

Challenges in Respecting the Autonomy of the Old

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Outline

- Context/ background
 - Autonomy
 - Ageing populations
- Consent and choice
- Safety and independence

Autonomy

- Autonomy has a central place in contemporary medical ethics
- The term comes from the Greek for self governing, and was originally applied to city states
- It is now standardly taken to be a feature of persons
 - The idea of self governance remains
 - There has been some concern that autonomy is really a value tied to individualistic liberal political and cultural settings

- The term ‘autonomy’ has multiple meanings
 - It can refer to a feature of acts
 - E.g. where it is claimed that informed consent requires a patient’s autonomous authorization
 - Or it can refer to a feature of individuals
 - E.g. where it is claimed that we must respect the autonomy of patients
- Here I will be taking it as a feature of individuals

Respect for autonomy in medical ethics

- As a feature of individuals work in medical ethics has characterised autonomy in two different ways
 - As a capacity that is valuable
 - As sovereignty
- In medical ethics the idea of respect for autonomy has most frequently been addressed in relation to informed consent for treatment or research

This focus on informed consent has the potential to create two problems when we turn to care for older people:

1. It tends to conflate making a choice about what will happen and giving permission for that thing to happen
2. It tends to focus on discrete interventions, and has had less to say about the ways in which both chronic illnesses and the actions of healthcare professionals can interfere with a person's autonomy

Consent and choice

- Both choice and consent relate to autonomy
- Choice relates to the claim that it should be up to the patient what treatment if any they receive.
 - This is in turn linked to the value of making your life your own (at least to some extent)
 - As already noted the extent to which this is a value may be disputed depending on the cultural context.
- Consent (in the sense of making permissible) relates to the claim that it would be wrong to do something to a person's body without that person's permission (at least if they are a competent adult).

Consent and choice can come apart

- Sometimes the choice that should be respected is a choice to have no treatment
 - Strictly speaking in this case no consent is needed, but autonomy still needs to be respected
- Sometimes the choice that should be respected is not about what treatment to have
 - E.g. it could be about where treatment is provided (at the individual's home, at their family's home, in a care home) or about the activities of daily living (e.g. if in a care home, or being helped by a care worker in their own home)

How does age create specific challenges for respecting autonomy?

The answer lies in different patterns of ageing:

- Some people die suddenly after living into old age with very few health problems
- Others experience what in the past would have been life shortening illnesses but which can now be treated, leading to a pattern of treatment and recovery where the recovery leaves the patient with a lower level of health than before
- For yet others the pattern is one of gradual decline in functioning - the individual experiences one or several conditions that whilst not necessarily life threatening require medical treatment or assistance if they are not to adversely affect the quality of life

In this third pattern the end comes as a result of “the accumulating crumbling of one’s bodily systems while medicine carries out its maintenance measures and patch jobs. We reduce the blood pressure here, beat back the osteoarthritis there, control this disease, track that one, replace a failed joint, valve, piston, watch the central processing unit gradually give out. The curve of life becomes a long, slow fade” (Atul Gawande, 2014, *Being Mortal: Illness, medicine and what matters at the end*, London: Profile books, p.28)

“As people age, they experience a gradual accumulation of molecular and cellular damage that results in general decrease in physiological reserves. These broad physiological and homeostatic changes are largely inevitable, although their extent will vary significantly among individuals at any particular chronological age. On top of these underlying changes, exposures to a range of positive and negative environmental influences across the life course can influence the development of other health characteristics, such as physiological risk factors (for example, high blood pressure), diseases, injuries and broader geriatric syndromes.” (WHO, 2015, World Report on Ageing and Health, at p.29)

A consequence of this is that two things are more prevalent among older people:

1. Declining cognitive capacity

- a. The proportion of the population with dementia or other conditions that affect whether they have the capacity to consent is higher among the old.
- b. Cognitive decline happens at different rates, and is not a steady process. There are good days and bad days. While for many people it may be clear that they are autonomous (or not) for others this becomes less clear.

