



Randall, Fiona Maria (2000) *The philosophy of palliative care: a critique*.
PhD thesis.

<http://theses.gla.ac.uk/3481/>

Copyright and moral rights for this thesis are retained by the author

A copy can be downloaded for personal non-commercial research or study, without prior permission or charge

This thesis cannot be reproduced or quoted extensively from without first obtaining permission in writing from the Author

The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the Author

When referring to this work, full bibliographic details including the author, title, awarding institution and date of the thesis must be given

**THE PHILOSOPHY OF PALLIATIVE CARE:
A CRITIQUE**

by

Fiona Maria Randall

F.R.C.P.

**A thesis for the degree of Doctor of Philosophy
submitted to the Faculty of Arts**

University of Glasgow

July 2000

© Fiona Randall, 2000

Acknowledgements

Thanks are due to many people who have assisted me during this course of study, and have made it possible to undertake a PhD alongside clinical work.

At the outset I wish to express my gratitude to the Royal Bournemouth and Christchurch Hospitals Trust and the Macmillan Cancer Trust for funding the sabbatical leave which enabled me to reflect on the moral problems inherent in palliative care, and which gave me the impetus to commence this course of study.

My colleagues in the Macmillan Unit at Christchurch Hospital have given me encouragement, discussed clinical problems, enabled me to see other points of view and sustained me with their understanding, companionship and humour.

I wish to thank my husband, Bob, for his encouragement and enthusiasm for my studies, his patience with my anxieties, and for his technical assistance with computer technology.

I am greatly indebted to my supervisor, Robin Downie, who rekindled in me a desire to think, and to accept an intellectual challenge much more stimulating than medical training ever provided. His unfailing patience and willingness to discuss the moral problems of clinical palliative care have enabled me to keep in mind the issues central to the thesis during my clinical work. He has taught me to be more open to alternative ways of looking at the world, so that I have never again felt tempted to say, as I did when first exposed to philosophical discussion, 'And what use is that?' His influence has

enabled me to gain greater pleasure and satisfaction from my work and from many other aspects of life.

Lastly, I wish to thank my patients, whose courage, common sense and unselfishness sustain both my enthusiasm for medical practice and my faith in human nature. I can only hope that as a result of this course of study I will look after them better.

Summary

Palliative care is unusual as a specialty within health care in that it has its own philosophy, which is summarised in the WHO definition of palliative care. This philosophy has influenced clinical practice so that specialist palliative care differs significantly from other aspects of health care. The thesis is a critique of that philosophy. It examines the moral problems inherent in implementing the philosophy in clinical practice. It concludes with suggestions for improvements which could be made to the philosophy statement so as to influence clinical care for the better.

The World Health Organisation definition of palliative care states that:

'Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families.'

Five separate theses are discussed in chapters 1 to 5. Each is related to an aspect of the philosophy statement.

Thesis 1 is that decisions regarding the use of treatment to control symptoms or prolong life do not need to depend on complex doctrines such as double effect, but instead ought to be based on weighing up the benefits, harms and risks of treatment. The distinctions between killing and letting die, and between intending and foreseeing an adverse effect of treatment are discussed. It is suggested that the methods of casuistry are helpful in both education and clinical practice for resolving the moral problems arising in

treatment decisions. Further discussion of casuistry and its similarity to methods of decision making in health care is contained in the Appendix.

Thesis 2 is that the relatives should not be an equal part of the remit of care. It is argued that whilst there is a special relationship, founded on an implicit promise and associated with specific obligations, between patients and health care professionals, this special relationship should not be extended to relatives of the patient. The interests of relatives should not be pursued at the expense of the patient's health interests, and improving the quality of life of relatives should not be regarded as an intrinsic aim of palliative care.

Thesis 3 is that quality of life as a global concept should not be used. Since quality of life depends on many incommensurable factors, and it is not possible to construct a coherent account of quality of life from our everyday notions of what it means, it is not possible to construct a quality of life scale. Quantitative assessment of global quality of life should be abandoned, and instead qualitative studies on the impact of specialist palliative care on the various domains of quality of life should be undertaken.

Thesis 4 is that there are constraints of expertise and propriety on attempts to influence the patient's psychological, social and spiritual well-being. It is argued that neither a close personal relationship, nor the counsellor/client relationship, should serve as a model for the professional/patient relationship. Instead of seeking to control the patient's psycho-social and spiritual state, professionals should offer explanations and advice in a sensitive and friendly manner.

Thesis 5 is that within health care there ought to be a just distribution of resources to specialist palliative care, and then among terminally ill patients regardless of their illness. Professionals should see themselves as trustees of resources, with responsibility to ration scarce specialist palliative care

resources so that a decent minimum of care is available to all. The use of the health-economics concept of the Quality Adjusted Life Year to allocate resources to specialist palliative care is not morally justifiable. It is argued that patients' ability to benefit from specialist care is the criterion which ought to be used when allocating that care between individual patients.

Chapter 6 includes a discussion on the desirability of a philosophy statement for palliative care. It also introduces a suggestion for a new philosophy statement which might bring about improvements in patient care by using concepts which are well understood, and by stating clearly the role of health care professionals in relation to patients and their families.

CONTENTS

Introduction

- 0.1 The Aim
- 0.2 A 'philosophy' of palliative care.
- 0.3 The normative function of a philosophy of palliative care.
 - 0.3.i Theoretical questions.
 - 0.3.ii Practical questions.
- 0.4 Objectives: five theses.

Chapter 1. Control of symptoms

- 1.1 Moral issues of treatment decisions where the only outcome is potential relief of pain and other symptoms.
- 1.2. Treatments which may prolong life.
 - 1.2.i Postponing death or prolonging life?
 - 1.2.ii Withholding and withdrawing life-prolonging treatment.
- 1.3. Treatments which may hasten death.
 - 1.3.i Not hastening death or not intending to hasten death?
 - 1.3.ii Killing versus letting die, the issue of causation.
 - 1.3.iii Intending versus foreseeing death.
 - 1.3.iv Double effect.
 - 1.3.v Euthanasia and letting die.
- 1.4. Conclusions.

Chapter 2. Relatives

- 2.1. Do health care professionals have obligations towards the patients' relatives, and if so what are those obligations?
 - 2.1.i. The nature of obligations owed, and to whom do we owe them?
 - 2.1.ii Intrinsic and extrinsic aims of palliative care.

- 2.1.iii Non-interference with the liberty of relatives to pursue their desires where these raise no other moral issue.
- 2.1.iv The obligation of veracity to relatives.
- 2.1.v The obligation of non-maleficence to relatives.
- 2.1.vi The obligation of beneficence to relatives.
- 2.2. Is the moral situation sufficiently different in palliative care from general health care to justify different obligations to relatives from those of general health care?
 - 2.2.i Is there some sort of benefit to relatives from the care promised?
 - 2.2.ii Is the benefit to relatives a health-related benefit?
 - 2.2.iii Is the health-related benefit to relatives sufficient to justify the expenditure of resources?
- 2.3. What should be the basis of decisions when professionals perceive a conflict between their obligations to the patient and to the relatives?
- 2.4. What, if anything, should the philosophy of palliative care say about obligations to the relatives of patients?
- 2.5. Conclusions.

Chapter 3. Quality of life

- 3.1. Is there a clear and shared concept of quality of life, and if not, could such a concept be developed?
 - 3.1.i The context of quality of life.
 - 3.1.ii The use of the term.
 - 3.1.iii Health-related quality of life.
 - 3.1.iv Quality of life in the broader sense.
 - 3.1.v A coherent concept of quality of life?
- 3.2. Is it possible to assess quality of life, and to measure it?
 - 3.2.i Theory of measurement and quality of life.
 - 3.2.ii Scales and numbers.

- 3.2.iii Weighting and summing scale items.
- 3.2.iv The use of the mean and other statistics.
- 3.2.v Utility rating scales.
- 3.3. How is quality of life data used, would qualitative data suffice?
 - 3.3.i Allocation of resources to services and treatment.
 - 3.3.ii Decision making for individual patients.
- 3.4. What should be the goal or goals of palliative care?
- 3.5. Conclusions

Chapter 4. Psychological, social and spiritual problems

- 4.1. Should professionals be attempting to control the patient's psychological, social and spiritual problems?
 - 4.1.i. The nature of the goal.
 - 4.1.ii. The nature of the patient/professional relationship required to achieve the goal.
 - 4.1.iii. Is such a close relationship a good thing for the patient and professional?
 - 4.1.iv. Do the potential benefits to patients justify the potential harms to both patients and professionals?
- 4.2. An alternative: the client/counsellor relationship.
- 4.3. Should the goal of controlling the patient's psycho-social and spiritual problems be modified or abandoned?
- 4.4. Conclusions.

Chapter 5. Rationing

- 5.1 Macro-allocation and palliative care.
 - 5.1.i Evidence of benefit.
 - 5.1.ii The proposed future role of specialist palliative care.
 - 5.1.iii The goals and moral necessity of rationing.
 - 5.1.iv Conflicts of responsibility perceived by doctors.

- 5.1.v Team responsibility for the health of a community.
- 5.1.vi Concepts of health, need and efficiency.
- 5.1.vii The concept of the QALY.
- 5.1.viii Criticisms of the QALY.
- 5.1.ix How should macro-allocation decisions be made?
- 5.2 Micro-allocation and palliative care.
 - 5.2.i Micro-allocation is unavoidable.
 - 5.2.ii Adverse consequences of micro-allocation.
 - 5.2.iii Relevance of various criteria or characteristics in micro-allocation.
- 5.3. Conclusions.

Chapter 6. Conclusions: The way forward

Appendix.

Bibliography.

Guide to abbreviations.

BMA	British Medical Association
PVS	persistent vegetative state
QALY	Quality Adjusted Life Year
NCHSPCS	National Council for Hospice and Specialist Palliative Care Services
NHS	National Health Service (UK)
NICE	National Institute for Clinical Effectiveness
WHO	World Health Organisation

Introduction: The Aim and the Objectives

0.1 The Aim

There are two concepts involved in the title of my thesis: the idea that there is a philosophy of palliative care and then a critique of the same. The main aim of this thesis then is to offer a critique of the philosophy of palliative care.

Palliative care is unusual in that it has an explicit philosophy. This is summarised in the following World Health Organisation definition:

‘Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families.’¹

This philosophy is expressed in practice, especially as staff often work in specialist units (sometimes called hospices) set apart from the main stream of health care. My questioning of this philosophy has arisen directly out of clinical experience, both in such a specialist unit and also in a general hospital and primary care settings. In addition to this practical experience participation in a general professional ethics committee and in the teaching of health care professionals has encouraged me to examine specialist palliative care from other perspectives. This thesis is the outcome of my attempt to examine the relationship of specialist palliative care to health care more generally.

I am using the term ‘critique’ in Kant’s sense when he speaks, for example, of a ‘critique of pure reason’. His critique of pure reason consists in his attempt to establish the limits of pure reason. He is obviously not dismissing the whole concept but is investigating it with the aim of discovering what can and cannot be established by pure reason. In a similar way I am not rejecting the whole idea of a philosophy of palliative care but attempting to establish its

strong and weak points. This is particularly important in view of the facts earlier mentioned: that those working in palliative care characteristically see themselves as different from other health care practitioners, and that they often work in locations which are physically separate from both primary and secondary health care. Before proceeding to detailed discussion of my critique some general points will be made regarding the 'philosophy' of palliative care, its impact on clinical practice, and possible links to major philosophical issues.

Firstly, it is important to ask whether the WHO is really expressing a 'philosophy' at all (0.2), and secondly, what it is that this statement is striving to achieve (0.3).

0.2 A 'philosophy' of palliative care.

It might be objected that the WHO is not offering a 'philosophy' of palliative care at all but simply a definition. But what kind of definition is it? It is certainly much more than a dictionary definition. The Oxford English Dictionary reports that (from 1588) the verb 'to palliate' means 'to alleviate the symptoms of a disease, to mitigate the sufferings of, to ease'. It would follow that palliative care is simply the branch of health care concerned with that activity, just as orthopaedics is the branch concerned with correcting injuries and deformities of bones. The O.E.D. is simply reporting how the words 'palliative' or 'to palliate' are used in ordinary speech. The WHO is clearly going well beyond this.

Nearer the mark is the 'definition' of 'health' offered by the WHO in 1946: 'Health is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity.'

This definition has several characteristics. Firstly, it is not reporting how the word 'health' is used; rather it is attempting to say something about the thing itself - health. Secondly, it is attempting to persuade us to see health in a much wider way than at that period had been common (i.e.. involving the social and psychological). Thirdly, it was intended to influence health care practice, or,

in other words, it had a normative function. To say all this, however, is tantamount to saying that the WHO definition of health was introducing, via a persuasive definition of health, a philosophy of health promotion.

All the above characteristics hold of the WHO 'definition' of palliative care: it is not reporting word usage; it is saying something about the activity of palliative care; and it is intended to influence practice. In short, the WHO definition is really the condensation of a 'philosophy'. But what sense of 'philosophy' is involved? Let us look at typical descriptions of 'philosophy'.

David Raphael acknowledges that philosophy itself cannot be easily or simply defined, but notes that its main purpose 'is the critical examination of assumptions and arguments.'² He states that the critical evaluation characteristic of philosophy begins as a critique of assumptions but then goes on to a critique of argument. It is in this sense of philosophy that I shall offer a critique of palliative care. On the other hand, the WHO statement of the philosophy of palliative care is certainly not a critical evaluation of assumptions, but instead is more like a list of assumptions. Nothing in the statement encourages questioning of those assumptions. It seems that the statement is not really 'philosophical' in Raphael's sense at all, although perhaps it is related to philosophy in the sense that it is at least a list of assumptions.

