

'The Ethics of Rationing and the Value of Time'

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Summary

Why do people seek to extend their lives in the face of old age, chronic illness or death? We do not know. Yet, if the desire to prolong life can be irrational – reflecting despair, ignorance and manipulation by families, pharmaceutical companies and the media - it may also show us that life is valuable even when we suffer pain, chronic illness and fear of imminent death. In short, until we know why people want to live, we risk treating unfairly both those who love life, despite its limitations, and those who are ready, even eager for death.

This project therefore describes and evaluates the motives, assumptions and beliefs of those who, though ill and/or elderly, seek to prolong their lives. It uses interviews, existing surveys and secondary literature to capture the perspective of patients, as well as of oncologists, gerontologists, psychologists, social scientists and philosophers. It aims to provide information that is policy relevant, whatever one's view of the merits of QALYs, or conception of life's value. However, it aims also to improve ethical judgement, by using feminist and democratic theory to supplement familiar perspectives on the value of life drawn from moral philosophy.

Aim

Different conceptions of what it means to value lives equally underpin ethical controversy over QALYs. ¹ Thus, Dworkin believes that equal consideration can be modelled by an ideal auction, and expects this to result in the allocation of more resources to the beginning, rather than the end, of life. Others, such as Lockwood, believe that equal consideration implies that resources should ensure a 'fair innings' or a sufficient quantity and quality of life for everyone, even though this likely implies merely palliative care for those above sufficiency. Then there are those, like Harris, who believe that equal consideration means directing collective resources to healthcare so that we are able to provide as much good quality life for people as they desire and are capable of using. ²

It is not obvious how we can resolve this controversy because these are largely reasonable and internally consistent views of what it is to treat people as equals, and what it is to value life. I am sceptical, therefore, that we will get much policy guidance at present from further analysis of their relative merits. However, ethical debate over equality in health care suggests two areas where progress is possible: (1) the description and evaluation of people's desires for life-prolonging treatment and (2) the clarification and evaluation of procedures by which rationing/distributive decisions are made.

The aim of this project, therefore, is to improve the empirical and philosophical evidence on which debates over the rationing/distribution of healthcare are made. It asks (a) WHY people want to prolong life, and evaluates the consistency, rationality, and moral justification of the answers; and (b) HOW we might improve participation by the seriously ill, and those who look after them, in public deliberations on health priorities.

Method

This project combines moral and political philosophy with the analysis of existing surveys of patients, their families, and medical professionals. Experience teaching, presenting and writing on reproductive rights has shown me the importance of looking at arguments for abortion in light of people's interests in having children, and vice versa.³ This is essential if reproductive rights and policies are to treat women as the equals of men, despite the differences between and amongst them. Something similar, I suspect, is true of the desire to prolong life and the desire to end it. The same person may have compelling reasons to seek both at different times in life; and informed, conscientious people disagree profoundly over the morality of extending and ending life. So it is important to understand the desire to live in a way that does justice to the claims of those who believe death can be desirable, merciful and right. The best way to ensure this is to consider each in light of the other.

Palliative care means that we need not choose between ending or prolonging life, and therefore do not have the starkly dichotomous options facing those with unwanted pregnancies. This makes it more, not less, important to try to consider people's interests in prolonging and ending life together. If palliative care is to extend the freedom of the ill, and to contribute to, rather than diminish, the value of life for them, we must acknowledge that some people find life unbearable, even if free of pain, whereas for others part of its value lies in the triumph over pain and adversity.

This project, therefore analyses the literature in medical sociology, anthropology, psychology and philosophy⁴ in order to establish the main lines of agreement and disagreement amongst experts over why people wish to prolong their lives, why they desire palliative care and why they seek to end their lives. It uses interviews with the sick and elderly to supplement this information, and to indicate how far the literature reflects the interests of those who wish to prolong their lives.

Interviews will take place only in the UK, and will cover elderly patients and those facing what, by British standards, is premature death. The purpose of interviews is to give 'voice' to patients, (and their carers) in philosophical and policy-oriented accounts of the value of life, rather than to provide a social scientific testing of theories. Following Wolff, therefore, I would say that this 'is empirical research that is meant to inspire rather than conclude'.⁵ So, the interviews will not be valueless even if the best that is possible, at this stage of research, is a limited, and possibly a-typical, sample of the elderly ill and those facing early death.

