The Ethics of ‘Grandfather Clauses’ in Healthcare Resource Allocation

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Plan

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Grandfather Clauses

NICE: “People currently receiving treatment initiated within the NHS with Drug X that is not recommended for them by NICE in this guidance should be able to continue treatment until they and their clinician consider it appropriate to stop. For children with Condition X, this decision should be made jointly by the clinician and the child, and the child’s parents or carers.”

• HST context: very few patients, high cost, high uncertainty about effect or cost-effectiveness, often in the context of no other treatment, significant proportion getting the treatment
Withdrawing and withholding

The “Equivalence Thesis”: withdrawing and withholding are ethically equivalent other things being equal.

Arguments for non-equivalence:

• Acts/omissions: withdrawal and withholding are commonly taken to be omissions, particularly in the context of killing and letting die

• Autonomy: (Ursin, 2019) the patient may have attached extra significance to their life with the treatment

• Responsibility: (Ursin, 2019) Commencing treatment involves taking on a responsibility – stopping treatment involves relinquishing it
Withdrawing and withholding

Situations of non-equivalence (Wilkinson and Savulescu, 2019)

•  Prognostic non-equivalence: where there is reason to think that withdrawal makes a patient worse off than they would have been had the treatment been withheld
•  Preference non-equivalence: not decisive in the resource allocation context
•  Ownership non-equivalence: withdrawing an artificial leg or glasses
•  Bodily integrity non-equivalence: removing a pacemaker
Residual Issues

Responsibility and relationships: Doctor-patient obligations

• Rare disease context: close(r) relationship between the patient, carers, doctors, researchers

• Agent-relative vs agent neutral obligations: obligation in virtue of your relationship with the patient

• Importantly, this is not a claim about actual obligations: by engaging with and developing a relationship with a patient, the doctor comes to have a distinctive set of considerations in their dealings with respect to that patient
Residual Issues

Institutional agent-relative obligations

- Saving Private Ryan – an exploration of the two obligations in question (why we find it a difficult or interesting case)

- Plausible account of the nature of an institution and how it can have agent-relative obligations (but not when and how they are trumps)
Fair process

Fair process in resource allocation
• First come first served: appears unjust when there may be important, ethically relevant features
• Move to fair process:
  • is able to include a range of relevant ethical considerations
  • allows for decisions to be made in the context of reasonable disagreement
• (Sandeman and Lilemark, 2018): Fair-mindedness doesn’t help because people disagree about withdrawing and withholding
Fair process

Reconstituted difference between withdrawing and withholding look similar to justice considerations: institutional and professional agent-relative obligations
Rare disease context: uncertainties surrounding effect/effectiveness of treatment, makes the ‘other things being equal’ judgement difficult/uncertain.

• It is plausible and reasonable to disagree about each case and to disagree about how to disentangle the ethical disvalue from ‘other things being equal’
• Pragmatic managing of persistent expectations: empirical question about the legitimacy of the process
Conclusion

There should not be an automatic Grandfather Clause: non-equivalence is sufficiently uncertain as it applies in specific cases.

A judgement is required in each case about either

i. the presence of relevant ‘other things being equal’ features or

ii. the relative ethical disvalue associated with withdrawal in the context of broader fair allocation considerations
Practical Consequences

- Consideration of alternative care arrangements in situations where the treatment would be withdrawn.
- Specific consideration of the cost, cost-effectiveness and needs of those currently receiving the treatment, including various ‘other things being equal’ considerations.
- A decision about all cases (the total population) followed by a second decision about the withdrawal cases – and, in particular, about the extent to which the considerations that are relevant in the withdrawal case are sufficiently pressing to over-ride the consideration as they apply to all.