Carl Elliott, a doctor and a philosopher now working as a bioethicist, in describing what he calls the 'traditional conception' of philosophy, provides us with a second account of philosophy. He notes that 'the aim of philosophy is to provide us with general explanations of the way things are, and ultimate justifications for our ethical and epistemological practices.'³ But the WHO statement does not explain the way things are in relation to palliative care, although it might perhaps be making a statement about the way it thinks things ought to be. Furthermore, it certainly does not provide us with any justification, ultimate or otherwise, for those assumptions. So it is not a philosophy statement in Elliott's sense either.

There is a third, a non-professional, sense of 'philosophy'. This is found in claims such as 'My philosophy, or my philosophy of life, is....' followed by a list of beliefs about what I ought to do, attitudes to others etc. This sense of 'philosophy' is close to the idea of an ideology, since it is a statement of assumptions, beliefs or values held by a group of people, in this case by the WHO representing health care professionals who specialise in palliative care.

This sense of 'philosophy' resembles a statement of a religious faith. Firstly, it is similar to a list of articles of a faith in that no grounds for the assertions it makes are given, and indeed it may not be possible to prove the assertions in the way that statements of fact can be proved. Secondly, it resembles a faith in that the assertions are thought to express truths which are self-evident to professionals working in the field. Thirdly, like a faith, those truths are not self-evident to all people, for it is clear that many professionals working outside the context of specialist palliative care might not accept or follow the normative content of the statement. For example, they would not consider that the relatives should form part of the remit of care. Fourthly, it resembles a faith in that critics may be viewed as a threat, or perhaps are to be pitied, since they are unable to accept the truths self-evident to others. Lastly, it resembles a faith in that its articles declare not just what one ought to believe but how one ought to live.

Supporters of the WHO statement might object that this interpretation is unfair. They might claim that it is not strictly a statement of faith but rather that it presents a reasoned point of view, and that in being a reasoned point of view it is more like a philosophy according to Raphael, Elliott and many others. They might argue that there is evidence from clinical practice to support the ideology it describes. They might further state that commitment to this ideology follows from general beliefs in the importance of close relationships and of psychological as well as physical well-being. But if it is indeed a reasoned point of view then it should be open to a critique. Such a critique would examine its

assumptions and any arguments supporting them. Palliative care does not have such a critique, but I aim to offer one in this thesis.

0.3 The normative function of a philosophy of palliative care.

If we assume for the moment that the 'philosophy' of palliative care is in fact a description of an ideology (which may or may not be well-founded on reason and evidence) then it is possible to address the second question, namely what is the explicit statement of the ideology aiming to achieve. It seems that its function is not simply to state what palliative care is about, by way of a description of the way things are, but rather to fulfil a normative function in stating the way that things ought to be. It is a statement about how health care professionals ought to care for people whose illness is incurable and progressive to the point of death. Now a statement about how health care professionals ought to care for people as they approach death can take us along two different paths, which I shall call the 'theoretical' and the 'practical'. These terms must not be taken to be mutually exclusive for, as we shall see, the theoretical can have practical implications, and the practical makes theoretical assumptions. The paths can overlap.

0.3.i Theoretical questions

Since the ideology proposed relates to care at the end of life and implies acceptance of our mortality, then any discussion about palliative care occurs against the background of those major questions which relate to the meaning of life and death, or what constitutes a good life (and perhaps death) for man. The answers to such questions are what Carl Elliott calls 'ultimate justifications' for our actions, or ultimate explanations of what we think is right. The ideology of palliative care does not contain explicit statements about the meaning of life or what constitutes a good life for man. Yet it is intended to influence, and does influence, the way professionals care for patients at the end of life. In so doing it

implies that there is a 'right way of living and dying' for both patients and professionals. But the 'right way of living and dying' must depend on answers to the ultimate questions about what makes life worthwhile and about the meaning of life. It is perhaps strange that the ideology describes the right way of living and dying in the context of palliative care without even alluding to those ultimate questions or providing any answers to them. The explanation may be that the origins of palliative philosophy are religious but the practitioners wish their special type of care to be widely available so they do not make explicit the metaphysical beliefs on which the philosophy is based.

It is not just in the sphere of palliative care that the ultimate questions are not acknowledged or addressed. Carl Elliott comments that 'Bioethics assumes it is about conduct and character, or, more narrowly, human obligations to each other', but that it does not ask or answer the ultimate questions about the meaning of life.⁴ Instead, it asks only indirectly and unsatisfactorily (via the 'quality of life' concept), what makes life worth living. He goes on to ask 'Is it possible to think philosophically about the sense of life, and how it is situated in relation to other lives and to the institutions of medicine, once we have given up on ultimate explanations?'⁵ This is an important question, for the ideologies of palliative care and of bioethics are each attempting to influence people into the 'right way of living and dying' without producing the answers and explanations which must act as reasons why one life or death should be better than any other life or death. Is it reasonable for the ideology of palliative care, and for bioethics in general, to try to influence people into living life in a particular way without basing the values and assumptions put forward on answers to the ultimate questions?

If one postulates that in order to provide a basis for trying to influence the way of living of others one must put forward some answers to the ultimate questions, then those answers must be framed in some way and used to justify principles or rules which govern behaviour. Such a framework of answers (and

perhaps explanations) has been called an 'ethical theory', from which are derived principles and rules to govern individual actions.

Childress and Beauchamp in their influential work 'Principles of Bioethics' proposed four principles which, even though not fully grounded in a comprehensive theory, were said to be sufficient as a framework for describing ethical problems and reaching solutions.⁶ They discussed at some length the characteristics of an ideal ethical theory, but noted that to date no single theory had satisfied them all.

Daniel Callahan, in describing the impact of ethical theory in the development of bioethics, states that 'Good ethical theory, it was believed, should be objective, rational, internally coherent and consistent, universally applicable, detached from individual self-interest, and impersonal in its capacity to transcend the particularities of time and culture.'⁷ He suggests that one might be able to frame a logically consistent moral theory, but he notes that 'the hard part is to devise a theory that can readily join universality and the moral complexity of everyday life. A flavor of cruel fanaticism seems often to go with single-minded, unnuanced applications of, say, utilitarian or deontological theory, running roughshod over that complexity and usually devoid of moral imagination and sensitivity.'

Even if it were possible to produce an ethical theory satisfying the criteria suggested by Callahan and discussed by Childress and Beauchamp, how successful would its application be in practice? Carl Elliott asserts that if the task/aim of applied ethics is to apply normative moral theories to ethical problems, then it does not work. He notes that 'the practical difficulty with applying ethical theories is that ordinary people pay little attention to theories when they make their moral decisions. Moral decisions are, of course, influenced often by theories of one sort or another, but this influence is usually indirect rather than explicit.'⁸ My own experience teaching medical ethics to doctors and nurses is that whilst one may present them with the four principles

as an ethical framework, and even if one links the principles with the rules of established professional codes, health care professionals do not seem to 'use' the principles in the resolution of cases discussed immediately afterwards. Moreover, if one analyses a case simply in terms of principles one is likely to overlook many details which are morally relevant. Simplifying a case so that it appears as a conflict between, for example, the principles of respect for autonomy and beneficence, may make it appear easier to resolve, but that appearance may be misleading and may hide morally important features of the case.

So given the difficulties of coming up with a satisfactory ethical theory, and having discovered that health care professionals are unlikely to use such a theory when resolving the moral problems of particular cases, and that there are disadvantages and difficulties inherent in the application of theory to individual cases, then perhaps it is acceptable to discuss the ethical problems of health care and palliative care without appeal to ultimate answers about the meaning of life and the good life for man. However intellectually attractive the construction of a universal ethical theory may seem, it is impractical in health care and palliative care, and should be left to pure moral philosophy. I shall now turn to the practical interpretation of the philosophy of palliative care.

0.3.ii Practical questions

The 'philosophy' of palliative care influences clinical practice - that is to say, it influences the decisions people actually make. If those decisions are made, as Elliott suggests, without explicit reference to ethical theory, then how are they made, and how does the expressed ideology of palliative care influence practice?

Whenever clinicians recognise a moral problem in a particular case, they describe the case to themselves and hopefully to the rest of the team. This description is drawn against the background of the ideology of palliative care

which forms part of their cultural background and values. What part does the description of the case play in the resolution of the problem, and what part does the ideology of palliative care play?

When faced with the task of sorting out what is wrong, and what is to be done, health care practitioners first listen to the patient's story. The importance of listening to the patient's account has been much stressed recently in articles on 'narrative based medicine'. This idea is not new, for the importance of 'taking a good history', which simply means listening carefully to the patient's own account, has been stressed in medical education for many years. Proponents of narrative based medicine suggest that having listened attentively to that story, a professional interpretation of it is constructed and recorded.⁹ The way that the story is described, interpreted and recorded is part of the analysis of any moral problems inherent in the case.

Carl Elliott notes that 'the real work of bioethics, more often than not, is in listening, reading, and watching carefully in order to judge what is important and what is not.'¹⁰ He goes on to stress that the way in which we recount the story of the case plays naturally into a certain way of thinking about it. He concludes that 'When we use language, we are not just representing the world; we are interpreting it, and in some ways, creating it the manner in which a bioethicist writes the case narrative - the setting, the narrator's voice, the use of irony and so on - will reflect his or her own philosophical arguments.'¹¹

A purely objective presentation of a case is not possible, for such a presentation always entails inclusion of factors considered relevant and exclusion of others, plus some interpretation of the scenario presented. The language chosen greatly influences the way actions are interpreted. For example, in the context of palliative care removal of a life-prolonging treatment may variously be described as an act which allows the patient to die or an act which brings about the patient's death. The words used clearly indicate the author's own perspective. Elliott notes that what is problematic is not that

narrative style communicates a personal moral vision, for this is obvious, but rather that the case presentation 'packages a personal moral vision in the surface wrapping of objectivity.'¹²

The way that a case is described causes it to fall into a certain class of similar cases. This resembles the process of diagnosis itself; doctors make diagnoses by comparing the package of symptoms and signs with those typical of certain diseases, and deciding which disease the presenting package most resembles. They then conclude that the presenting illness is most likely to be a case of that disease, and treat it accordingly. When confronted with a moral problem in a case they will tend to react in the same way; they will gather together the features of the case they consider relevant, and then they will try to classify the case by deciding what general type of case it most resembles. How they classify the case will much depend on the words used in the description. For example, it may be seen as a case of either killing or letting die, or of a patient refusing a life-prolonging treatment or of a patient committing suicide. For each class of cases there will be a paradigm case, one in which there is general agreement about the right course of action, rather in the same way as there is general agreement about the best treatment for a certain disease. When the problem case has been identified as similar in important ways to the paradigm case, doctors will tend to conclude that they should act in the way accepted as right for the paradigm case, unless of course there are certain features of the problem case which suggest otherwise.

This approach to moral problems has a long history. It developed in the early modern period and acquired the name of 'casuistry', a name which refers to the central role of paradigm cases in moral reasoning. It acquired a bad reputation, was heavily criticised and abandoned as a model of moral reasoning until recently. I shall discuss the method in detail in the appendix but note here simply that it appeals to doctors as a method of moral reasoning because of its similarity to the process of diagnosis. This similarity was pointed

out by Albert Jonsen and Stephen Toulmin in their book 'The Abuse of Casuistry'.¹³

It is certainly true that doctors and nurses working in palliative care tend to identify a particular case with a paradigm case. For example, they might see the question of whether or not artificial rehydration should be given to a dying patient as resembling a paradigm case of providing a treatment which will simply prolong dying. In contrast their colleagues outside palliative care would be more likely to consider the case as resembling a paradigm where adequate hydration is considered essential to prolong or sustain life, as in acute care. So the way that doctors and nurses describe a particular case determines how they think it should be managed, for they tend to decide how to manage individual cases by considering how a similar but paradigm case would be managed. The ideology of palliative care influences how professionals describe the ethical problems they recognise in individual cases.

This is an important point because it means that the moral reasoning of casuistry is not a value-neutral process. For example, when professionals outside palliative care describe cases they tend to present the 'facts' of the case but may omit details relating to the emotional impact of the situation on the patient, family and professionals. This omission occurs because such emotional issues are considered either as irrelevant, or even dangerous because they may cloud judgement. In contrast, professionals working in palliative care are charged with maximising the patient's and family's psychological, spiritual and social well-being, and so they tend to include in their package of relevant features the emotional impact of the situation on all concerned. In this way the philosophy or ideology of palliative care can influence professional decision-making.

It is debatable whether emotional engagement in the case story by professionals is dangerous or provides essential enlightenment. As Elliott notes, emotional engagement may either illuminate judgement or cloud it.¹⁴ It is

difficult to argue that moral judgement should be completely detached from sympathy and the imagination, but it is also clear that too much 'empathy' or 'suffering with' the patient may lead to personal emotional trauma and loss of ability to weigh up all the relevant features of the case. This latter possibility is discounted by some writers. For example, Ann Scott considers it important to identify imaginatively with the patient, a process which she thinks will enable the doctor or nurse to understand what a particular treatment would be like for the patient.¹⁵ This sort of approach is often encouraged in palliative care, but it is associated with risks of emotional distress sufficient to cloud the judgement of professionals (and also sufficient to lead to emotional exhaustion). I shall discuss this in more detail in chapter 4. In the present context the important point is that the presentation of a case is not simply a matter of neutrally describing objective facts; it involves interpretation and therefore value judgements.

