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Introduction

LUKE GORMALLY

All the chapters in the present volume are based on papers which were originally delivered at two related Conferences planned by the editor for the 1990 Meeting of the European Association of Centres of Medical Ethics. Most have been revised in the light of the responses to them at that Meeting.

Both Conferences were concerned with certain of the major ethical issues which arise in relation to the care of the dependent elderly, namely those old people whose condition is such that they require continuing care. It was decided to consider those issues principally as they present themselves in the context of UK Geriatric Medicine, though attention was also devoted to certain influential trends in the USA and The Netherlands.

The speciality of Geriatric Medicine has developed remarkably in the UK since the Second World War and is characterised, in the persons of so many of its practitioners, by a high degree of expertise and by admirable commitment to the health care of elderly people. These features of clinical practice of themselves are cause for hope in face of the increasing need for that expertise and commitment coming from the growing population of the dependent elderly. But realism demands that we should recognise the threats posed to the position of the dependent elderly in our society both by trends in social policy and by ideological trends. Some of the latter, if given expression in social and health care policy, would present a radical threat to the position of the dependent elderly in our society. A number of the papers in the present volume are concerned to confront those ideological trends as they find expression in proposals for age-limits to health care, in the advocacy of living wills and euthanasia, in arguments for withdrawing tube-feeding from certain categories of patient, and in specific proposals for resource allocation. Other papers identify the challenge
of achieving good quality care of the dependent elderly, the chronic inadequacies of policy-making in that field, and the prospects in the medium term given current policy.

The issues on which the Conferences focussed are summarily named in the subtitle of the present volume: autonomy, justice and quality of care. Autonomy, properly understood, is an entirely admirable moral objective. But the notion of autonomy is employed in the advocacy of causes inimical to genuine respect for the dignity of the dependent elderly and corrosive of commitment to their care. Quality of care in the present volume is perceived as an issue of justice. The concerns which the idea of justice is intended to capture over the range of the following chapters are various:

that in the ordering of society's affairs we should seek to obviate conditions which present a threat to the dignity of the most vulnerable members of society. It is that kind of concern which demands that we provide good quality of care for the dependent elderly.
That everyone should refrain from choosing to act in ways which are incompatible with decent treatment of other human beings. This concern excludes abusing the dependent elderly, deliberately abandoning them when the resources exist to help them, and in the extreme killing them.
And that we should avoid behaving in ways which have unfair consequences for others, even though what we choose to do is not precisely aimed at imposing those consequences on those who find themselves unfairly dealt with. This concern would exclude, for example, resource allocation policies the predictable consequences of which would be unfair to the dependent elderly.

Given the varied character of the concerns of justice identified here, the entire volume could be said to be about justice in the care of the dependent elderly.

Less evident in the content of the volume is the concern with autonomy, though it is an explicit concern of Professor Horan’s paper and my own paper on the ethical framework of the Report on The Living Will, and is central in the apologetics for euthanasia as practised in The Netherlands (the subject of Dr Keown’s paper) and as advocated in the UK and elsewhere.

The concept of autonomy is indeed so rhetorically attractive that it is employed in advancing ethical positions which are quite incompatible. Not surprisingly, therefore, it is associated with a good deal of confusion.
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It might be useful, in this introduction, to cut a path through the contemporary jungle of talk about ‘patient autonomy’ and ‘respect for patient autonomy’. Some may be grateful for the path though, doubtless, others will have plotted other routes. I shall first say something about autonomy in general and then something more particular about patient autonomy.

Autonomy in general

The words ‘autonomy’ and ‘autonomous’ are used in respect of a capacity, a condition and a right.

To be autonomous, as the word implies, is to be ‘self-governed’ or self-directed in the conduct of one’s life; that is the condition. ‘Autonomy’ is used of the capacity to be self-directed in the conduct of one’s life. ‘Respect for autonomy’ involves respect at least for this capacity. People speak of a ‘right to autonomy’ which demands respect. A right to autonomy must be a right to at least some exercise of the capacity for self-direction in one’s life. But what exercise of that capacity? The answer we give to that question must surely depend on the understanding we have of the value of autonomy.

Some semi-popular talk about autonomy and the right to have one’s autonomy respected seems to suggest that what people value is doing what they want (in the sense of acting on the wants, wishes and desires they happen to have) as distinct from having to do what someone else wants.

But it seems fairly clear that the ability to do what one happens to want to do is not sufficient for ‘self-government’ in the conduct of one’s life. Someone whose condition is one of wanton self-indulgence does what he happens to want to do. What is valued in the capacity for self-government is at the very least our ability to evaluate our desires and to act selectively in accordance with our evaluations.