2. Things (e.g. flu or falling) that can happen at any age may pose greater risks of serious harm among older people

- a. This may shift the balance between respecting a person's autonomy and protecting them from harm (keeping them safe)

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Consent and choice

I want to look at two issues here:

- Consent: determining if someone has the capacity to consent
- Choice: why might it be valuable to older people that choices about what happens to them are theirs to make

Capacity and consent

- In England and Wales the law requires that for a person to have capacity he or she must be able to understand, recall, and weigh up the material information and communicate his or her decision
- It takes it that capacity is decision specific
- It also requires that all adults are to be treated as having capacity unless there is good reason to think otherwise

Case vignette: Mrs B and going home (from Julian C. Hughes)

- Mrs B is a 93-year-old widow who has been admitted to a medical ward slightly confused following a fall. She has lived for some years with her 84-year-old sister who has mild dementia. The younger sister is, however, physically fit and is looked after by a neighbour whilst Mrs B is in hospital. Mrs B remains unsteady on her feet.
- A question is raised concerning whether Mrs B has the capacity to make a decision about returning home. She is able to recall why she had to come into hospital, and remembers the fall. She readily agrees that she is unsteady, but says that she will be able to manage at home by avoiding those activities that have in the past led her to fall over. She seems, therefore, to understand at least some of the material information.
- It is not so clear, at least to the medical staff, that she is able to weigh the information in making her decision. In their view she appears to give little weight to the concerns about falling. Instead, she emphasizes her desire to return home to look after her younger sister.

In cases like this there may be reasonable disagreement about whether a person has capacity or not. But two features of the context might tilt the balance towards deciding that she is not:

- A focus on the wellbeing (fairly narrowly defined) of the individual patient
- Assumptions within the broader culture about ageing and decline
 - Shakespeare's seven ages of man
 - Samuel Johnson's hat

- If we are aware of these factors we may consciously try to resist them
- But in doing that there is also a danger of over compensating. If the patient really does not understand the risks to treat her as if she does is to abandon her (to fail to keep a vulnerable person safe)
- And that looks to be a problem too

Why is choice valuable when we are old?

- In much of the medical ethics literature on autonomy and consent this is put in terms of self-governance and making our life our own
 - E.g. according to Gerald Dworkin it is by exercising the capacity for autonomy that we “define our nature, give meaning to our lives, and take responsibility for the kind of person we are.” (Dworkin, 1988, p.108)
- But as already indicated this may reflect a particular (individualistic) context – connected to American liberalism. It may also seem at least somewhat problematic. Our abilities to do this are limited at the best of times, and given the decline that sometimes comes with old age it may also decline with age

But this is not the only reason choice might be valuable

- Choices can have instrumental value
 - The medical practitioner does not have any special expertise in determining what the effects on a patient's wellbeing will be, as this depends on how it affects his goals, values and aims (Robert Veatch)
 - The patient is a better judge of his own interests than his medical practitioner (J S Mill)
- Being the one to choose, or being denied a choice, can have symbolic value

The symbolic value of choice

“In a situation in which people are normally expected to make choices of a certain sort for themselves, individuals have reason to value the opportunity to make these choices because not having or not exercising this opportunity would be seen as reflecting a judgment (their own or someone else’s) that they are not competent or do not have the standing normally accorded an adult member of the society.” (Scanlon, 1998, *What We Owe To Each Other*, p.253)

“If I live in a society in which most people are allowed the choice of whether to wear a crash helmet whilst cycling, the fact that I (and people like me) are deprived of this choice will be demeaning. It carries the message that they are competent to decide this matter but I am not.”
(Owens, 2011, ‘The possibility of consent’, Ratio, volume 24, p.409)

- According to Scanlon where others are expected to choose, having the opportunity to choose, or being allowed to choose, is valuable because “it is an important form of recognition as competent independent agents”
- Having someone else make the choice is both potentially “demeaning”, and “would stigmatize those who are interfered with by labelling them as immature or incompetent” – both things that we have an interest in avoiding

- The basic point here is that whether we let someone make a choice for herself or make it for her, we send a message (we communicate something, perhaps unintentionally, about how we view them).
- Communicating a message that is potentially demeaning can be particularly troubling in a culture where some people are already being treated in ways that say that they are not as good or as able as others
- For this reason the symbolic value of choice may be particularly important for those who are in some sense already struggling to be treated as equals, and to have their capacity recognized (e.g. teenagers and the old)