Moreover, the way that a case is described and interpreted by professionals actually leads to their resolution of it, just as the description of symptoms and signs leads to diagnosis and treatment. When specialists in palliative care describe a case they will be influenced by their culture and values, and that culture and value set is currently strongly determined by the ideology described in the WHO statement. So the ideology of palliative care determines how specialists in the field perceive the moral issues which arise in palliative care. The ideology easily becomes pervasive.

Since this ideology is not shared outside palliative care, specialists in palliative care frequently 'see' cases differently from their non-specialist colleagues, and hence often come to different conclusions about what is the right course of action. Thus patients in the care of specialists, for example in hospices, may well receive different treatment and care from those in the non-specialist setting. Specialists have tended to want to influence their colleagues in other settings to share their own ideology and thus follow the pattern of their

clinical practice. But would this be desirable? Health care aims to provide for each individual patient the best treatment and care in the particular circumstances. The ideology of palliative care, and the impact it has on clinical decisions, should be examined in order to determine whether its adoption more widely in health care would lead to better treatment of terminally ill patients.

Granted the accuracy of my brief account of the nature and implications of the philosophy of palliative care, and the legitimacy of a philosophical critique, I can now state the detailed objectives of this study, which are to discuss the following theses:

0.4 Objectives: five theses

1 That decisions regarding the use of treatment to control symptoms or prolong life do not need to depend on complex doctrines such as double effect, but instead ought to be based on weighing up the benefits, harms and risks of the treatment;

2 that the relatives should not be an equal part of the remit of care;

3 that quality of life as a global concept should not be used;

4 that there are constraints of expertise and propriety on attempts to influence the patient's psychological, social and spiritual well-being;

5 that within health care there ought to be a just distribution of resources to specialist palliative care, and then among terminally ill patients regardless of their illness.

Each of the following chapters will discuss one of these theses.

References to the Introduction

- ¹ World Health Organisation. *Cancer Pain Relief and Palliative Care*. Report of a WHO Expert Committee. *Technical Report Series*, 1990 No. 804
- ² Raphael D, *Moral Philosophy*. Oxford: Oxford University Press, 1981. p. 1
- ³ Elliott C, *A Philosophical Disease*. London: Routledge, 1999. p. xix
- ⁴ as above, p. xxxi
- ⁵ as above, p. xxxiv
- ⁶ Childress J, Beauchamp T, *Principles of Biomedical Ethics*, 4th ed. Oxford: Oxford University Press, 1994 chap. 2
- ⁷ Callahan D, Universalism and Particularism: Fighting to a Draw. *Hastings Centre Report* 30, no. 1 (2000): 37-44
- ⁸ Elliott C, *A Philosophical Disease*. London: Routledge, 1999 p. 148
- ⁹ Greenhalgh T, Narrative based medicine in an evidence based world, *Narrative Based Medicine*, ed. by Greenhalgh T, and Hurwitz B. London: BMJ Books, 1998 p. 258
- ¹⁰ Elliott C, *A Philosophical Disease* London: Routledge, 1999 p. xxvi
- ¹¹ as above, p. 123
- ¹² as above, p. 125
- ¹³ Jonsen A, Toulmin S, *The Abuse of Casuistry*, Los Angeles: California University Press, 1988 pp 36-46
- ¹⁴ Elliott C, *A Philosophical Disease* London: Routledge, 1999 p. 127
- ¹⁵ Scott A, Nursing, narrative and the moral imagination. *Narrative Based Medicine*. ed. by Greenhalgh T. and Hurwitz B. London: BMJ Books, 1998 p. 152

Chapter 1

Control of symptoms

Thesis 1: Decisions regarding the use of treatment to control symptoms or prolong life do not need to depend on complex doctrines such as double effect, but instead ought to be based on weighing up the benefits, harms and risks of the treatment for the particular patient.

Introduction

The central aims of health care are the prolongation of life and the relief of suffering due to disease. In the context of terminal illness the importance of relieving pain and other symptoms is not disputed, and few moral problems arise in decisions regarding treatments whose sole aim and outcome is the relief of symptoms. In contrast many problems arise in relation to treatments which may alter the remaining length of life, either by prolonging it or by hastening death. I will mention only briefly the moral issues arising from the former group of treatments, and will devote most attention to those arising from treatments which either prolong life or which may shorten it.

I have mentioned in the introduction the importance of language, interpretation, and background ideology in the description of a case and its subsequent resolution. Where decisions regarding symptom control and prolongation of life are concerned, some ways of looking at cases are more helpful than others in reaching a solution. Neither the four principles approach, nor narrative-based medicine, nor a discussion of 'virtuous character' are helpful in resolving moral problems in this area.

On the other hand, health care practitioners do use case description and comparison in a way reminiscent of casuistry, both in terms of making diagnoses and treating patients, and also in terms of looking at the moral problems they identify in symptom control and the use of life-prolonging treatment. Health care is very much about deciding 'what is wrong' and 'what is to be done' in the particular patient's case.¹ In a similar way casuistry sets out to decide what sort of a moral problem the case presents, and then to decide what ought to be done in the particular case. Further development of professionals' current practice, by encouraging them to employ the rules or maxims derived from paradigm cases, but interpreting those rules carefully in the context of the patient's particular circumstances, might enhance their decision-making.

1.1 Moral issues of treatment decisions where the only outcome is potential relief of pain and other symptoms.

Unfortunately most treatments for the relief of pain and other symptoms have side-effects which are harmful and so may cause further symptoms and distress. They may also be associated with risks, particularly when an invasive procedure is undertaken. As symptoms in terminal illness, particularly pain, breathlessness, and nausea and vomiting may be severe it is often considered that some harms and risks are worth tolerating in order to relieve the initial symptom. Moral problems arise when the balance of harm and risk to benefit is either uncertain, as is often the case, or when the harms and risks are high in relation to the potential benefit. In such cases it can be difficult to decide which treatments provide sufficient potential benefit in comparison to their harms and risks to justify offering them to the patient.

In palliative care, as in health care generally, the patient's informed consent is a pre-requisite for the provision of treatment, unless the patient is

incompetent to make decisions. Moral judgements must be made by clinicians regarding which treatments should be offered, how much information the patient actually wants and should be given, and what to do if a patient requests a treatment which the clinician considers will not confer overall benefit.

Judgements about competence may also give rise to problems. All adults are presumed competent to give or withhold informed consent, but some are clearly judged incompetent to make the particular decision. The responsibility for judgements about competence generally lies with the health care team. Such judgements are complex and often morally difficult, especially as competence is really a spectrum phenomenon but legally a patient must be judged either competent or incompetent and cannot be said to be partially competent.

It makes sense to follow the method of casuistry in reaching solutions to these problems. It is easy to describe paradigm cases on which the rules of informed consent, the criteria for competence and the maxim that one should benefit and not harm patients are based. These rules and criteria must then be interpreted in those cases where consent (or refusal) is clearly not fully informed, where competence is compromised or where the balance of benefit to harm and risk is uncertain or marginal. The process of comparison of the incident case with the paradigm case followed by justification of one's decision regarding the applicability of the rules or maxims in the incident case would enable practitioners to make reasonable and morally justifiable decisions for the particular case.

1.2. Treatments which may prolong life.

The absence of any mention of the aim of prolonging life from the WHO definition of palliative care is perhaps surprising since this aim is indisputably intrinsic to health care. An expansion of the WHO summary definition of palliative care states that

‘Palliative care...affirms life and regards dying as a normal process,...neither postpones nor hastens death...’²

It is quite extraordinary that a description of the philosophy of a health care activity should actually state that practitioners should not seek or aim to postpone death. I shall explore the reasons for this position.

1.2.i Postponing death or prolonging life?

In stating that palliative care ‘neither postpones death’ the definition probably means that practitioners should not *intend* to postpone death, for clearly there will be circumstances when, as a secondary effect of treatment for symptom relief, death may be postponed. For example, patients exhausted and immobile because of constant pain will live for a shorter time than those with good pain relief. So providing pain relief could be said to postpone death. Yet no-one would wish to assert that pain should not be relieved in case death were, as a secondary effect, postponed. Indeed, the situation of pain in an illness which will shortly culminate in death serves for most people as a paradigm case illustrating the importance of pain relief, for pain in this context is seen as pointless and meaningless - there is no possible gain from it nor happy outcome afterwards.

Postponing death could be interpreted as meaning the same as prolonging life. But this alternative meaning is probably not the one which readers are intended to derive from the definition. For ‘postponing death’ suggests merely putting off for a short while the inevitable. It suggests more the prolongation of dying rather than the prolongation of living. The idea of prolonging dying would not be considered by most people, lay and professional, to constitute a benefit and it is more likely that it would be construed as a harm. Thus ‘neither postpones death’ is probably intended to mean ‘does not prolong dying’. This interpretation is morally unproblematic.

Unfortunately the definition is undoubtedly the source of important ambiguity on this point, for many people might consider that postponing death is equivalent to prolonging life. They would thus conclude that the definition, which describes the philosophy of palliative care, means that palliative care practitioners should not intend to prolong life. This concept is the source and the cause of many moral problems in palliative care.

The difficult decisions surrounding the possible provision of life-prolonging treatment in the context of terminal illness are real and will always exist. Unfortunately the WHO definition, when interpreted as meaning that in the context of palliative care one should not intend to prolong life, actually compounds the problems because it influences the judgement of specialists in palliative care whilst at the same time puzzling patients and other health care professionals.

Specialists in palliative care are very aware of their philosophy and it influences their thinking. They know that in the early days of palliative care, when specialists cared for patients in hospices which were largely independent of the National Health Service, life-prolonging measures such as drips and transfusions were very rarely provided. There were three reasons for this. Firstly, such measures were seen as yielding little benefit in the face of inevitable death. Secondly, the technology involved was considered to make death less dignified and to prolong the dying phase of the illness attached to tubes and machines. Thirdly, the provision of such treatment was thought to discourage acceptance of the inevitable approach of death, and acceptance was thought to be the attitude associated with least emotional suffering for the patient (and probably everyone else as well)!

On the other hand health care professionals looking after terminally ill patients but not coming from a specialist palliative care background remain largely ignorant of and uninfluenced by the palliative care philosophy. They know that it exists, but tend to pay little attention to it. They tend to consider it

morally acceptable or even morally required that they should try to prolong life. Thus they tend to provide a life-prolonging treatment unless it is very clear that in the clinical circumstances its harms far outweigh its expected benefits.

Thus a situation has developed where 'generalist' health care professionals looking after terminally ill patients tend to think rather differently from specialists in palliative care, despite the fact that both professional groups are looking after the same cohort of patients. So a patient in a particular set of circumstances is likely to be treated differently by specialist and non-specialist health carers.

It is clearly undesirable for this difference in philosophy and therefore in treatment provision to exist within a single profession and health care service. It matters morally because one set of health care decisions may yield a better process and outcome of care than the other for the patient. It is important to ask whether the philosophy of palliative care leads to a better or worse process and outcome of care for patients.

If 'neither postpones death' is interpreted as meaning 'does not prolong dying' then it is likely to lead to a good outcome for patients. In this sense it would influence health care professionals, patients and their families not to pursue treatments which simply prolong the very end of life when consciousness is likely to be diminishing and disturbance to the patient is likely to be distressing. If non-specialists in palliative care were familiar with and accepted this maxim as part of their philosophy then fewer patients would be subjected to invasive and non-beneficial treatments in a misguided and necessarily futile attempt to prolong life. Furthermore, resources would not be expended on the provision of such treatments and care for highly dependent patients for a longer period of dying - for example two weeks instead of a few days where artificial hydration might prolong life for this period in dying patients who have lost the ability to swallow. These resources could be used to benefit other patients.

On the other hand if 'neither postpones death' is taken to mean 'does not prolong life' then two serious consequences would arise. The first is that patients would not be offered life-prolonging treatments which could provide overall benefit as compared with harm or risk. For example, tube feeding would not be considered for patients unable to swallow because of motor neurone disease or stroke, and stents to keep the ureters patent would not be considered or offered to patients going into renal failure because of incurable pelvic malignancy. Yet for some patients these treatments could provide significant net benefit.

The second serious consequence is that patients would not be offered treatments primarily intended to alleviate suffering but with a secondary effect of prolonging life. For example, oesophageal stents to alleviate the symptom of dysphagia (difficulty in swallowing) in patients with cancer of the oesophagus very often alleviate the dysphagia. However, in so doing they prolong life. If palliative care practitioners should not intend to prolong life, then such treatments should perhaps not be considered or should be offered less readily because the secondary effect of prolonging life was considered to be a harm.

Both of these consequences lead to major adverse outcomes for patients. They constitute sufficient reason for rejecting a philosophy of palliative care which suggests that practitioners (and perhaps also patients and their relatives) should not seek to prolong life.

In fact specialists in palliative care do offer life-prolonging treatment to their patients. This might indicate either that they do not actually believe that they should not intend to prolong life, or that they believe alleviating suffering is such an important goal that it should override the 'adverse' effect of prolonging life, or that they really do not intend to prolong life but are so unsuccessful at achieving other goals that they inadvertently prolong it! Of these three possibilities the first two sound the most plausible.

Since the idea of not postponing death can be interpreted as not prolonging life it should be rejected as part of the philosophy of palliative care. Rather than stating that palliative care 'neither postpones death' the WHO definition might say 'does not prolong dying'. The incorporation of this idea into health care ethics as a whole (not just palliative care) would discourage the provision of invasive, distressing and expensive life-prolonging technology in those circumstances where it is likely to provide overall harm and risk rather than benefit.