But will action in accordance with any kind of evaluation count as an exercise of autonomy? Our answer to this question will depend on what we think the point of self-government or self-direction is.

The capacity for self-government is properly exercised and developed with a view to the flourishing or well-being of the person who possesses it (a well-being which includes friendship and justice in community). If so exercised it is indeed an aspect of that flourishing. In what way is it an aspect?

Human happiness or well-being is not left to be wholly a matter of luck,
or of grace which does not require willing cooperation; what we make of ourselves (in other words, our character) makes a big difference to whether or not we flourish as human beings. And our characters are decisively shaped by our chosen actions; these do not merely bring about effects external to us, they also serve to form our dispositions. Thus, if I choose to lie to someone I may or may not deceive that person, but I will certainly reinforce in myself the disposition to be a liar.

So choice and acting on choice are fundamental to the formation of character, and to the influence on human well-being or human misery that character has. A person’s exercise of choice will in this way inescapably make for well-being or misery in his or her own life.

Now there is a clear case for valuing human choice, and so for valuing the exercise of autonomy, precisely in so far as it serves to form in us those dispositions which are conducive to human flourishing.

People differ in their views on how wide an exercise of the capacity for self-direction should be respected. One very important factor in determining those differing views is whether or not one believes there is human knowledge of moral truths, in particular knowledge of the objective requirements we need to meet if we are to flourish as human beings.

If there is such knowledge, then it is clear why we should value the exercise of choice in conformity with that knowledge: for evidently that would be an exercise of autonomy which makes for human flourishing. But it would not be obvious why we should value exercises of autonomy at variance with the objective requirements of human flourishing.

Still, if there is to be choice one has to allow not just for the possibility but also for the reality of erroneous choices. So, necessarily, respect for autonomy must leave scope for some erroneous choices. But it does not follow that any and every exercise of choice is to be respected. We need to bear in mind why this capacity is to be valued; and if our choices seriously undermine in us the capacity to flourish as human beings there is no reason of moral principle why those choices should be respected.

The two previous paragraphs explain what may be held to follow for our understanding of respect for autonomy from the belief that there is human knowledge of moral truths. But it is evident that many people in our society hold no such clear belief. For that minority who are seriously sceptical about the existence of any moral truths, there will be no reason to believe the claim that one should respect people’s autonomy. For that much larger body of opinion which holds that morality essentially rests on subjective preferences (“Abortion may be wrong for you but I don’t think it is.”), talk about respect for autonomy suggests the following: if
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people are not permitted to do what they want, it cannot be because of truly objective constraints, since they do not exist; it must be because of constraints imposed by the more or less arbitrary exercise of power.

The favourite ‘theory’ in our society about constraints on the exercise of autonomy maintains that such constraints are reasonable precisely in so far as they prevent ‘harms’ to third parties; what people choose to do to themselves or to consenting partners (‘private choices’) should not be the subject of constraints. But there is an element of arbitrariness about the theory. For if in talking about ‘harms’ we are to assume knowledge of the objective conditions of human flourishing, and if autonomy is to be valued just in so far as it makes for human flourishing, then why should we respect deeply harmful ‘private choices’ (choices by which people make themselves vicious)? But if we disclaim knowledge of the objective conditions of human flourishing, what entitles us to identify anything as ‘harmful’?

Patient autonomy

What people understand by patient autonomy in our society is as varied as the understandings of autonomy in general.

Some who talk about patient autonomy primarily have in mind a right: the competent patient’s right to decide about his or her medical treatment on the basis of adequate information and to have that right respected without fear of coercive pressures.

It is perfectly possible to find a place for a version of such a right within a traditional understanding of morality. It is notable that the early development of theological reflection from the fifteenth century about when life-prolonging treatment was to be regarded as ethically mandatory (‘ordinary’) and when it might be blamelessly refused (i.e. when it might be judged ‘extraordinary’) took place in response to questions raised by patients about their responsibilities in the matter. The assumption behind the way the answers were framed was that responsibility for decisions about health care properly and ultimately lay with the competent patient. The responsibility was thought to lie with the patient, first because health is a personal good, an aspect of our well-being or flourishing as human persons, for which each of us needs to assume responsibility. But the extent to which each person can afford to cultivate his or her health (or attend to its restoration) must depend on that person’s other commitments, so that is a second reason why responsibility for health care decisions must ultimately lie with the competent patient.
Luke Gormally

There is, then, a context of traditional ethical reflection in which the right to self-determination in regard to treatment is insisted upon. But it is made clear that this right is limited by the patient’s duties to respect his own life and health, and to have regard to his own obligations to others, including his obligation to respect the moral responsibilities of his carers.