Interview Questions

I anticipate asking general questions about the value of life – drawn, in part, from the philosophical literature – in order to introduce and lay the ground work for more specific questions about the value that interviewees, themselves, attach to their lives. The point of these questions is, partly, introductory but it should also help to establish the consistency of people’s attitudes, valuations, and beliefs, and to illuminate the ways in which people think about the value of their own life, as opposed to the value of life in general.

I will also seek to establish how far a sense of injustice underpins people’s desires to prolong life, and how far this distinguishes the prematurely ill from those who have had a ‘good innings’. We often think of fate as unjust, not merely blind and unreasoning. So, I will try to establish how far a sense of injustice in this sense accounts for the desire to prolong life and the belief that one is entitled to a substantial share of scarce medical resources. Likewise, I think it important to find out if there are differences of class, and sense of entitlement, amongst those who actively seek to prolong their lives, as compared to those who do not.

As we know from Professor Marmot’s work, differences of power and status profoundly shape our prospects of life and health.⁶ People are aware of this to different degrees and, very often, it is the privileged that are least aware of the role of fortune in their lives. Our sense of entitlement therefore, not merely our prospects of life and health, are likely to reflect our socio-economic position in ways that are profound, unconscious, and often painful to acknowledge. Interviews will therefore have a component examining people’s attitudes to competing ideas about justice, as a way to probe people’s beliefs about what they are entitled to.

Our views on ‘pre-institutional desert’, as Rawls called it, are a pretty good indicator of our personal sense of entitlement.⁷ People do not deserve their natural talents or their social situation at birth, although you do not need to have heard of Rawls, or to adopt Rawls’s own theory of justice, to reach this conclusion. So, if people believe that they are entitled to do well (to have a high income, satisfying job, social status) simply on these grounds, we will have some reason to suspect that their sense of justice is based on a misconception of their own importance relative to others (whatever the direction of error), and confusion about the differences between luck and desert. This is only a rebuttable presumption, because people who are mistaken about what they deserve in one case are not therefore mistaken in all. Still, it can be helpful to establish how people think about their entitlement to scarce resources in general, how well founded these views are, and how far they influence people’s demands for life-extending care.

These issues are of obvious theoretical interest, given what we know about the ways social background can shape people’s beliefs and sense of entitlement. But they are of obvious practical importance as well: for if we better understand what people think they are entitled to and why, it will be easier to formulate, justify and defend policies whose predictable consequence is that some people will die earlier than they would under different policy decisions. This is why the distribution of healthcare will always be painful and controversial. It does not mean, however, that it must seem, or be, unjust.

Hence the importance of trying to understand and evaluate the reasons why people want to prolong their lives: for when we cannot give people what they have every reason to desire, it is especially important that we justify our decisions in ways which support, rather than undermine, their ability to feel valued members of society.⁸

Evaluating Results

In evaluating the interviews, then, I am primarily concerned to establish whether people's desires to prolong their lives reflect what Joshua Cohen has called, 'reasonable disagreement' about what is valuable⁹, rather than pressure from other people, ignorance of the available alternatives, or mistaken beliefs about the relative importance of their claims. I am also keen to see how far the way that people think about their own interests in living, once they are ill, are adequately described or reflected in the available literature on the subject, or the information on which healthcare rationing is made. The point of evaluation, therefore, is not to grade interviewees, as though we were in a philosophy seminar, but to see what they say about the value of their lives, to see what sorts of considerations illuminate their judgements of value, and to establish what similarities there are, if any, in the reasons why they want to prolong their lives.

Democratic Legitimacy

Interviews will be designed not only to clarify why people want to go on living, but to establish how far their views are incorporated into existing deliberations on healthcare. The value we attach to life is not simply a function of the information we have but of who we are and what criteria and procedures we use to evaluate life.¹⁰ So, in the unlikely event that the chronically ill, and those who care for them, told us nothing we did not already know, democratic norms of legitimacy mean that we would still be concerned about whether the seriously ill are able to participate adequately in public consultations on health care.