1.2.ii Withdrawing and withholding life-prolonging treatment.

This leaves the question about what should be said in a philosophy of palliative care, and in health care ethics generally, about the provision of life-prolonging treatment in the context of a terminal illness but when patients are not imminently dying. In 1999 the British Medical Association after a process of wide consultation produced a document giving professional guidance on this issue.³ In this guidance it is clearly stated that:

'The primary goal of medical treatment is to benefit the patient by restoring or maintaining the patient's health as far as possible, maximising benefit and minimising harm.

If treatment fails, or ceases, to give a net benefit to the patient (or if the patient has competently refused the treatment), the primary goal of medical treatment cannot be realised and the justification for providing the treatment is removed.'⁴

This guidance instructs doctors to weigh up carefully in the particular case the benefits, harms and risks of the treatment, and to consider (where possible together with the patient) whether the provision of a life-prolonging treatment would be a benefit to the patient. This guidance should be incorporated into a philosophy of palliative care, and could and should be accepted by all health care professionals to the benefit of patients.

There is one area of discussion in which the BMA guidance does not go far enough, but where specialists in palliative care are very aware of difficulties in clinical decision-making. Provision of a life-prolonging treatment may not just enable the patient to live longer - it is also very likely to alter the way in which the patient will die. Patients can die of an illness in more or less pleasant ways. Weighing up the benefits, harms and risks of a treatment does not just entail considering how long one will live plus the side-effects and risks of that treatment. It should also entail consideration of the mode of dying of the illness, with and without the treatment. Unfortunately this factor is given insufficient attention in the BMA guidance, yet it is a crucial factor for health care professionals and patients in making these decisions. Whilst specialists in palliative care are aware of the importance of this factor few other health care professionals routinely think through the likely illness scenarios with and without the treatment. Sometimes specialists in palliative care are less likely to favour a treatment in a particular case as compared with their non-specialist colleagues for the very good reason that the patient may live longer only to encounter a more distressing terminal phase of illness or death.

For example, providing artificial nutrition and hydration to patients with motor neurone disease will prolong their life. Instead of dying of poor food and fluid intake or aspiration pneumonia through trying to swallow, they can continue to live but will then become largely or completely paralysed and not able to speak or swallow, making communication very laborious. Ultimately they will become unable to breathe. When this occurs provision of non-invasive ventilation can once again prolong their life. They will then live until they develop an overwhelming chest infection. The longer their life is prolonged the more likely it is that they will develop the frontal lobe dementia which is associated with this illness. If this happens they will show personality changes, and strange behaviour. Thus decisions about provision of artificial feeding or

ventilation must take into account the future development of the illness and the ways in which the patient is most likely to die.

It is perhaps the awareness that life-prolonging treatment may lead to a more unpleasant illness course and death that has tended to make specialists in palliative care more reluctant to provide such treatment than their non-specialist colleagues. Life-prolonging treatment can be provided without bringing about a prolonged and undignified death, and it does not necessarily prevent patients from reaching a realistic acceptance of their prognosis. However, the achievement of a mode of life and death considered acceptable by the patient requires consideration of the various illness scenarios and ways of dying, as well as the specific benefits, harms and risks of the available treatments. Not every patient would be willing to tolerate a discussion of the ways in which they might die. This important point should be stressed in a philosophy of palliative care, and in guidance for professional practice generally.

For most people the mode of dying and the period leading up to it are very important. They often seek what Margaret Battin calls 'The Least Worst Death'. She states that:

'In the current enthusiasm for natural death it is not patient autonomy that dismays physicians. What does dismay them is the way in which respect for patient autonomy can lead to cruel results. The cure for that dismay lies in the realisation that the physician can contribute to the genuine honouring of the patient's autonomy and rights, assuring him or her of "natural death" in the way in which the patient understands it, and still remain within the confines of good medical practice and the law.'⁵

Patients cannot achieve what for them is 'the least worst death' which fits into the context of their lives unless health care practitioners consider the illness scenarios and explain these to patients who wish to be so informed.

Presenting a list of the benefits, harms and risks of the specific treatment in the circumstances is simply not enough.

1.3. Treatments which may hasten death.

The WHO definition states that palliative care neither postpones *nor hastens death*. There are two sets of ambiguities which arise from the latter phrase. The first concerns two possible interpretations of the idea that one should not hasten death; either that one should not, in any case, hasten death, or merely that one must not intend to hasten death. The second ambiguity surrounds the extent to which the term 'hasten' implies that one in some way causes the patient's death, as opposed to simply altering the time of death so that it occurs earlier. Both of these ambiguities can and do lead to enormous confusion amongst health care professionals and patients and so can lead to decisions being made which are not in patients' interests. Unfortunately the same confusion almost totally obfuscates any public debate about the issue of legalising euthanasia. It is regrettable that the ambiguities of the WHO definition of palliative care do nothing to dispel this confusion and actually contribute to it. Let us discuss these ambiguities in order.

1.3.i Not hastening death or not intending to hasten death?

Regarding the question of interpretation as to whether a requirement not to hasten death means that one should not hasten death or merely should not intend to hasten death there are two reasons why it is plausible that the former interpretation is that which the WHO is trying to put across. Firstly, since human beings are vulnerable and death is normally considered an evil there is a general social prohibition against causing or contributing to the death of another person, whether or not one intends to. Thus one will face legal scrutiny for an action, such as a road traffic accident, which contributed to the person's death

even if one did not intend injury to the person. Secondly, since an intrinsic function of health care is normally to strive to prolong life there is a general presumption that in health care in particular it is wrong to act so as to cause or contribute to the cause of death.

For these two reasons there may be a tendency to assume that in palliative care one must never hasten death, whether intentionally or not. There are serious adverse consequences to this interpretation; it leads to failure to provide any treatment to alleviate suffering if it may also incidentally shorten life, it is associated with confusion around the difference between not providing life-prolonging treatment and acting so as to cause death or alter the time of death, and it puts forward a totally unattainable goal for health care professionals since many treatments are associated with a risk of death through misadventure.

These consequences are so adverse as to constitute sufficient reason for interpreting the definition so as to mean that health care professionals engaged in palliative care should not intend to hasten the death of their patients. Thus it appears that this first ambiguity could be solved by re-stating the definition so that it clearly means that professionals should not intend to hasten the death of their patients. Unfortunately, the concept of intending as opposed to foreseeing an event is not in itself morally clear to many people in the context of health care. The difference, and the importance of recognising the difference, is discussed later (1.3.iii).

1.3.ii. Killing versus letting die, the issue of causation.

The second ambiguity intrinsic to the concept of 'hastening' death gives rise to major problems. As stated above, the idea of hastening death can be taken to imply actually causing or contributing to death as the outcome, or alternatively it may imply simply allowing death to occur as a result of the illness so that one can be said either not to prolong life or to allow death to occur

earlier. Whereas causing the patient's death or contributing substantially to it are commonly regarded as 'killing', allowing death to result from the organ failure consequent upon illness is commonly called 'letting die'. The use of these terms has tended to polarise the whole discussion into crude contrasts between killing and letting die. Unfortunately 'hastening death' could be taken to mean either or both.

Different people will compare the same clinical case to a paradigm case about killing or to a paradigm case about letting die. For example, one person might compare the act of switching off a ventilator to the act of killing in a paradigm case of murder, whilst another would compare it to a paradigm case of brain death where it is clearly wrong to prolong life with no prospect of recovery. The use of different paradigms leads to the employment of different maxims and yields different conclusions if the circumstances are not fully considered in interpreting the force of the maxims in the particular case.

The public debate around euthanasia has tended to produce opposing camps of people. On one side are those who agree with letting die, but who may or may not agree with legalising killing in the context of euthanasia. On the other side are those who are opposed to letting die and also to euthanasia and who think that life-prolonging measures should be pursued whenever possible. The definition of palliative care, by prohibiting 'hastening' death has produced ultimate confusion in the public mind as to the role of palliative care professionals - they may see them either as being willing to allow death to occur, or as always providing life-prolonging treatment, or as being willing to hasten death as a foreseen but not intended event, or perhaps as practising euthanasia under the screen of the latter statement via the doctrine of double effect.

When the discussion is so confused there is no hope of resolution of the clinical problems nor of making laws that will actually serve the interests of patients in infinitely diverse situations. A commonsense approach which is

based fundamentally on our agreement about paradigm cases is the only way forward. In the context of this issue it is vital that the philosophy of palliative care forms an integral part of health care ethics, and that it promotes the overall welfare of patients within a law that can be upheld and enforced but which allows sufficient interpretation to serve the best interests of patients and the rest of society.

It is clear from section 1.2.ii above that allowing death to occur (letting die) has to be permitted when the burdens and risks of life-prolonging treatment clearly outweigh its benefits, or when the provision of life-prolonging treatment so alters the terminal phase of the illness that a more distressing course occurs. At the same time society needs to maintain its prohibition against killing (murder) in order to protect its members. In order to achieve these two aims both the law and professional guidance have to uphold a clear distinction between killing and letting die.

The legal situation is fortunately quite clear. In law an act of killing is murder if one person intended to cause and did cause the death of another. It is prohibited in most cultures, and is severely punished. A charge of murder would be brought against a doctor who intended to cause and did cause the death of a patient. Thus if a doctor 'hastened' death by knowingly administering a lethal injection he or she would be charged with murder. On the other hand a doctor who withholds or withdraws a life-prolonging treatment from a patient because its burdens and risks outweigh its benefits, or because the patient refuses the treatment, is considered to have allowed a foreseen death to occur from natural causes and is not charged with murder. In this situation letting the patient die is legally permitted.

Unfortunately the moral situation is much less clear than the law. In the clinical context the withholding or withdrawing of life-prolonging technology can be seen as 'hastening death'. For example, in the context of irremediable dysphagia due to recurrent cancer of the oesophagus a patient regarded

cessation of fluids via a drip as 'bringing death nearer' rather than ceasing to put off inevitable and unavoidable death from the illness. The use of the ambiguous term 'hastening death' in the WHO definition causes patients and professionals to regard withholding or withdrawing a life-prolonging treatment as a decision to either cause or bring forward death, and not simply as a decision to allow death to occur from natural causes.

Whilst the use of ambiguous terms such as 'hastening death' has fuelled confusion, the advent of technology has unavoidably made the moral distinction between killing and letting die appear very blurred in some cases. There are two reasons for this.

The first reason is to do with understandable and perhaps unavoidable ambiguity around the cause of death in a minority of cases. In such cases it may be argued that the withdrawal of life-prolonging or life-sustaining treatment *causes* the death of the patient. For example, when life-prolonging treatments such as artificial feeding and hydration are removed from patients in the persistent vegetative state, or artificial ventilation is removed from stable but unconscious ventilator-dependent patients, it is overwhelmingly likely that death will follow, and so some people consider that such withdrawal of life-prolonging treatment actually causes the patient's death. They therefore think that it should be considered morally and legally to be the cause of the patient's death. Legally, causing the death is one of the two conditions for murder.

On the other hand I would wish to argue that the patient's death is caused by the underlying failure of essential organ function (for example permanent unconsciousness or inability to breathe) which renders the patient incapable of survival without constant life-prolonging treatment. The fundamental cause of death is the patient's condition, not the withdrawal of treatment, which should be regarded as incidental. Death would have been caused by the pathological conditions of the PVS or inability to breathe. The life-support treatments merely prevent on a temporary basis the occurrence of

death. Such temporary measures give doctors time to assess the situation and to consider whether the body can resume normal functioning or whether there is reasonable hope of improvement. If in these situations there is no reasonable hope of recovery of consciousness or the ability to breathe, further life-sustaining treatment cannot confer benefit and therefore it is not in the patient's interests to continue it. When it is removed the body's own causality results in death.

If this line of reasoning is rejected and it is considered instead that doctors cause the death of patients when they switch off ventilators or remove artificial nutrition and hydration from patients in the PVS, then it must follow that in all cases where doctors have withheld or withdrawn life-prolonging treatment for any reason they have to some extent caused the patient's death. Since the available array of life-prolonging treatment is so extensive, and since the precise timing of so many patients' deaths is now influenced by decisions to forgo some possible life-prolonging technology, one would have to conclude that doctors actually cause the death of the majority of their terminally ill patients. For example, one would have to conclude that doctors cause the patient's death whenever they discontinue a cardiopulmonary resuscitation attempt. The reason is that technically the doctors could have supported the patient's circulation artificially for some time longer. Similarly, the withholding of antibiotics for pneumonia from patients with a very poor prognosis would also be regarded as tantamount to causing the patients death (if it is thought that antibiotics might have prolonged life). Such a conclusion is deeply counter-intuitive.

Moreover, if doctors were considered to have caused the patient's death whenever they withheld or withdrew life-prolonging treatment the law would have to examine each incident as a possible case of murder. If it were judged that the doctor might have intended the death of the patient (which he or she was considered to have caused) then a charge of murder would have to be

made. This situation would be completely unmanageable legally. But if withholding and withdrawing life-prolonging treatment is considered to cause death this unmanageable legal situation could be avoided only if the prohibition against intentionally causing death were abolished. Such an alteration in the law would be highly undesirable because it would remove an essential protection for all members of society.

One must conclude that in health care ethics (including palliative care) and the law, 'letting die' in the sense of withholding or withdrawing non-beneficial life-prolonging treatment must be permitted and even advocated. As the BMA states, if there is no expected net benefit to the patient then there is no justification for providing the treatment.

1.3.iii Intending versus foreseeing death.