This framework of belief about obligations no longer informs what many people understand by patient autonomy. The phenomenon of moral pluralism suggests to some of them that there is no such thing as moral knowledge (knowledge of the objective conditions of human flourishing), so that patients should be entirely free to determine what is done to them, providing doctors and nurses are willing to do it. This is the theory of a realm of unconstrained ‘private choice’ applied to the exercise of patient autonomy.

But the theory, as we saw, has difficulties of principle about demarcating a private realm in which choice should be unconstrained. When this supposed private realm is intended to include doctors who collaborate in the execution of patient’s choices (as, for example, in euthanasia killing) it ought to be evident that what is taking place is not truly private. Doctors who kill patients profoundly shape their own characters, and the resultant characters cannot be a matter of indifference to the rest of us. Least of all could they be a matter of indifference to the dependent elderly, or a matter of indifference for the nature and quality of medical care.

This discussion of autonomy in fact returns us to the justice issues. It is clear from Michael Horan’s description of his practice in the care of the debilitated elderly that he seeks to give a proper place to respect for autonomy. But it is also clear that he resolves some of the most difficult issues which arise in caring for debilitated elderly patients by reference to considerations of justice. One of the issues which exercises Horan, tube-feeding of patients with advanced dementia, has links with the topic of Joseph Boyle’s paper on the American debate about artificial nutrition and hydration. Boyle identifies arguments advanced in North America for withholding tube-feeding from patients in a persistent vegetative state (PVS) which imply that a much more extensive group of patients (including those with advanced dementia) should be thought of as having worthless lives. On that view of the patients it is difficult to see what ought to prevent people from killing them. Boyle presents a defence of the view that, with certain well defined exceptions, we owe it to the majority of PVS patients to continue feeding them. While PVS patients are not a concern of Horan’s paper, there is at least the appearance of a conflict
between Horan and Boyle over the kind of considerations which should determine our obligations to patients who will die without tube-feeding. In a comment on their papers I seek to show how the assumptions behind Horan’s approach (which is a blanket policy of withholding tube-feeding from patients with advanced senile dementia who have no prospect of recovering the ability to swallow) may be thought to be consistent with the most fundamental requirement of justice in the treatment of patients: that one should never seek intentionally to kill them. This brief discussion paper does not, however, seek to provide a justification of what I take to be the crucial assumptions underlying Horan’s approach.

In my paper on The Living Will Report I examine the ethical framework which underpins the Report’s proposals for advance patient directives which, if the directives were enforceable, would oblige doctors to withhold treatment precisely with a view to ending a patient’s life. If that is a permissible objective of choice there are no sound reasons against seeking to achieve it by positive action. It is notable that this view of the permissible content of advance directives is urged upon us in the interests of patient autonomy. Patient autonomy, as I remarked earlier, is the favoured justification for the practice of euthanasia in The Netherlands. John Keown’s paper reports on his extensive empirical research into that practice. It reveals what many would have said was predictable: an inability to confine the practice to voluntary euthanasia. The framework of ‘safeguards’ is revealed as providing little effective obstacle to the slide from voluntary to non-voluntary euthanasia.

The first five papers in the volume are all concerned, in one way or another, with the limits imposed by considerations of justice to the claims which can be made in the name of autonomy. The most fundamental of these considerations is that we should avoid intentionally wrongdoing others.

Graham Mulley, Marion Hildick-Smith and Robert Stout, as experienced geriatricians, and David Hunter from his position as a health policy analyst, are concerned in the main with a different kind of justice issue: with the social provision of good quality health care for the dependent elderly both as something they need and in order to obviate any threat to their dignity.

Mulley shows that historically there has been an absence of necessary strategic planning for the long-term care of the dependent elderly. Stout brings out some of the consequent difficulties of securing fairness in the treatment of patients. He also highlights the importance of developing understanding of the distinctive health care needs of the dependent
elderly. Hunter analyses the uncertainties which surround the implementation of Government policy for community care of the elderly, and the consequent risk of a policy vacuum in this area, which would have adverse effects on care of the most dependent elderly. In the absence of clear policy commitments the potential in the medium term for conflict and confusion (involving the health service and local authorities) over care of the elderly is worrying. For the long term it is clear that the fundamental policy problem which is perceived to exist is the financing of care. The one proposition of which government seems to be convinced is that the care of a growing population of the elderly cannot be maintained on the basis of public expenditure. But the prospects for securing arrangements on the basis of insurance to provide care of those who are oldest and most in need are extremely remote.

