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Managing End-of-Life Care in the Critically Ill Child

(SOME OF) THE ETHICAL ISSUES

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A Common Starting-Point: Principlism

- Built around Beauchamp and Childress' "four principles of biomedical ethics":
  - Respect for autonomy
  - Beneficence
  - Non-Maleficence
  - Justice
- Others have added other principles, such as solidarity, compassion, and so on.
- For what it's worth, I don't think that principlism is particularly satisfactory as an account of ethics…
  - But I'll concede that it does provide us with a way in to this kind of problem.

A Common Starting-Point: Principlism (2)

- Obviously, not all of these principles are going to be relevant in all cases.
- I'll take it that non-maleficence is a given, and that justice is not a concern when we're dealing with critically ill children
  - We're left with beneficence and respect for autonomy (sometimes).
    - Where there is autonomy to respect, it may conflict with beneficence.
  - How to balance these other considerations may well depend on factors such as the age of the child.
    - (I'll take age as a proxy for any relevant factor – though, on reflection, age may be the *least* morally-relevant factor!)

Dealing with Children

- First things first: what do we mean by “children”?
- In English law, one is a child until the age of 18.
  - However, 16 is the accepted age at which decisions can be made.
  - And children under 16 can make medical decisions if they are deemed to have sufficient maturity.
    - (Implicit moral claim: autonomy trumps beneficence.)
- The end of “childhood” is likely to be a movable feast.
  - And, again, even if we think that someone is a child in the morally relevant sense, it doesn’t follow that they have no input.

Dealing with Children (2)

- The general rule in law is that it is parents who get to give consent to medical treatment on their child's behalf.
  - They don't have the legal right to request treatment that medical staff think is not warranted.
  - I think that the distinction between consent and request makes moral sense, and is pretty much the same as the distinction that applies to adults.
- However, there's a few questions we might want to ask about this.
  - Why the parents?
  - What if their refusal is irrational?

Dealing with Children (3)

- Why the parents?
  - One possible answer is that children are their parents' property: that in some sense parents own their children, and therefore have authority over them.
    - Some people actually think this.
    - No, really.
  - This would give parents certain rights to make decisions.

Dealing with Children (4)

- A better answer is that the convention is parasitic on a claim about the child's best interests.
  - The idea is that the overarching consideration is the child's best interests.
  - How those best interests are to be understood will be a matter for further consideration.
  - On this account, parents get to give or withhold consent because they're well-placed to judge what is best for the child.

Dealing with Children (5)

- This presumption in favour of parental decsionmaking is rebuttable in law, and – again – I think that that makes perfect moral sense.
  - This gives us an answer to the question of what we do in the case of the irrational parent.
  - In that case, the decision would devolve to… well, we'll see.
- In other words, best interests is the underlying moral consideration for those who can't decide for themselves.
  - Children and non-competent adults are therefore in a similar sort of position.

Best Interests v Substantial Harm

- Some have argued that parents may have the right to make decisions that are not necessarily in the child's best interests, but that the "substantial harm" criterion should be used. (cf Raa Gillon, "Why Charlie Gard's Parents should have been the Decision-Makers about their Son's Best Interests", *JME* 44(7)[2018])
  - Odd title!
- This makes a kind of sense when we're considering non-maleficence, but it's not clear how it'd fit with positive beneficence.
  - Which should be our motivating principle is a matter of argument.
  - It's not clear to me that non-maleficence is enough; it's not entirely consonant with other intuitions we might have about parenthood.

Dealing with Children (6)

- I think that it's important to keep a distinction between rights and duties here, too.
  - On one reading of the law, parents have the right to make medical decisions on behalf of their children.
  - But, that being the case, it'd be hard to make sense of why we generally think it's OK to allow others to decide in some cases.
- If we say that there is an overarching duty to act in the child's best interests, and that parents are the best judge of this, we can make sense of their "rights".
  - But those "rights" are only really quasi-rights.

Dealing with Children (7)

- So, for the sake of clarity, I think that we're probably safer talking about parental *duties* rather than *rights*.
  - Parents may have rights to decide how to go about protecting the child's best interests.
  - Where there's a range of treatment options, for example, they may get the choice.
    - (Suppose I have an obligation to go to Stoke. I might have the right to decide whether to use the M6 or the A34 or to take the train; taking the M62 would be incompatible with my obligation.)
  - HOWEVER: those rights would be secondary to the more fundamental duty, and would be rebuttable if the duty is not being discharged.