The second reason for the blurring of the moral distinction between killing and letting die is to do with the distinction between intending and foreseeing the outcome of a decision. The importance of this distinction in respect of the ambiguity around 'not hastening death' was mentioned above. The moral distinction between intending and foreseeing the death of the patient following withholding or withdrawal of life-prolonging treatment may be finely drawn. For example, it is sometimes argued that when a doctor switches off a ventilator-dependent patient's ventilator, or removes artificial feeding and hydration from a patient in the persistent vegetative state, that doctor is intending to cause the patient's death. Those who take this position assert that the doctor must inevitably intend the patient's death since he or she knows that it is overwhelmingly likely that death will follow withdrawal of these treatments. The contrary position, which I hold, is that the doctor intends only to withdraw a futile and non-beneficial treatment, and foresees but does not intend the patient's death.

There are two aspects to intention in this case. The first is to do with what the doctor wants, desires or seeks as the outcome of the decision. Some people who maintain that the doctor intends the patient's death seem to believe that the doctor wants or desires the patient's death. Yet this is surely not the most accurate representation of the case. The doctor is in no way seeking the patient's death, even if it is agreed that death is the least bad outcome because it is considered preferable to continued existence in a state of profound disability, distress or discomfort. The representation which I consider most accurately describes the case is that the doctor neither desires nor seeks the patient's death, but rather intends only to withdraw or withhold a non-beneficial and possibly burdensome treatment. No doctor should seek a patient's death, but equally no doctor wants (or should want) to impose a treatment which confers no benefit and which may be burdensome.

The second aspect of intention relates to the fact that it is intention *to cause* the death of the patient which is being considered. Thus those who believe that the doctor who withdraws or withholds life-prolonging treatment intends the patient's death must believe that the doctor intends *to cause* the patient's death. In reply I would argue that since doctors quite reasonably do not consider that the withdrawal or withholding of life-prolonging treatment is the fundamental cause of the patient's death, they cannot logically intend to cause death by withholding or withdrawing treatment. It makes no sense to say that doctors intend to cause death when they do not think their decision is the cause of that death.

In summary, then, I would argue that doctors who withhold or withdraw life-prolonging treatment when its burdens outweigh its benefits do not cause nor intend to cause the patient's death. Rather, they withhold or withdraw treatment which they consider is inappropriate because its burdens exceed its benefits, and they foresee the patient's death but do not desire or seek it, nor

intend to cause it. Somehow the philosophy of palliative care, as an integral and consistent part of health care ethics, must succeed in making these distinctions clear whilst at the same time continuing to prohibit professionals from intentionally causing the death of their patients.

1.3.iv. Double effect.

The preceding discussion centres around the possible interpretation of withholding or withdrawing life-prolonging treatment as in some way causing or 'hastening' death. However, there are clinical situations in which a treatment given with the aim of relieving distressing symptoms at the end of life may actually have other effects which may make death occur earlier than it would have done without the treatment. It is important to remember that such treatments do not cause the death entirely, but in the context of the patient's advanced illness and frailty death may occur earlier than without the treatment. The doctrine of double effect is commonly used to justify the provision of such treatments even though they may 'hasten' death in the sense of bringing it forward. One must ask whether this doctrine is essential or even useful in the philosophy of palliative care, and whether there is any alternative professional guidance which would lead to better decisions.

It is important to note that the circumstances in which the only way to alleviate pain or distress is to use a treatment which may bring forward death are really quite rare. There is a common misconception that morphine will shorten life by causing respiratory depression and sedation. Properly used, and used only as an analgesic (not as a sedative) this is not the case. Patients given only the amount of morphine needed to counterbalance and relieve a morphine-sensitive pain do not suffer respiratory depression and are not sedated. Thus the example of morphine, which is unfortunately commonly given in the media, is totally misleading and simply causes the public and professionals to maintain fear and reluctance regarding its use.

On the other hand there are circumstances where sedation or sometimes a technical procedure may bring death nearer. For example, patients who are confused at the end of life may become restless and agitated. Sedation by drugs like valium alleviates this distress but if the distress passes only when the patient is rendered very drowsy or asleep then clearly the patient drinks less, moves less and so may be more likely to develop pneumonia. Similarly, a procedure like paracentesis (removal of abnormal fluid collections from the abdomen) may be the most effective way to alleviate distress due to a very distended abdomen associated with difficulty breathing. However, when the patient is very ill the loss of litres of fluid from the abdominal cavity may precipitate shock and death may occur earlier than if the paracentesis had not been done. These are genuine examples of situations where a treatment intended to alleviate symptoms may cause death to occur earlier, but the treatments are not themselves the cause of death (the same treatments given to a healthier person would not bring about death at all, and death occurs in these patients primarily because of the advanced state of their illness).

The doctrine of double effect claims that a single act with both good and bad effects is justified *if, and only if*, four conditions are met. It is important to note that all four conditions must be met. The doctrine itself dates from St. Thomas Aquinas. The precise description of the conditions is taken from the account by Tom L. Beauchamp and James F. Childress in 'Principles of Biomedical Ethics'.⁶

The four conditions are:

1. *The nature of the act.* The act must be good, or at least morally neutral (independent of its consequences).
2. *The agent's intention.* The agent intends only the good effect. The bad effect can be foreseen, tolerated, and permitted, but it must not be intended.
3. *The distinction between means and effects.* The bad effect must not be a means to the good effect. If the good effect were the direct causal result of

the bad effect, the agent would intend the bad effect in pursuit of the good effect.

4. *Proportionality between the good effect and the bad effect.* The good effect must outweigh the bad effect. The bad effect is permissible only if a proportionate reason is present that compensates for permitting the foreseen bad effect.

It can be seen that decisions to provide a treatment to alleviate distress or pain in the context of terminal illness may sometimes meet all of the above conditions and so be considered permitted according to the doctrine. For example, the nature of the act of providing symptom relief is morally good, the agent might intend only the good effect of relief of distress but not the bad effect of hastening death, the relief of suffering is brought about by the treatment and not by the bad effect which is the death of the patient, and the good of relieving suffering in the face of inevitable death in the near future outweighs the bad effect of hastening that death.

The main problem with the use of the doctrine in health care ethics, even in the specialist field of palliative care, is that many if not most health care professionals are unaware of the four conditions, or are unable to understand them, or are unable to remember them. They therefore tend to think that the doctrine means simply that an act with a bad effect, such as the death of the patient, is justified if the agent did not intend the bad effect, even though it was foreseen. This misconception of the doctrine actually leads to its abuse. For example, some people have suggested that euthanasia is justified by the doctrine of double effect, whereas this could never be the case because in euthanasia the bad effect is intended and good effect is brought about via the bad effect, so conditions 2 and 3 above are not met. For these reasons the doctrine itself should be rejected as a part of a philosophy of palliative care, even though its proper use might in theory be helpful in clinical practice.

Instead, a philosophy of palliative care as part of health care ethics should make clear that in making decisions practitioners must weigh up carefully the benefits, harms and risks of a treatment in the particular patient's case, and that practitioners must not intentionally cause the patient's death. Most health care professionals will fully comprehend and use such guidance only if examples in the form of case scenarios are used in education. The methods of casuistry would help practitioners to judge whether provision of a treatment with a foreseen bad effect as well as the intended good effect was justified in particular circumstances.

1.3.v. Euthanasia and letting die.

I have stated that I think the philosophy of palliative care, and health care ethics in general, should continue to prohibit practitioners from intentionally causing the death of their patients. However, since euthanasia is one of the many moral questions on which opinions differ some people will inevitably disagree with me, and those who do sometimes develop an argument to suggest that the legal prohibition of 'mercy killing' should be revoked. (In this context I mean by mercy killing or euthanasia an intentional act which causes the death of the patient and which is done through compassionate motives.) If the legal prohibition of euthanasia were revoked and it were legalised, then clearly the philosophy of palliative care and professional ethics in health care would have to be altered in very significant ways with many important implications.

The proponents of euthanasia often argue that there is no significant moral difference between intentionally causing the death of a patient (mercy killing or euthanasia) and withholding or withdrawing life-prolonging treatment (acts fitting my description of letting die). In other words they assert that letting die is morally indistinguishable from euthanasia or mercy killing. They also assert that the law should treat acts which are considered morally

indistinguishable in the same way, so that if letting die is permitted so should acts of mercy killing or euthanasia be permitted. Their arguments can be presented as a logical syllogism as follows:

Major premise: Morally indistinguishable cases should not be treated differently by law.

Minor premise: Acts of letting die are morally indistinguishable from acts of mercy killing or euthanasia.

Conclusion: Therefore the law should not treat acts of mercy killing or euthanasia differently from acts of letting die.

Whilst the conclusion does follow logically from the premises I would contend that the premises are seriously flawed and so the conclusion based on them should be rejected.

The minor premise has already been examined above, where I concluded that there are important moral differences between acts of letting die and acts of mercy killing or euthanasia. These differences lie in both intention and in causation of death; in cases of 'letting die' the doctors neither intend to cause nor cause the death of the patient whereas in acts of euthanasia they both intend to cause and do cause the death of the patient. Therefore euthanasia and letting die are not morally indistinguishable and so the minor premise is false.

The major premise, that morally indistinguishable cases should not be treated differently by law, raises issues about the function of law and its relationship to morality. Three essential points should be considered. Firstly, it should be remembered that the function of the law is to safeguard the interests of everyone in the community and not just the interests of a minority, however

deserving, against the majority. Secondly, morality is much more complex than the law could ever be. An enforceable, consistent and comprehensible law is necessarily a relatively 'blunt instrument' compared with the great complexity of moral judgements in particular cases. Yet it is with this blunt instrument that the good of the community must be upheld. So the law has to make distinctions which are unambiguous and comprehensible to ordinary folk, and it cannot possibly follow all the intricacies and nuances of thought and feeling which exist in morality. Thirdly, in treating acts of letting die differently from mercy killing or euthanasia the law is not saying that there is *always* a moral difference between letting die and killing. It is saying only that for legal purposes related to the best outcome for the whole community it is necessary to make this distinction. Indeed, the purpose of law is not to say which acts are or are not morally indistinguishable. In addition I would argue that in general there is a significant moral difference between acts of mercy killing and letting die, although it may be possible to produce scenarios where there is no significant moral difference, as shown by James Rachels.⁷ It follows from all of these considerations that it is likely that there will be unusual occasions when morally indistinguishable cases will have to be treated differently by law, in the interests of everyone in the community. Although at first sight this situation appears morally undesirable it is not wrong if the good of everyone requires it. Moreover it appears to me that whether it is right or wrong this situation is probably unavoidable.

I have asserted that both premises are false. Nevertheless, if they are accepted by some people the conclusion will logically follow, and so we should consider the consequences of accepting the conclusion. The conclusion suggests that letting die and mercy killing or euthanasia should not be treated differently in law. This would mean treating intentional acts of 'causing death' in the same way as acts of withholding or withdrawing life-prolonging treatment in

the context of allowing to die. It would follow then that either both should be prohibited, or both should be permitted.

I have already argued that disastrous consequences for patients would ensue if the withholding or withdrawing of life-prolonging treatment were prohibited. All patients would then be allowed to die only after the application of all possible means to prolong life. Indeed, the phrase 'allowed to die' would no longer have any application; patients would in fact die if but only if they defeated the medical technology! This would have disastrous results; the autonomy of patients and doctors would be grossly infringed by the law, life-prolonging treatments could not be withheld or withdrawn even if their harms outweighed their benefits, thus increasing suffering, and intensive care units would consume the lion's share of the community's resources for health care.

In fact it is much more common to hear it argued that both letting die and mercy killing should be permitted. For example, it might be suggested that withdrawal of feeding from patients in the PVS (persistent vegetative state) is morally indistinguishable from euthanasia and that both should be permitted. The consequences of such a view must be examined. Proponents of this view would contend that when doctors withdraw feeding from a PVS patient they have intentionally caused the death of the patient because they consider that the patient's quality of life is so poor that he or she should not be kept alive. They would then conclude that if allowing to die is permitted for this reason in the PVS cases then voluntary, and indeed non-voluntary euthanasia for the same reason must also be permitted. This would mean that if it was thought that a person's quality of life was considered so poor that he or she should not be kept alive by means of life-prolonging treatment, then a deliberate act to cause the death of that person should also be permitted. It would then follow that doctors, and indeed perhaps anyone, would be permitted to kill such patients. This would severely weaken the prohibition against killing which currently protects such vulnerable patients. Together with the vast majority of

specialist doctors in palliative care in the United Kingdom (according to a survey carried out by the Association for Palliative Medicine in 1997) I consider that any benefit of legalising euthanasia is outweighed by the harms which would result from weakening the prohibition against killing which currently protects them.

1.4 Conclusions.

1 The philosophy of palliative care should be consistent with health care ethics in general, and should form an integral part of the latter.

2 The WHO statement that palliative care 'neither hastens nor postpones death' should be rejected because of its intrinsic ambiguities. Health care practitioners may justifiably hasten death as a foreseen but not intended effect of treatment whose aim is the relief of pain and distress at the end of life, where the benefit of symptom relief outweighs the harm of bringing an inevitable death nearer. Prolonging life (thereby postponing death) is a goal of health care, and is often appropriate in the palliative context.

3 Guidance for practitioners should state that the benefits, harms and risks of a treatment in the patient's particular circumstances should be weighed up carefully. This includes analysing as far as possible the illness scenarios and ways of dying which are likely to occur with and without the treatments.

4 In the philosophy of palliative care, and in health care ethics and law generally, 'letting die', in the sense of withholding or withdrawing a life-prolonging treatment when its harms and risks exceed its benefits, must be permitted. Health care practitioners who so act neither cause nor intend to cause the patient's death.