Despite the note of optimism which Hunter strikes at the end of his paper (on the basis of anticipating a growing political influence of the elderly) the fundamental picture which emerges is not one to suggest that the prospects for justice in the care of the elderly are good in our society. There may be felt to be some irony, therefore, about providing a picture of what is required for good quality care. But Marion Hildick-Smith’s delineation of those requirements simply makes clear the standards which as a community we should at least seriously seek to meet. The clearest needs she sees in the present situation are for more skilled carers, for investment in their training, and for the provision of more suitable accommodation for care.

Against the background of confusion, uncertainty and a lack of long-term commitment on the part of Government to good quality care of the dependent elderly, it is distinctly chilling to contemplate certain currents of thought which, to the degree they gain influence, can only further marginalise the dependent elderly.

Joseph Boyle examines the proposal of the influential American bio-ethicist Daniel Callahan that we may fairly deny people certain forms of health care after they have completed what Callahan calls a ‘natural life span’. Boyle finds the arguments for the proposal distinctly weak.

Michael Banner discusses the health care economists’ device of the QALY (quality adjusted life year) for measuring the relative worth of different health care activities with a view to determining the distribution of resources. Banner begins by remarking on the insurmountable difficulties of making the kind of calculations which the idea of a QALY suggests should be possible: they stem most importantly from the fact that there is no common measure for the range of features that we count as
composing the quality of life. But if one waived those fundamental objections it is clear that specific treatments for the elderly are for the most part likely to yield small returns of QALYs. Banner shows that a policy of QALY maximization is inconsistent with the requirements of justice to the dependent elderly both in respect of fairness and of need.

Michael Banner’s understanding of the claim on health care provision which the dependent elderly can rightly make is one that relates that claim precisely to the dependency and fragility of their condition. Without special care their condition renders them peculiarly liable to be extruded from the human community. But since our claim to belong to that community rests most surely on our humanity, a fragility which threatens to marginalise the elderly demands a care for them which affirms the humanity they share with the rest of us. In my paper, ‘The Aged: non-persons, human dignity and justice’ I seek to show how a current of philosophical thought, which has been influential in rationalizing bad choices in other areas of medical practice, would be amenable to rationalizing bad choices in geriatric practice. It would do so precisely by proposing that numbers of the dependent elderly – those who are demented – have no serious entitlements to health care, and indeed no serious right that their lives be respected. To the degree the proposal influenced practice we would have abandoned concern for justice for the debilitated elderly and solidarity with them.

John Finnis closes the volume with an expanded version of the illuminating comments with which, as Co-Chairman, he closed the 1990 Conference. He opens with some critical observations on the ‘economism’ which infects too much reflection on health care policy. As he indicates, it is inherently incapable of recognising the requirements of justice. But his principal criticism is aimed at the substance and the logic of Ronald Dworkin’s views on the permanently comatose. As with the subject of Joseph Boyle’s first contribution to the volume, what matters for geriatric practice is the logic of the viewpoint under examination. Dworkin’s view that the permanently comatose would be better off dead is based, as Finnis indicates, on confusing the emotionally repugnant features of certain states of extreme deprivation with a fundamental lack of human dignity in the human beings who are in those states. Finnis concludes by reflecting on the solidarity with very deprived and debilitated human beings which is required by recognition of their dignity.

It is hoped that the entire volume will aid reflection on the health care we owe to the dependent elderly. In contemplating the challenge of securing justice for them we need to keep a clear view not only of the
immediate difficulties but of the social and ideological forces which threaten to undermine the character and ethos of geriatric care.

I owe debts of gratitude to friends and colleagues both for the important parts they played in relation to the original Conferences and for the help they have given in the preparation of this volume. The Conferences received moral, intellectual and financial support from the European Association of Centres of Medical Ethics and gratitude is owing to its then President, Dr Nicole Lery (Lyon), to Professor Jean-Francois Malherbe (Louvain-la-Neuve), to Professor Paul Schotsmans (Leuven), and especially to Professor Edouard Boné SJ (Brussels). Generous financial support for the Conferences was received from others, most notably Mr T. G. A. Bowles, to whom I am greatly indebted. The organization of the Conferences was largely made possible by the Deputy Director of The Linacre Centre, Mrs Agneta Sutton, and she has helpfully relieved me of some of my duties during the preparation of this volume. I am most grateful to her. The whole enterprise would not have been possible without the enthusiastic support given to it by the Governing Body of The Linacre Centre. Particular debts of gratitude are owing to its Chairman and Vice-Chairman, Professor John Utting and Professor John Finnis. They were active participants in the Conferences and unfailing sources of encouragement and advice.

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Notes
1 The member Centres of the Association come from some dozen Western European countries. Membership is due to extend to a number of Centres in Eastern European countries.