Deciding Best Interests

- “Best interests” is a wide concept.
  - Medical best interests may not coincide with best interests more widely conceived.
  - Consider the classic example of the JW who refuses a life-saving blood transfusion.
  - We might want to say that he has misidentified what is in his interests.
    - But it’s at least as likely that we’d want to say that one has an interest in living one’s life in the way that one sees fit.
    - Medical best interests are likely to be a part of that, but there’s no real reason to think that they’d come out trumps.

Deciding Best Interests (2)

- So any reasonably powerful account of best interests will take into account the character of the person, their known wishes and preferences, and so on.
- The Mental Capacity Act (at s. 4(6)) acknowledges this in respect of adults: in determining best interests, one must consider

> (a)the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
>
> (b)the beliefs and values that would be likely to influence his decision if he had capacity, and
>
> (c)the other factors that he would be likely to consider if he were able to do so.

Deciding Best Interests (3)

- With children, things might be a bit trickier.
  - Older children may quite plausibly have settled beliefs, preferences, and so on, and may have reflected on them in some depth, and so therefore have a “rich” set of interests.
    - Indeed, some of them might have made an advance directive of some sort to make their preferences known.
    - It may well be a serious wrong to ignore these preferences – although it doesn’t follow from that that they have to be taken as binding.
  - Young children will have no particular beliefs, preferences, and so on; they are therefore also fairly easy to deal with.
    - Best interests will be more likely to mean “medical best interests” simply because there’s nothing else for them to be.

Deciding Best Interests (4)

- Some children fall between these two poles.
  - Children can be – almost by definition – fickle, changeable, open to influence, uninformed, and so on.
  - They may have a tendency to say what they think adults want to hear.
  - They may be adamant that they believe φ, but be mistaken about that (or about what φ implies).
  - Their belief in φ might be fairly new, too.
- So using character, beliefs and so on to help form a picture of best interests is of only limited use if the patient has a protean character and belief set!
  - How well-established do beliefs have to be in order to help us interpret best interests?

Deciding Best Interests (5)

- What about situations in which there's an irrational choice (often by parents in critical cases), or a dispute? Who should settle things?
- This points to a general quandry about who ought to have the final say.
  - Parents arguably know the child better than anyone, but may be unable to be dispassionate.
  - Doctors may well be the best-informed medically, but medical interests are not the whole story.
  - Judges may be dispassionate… but can they be *too* dispassionate?

Importance of Life

- A possible principle that one might bring to the table is something like the principle of the sanctity of life.
  - Maybe we think that human life is of overwhelming moral significance.
  - This might tell us something about the permissibility of ending it. For example, if we think that human life is sacred, it would give us a line of argument against the permissibility of euthanasia/ the Groningen Protocol.
  - Suppose we accept this principle, then. What follows?

Importance of Life (2)

- Thinking that it's seriously wrong to end a life doesn't imply that it's seriously wrong not to try to save it.
  - (Some people may adopt this strong position, but they'd have to explain how they'd deal with people who refuse life-saving treatment.)
- There's a moral difference between ending a life and not saving a life.
- Foreseeing a death is not the same as intending it.
  - By analogy, my choosing to stay at home eating cake rather than exercising allows me to foresee that I'll get fat; but we don't have to think that that's what I intend.

Importance of Life (3)

- It makes sense to wonder whether saving a life is always the best possible use of one's time, energy, and resources.
  - Most obviously, if the saved life will be one filled with suffering, it may be better for the patient not to live it.
  - That *may* justify positive steps to end it, but it may not.
- In cases of the critically ill child, it may be decided that intervening simply for the sake of maintaining life would be burdensome.
  - Of course, all interventions are burdensome – but they may be *unjustifiably* so.

Importance of Life (4)

- Suppose we can intervene to keep someone alive who would otherwise die in short order.
  - Imagine that the patient is in no way sentient, so will not suffer any discomfort.
  - Imagine, too, that there is no hope of medical improvement.
- Is treatment in this kind of case justified?
  - I'm inclined to think not.
  - All we'd be preserving is biological function. If human life is important, then it is presumably for reasons beyond that.
    - "Oh, but you're still alive" seems to me not to count for much in its own right.
- This brings us to the question of futility.

