



Question 1

Using the two case studies presented above, or your own examples, consider how autonomy and informed consent could have changed the way these patients were treated.

Possible Answer

Alder Hey Children's Hospital

- Fundamentally a problem of *informed consent*. The issues surfaced because the parents felt they had not consented to the treatment that their children experienced. In some cases this could have been avoided had the doctors been more explicit in their explanations
- There is also a further problem of *autonomy*: the patients' autonomy was not respected as the doctors were intervening in ways that neither the parents or children consented to.
- It seems that had informed consent and autonomy been fully respected, then the problems that arose in Alder Hey could have been easily averted.

Tuskegee Syphilis Experiment

- A slightly more complex case, but one that still draws clearly on issues of autonomy and informed consent.
- The fact that the patients were tricked into thinking they were receiving medical care is a clear breach of informed consent, as in no sense were the patients informed. This could be taken further in that we could begin to question whether the patients could ever have given informed consent for this study, given that even the doctors were unaware of the possible risks of letting them go untreated for this disease.
- These patients' autonomy was very clearly breached in this case, as they had no say in the treatment they were receiving (or in this case, not receiving). It doesn't seem a stretch to imagine that had the doctors informed the patients that there was a safe and effective treatment for syphilis, most or all of the patients would have requested to be removed from the study and treated. They were never given this option and so were a victim of medical paternalism.



Question 2

“Autonomy” can be interpreted to mean having control over what happens to your own body. Is this an absolute right? Can you think of cases where it might be appropriate to infringe on people’s autonomy? Another way of approaching this might be - is there anything you *can’t* consent to, even in principle?

Possible Answer

While it may initially seem to be the case that bodily autonomy should be a very fundamental right of the individual, there are in fact many cases where the interests of the public at large override the choices of the individual.

Fluoridation of water is a classic example, with some people worrying about the *mass treatment* of the entire population with fluoride. While the government and public health experts may claim this is supposed to benefit the population by reducing the incidence of dental caries, it is equally clear that the population has very limited means to opt out of this treatment, unless they only use bottled water. A more contentious example emerged in the COVID-19 pandemic, where widespread lockdowns, quarantine and social distancing were enforced, often with fines for nonadherence. While this was argued to be for the good of the public generally, and the NHS in particular in the UK, clearly this necessitated serious and sustained breaches of the ability to make *choices* about where you go, who you see and what you do.

The second suggestion about whether there is anything you *cannot* consent to, even in principle, is more tricky. Some people would say that competent adults should be allowed to make any decision they like, provided it does not negatively affect anyone else. Indeed in medical ethics generally a doctor cannot override the decision made by a competent patient just because they disagree with it.

However, there are also *dignitarian* concerns, which refers to the belief by some people that human lives possess a certain *dignity* and that some actions are simply *not appropriate* for humans to perform. One example that frequently causes disagreement is whether people should be allowed to consent to assisted suicide. While opinions are changing in the population, in UK law it is still illegal to help someone end their own life, regardless of how much the person may have asked for help to do so. In other words, the law still believes that you cannot *consent* to the active ending of your life.



Question 3

In what cases might the freedom of “mere sheer choice” not align with the more complex idea that a patient should be able to make decisions that allow them to truly express their individuality?

Possible Answer

This question is attempting to delve into when simply making a *choice* might not actually serve to protect patient autonomy. The risk with collapsing the *concept* of autonomy into the simple *act* of choosing is that we may be fooled into thinking that by making a choice we are being autonomous.

A simple example of this case is when a parent asks their teenager whether they would rather clean their room or wash the car. While the teenager is making a choice as to which option to perform, this is a highly constrained decision in that there is no third option. In reality, the teenager would probably much prefer to be on their phone in their uncleaned room, but that was not a possibility. In this case, the teenager's *autonomy* has not been respected as they were forced into picking between options that were not aligned with their *individual desires*.

Can you think of a medical case that might highlight this issue?