Democratic legitimacy requires the 'equal consideration of interests', or a commitment to treat the well-being of each person as of equal intrinsic value.¹¹ But that is not all that democracy requires, since a benevolent spectator could, in principle, meet this requirement. Rather, democratic government means that people are entitled to participate in the decisions that fundamentally shape their lives, and to do so freely and as equals. This participatory ideal is essential to the legitimacy of democratic deliberation, explaining why people can be morally bound, and can willingly accept, decisions which they believe to be mistaken, even immoral. In the interviews, therefore, I will try to establish how much people know about the principles and practice of healthcare rationing, the opportunities for public consultation that are currently available, and such experiences as they have had in influencing healthcare professionals. I will use the literature on citizens' juries, participatory polling and democratic deliberation to help me interpret and to evaluate this part of the interview data.¹²

The aim of this part of the project is to establish what changes in the opportunities, procedures and settings currently used for public health consultations might be necessary

or, simply, helpful to ensure that the seriously ill are able to participate in them. In recent work I have stressed the ways in which democratic ideals support secret and anonymous participation in politics, and the use of judicial, as well as legislative, procedures in democratic government.¹³ My experience teaching feminist theory in the United States has confirmed the need for tact and care if people are freely to discuss sensitive topics like abortion, homosexuality and racism without hurting each other, or themselves. It would therefore be wrong to assume that the form and procedures of deliberation suitable for other topics in public health are appropriate if we want the sick and dying to be able to discuss the value of life for them, or to have the chance to respond to those whose views may be very different from, but no less passionately held, than are their own. I do not expect my interviews, then, or my evaluation of them, to single out some favoured way for promoting fair deliberation in healthcare. However, I hope to suggest some practical measures to promote participation and to help us to treat the sick and healthy as moral and political equals.

¹ For a sample of an extensive literature, see, Alan Williams, 'Ethics and Efficiency in the Provision of Health Care', 111 – 126; John Broome, 'Good, Fairness and Qalys', 57-74 and John Harris, 'More and Better Justice', 75 – 96, in *Philosophy and Medical Welfare*, ed. By J. M. Bell and S. Mendus, (Royal Institute of Philosophy, 1988); John Harris, 'Qalyfying the Value of Life', in *The Journal of Medical Ethics*, 13, 117- 123; John Harris, 'Deciding Between Patients' in *A Companion to Bioethics* eds. P. Singer and H. Kuhse (Basil Blackwell, 2009); K. Calxton and A. J. Culyer, 'Wickedness or Folly? The Ethics of NICE's Decisions', *Journal of Medical Ethics* (32) 373-377; M .Rawlins and A. Dillon, 'NICE Discrimination', *Journal of Medical Ethics*, (31) 683-4 I will be using the fellowship, in part, to get a better sense of the ideas about life, equality, and rationing which underpin these debates.

² R. Dworkin, 'Justice in the Distribution of Healthcare' in *The Idea of Equality*, ed. M. Clayton and A. Williams, (Palgrave Macmillan, 2002), 203-222; M. Lockwood, 'Quality of Life and Resource Allocation, in *Philosophy and Medical Welfare*, 33-56; R. Wagland, 'A Fair Innings or a Complete Life: Comparing Egalitarian Justifications of Ageism', and 'Social Injustice: Distributive Egalitarianism, The Complete Life View and Age Discrimination', both forthcoming in A. H. Lesser (ed) *Age and Justice* (Rodolphi, 2010); O. Leaman, 'Justifying Ageism' in *Ageing, Autonomy and Resources*, ed. A. H. Lesser, (Ahgate, 1999), 180-187; and J. Harris, 'More and Better Justice' in *Philosophy and Medical Welfare*, pp. 75-96.

³ A. Lever, *A Democratic Conception of Privacy*, unpublished PhD thesis, Massachusetts Institute of Technology, 1997, ch. 4; A. Lever, 'Must Privacy and Equality Conflict? A Philosophical Examination of Some Legal Evidence', in *Social Research: An International Quarterly of the Social Sciences*, (67.4. 2000), 1137- 1171; and for the implications of these arguments for the way we think about sexual equality and sexual harassment, see A. Lever, 'The Politics of Paradox: A Response to Wendy Brown', *Constellations: An International Journal of Critical and Democratic Theory*, (7. 2. June, 2000) 242-254;

⁴ J. Seymour, 'Windows on Suffering: Sociological Perspectives on End of Life Care', *Medical Sociology Online*, (2), Nov. 2007; A. Alberinie et. al. 'Does the Value of a Statistical Life Vary with Age and Health Status? Evidence from the US and Canada', *Journal of Environmental Economics and Management*, 48. (2004), 769-792. F. M. Kamm, 'A Right to Choose Death?', *Boston Review*, available at

<http://bostonreview.net/BR22.3/Kamm.html> I will be using the first year of the fellowship to map out the literature I need to read in this area, and then to read it.