5 There is a significant moral difference between intentionally causing the death of a patient by administering lethal medication (mercy-killing or euthanasia) and withholding or withdrawing a life-prolonging treatment because of lack of net benefit with the result that the patient dies of the underlying illness (letting die).

6 The philosophy of palliative care, health care ethics in general, and the law, must continue to uphold the prohibition against killing which protects all members of society. In law, in professional codes and in clinical practice, it is necessary to distinguish between intentional acts which cause the death of patients (acts described as 'killing' or euthanasia) and the withholding or withdrawing of life-prolonging treatment so that the illness causes death (acts regarded as letting die).

6 The methods of casuistry are the most helpful in both education and clinical practice for resolving the moral problems associated with treatment decisions in palliative care.

7 The doctrine of double effect is too complex for practitioners to use in clinical practice. It should be replaced by guidance to the effect of points 2 and 3 above together with education in the methods of casuistry using real case scenarios.

References for Chapter 1

¹ Marinker M, The Narrative of Hilda Thomson. *Narrative Based Medicine*. ed. by Greenhalgh T. and Hurwitz B. London: BMJ Books, 1998, p. 109.

² World Health Organisation, *Cancer Pain Relief and Palliative Care* Report of a WHO Expert Committee *Technical Report Series* 1990 No. 804

³ British Medical Association, *Withholding and Withdrawing Life-prolonging Medical Treatment*, London: BMJ Books 1999.

⁴ As above, p. 65.

⁵ Battin M.P, *The Least Worst Death*. New York: Oxford University Press, 1994. pp. 33 & 39.

⁶ Beauchamp T, Childress J. *Principles of Biomedical Ethics*. New York: Oxford University Press, 1994 p. 206-11.

⁷ Rachels R. Active and Passive Euthanasia. *New England Journal of Medicine*, 1975. 292: 78-80.

Chapter 2.

Relatives

Thesis 2: that the relatives should not be an equal part of the remit of care.

Introduction.

In stating that the goal of palliative care is 'the best possible quality of life for the patient and family' the World Health Organisation description of palliative care clearly implies that the welfare of the patient's family is the concern of the health care team. Moreover, it also implies that the welfare of the family is *as much* their concern as that of the patient. In terms of clinical activity this implies that the obligation to improve the relatives' quality of life is as strong as the corresponding obligation to improve the patient's quality of life.

Yet professional codes of conduct for doctors and nurses do not include statements about any obligations to relatives but only obligations to patients. For example, it is clear in such codes that obligations of confidentiality towards patients should override requests from relatives for information about the patient's illness, unless patients give consent to the sharing of that information. These codes are accepted by the National Health Service which employs health care professionals, and so are implicitly accepted by the community which funds and uses the service.

Similarly, whilst the law clearly states that health care professionals have a duty of care to patients it does not state that there is a duty of care to the relatives, and it too upholds the interests of patients (versus the relatives) in terms of confidentiality and informed consent, and in decision-making for incompetent patients.

In general, health care (outside the sphere of palliative care) professionals consider that their obligations are to patients; when a patient has a myocardial infarction, or would benefit from an operation, members of the health care team consider that their obligations are to the patient, not the relatives. Thus the team would act in accordance with the patient's best interests, not the relatives' interests. When a patient is incompetent, both professional guidance and the law dictate that decisions made by the health care team must be made on the basis of the patient's best interests, bearing in mind what can be known about the patient's wishes. Professional guidance and the law do not state that professionals have obligations to the patient's family.

So specialists in palliative care are in a very small minority in maintaining that they have obligations towards relatives. The marked difference in view on this point between the philosophy of palliative care and what we might call the philosophy of health care in general raises the following questions:

1 Do health care professionals have obligations towards the patients' relatives, and if so, what are those obligations?

2 Is the moral situation sufficiently different in palliative care from general health care to justify different obligations to relatives from those of general health care?

3 In the context of palliative care, how should health care professionals decide how they ought to act when there is a conflict between their obligations to the relatives and to the patient?

4 What, if anything, should the philosophy of palliative care say about obligations to relatives?

2. 1. Do health care professionals have obligations towards the patient's relatives, and if so, what are those obligations?

Despite the fact that professional codes and the law do not mention or recognise obligations towards relatives, professionals seem to be spending an increasing amount of time with them, even at the expense of time available for patient care. They divulge information about the patient's illness to relatives without the patient's consent, and they may sometimes pursue the relatives' interests at the expense of the patient's interests.

Of course, the fact that professionals are so acting does not lead to the conclusion that they believe that they ought to be doing so. From the way that people actually behave we cannot conclude that they believe they ought to behave in that way. Whilst in general people will act as they believe they ought, they may also act because of desires, or pressure or coercion.

It does seem reasonable to assume that professionals are not pursuing the relatives' interests simply because they have a desire to do so. Granted this assumption, then professionals may behave in this way either because they consider that they are under some form of obligation to do so, or because they are under some form of pressure or compulsion to do so.

Recent guidance from the British Medical Association on decision-making for incompetent patients may signal a change towards the view that there may be some sort of obligation to the families of patients. This guidance stresses that, wherever possible, the approval of the family regarding decisions made for the patient should be obtained.¹ This statement implies that there is some form of obligation to gain the family's approval, even though it is acknowledged that the family are not in any way consenting to or refusing a treatment plan, responsibility for which lies with the health care team.

Is this assumption justified? The various methods which have been advocated for approaching moral problems in health care might be used to try to answer this question.

The 'four principles' approach, as described by Childress and Beauchamp, is unhelpful in this respect as it does not make clear to whom the obligations of beneficence, non-maleficence, respect for autonomy and justice are owed.² Similarly, virtue ethics is unable to provide an answer to the problem; it is not clear what the compassionate, courageous professional who also has practical wisdom might decide in this regard. An ethic of care would seem to apply equally to all potential recipients of that care, so cannot discriminate between duties to patients and to relatives. Narrative based medicine would suggest that the stories of the family as well as the patient should be heard and used in making a judgement regarding treatment, so this too is unable to clarify to whom obligations are owed once those stories have been heard.

On the other hand casuistry, in comparing cases about which we are not clear with those about which there is no apparent doubt regarding obligations, might provide some method for determining professional obligations to relatives. For example, in acute care decisions regarding the patient's treatment are made on the basis of the patient's best interests - if a patient has heart failure or asthma then treatment is given promptly (on the basis of the patient's consent). Professionals do not consider that they are under an obligation to consult the relatives or devote time to them while the patient struggles for breath! Alternatively, if a patient was expecting relatives to lift him bodily, rather than use a hoist, professionals would insist that such a manoeuvre was dangerous to the relatives and should not be expected of them, thus upholding the interests of the relatives in opposition to the patient's wishes. Such paradigm cases could be analysed and maxims drawn from them. Those maxims would yield some conclusions regarding the obligations which we are certain we owe (or do not owe) to relatives in particular situations. Clinical cases could be compared to the paradigm cases leading to justifications of views regarding obligations to relatives.

2.1.i The nature of obligations owed, and to whom do we owe them?

Perhaps the most helpful analysis of this issue would be based on the ideas of W. D. Ross as described in his book 'The Right and the Good' published in 1930.³ Ross initially described the obligations of beneficence, non-maleficence and justice which were subsequently taken up and elaborated by Childress and Beauchamp for application in health care ethics. But Ross also considered it important that we should bear in mind to whom obligations were owed, and he distinguished between general obligations which were owed to all others and obligations of special relationship which were owed only to those to whom we stand in particular relationships. His arguments are convincing and help to clarify the debate about possible obligations to patients' families.

At the outset it should be noted that Ross believed that the moral convictions of ordinary people should form the basis of our moral philosophy. In a foot note he comments that 'The main moral convictions of the plain man seem to me to be, not opinions which it is for philosophy to prove or disprove, but knowledge from the start'.⁴ Later on he states that 'the moral convictions of thoughtful and well-educated people are the data of ethics... [They] are rejected only when they are in conflict with other convictions which stand better the test of reflection... The existing body of moral convictions of the best people is the cumulative product of the moral reflection of many generations, which has developed an extremely delicate power of appreciation of moral distinctions; and this the theorist cannot afford to treat with anything other than the greatest respect'.⁵

It should be noted that in casuistry also the moral convictions of ordinary people regarding paradigm cases provide the maxims used in moral justification.

In terms of health care ethics, 'the existing body of moral convictions' which has developed over many generations is encapsulated in professional codes of conduct and the law. It seems reasonable to assert, following Ross, that those convictions should be treated with the greatest respect. They do not include obligations towards relatives! Since the new philosophy of palliative care conflicts with those long-established codes it should be exposed to scrutiny or 'reflection', as Ross suggests, to see if this new idea of obligations to relatives stands the test of moral reflection.

Ross considered that the tendency of acts to promote the general good is one of the main factors in determining whether they are right, but it is not the only factor. He asserts that right acts are not right *only* in virtue of promotion of the general good, for special obligations such as promise-keeping are also very important. So production of the maximum good is *not* what makes *all* right actions right.⁶ He states that 'we are all in fact sure that it makes a vast difference' to whom we have the duty to produce the good.⁷

Ross distinguishes duties of general obligation (beneficence, non-maleficence, and justice) from duties of special obligation (promise-keeping, gratitude, and reparation of a wrong). We owe to our fellow human beings (including patients) the duties of beneficence - the duty to make the condition of others better in terms of virtue, intelligence or pleasure, non-maleficence - the duty not to harm, and justice. He notes that the duty of non-maleficence is more stringent than that of beneficence.

It is reasonable to assert that the health care professional has duties of special obligation to the patient, as is laid down clearly in professional codes which are upheld by the law. In establishing and funding the National Health Service, the community has explicitly promised health care to the sick, and the relationship between health care professionals and their patients is characterised by that promise. Ross notes that 'To make a promise...is to put oneself in a new relation to one person in particular, a relation which creates a

specifically new *prima facie* duty to him, not reducible to the duty of promoting the general well-being of society.⁸

Ross's account of special obligations is reflected in the moral style of professional codes. But professional codes, the law and general health care (as distinct from specialist palliative care) do not imply any sort of promise (explicit or implicit) to the relatives of patients. It is only the relatively new philosophy of palliative care which makes an explicit promise that health care professionals will work to improve the quality of life of the relatives of patients. Ross asserts that the *prima facie* rightness of certain types of acts, such as promise-keeping, is apprehended by us, and is self-evident to us. He claims that 'The moral order expressed in the proposition that these acts are right is part of the fundamental nature of the universe'.⁹ He uses the example of promise-keeping to illustrate the idea that maximising the good is not the only criterion which makes an act right, but that honouring a duty founded in a special relationship is also important and indeed, is often considered to be more important. He illustrates this point by saying: 'If, so far as I can see, I could bring equal amounts of good into being by fulfilling my promise and by helping some one to whom I had made no promise, I should not hesitate to regard the former as my duty. Yet on the view that what is right is right because it is productive of the most good I should not so regard it.'¹⁰

Ross acknowledges that duties or obligations may conflict, and the term *prima facie* duty means that it is only a 'conditional duty' or 'tending to be our duty', rather than a duty proper. Whether it is a duty proper depends on the circumstances regarding other co-existing duties - where duties conflict we have to make a judgement regarding which is more pressing, and this judgement is not certain in the sense that a logical deduction from premises is certain. He says 'Our judgements about our actual duty in concrete situations have none of the certainty that attaches to our recognition of the general principles of duty..... Where a possible act is seen to have two characteristics,

in virtue of one of which it is *prima facie* right, and in virtue of the other *prima facie* wrong, we are (I think) well aware that we are not certain whether we ought or ought not to do it; that whether we do it or not, we are taking a moral risk. We come in the long run, after consideration, to think one duty more pressing than the other, but we do not feel certain that it is so.... Again, our judgements about our particular duties are not logical conclusions from self-evident premises. ...in the moral case we have more or less probable opinions which are not logically justified conclusions from the general principles that are recognized as self-evident.¹¹

It should be noted that promise-keeping and other duties are 'duties proper' if, but only if, other things are equal. Whatever one actually does when duties conflict, one does not feel good about the decision, because one has failed to do something which is *prima facie* right. This position contrasts with utilitarianism, according to which one can always feel good about a decision which results in maximum happiness or benefit because maximising happiness or benefit is seen as the *only* duty. Utilitarianism effectively ignores the moral relevance of the bad feeling which one has when there are conflicts of duties.

Ross stresses the importance of reflection. He states that 'we are more likely to do our duty if we reflect to the best of our ability on the *prima facie* rightness and wrongness of various possible acts in virtue of the characteristics we perceive them to have, than if we act without reflection. With this greater likelihood we must be content.'¹² This point regarding reflection is important, for it is likely in the context of health care that we may often have to decide between two conflicting sets of duties, those of general obligation and promise-keeping to patients, and those of general obligation to relatives. In making these judgements, some ideas on the stringency of these obligations are helpful in deciding which duty is more pressing. For example, we might be able to draw distinctions between acts which it would simply be morally appropriate or fitting that we should perform, and those which are *prima facie* duties.

Professor David Raphael drew such a distinction when he further developed the original classification of Ross in his book 'Moral Judgement', published in 1955.¹³ He divided moral acts into those which are obligatory and those which are merely fitting. Acts which are obligatory are further subdivided into those of general incidence, corresponding to Ross's general obligations, and acts of specific incidence where special obligations arise from the relationship between particular persons. His classification could be represented as follows:

Obligatory acts:

1 of general incidence - obligatory upon all moral agents and obligatory towards all persons and other sensitive creatures whom they may affect by their actions. These are

- i non-interference with the liberty of others to pursue their desires where these raise no moral issue,
- ii relief of pain, and refraining from giving pain
- iii veracity or non-deceit
- iv treatment on a basis of equality.

