomes. Metaphorically, you can’t “see” the outcomes in order to knowledgably assess them in the relevant way’;
  - personal premise: ‘if an experience irreversibly changes who you are, choosing to undergo it might make you care about very different things than you care for now: who you are and what you care about may change when you strike out into the unknown’;

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Transformative experience: a problem for decision theory (cont)

- L A Paul:
  - 'If, before you make the transformative choice, the dramatic future changes in yourself are phenomenologically inaccessible to you, then from within your first personal perspective, you cannot "foresee" the ways your future self will change or foresee how your high order values will evolve. Thus, you cannot first-personally foresee or understand who you'll become'.
- Transformative choices impair rational decisions because:
  - a) we lack epistemic access to what {x, *y*} is like, and thus can't assign a value to x or *y* on this basis; and
  - b) we also can't assign a value to {x, y} because we can't predict how the experience of x or *y* will influence what we care about.

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Does refusal of LPT involve transformative choice?

- Epistemic:
  - There seems poor epistemic analogue for bodily decline/breakdown associated with life threatening illness.
    - Breaking limbs seems the wrong kind of experience.
    - Having the flu, food poisoning etc seems the right kind of experience, wrong intensity/duration?
- Personal:
  - This seems plausible in light of folk accounts of dying.
    - Burying the hatchet w/estranged loved ones;
    - Revisiting life preferences and goals after 'near death' experiences.

Transformative choice to refuse LPT: caveat

- For children and adults with experience of serious illness, the choice to consent/refuse LPT may not be transformative.
  - eg Hannah Jones who successfully refused a heart transplant aged 13 (but consented one year later);
  - eg *Re E* (haemophilia), who ultimately refused blood transfusion aged 18 with fatal consequences.
  - Also senescence?
- Such *Ps* may know what dying *is like*, and thus have preferences informed by these experiences.
- Therefore, such *Ps* may be able to assign utilities to the options to consent/refuse.

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Transformative choice to refuse LPT: general conclusion

- Capacity tests like *Gillick*, MCA 2005 seem decision theoretic (assess instrumental rationality).
- Capacity to refuse LPT depends on demonstrating instrumental rationality.
- Transformative choice impairs instrumentally rational decision-making.
- Refusing LPT is a transformative choice.
- *P* cannot demonstrate that refusing LPT is instrumentally rational.
- *P* lacks capacity in respect of refusing LPT.

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Transformative choice to refuse LPT: implications

- The decisions of the courts in *Re E*, *Re S*, and *Re L* seem more attentive to the fact of transformative experience than the approach of the courts in *Re Ms B*.
- We may need to know *what an outcome is like* in order to have capacity in respect of the choice to pursue/avoid it.
- If the fit b/w capacity tests and instrumental rationality is important, this seems an argument to *level up* the capacity test for adults to that which applies to adolescents.

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Transformative choice to refuse LPT: implications (cont)

- It need not follow that failure to take a rational decision entails that the decision ought to be taken away from *P*.
- We may wish to *level down* the capacity test for all, b/c of the value of choice, lack of better decision-maker, horrendous practical implications etc?
- In this case, if we want to limit minor/adolescent refusals of LPT, it must be on other (principled) grounds.

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Thank you!

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