Futility

- Go back to the legal requirement that we should act in the patient's best interests.
  - Allow that it is an accurate reflection of the moral requirements.
- There will be some medical treatments that are contrary to best interests.
  - We have a clear moral reason to discontinue them.
- But there'll also be others that will be neither in, nor against, the patient's best interests.

Futility (2)

- If the requirement is to act in the patient's best interest, and treatment *p* is less beneficial than treatment *q*, then we have a reason to use *q*.
- But what if *p* is neutral, and there is no *q*?
- We could not easily say that it is in the patient's best interests to receive *p*, since it's not going to make any difference…
  - ... save, perhaps, preserving life for life's sake; but I've already suggested that this isn't all that compelling a reason to administer it.
- It's certainly not clear that it'd be required by beneficence.

Providing Hope?

- How important is hope in this kind of debate?
  - Lots of media coverage in the Gard and Evans cases talked about suggested new treatments providing hope and so on.
  - This implies that hope is a good thing.
  - Indeed, it's one of the Christian virtues!
- So how important is hope in this kind of debate?
- I'm not entirely on board with it…

(A Brief Interjection about Hope)

- That it's one of the Christian virtues doesn't mean that it's a virtue.
- Here's Hesiod:

Before this time men lived upon the earth
Apart from sorrow and painful work,
Free from disease, which lets the Death-gods in.
But now the woman opened up the cask,
And scattered pains and evils among men.
Inside the cask's hard walls remained one thing,
Hope, only, which did not fly through the door.
The lid stopped her, but all the others flew,
Thousands of troubles, wandering the earth.
The earth is full of evils, and the sea.
Diseases come to visit men by day
And, uninvited, come again at night
Bringing their pains in silence, for they were
Deprived of speech by Zeus the Wise. And so
There is no way to flee the mind of Zeus.

– *Works and Days*, ll 90-104

(A Brief Interjection about Hope) (2)

- … and here's how Nietzsche responds to Hesiod:

  Hope. [T]he jar which Pandora brought was the jar of evils, and *he takes the remaining evil for the greatest worldly good – it is hope, for Zeus did not want man to throw his life away, no matter how much the other evils might torment him, but rather to go on letting himself be tormented anew. To that end, he gives man hope. In truth, it is the most evil of evils because it prolongs man's torment*.

  – *Human, all too Human* § 71; emphasis mine

Providing Hope? (2)

- Sometimes hope is a desirable motivator.
  - Most obviously, it plays a role in encouraging us to try new things.
  - In a medical context, it is likely to be important.
  - It has certain psychological benefits.
- However, I think that hope can sometimes be a vice, too.
  - The inveterate gambler seems in some sense to embody vicious hope.
  - “Foolish hope” is dangerous!

Providing Hope? (3)

- So there may be situations in which a person's self-regarding decisions are distorted by foolish hope, at potentially great cost to that person.
- However, we might also do well to keep in mind the question of who it is on behalf of whom we are hoping anything.
- That is to say: is there a risk that pursuing hope sometimes sacrifices the child's best interests on the altar of parental hope?

So… Who Should Decide?

- In a case like that of Charlie Gard or Alfie Evans, what should we do?
  - In one sense, both are fairly straightforward: further treatment was universally held to be futile, neither child was old enough for best interests to be anything other than medical.
  - One proposal in both cases was for mediation.
    - I think that this is the wrong move.
    - It treats the correct answer as something to be constructed, rather than discovered.
    - Moreover, it shifts the moral focus from the child to the parents and the medical staff.
    - (Mediation can work to assist communication between parties – but in that case, it's still a matter of communicating what will be done, rather than generating an answer to questions about what should be done.)

So… Who Should Decide? (2)

- Forced to put my cards on the table, I'd opt for the judges.
- There is no reason to suppose that the medical team were inaccurate in assessing medical best interests.
- If I'm correct about rights and duties, in neither case were the parents discharging their duties.
- It strikes me that the courts have the power and the authority to break the deadlock
  - they aren't "too disinterested"
  - This deadlock was broken in favour of the hospital staff in both cases; and I think that that was proper.