2 of specific incidence, i.e. determined by the specific character of specific situations. The moral character of the act is that of obligation arising from the relationship between particular persons. The obligations may arise from:

- a. past acts of the individuals involved,
 - obligations of promise-keeping and reparation
 - or obligations towards the claimant arising from gratitude
 - or past acts of agent and claimant as in fulfilling contracts
- b. association between particular persons, such as the

obligations of love and friendship or
obligations arising from loyalty to a group or person.

Fitting acts:

are only of general incidence, aim at the good or prevention of evil, and always relate to the interests of persons.

Raphael stated two qualifications which apply to all specifications of obligatory and fitting acts; firstly, they apply only 'if one can', or 'as far as one can', and secondly, obligations may conflict with and be overridden by other instances of obligation. This second qualification resembles Ross's concept of prima facie obligations or duties. Raphael does not deduce that a fitting act would always be overridden by an obligatory act, although such a deduction would be important in health care ethics if fitting acts towards relatives were always to be overridden by obligations to patients.

He also points out that there is an underlying condition that the agent must be capable of making a free choice, and that the obligation (and therefore the claim by the recipient) depends on the awareness of the agent of the desires and interests of the recipient. In respect of the latter condition it is important to note that perceiving the wishes of others does not necessarily entail an obligation. He says 'The sympathetic imagination of the wishes of others is not always held to involve an obligation. It is so far as negative action is concerned. If there are no countervailing ethical considerations, there is always an obligation not to thwart the desires of others. But positive action to satisfy the desires of others is sometimes obligatory, sometimes merely fitting.'¹⁴

In distinguishing obligatory acts from fitting acts, Raphael asserts that obligation depends on the satisfaction of the interests of others plus some form of inter-personal tie. Where it is an obligation of general incidence the tie is

based on being members of the same community - it is not based on what has passed before between the agent and claimant, whereas obligations of specific incidence do depend on what has previously passed between them. Raphael asserts that an act which is merely fitting is one which satisfies anyone's interests or 'promotes happiness no matter whose'.¹⁵ It resembles a general policy statement and no inter-personal tie is involved. However, he admits that there are some desires which are bad, and which it is fitting to repress and not to satisfy.¹⁶

Like Ross, Raphael acknowledges that obligations to satisfy the interests of others, in situations of general incidence or in special relationships, may conflict. He addresses this problem as follows: 'Our capacity to serve the interests of others, however, is limited, both because of the strength of egoistic desires which may conflict with the thought of altruistic action, and because my serving the interests of *A* will often prevent my serving the interests of *B*. Therefore implicit conventions have arisen that only in certain types of situation is altruistic action strictly obligatory as opposed to fitting, and that in such-and-such a set of circumstances my obligation to *A* is greater than my obligation to *B*. These conventions are usually due to the relative strength of most people's natural dispositions or to proved social utility, and often to a combination of both....Particular types of situation in which one person can make the ends of others his own, are singled out, by the growth of convention, as *specifically* obligatory on particular groups of persons.'¹⁷

Raphael goes on to say that promises and contracts are specific obligations which bind people by a specific inter-personal tie. The relationship between health care professional and patient is one of specific obligation, founded on the promise of health care for the patient. That promise entails the provision of the benefits of health care, namely life-prolonging or life-sustaining treatment, relief of pain and other symptoms of illness, and some forms of care required because of illness. This promise has obvious social utility. In some

ways, since health care in the UK is publicly funded, it resembles a contract between the individuals and the state, whereby a contribution via taxation is rewarded by health care to a certain level.

The obligations of promise-keeping are contrasted with those of general incidence by Raphael as follows: 'A promise is the conscious setting-up of an inter-personal tie by pronouncing that some event, the production of which is thought to be in the agent's power, and which will benefit the future claimant, will be brought about by the agent. He thereby gives rise to the expectations of benefit from himself and 'binds' himself to fulfil them.'¹⁸ At the first meeting of a patient and health care practitioner the implicit promise of health care by the practitioner is mutually accepted. At this meeting an inter-personal tie is consciously established between patient and professional. This promise underlies their subsequent relationship.

In contrast Raphael states that obligations of general incidence do not depend on the thought of what has passed between the agent and claimant. Instead, they 'do depend on knowing or believing that the person to whom the obligation is due has affective-conative dispositions to be satisfied.'¹⁹ The obligations that health practitioners may have to relatives do not depend on the thought of what has passed between them.

In the context of health care we must ask whether there are any grounds for asserting that there is a special relationship between the relatives of patients and health care practitioners. The moral convictions of health care professionals, as expressed in their codes of conduct, do not entail a promise-keeping obligation between health practitioners and relatives of patients. Nor do those convictions entail any form of contract between the relatives and health professionals, nor any debts of gratitude, nor any special ties based on loyalty and friendship. Since these special relationships, associated with specific obligations, do not exist between health professionals and the relatives of

patients, it follows that the only obligations owed to the relatives are those of general incidence.

It might be objected that the existence of a close bond between the patient and relative should provide the justification of a special relationship between the professional and relative, by way of a sort of extension of the patient-professional relationship. There are three linked arguments which refute this assertion. Firstly, the patient and relative are still separate persons, with individual and frequently different interests, and conducting a separate relationship with the health care professional. Secondly, only the relationship with the patient is characterised by the promise of health care. Thirdly, since the interests of patient and family will often conflict, it is impossible simply to extend to the relative the promissory relationship which exists between the patient and professional. It would frequently be impossible, by the same act, to further the interests of both patient and relative. Whilst it is important to acknowledge the very strong bonds of love and loyalty within families and friendships, their existence does not provide sufficient grounds for claiming that the promise-based relationship of professional to patient can or should be extended to close family and friends.

If it is accepted that only obligations of general incidence (Raphael's classification) are owed to relatives, then it follows that those obligations comprise non-interference with the liberty of relatives to pursue their desires where those desires raise no other moral issue, veracity, and justice. The relief of pain hardly applies in the general sense because a health care practitioner confronted with a member of the community in pain might be said to have some obligations to that relative as a patient.

According to Ross's classification, general obligations towards the relatives would comprise non-maleficence, beneficence and justice. It should be remembered that non-maleficence is more stringent than beneficence, and

the latter is said to be an obligation to improve the condition of others in terms of virtue, intelligence or pleasure.

It seems reasonable to assert that in most circumstances the specific obligations of promise-keeping which health practitioners owe to patients would outweigh the general obligations owed to relatives. Serving the interests of patients, to whom health practitioners have specific obligations (as well as general obligations) would, in most circumstances, rightly prevent them from serving conflicting interests of relatives. For the duty of promise-keeping by providing the benefits of health care would, in the vast majority of clinical situations, constitute a more pressing duty than the duty of beneficence as a general obligation to relatives.

Fortunately, there is not always a conflict between obligations to patients and obligations to relatives. For example, it is unlikely that providing health care for the patient would infringe the liberty of relatives to pursue their own interests, for most often the relatives are capable of continuing to pursue their own interests if they so wish - they can decide how much they are willing to do for the patient. Similarly, it is difficult to imagine a situation where the provision of health care for the patient would be enhanced by deliberately deceiving or lying to the relative or by acting towards the relatives in an unjust manner.

On the other hand, one type of conflict which health practitioners experience frequently is that between the promise to provide health care to patients and a perceived duty to act beneficently towards relatives. It should be noted that whilst Ross includes beneficence as a general obligation Raphael does not - for him it seems that beneficent acts of general incidence are classified as 'fitting' rather than obligatory. This stance would considerably weaken the force of any duty to further the interests of relatives as opposed to the health interests of patients.

2.1.ii Intrinsic and extrinsic aims of palliative care.

It should also be noted that there is a fundamental difference between the health care benefit promised to patients and other, non-health care benefits, which practitioners may consider they should provide for relatives. The explicit purpose of health care services is to deliver health care to patients. The intrinsic aim of palliative care must be to provide that health care benefit to patients. In contrast to patients, the relatives are not 'ill' - merely having a family member who is terminally ill does not itself constitute an illness, nor is bereavement an illness. The relatives will not derive a health care benefit from palliative care. It follows that improvement in the quality of life of relatives cannot be an intrinsic aim of palliative care.

Instead it might be described as an extrinsic aim, something which it is 'fitting' to achieve. Since an intrinsic aim cannot be trumped by an extrinsic aim, it is fitting for health practitioners to work to improve the quality of life of relatives if, and only if, so doing will not significantly compromise the achievement of health care benefits for patients.

An extrinsic aim, something which it is merely 'fitting' to achieve, cannot give rise to an obligation. If it is accepted that improving the quality of life of relatives is an extrinsic aim, then there is no obligation or duty binding on health care professionals towards relatives. Obligations to patients do not extend to relatives - their close relationship to the patient provides no grounds for an obligation to improve their quality of life.

The point here is that if there were an obligation towards relatives it could not be an obligation to provide health care, since the relatives are not ill. Hence it could not be an obligation for health care professionals as such. Of course it might be argued that health care professionals have obligations wider than those to provide health care. For example, they might have an obligation to improve quality of life. But this, as we shall see later, would be an open-

ended commitment and too wide to be undertaken by a publicly funded health service.

The philosophy of palliative care, in stating that health care professionals have an obligation to improve the 'quality of life' of relatives, leaves health care professionals delivering palliative care with the difficult conclusion that somehow, outside the realm of the treatment of illness, they have an obligation to improve the relatives' quality of life. The problems associated with the concept of quality of life are described in chapter 3, whilst the problems associated with the concept of an obligation to improve the relatives' lives in some way are the subject of this chapter.

The philosophy of palliative care functions as an ideology or set of beliefs which practitioners try to live out in clinical practice. The belief in obligations to relatives is rarely questioned, as is shown by statements such as the following in a systematic review of the level of need for palliative care: 'Clearly, palliative care services must address the psychological as well physical symptoms associated with the disease process, not only in the patient, but also in the family units supporting the patient.'²⁰

It might be asserted that bereaved relatives are ill, and that interventions by health care practitioners towards relatives may prevent depression during the patient's lifetime or in bereavement. Not surprisingly, there is some evidence that depression is common in the spouses of patients who are dying.²¹ But it is not really appropriate for the health practitioner to treat the spouse's depression as part of his or relationship with the patient. Moreover, normal bereavement is not an illness. Depression and adjustment disorders can occur and may then constitute a mental illness, but it is not clear that the professional caring for the dying patient has any obligation to try to treat the possible future illness of the relative, particularly as attempts to do this are likely to compromise the patient's care as is noted later in section 2.2.

Having established that professionals, who are not meeting the relatives as patients, do not have an obligation to provide those relatives with health care, and do not have an obligation of promise-keeping to those relatives, it remains to describe in more detail those obligations of 'general incidence' which they do have to patients' families.

A plausible list of obligations owed to relatives can be drawn from Raphael's obligations of general incidence plus Ross's general obligations; non-interference with the liberty of relatives to pursue their desires where these raise no moral issue, non-maleficence or prevention of harm, veracity and non-deceit, treatment on the basis of equality or justice, and beneficence. I shall discuss these in turn.

2.1.iii Non-interference with the liberty of relatives to pursue their desires where these raise no other moral issue.

In the context of health care this duty implies that practitioners should not impede relatives' pursuit of their own aims when those aims do not conflict with the good of the patient. Unfortunately, there are many circumstances where the relatives' goals may compromise the patient's welfare, and in this case the health care professionals may rightly decide that they should have no part in furthering the relatives' goals, and may directly oppose them. Some clinical examples illustrate common problems.

It still happens that relatives may be told the diagnosis of a terminal illness before the patient and they then request health care practitioners either to withhold the information from the patient or deliberately to deceive the patient. But those practitioners, in virtue of their special obligation of health care to the patient, and also because of their general obligation of veracity, have a clear duty to provide the patient with any information he or she desires regarding the illness, or which is necessary as a basis for consenting to or

refusing treatment. This obligation to the patient clearly outweighs any possible obligation to the relative. It is now generally agreed that the wishes of relatives should not prevent professionals from answering patients' questions truthfully and from providing them with the information they need in order to participate in decisions regarding their care. At the very least there is an obligation to offer patients information about their illness. Patients are able to indicate whether or not they want information, and the degree of detail they require.

Strangely, despite this general agreement and unequivocal statements in codes of professional ethics that patients should be informed about their illness and treatment options, professionals still sometimes deliberately withhold information from a patient in order to comply with the relatives' request. Even more strangely, in 1999 the British Medical Journal published a short piece entitled 'A lesson to be learnt, A word out of place' which clearly imparts the lesson that it was 'right' and correct professional practice to withhold information from a patient (who had not indicated that he did not want information) in order to comply with the relatives' wishes.²² Some professionals deliberately withhold information regarding a terminal illness from patients if relatives have said the patient will be distressed by it, or will give up hope and so die sooner, or would not want it. It is clear that none of these reasons can justify failure to offer the patient the amount of information he or she wants.

The most likely explanation, but not justification, of such professional conduct is that it is simply easier to comply with the relatives' wishes than to explain to them that the patient is entitled to information and that one's professional duty requires one to make it available. It is always tempting to take the easiest way out of this situation, and to justify it either by stating that one's obligation to relatives in this case overrides one's obligation to the patient (a very implausible account) or by stating that one should not 'harm' patients by informing them of the nature of their illness. Even if relatives consider it is not in

the patient's interests to be given certain information, the patient should be assured that any questions he or she asks will be answered willingly and truthfully. Furthermore, the necessity for adequately informed consent to treatment may require that the patient is given certain information. This is one example of circumstances where relatives appear to exert considerable pressure on professionals. This situation still occurs only because professionals appear extraordinarily reluctant to uphold the patient's interests versus those of the relatives.