- If this is right then the value of choice is not dependent on us accepting that choice is important because it is how we shape our own lives – how we govern ourselves.
 - So some of the cultural worries about autonomy may be weakened
- It also suggests that respecting choice can be important because it treats an individual with respect (it avoids acting in ways that might be belittling or demeaning). This goes beyond decisions about treatment per se, and includes much more that is involved in care

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Balancing safety and independence

- The story about Mrs B concerned the decision about whether she would go home after a period in hospital
- Decisions of this type raise another issue that is more prevalent when we are dealing with older people – that of balancing the safety of the individual against respecting their autonomy (in this context sometimes referred to as their independence)

- As with 'autonomy' the importance of independence may be culturally dependent
 - In her study of policy around independence in old age Debbie Plath argues that while it is central to policy in some countries (e.g. Australia, UK) it is not in others (e.g. Denmark, India)
- It is also the case that what 'independence' means varies
 - Here I am not taking it to refer to being self-sufficient or completely independent or others
 - We can retain a degree of independence even while being partly dependent on others

The place of care

- Some treatments can really only be done in an institutional setting – if I need a heart transplant, it will have to be done in a hospital.
- But much care for older people is not like this.
- In such cases decisions sometimes have to be made about where care will be delivered:
 - In the patient's own home
 - In the home of his children (if this is different)
 - In an institutional setting (such as a care home)

- In places like the UK (and here I will focus on the UK because that is where I am most familiar with) people tend to want to avoid moving into a care home
- One reason, perhaps the main reason, for this is that they fear losing their independence – becoming institutionalized. They would lose their freedom, and their autonomy would be compromised
- However, given their underlying health problems – e.g. they are forgetful, and unsteady on their feet – living on their own could pose a risk to their health and safety
- This poses a question – is it safe for them to go home, and if it is not should we let them anyway?

- In practice these decisions can be complex, and family members often play a role
- This is particularly the case where, as is sometimes the case, a potential solution is for the family to be involved in providing care. They can protect safety while still allowing the individual a degree of independence.
 - The Granny flat solution
- But this not always an option. There may be no children to provide the care, or they may not live sufficiently near by

- Even when the family are nearby two other kinds of problems can arise
- First, the family may not be able to provide the needed help, or may not be willing to do so (given what it may cost them)
 - It can be hard to disentangle whether the issue is a lack of ability or a lack of willingness
 - These decisions are frequently strongly affected by what other commitments family members have
 - An example will help to illustrate some of the complexities

- There are three things that I want to pull out of this story:
 - The initial decision that he could not go home unless it was safe, and of what ‘safe’ looked like was made entirely by health and social care staff
 - The decision about whether the required level of safety could be provided was made entirely by his children
 - The children did not challenge the idea that if it was not safe (as defined) he should not go home. Our father’s safety mattered to us too
- If our concern is with autonomy we should be surprised that my father had effectively no input into this decision about where he would live (despite autonomy being so highly valued in the UK health system)

- Second, the older person may not want to move in with his family or have them care for him
 - He may refuse help on the basis that he does not want to be a burden on his children
- Or he may want to maintain independence from his children, and resist the changes that inevitably occur in a relationship as who is dependent on whom changes

When attempting to balance safety against choice and independence, three things can tend to bias this in favour of safety:

- In a litigious culture failing to keep people safe can risk being sued for damages.
- Where family are involved in decisions they do not always focus on what their relative wants, but on what they want for their relative.
 - And in many cases their priority is that he is safe
- There are cultural assumptions that as people get older being safe becomes their prime concern
 - “our most cruel failure in how we treat the sick and aged is the failure to recognize that they have priorities beyond merely being safe and living longer” (Gawande, 2014, p.243)

In addition, in these cases the role of the family becomes important

- If we are to respect people's autonomy does this extend to the autonomy of family members? If the older person wants to go and live with their family and this would get in the way of their daughter living her life is there an obligation to take the affect on her autonomy into account?
- Or, is it the case that a focus on autonomy (as a feature of individuals) is missing something of value here
- Where family members disagree – and the family are all affected by the decision – what role should a concern with individual autonomy play?

- The issue here may be that the autonomous choices of one person can affect the autonomy of others (including family members)
- Because of this it may be that our right to have our autonomy respected is limited by the equal need to respect the autonomy of others
- These kinds of issues do not come up in the same way where our concern is with respecting autonomy by obtaining informed consent to discrete interventions

Thank you