5. Dr. Sarah Edwards, is a leading expert in research ethics and governance. I will work closely with her on the design and ethical approvals of my interviews. I should emphasise that, while I will try to interview people who are facing premature death, by British standards, such death would be prospective, not imminent.

⁵ J. Wolff and A. De-Shalit, *Disadvantage*, (Oxford University Press, 2007), p. 190.

⁶ M. Marmot, *Status Syndrome: How Your Social Standing Directly Affects Your Health*, (Holt Paperbacks, 2005), and M. Marmot, 'The Importance of Psychosocial Factors in the Workplace to the Development of Disease' in *The Social Determinants of Health* (eds.) M. Marmot and R. Wilkinson, (Oxford University Press) 1999.

⁷ J. Rawls, *A Theory of Justice*, (Harvard University Press, 1971), ch. 5 para. 48, pp. 273-6

⁸ N. Daniels and J. E. Sabin, *Setting Limits Fairly: Can We Learn to Share Medical Resources?* (Oxford University Press, 2002). I need to read more of Daniel's work on justification in healthcare contexts; as well as that of feminist bioethicists such as Shelley Tremain.

⁹ J. Cohen, 'Moral Pluralism and Political Consensus' in *The Idea of Democracy*, ed. D. Copp, J. Hampton and J.E. Roemer, (Cambridge University Press, 1993) esp. pp. 281-5

¹⁰ See J. Wolff and S. Orr, 'Cross-sector Weighting and Valuing of QALYS and VPFs: A Report for the Inter-Departmental Group For the Valuation of Life and Health, (draft, Dec. 2008).

¹¹ J. Cohen, 'Procedure and Substance in Deliberative Democracy' in *Democracy and Difference: Contesting the Boundaries of the Political*, ed. S. Benhabib, (Princeton University Press, 1996), pp. 95-119; and B. Manin, 'On Legitimacy and Political Deliberation', *Political Theory*, 15 (1987) More generally, see Albert Weale, *Democracy*, (St. Martin's Press, 1999) and Anne Phillips, *Engendering Democracy* (Pennsylvania University Press, 1991); A. Phillips, *The Politics of Presence*, (Oxford University Press, 1995); James Fishkin, *The Voice of the People: Public Opinion and Democracy*, (Yale University Press, 1995); Melissa S. Williams, *Voice, Trust and Memory: Marginalised Groups and the Failure of Liberal Representation* (Princeton University Press, 1998); Iris Marion Young, *Inclusion and Democracy*, (Oxford University Press, 2002).

¹² James Fishkin, *Democracy and Deliberation: New Directions for Democratic Reform* (Yale University Press, 1991); D. Leighton and Stuart White, eds. *Building a Citizen Society: The Emerging Politics of Representative Democracy*, (Lawrence and Wishart, 2008). See also, Bernard Manin, 'Democratic Deliberation: Why We Should Promote Debate Rather Than Discussion', *unpublished paper*, (delivered at the Program in Ethics and Public Affairs, Princeton University, Oct. 2005). I should note that my knowledge of this literature is superficial, and that I will use the fellowship to examine it in more depth.

¹³ A. Lever, 'Privacy Rights and Democracy: A Contradiction in Terms?' *Contemporary Political Theory*, (5.2. May 2006), 142-162; A. Lever, 'Mill and the Secret Ballot: Beyond Coercion and Corruption', *Utilitas*, (9.3. 2007) 354-378; A. Lever, 'Mrs. Aremac and the Camera: A Response to Ryberg', *Res Publica: A Journal of Legal and Social Philosophy*, (14.1. March 2008) 35 - 42; A. Lever, 'Is Judicial Review Undemocratic?' *Public Law*, (Summer, 2007), 280-298 and 'Democracy and Judicial Review: Are They Really Incompatible?' (a new and more philosophical version of the argument), under review at *Perspectives on Politics*, (Sept. 2008); A. Lever, "A Liberal Defence of Compulsory Voting": Some Reasons for Scepticism', *Politics*, (28.1. Feb.2008), 61-64 and 'Is Compulsory Voting Justified?' forthcoming in *Public Reason*, (Feb. 2009); and 'Compulsory Voting: A Critical Perspective', (a more sophisticated and philosophical version of these arguments) revised and resubmitted to the *British Journal of Political Science* (Dec. 2008).