

Ethical challenges of managing chronic diseases: A panel discussion

{ CUHK Centre for Bioethics Conference
{ Friday 9th January 2015

Michael Dunn, PhD
The Ethox Centre
University of Oxford

The ethics of chronic disease management: A 'bioethical backwater' transformed

⌘ Reconfiguring autonomy

- ⌘ Recognition that the duty to respect patients' autonomy takes place against a backdrop of transformations to self-identity
- ⌘ Negotiating and promoting autonomy as values and preferences evolve over time, in context, and under crisis

⌘ Conceptualising justice

- ⌘ A clarification of the obligations of professional and family caregivers
- ⌘ Obligations to non—professional caregivers
- ⌘ Social and transnational justice in the care workforce

Progress thus far

⌘ What is the care provided to people with chronic diseases *for*?

- ⌘ What does it mean to do good in the provision of care, treatment and support to those living with chronic or other long-term conditions?
- ⌘ What is the purpose of intervention?
- ⌘ How should the principle of beneficence be fleshed out in a way that is fit for purpose in chronic disease settings
- ⌘ In acute care, we have a (relatively) stable account of the purpose of intervention: to cure or treat disease

The missing piece of the puzzle

Case 1:

A 38 year old man who has lived with schizophrenia for 20 years currently lives alone with the support of primary care and outpatient mental health services. He engages in few activities but recently told his Occupational Therapist that he is now interested in football – a hobby that he pursued as a teenager but had abandoned upon the onset of his illness.. The man suggests that the team could buy him a season ticket to go and watch his local team. The OT supports this idea and reports to her manager. The manager is uncertain whether this would be a good use of public resources.

Case 2:

... The man suggests that the team could buy him a widescreen TV so that he can watch his local team on television every week. The OT supports this idea and reports to her manager. The manager is uncertain whether this would be a good use of public resources.

A step into the real world

1. **Autonomy is the only value**

- ⌘ The purpose of chronic care is to enable a person to pursue life choices that are in line with his or her changing values, preferences and desires
- ⌘ No additional account of the purpose of the service is required
- ⌘ “Chronic care medicine must... create within itself a holistic, supportive environment where persons with chronic illness can construct their own lives in a meaningful way” (Caplan et al., 1998)

Which way forward?

2. 'Consequentialising' autonomy

- ⌘ Promoting autonomy is not ethically defensible because it is the right thing to do, but because it will maximise outcomes for a person
- ⌘ A move towards subjective, or preference satisfaction, accounts of well-being
- ⌘ **BUT:** There are problems with relying on autonomy to do all the normative work
- ⌘ It is counter-intuitive to think that chronic disease management should focus solely on meeting 'wants'
- ⌘ No assistance in resource allocation dilemmas where the requirement is to choose between autonomous preferences

Which way forward?

3. Bolstering autonomy with other person-centred non-consequentialist values

- ⌘ Drawing on other values to account for how people should be cared for when living with chronic conditions
- ⌘ The values of **dignity** and **compassion**, for example
- ⌘ Again, however, there are problems here: the account of the purpose of support is under-determined
- ⌘ Like autonomy, these values articulate how a person should be treated when being cared for, but they do not constitute an account of the purpose of that care

Which way forward?

4. Substituting in a modified account of the purpose of health care

- ∅ The purpose of care is to *manage*, as opposed to cure or treat, disease
- ∅ A 're-medicalised' focus on health interventions: symptom control, medicine management etc.
- ∅ But: in general terms, this account misses something important about the reach and nature of the life-transforming effects of living with a chronic disease

Which way forward?

⌘ What impacts do the onset of chronic diseases have?

⌘ They disrupt the stable conceptions people have about their life goals, leading them to modify our values, desires and preferences in changing personal and social circumstances

⌘ But, they also impact on people's agency in a broader sense: they can prevent people from engaging in a range of activities in the world that are commonly understood as being part of a life lived well.

Back to basics

- ⌘ Drawing on work in capability theory, we can make progress from this observation about the opportunities that are denied through the onset of chronic diseases
- ⌘ A person may come to lack the real-world opportunities to do things that they have reason to value
- ⌘ What do people have reason to value?
 - ⌘ Nussbaum's 10 central human capabilities: life; bodily health; bodily integrity; senses, imagination and thought; emotions; practical reason; affiliation; other species; play; control over one's environment

Supporting people to lead lives that they have reason to value

- ⌘ It is being enabled to have at least a minimum level of opportunity to function in these ways that is significant
- ⌘ Human capabilities are to be understood as objective and non-consequentialist in nature: they are good because they are conducive to human flourishing (not because they maximise welfare)
- ⌘ This account would need to be tailored to individuals living with different conditions, but supports multi-disciplinary and integrated service provision models
- ⌘ Functions to bound the requirement to respond to a person's expressed preferences, and can assist in resolving distributive justice problems.

Supporting people to lead lives that they have reason to value

Thank you for your attention.

michael.dunn@ethox.ox.ac.uk