

Challenges for Principles in End-of-Life Care

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What are the role and effect of principled philosophical argument in practical debates on end-of-life care, and the limitations of principled contributions? Focus on:

1. The nature of 'end-of-life care' debates
2. The effect of these debates on the form of arguments
3. The role and limits of theoretical contributions

1.1 The Nature of the Debates

- Within health care law and ethics, discussion of ‘end of life’ questions is often reducible to analyses of:
 - ‘Assisted dying’
 - Patients’ rights to refuse treatment
 - Treatment withdrawal from patients who lack capacity
- More peripherally, questions on:
 - Rights to demand treatment (including basic care)
 - Organ donation policy
- The euthanasia debate assumes a dominant position; heightened importance appears to be given to it, to the exclusion of other matters

1.2 The Nature of the Debates

- Nevertheless, we find in parallel (and sometimes together), debates on the Philosophy of Palliative Care:
 - Seen as opposed to ‘assisted dying’ on various grounds:
 - Unnecessary
 - Unethical
 - Mutual exclusion
 - Political efforts to improve and extend palliative care, but (too?) much energy given to responding to the euthanasia debates

1.3 The Nature of the Debates

- The ‘Medicalisation’ of the Debate
 - End of life debates (self-fulfillingly?) become medicalised in health care law and ethics
- This ‘medicalisation’ has implications for what principled arguments do and do not get ‘aired’, e.g.:
 - Sometimes they come to the exclusion of philosophies such as an ‘ethics-of-care’
 - Sometimes they draw unique or overbearing attention to the role of doctors, whilst marginalising the roles of other actors

2.1 The Effect of the Debates

- Beyond the matters already noted, principle can become skewed in various ways, and emphases misplaced/overstated. Note in particular:
 - a) The prioritisation of medical concepts of health over wider concepts of welfare
 - b) The focus given to patients over carers
 - c) The heat generated by moralistic debates, e.g. on the value of autonomy or the sanctity of life

2.2 The Effects of the Debates

- There are, of course, notable exceptions, from theorists who work to redirect our attention. See *eg*:
 - Simon Woods, *Death's Dominion*, (Open University Press
 - On the philosophy of palliative care, philosophy and palliative care, and the value of choice at the end of life
 - Jonathan Herring, “Where are the carers in healthcare law and ethics?” *Legal Studies* (2007) 27:1, 51-73
 - “[T]he fact that the interests of carers are so easily lost is not simply the story of another disadvantaged group within society whose political muscle is not sufficiently strong to bend the government’s ear. It may be that in part, but it is also due to the way that medical law and ethics tends to view patients and medical professionals as isolated individuals.” (p. 52)

3.1 The role and limits of theory

- What role does moral philosophy play?
 - Inspires public debate, but can it resolve public debate?
- What about political philosophy?
 - Seems more apt to resolution, but...
 - Can it be based on pure theory?
 - What explanatory value do we find in theory?
 - How much account can be given to real politics?
 - How much account must be given to real politics?

3.2 The role and limits of theory

- Theory seems to have a firm place. Without it:
 - We can't aspire to a better system
 - We can't explain the source of ethical imperatives
 - We can't examine properly our reasons and reasoning
- Maybe we should seek here too to contribute to engagements in 'public ethics'
 - Debates in public *fora*
 - Public regulatory/advisory bodies

Conclusions

- Three questions to leave on...:
 1. Is ethics a good or bad force in debates on palliative care?
 2. Can better use be made of ethical argument in public and practical debates on end of life care?
 3. Are current problems and limitations ones of emphasis, over/under-emphasis, association, or something else...?