In other circumstances the relatives' pursuit of their own goals may harm the patient. For example, sometimes relatives sitting with a dying patient who is semi-conscious may attempt to give the patient oral food or fluids when the patient's ability to swallow is seriously compromised, and there is a risk of aspiration of food into the lungs. Since this is a risk of serious harm, professionals must try to prevent relatives from continuing feeding, (although if this occurs when the patient is at home they have a limited ability to prevent it). Usually, all that is required is adequate explanation regarding the dangers of the practice, and the lack of benefit from food and fluids when the patient is actually dying.

Many conflicts between relatives' desires and the interests of patients arise when decisions regarding treatment and care have to be made for incompetent patients. In the UK, decision-making authority and responsibility for incompetent patients lies with the health care team, not the relatives, (although in the future this situation may change). This means that no adult can consent to or refuse treatment on behalf of another adult, nor can any adult demand for the patient a treatment which the health care team consider is not in the patient's interests. The relatives do have a role in decision making in that they should inform the health care team about the patient's wishes, so far as these are known or can be deduced from previous statements.

It is not uncommon for relatives to request a treatment which health care professionals consider should not be provided because they judge that in the circumstances its harms and risks outweigh its benefits. It is clear that in this situation the health care team should bear in mind what can be known of the patient's wishes and consider carefully the balance of benefit to harm. But they should not provide a treatment they believe to be harmful in order to fulfil the family's desires. However, in this situation it is easier to comply with the family's wishes, particularly if the patient is not likely to be in a position to complain or to litigate afterwards. Nevertheless, there is no doubt that where treatment decisions are concerned the obligation of every member of the health care team to the patient, in context of the promise of health care and the general obligation of non-maleficence, outweighs any obligation to the relatives.

In other circumstances it seems clear that health care professionals ought not to thwart the relatives' desires or goals. For example, if the patient is at home the relatives are quite free to decide how much care they are willing and able to give. This is a decision for which family members must take personal responsibility, and whilst professionals can and should give encouragement, realistic reassurance and explanation regarding the patient's care needs it is clearly not the professionals' duty to try to coerce relatives to provide care. Indeed, such coercion would be wrong, for relatives must be permitted to decide what they are willing to do in this situation. The patient should be informed of their decision (preferably by the relatives themselves), unless the patient is confused or not fully conscious. In this case there is an obligation to respect the relatives' liberty to decide how much care they are willing to provide for the patient, and relatives take responsibility for the decisions they make in this regard.

On the other hand, if relatives wish to prevent a patient from returning to his or her own home, the health care professionals generally have a stronger obligation to further the patient's interests than those of the relatives. If the

patient's care needs can be met largely by outside agencies (assuming the relative does not want to provide care), and if the patient wishes to go home, then the health care team have an obligation to enable that patient to return home despite the relative's desire to prevent this. This situation does occur where the relationship between the patient and relative has been poor, or where the relative is frightened of the presence of the very sick patient or of the possibility of a death in the home.

It is not an obligation of the health care team that they should ensure that patients who wish to be at home and to die at home are enabled to do so, for often it is not possible to meet the patient's care needs at home. Patients who are living alone but require 24-hour supervision cannot have 24-hour care provided within the NHS budget. In the UK, enabling the patient to go home is taken to entail ensuring that adequate care can be provided there. If not, then patients are free to discharge themselves home, but health care professionals are prevented by law from discharging them to their homes.

In those cases where the patient's care needs can be met within available resources, professionals have an obligation not to prevent the patient from going home - a hospital should not be used as a custodial institution at the request of relatives. Whilst the ability to be in one's home cannot be described as a health care need, there is a freedom to go to one's home, and a freedom to leave hospital. When the patient's care needs can be met by outside agencies at home these freedoms require that health care practitioners do not prevent the patient from going home. Instead, it is clear that they should co-operate with discharge according to the patient's wishes - even in the face of opposition from relatives.

The idea of not restricting the liberty of relatives to pursue their desires resembles the more recent use of the concept of respect for autonomy in health care ethics. This concept has now come to mean respect for what a person wants, (as distinct from respect for a person's considered decision which has

been taken with regard to the interests of others and which in Kant's language could be universalised). It is likely that, given this current concept of respect for autonomy, health care practitioners may consider that respect for the relatives' autonomy entails enabling them to achieve their wants, or at least not preventing them from doing so. But autonomy is self-rule, it relates to the conduct of the individual's own life, not that of another. So respecting the autonomy of relatives entails permitting them to make choices regarding the conduct of their own lives. It does not entail respecting their choices about the conduct of the patient's life.

Raphael notes that the liberty of others to pursue their own desires should not be impeded provided there is no other moral issue. In the health care context, this means that one should respect the relatives' autonomy provided that there is no other moral issue - but there is usually another pressing moral issue, that of the welfare of the patient. Respecting the autonomy of one person cannot entail assisting that person to attain a goal which is harmful to another person to whom one has a special duty, such as the duty of health care professionals towards the health of their patients.

2.1.iv The obligation of veracity to relatives.

Although relatives sometimes request that patients be deliberately deceived, it seems very rare for patients themselves to request that health care practitioners deceive their family about the illness. Occasionally, mothers who are ill request that news about a grave illness be kept temporarily from their children during particularly stressful periods, such as examinations. Sometimes middle-aged patients who are seriously ill want to withhold information about the gravity of the situation from their elderly parents. The rarity of requests by patients to deceive their relatives suggests that patients themselves recognise the general obligation of veracity which health care professionals owe to the families of patients. (Perhaps it is surprising that relatives of patients frequently

do not recognise the obligation of veracity which health care professionals owe to patients).

When health care professionals divulge information to relatives about the patient's illness (with the patient's consent) they seem to be very truthful. This may not be because of consciousness of an obligation of veracity, but may simply be because they have no motive to be otherwise. In the case of children or other very vulnerable groups, such as slightly confused elderly relatives, they may give information cautiously and in stages, but I cannot recall an occasion where professionals deceived relatives.

The obligation of veracity to relatives does not entail an obligation to divulge information to the relatives about the patient's illness. It requires professionals to be truthful in such disclosure, but it does not bind them to divulge confidential information about the patient's illness.

Professional codes and the law regarding confidentiality of patient information are clear. Practitioners seem to accept (in theory) that whenever the patient is competent to consent to or refuse the disclosure of information about the illness to others there is an obligation on professionals to seek consent to disclosure. Despite these clear rules the issue of how much information the family of the patient should be given is perceived as a common problem in clinical practice. In fact it frequently happens that the patient's family is given information without the consent of the competent patient, so that family members often have more information than the patient! There are several reasons for this.

Firstly, some members of the public and a few professionals believe that family members, especially next of kin, are legally and morally entitled to information about the patient's illness whether or not the patient consents to such disclosure. Whilst the state of the law is a matter of verifiable fact, the moral issue of the family's entitlement to information is more complex. There are a few circumstances where it is justifiable for health care professionals to

divulge information to relatives without the competent patient's consent, but it will be seen that in those cases the justifications rest on ideas of non-maleficence rather than veracity.

The example of relatives caring for an HIV positive patient is often discussed, but in this situation it is very rare for patients not to disclose their HIV status. If they did not, the significant risk of serious harm to a relative who was providing intimate care would justify divulging to the relative the information about the risk of infection. The justification for a breach of confidentiality in this case is the significant risk of serious harm to the relative. This justification rests more on the general obligation of non-maleficence than on the obligation of veracity.

Sometimes it is thought that sharing the information with the family may be essential in order for them to provide safe care for the patient, for example if the latter is an unstable diabetic. In this situation it is also very uncommon for patients to withhold consent to divulging the important facts. If the patient was at significant risk of serious harm because the relatives were ignorant of important facts regarding the illness, then the health care professionals would have an obligation to divulge the necessary information to the relatives. This breach of confidentiality is justified more by the promissory relationship of health care and the obligation to prevent harm to the patient, than by any obligation of veracity to the relatives.

It is the case that breaches of confidentiality by divulging information to relatives are justified by an obligation to prevent a significant risk of serious harm to someone.

Whilst family members often think that a breach of confidentiality is justified by some obligation of health care professionals to divulge information to them, it is clear in law and professional codes that there is no such obligation, nor could one be derived from the obligation of veracity.

Secondly, it is sometimes judged that an obligation to benefit the relatives, by divulging information without the competent patient's consent, outweighs the obligation of confidentiality. This possible justification is discussed in the section below on an obligation of beneficence towards relatives.

Thirdly, when patients are incompetent, and health care professionals are charged with the responsibility of making a 'best interests' judgement regarding the patient's treatment, then it is necessary for them to ask the relatives what the patient's wishes in the circumstances might have been. A best interests judgement is based on outcome in a medical sense plus what can be known of the patient's wishes. Clearly, where practitioners are required to make best interests judgements for incompetent patients, then they have an obligation to describe the patient's current circumstances to the relatives in order for those relatives to explain what they think the patient's wishes in the current circumstances might have been. This process inevitably entails divulging information about the illness. The justification for divulging such information in this case, and the basis for the obligation to do so, is the benefit of the patient. It is not a 'free-standing' obligation to relatives of incompetent patients, but derives solely from the obligation to the patient.

Fourthly, professionals may divulge information to relatives without the competent patient's consent because this is the easiest course of action for a variety of reasons. Seeking consent from the patient takes time, and requires explanations to the family that such consent must be sought. Family members may then think that the patient's interests are being placed above their own (which of course they are) and they may not be pleased by this. Refusing to divulge information without patient consent basically entails opposing the relatives' wishes, and opposing people's wishes means that one may have to confront their anger/frustration/distress which is unpleasant or uncomfortable.

So it is easier for the professional to breach confidentiality. The fact that this is done does not mean that professionals believe they ought to do so.

2.1.v The obligation of non-maleficence to relatives.

Health care professionals have an obligation not to harm relatives. This is the same obligation that all members of the community have to each other. There are not many circumstances where the treatment of a patient could be said to harm the family, but there are some circumstances where the treatment of the patient could prevent harm to the family members.

In the latter case conflicts of interest do not arise - professionals have an obligation to treat the patient and by so doing they protect the relatives from harm. Two examples illustrate this clinical situation.

Patients who are mentally ill (violent or demented) may become a danger, not just to themselves but also to those around them. In such a case it is considered morally obligatory to treat the patient, even against his or her will, and the law makes provision for this. The grounds for the obligation to treat the patient are both the obligation to benefit the patient and the obligation to prevent harm to the family.

Occasionally competent patients at home request that their family lift them bodily, rather than using a hoist. In this situation health care practitioners have an obligation to prevent harm to the relatives, and they therefore inform both relatives and patient of the dangers involved (to both parties) in not following safe lifting procedures.

It is very difficult to imagine realistic examples where treating the patient, in the context of general health care, could give rise to a harm to the relatives. It might be argued where a patient is seriously ill, and life-prolonging measures may result in him surviving in a very disabled condition, and requiring care from the family, that the survival of the patient constitutes a harm to the family. Patients who are very ill (for example, after a severe stroke) are frequently

incompetent to make decisions. Decision-making responsibility then lies with the health care professionals, whose codes of conduct, backed up by the law, indicate that they should act in the patient's best interests, not the best interests of the family. Professionals working in general health care do seem to follow these codes and the law.

For example, during cardiopulmonary resuscitation, it is the patient's condition and prognosis which determines the actions of the resuscitation team, not the fact of whether the family might suffer harm if the patient survives! When patients have had a severe stroke, if their condition is stable but they cannot eat and drink, they are now fed and hydrated via nasogastric or gastrostomy tube because many of them will improve considerably. Feeding and hydration are not withheld if the family consider that the patient's continued existence is likely to be harmful to them.

Even if one considers that one's life would be more pleasant, and some of the factors which are harmful to oneself could be removed if a sick relative died, it would clearly be wrong for health care professionals to use such a factor in making treatment decisions for a patient. In general health care it is acknowledged that any suggested obligation to remove or prevent harm (entailed in the patient's continued existence) from relatives could never justify a decision to withhold life-prolonging treatment from a patient. The British Medical Association's guidance on withholding and withdrawing Life Prolonging Treatment, published in 1999,²³ does not include the prevention of harm to the relatives as a justification for allowing the patient to die!

Although treatment decisions rarely cause harm to the relatives of patients, decisions regarding the place of care of the patient - where he or she should live - can have a major impact on the mental and physical well-being of the relative. Sometimes relatives may consider that it would be harmful to them if the patient with moderate care needs were to return home from hospital or residential care. This situation commonly arises where the patient is physically

or mentally disabled, or both, and requires care and/or supervision from the relative. Such care is often physically or mentally burdensome to the relative, who is often elderly. There may then be a significant risk to the relative of the serious harm of mental and physical exhaustion. If the patient is competent, then he or she should make a decision, together with the relative, about the most appropriate place of care, taking into account the interests of both. If the patient is incompetent, then health care professionals (mainly social workers), will usually be involved in deciding, together with the relatives, where the patient should live. This decision does pose moral difficulties for all concerned.

One of the problems is that, strictly speaking, *where* the patient should receive the necessary care is not a 'treatment' or 'health care' decision, assuming that the required care could be provided either at home with outside assistance or in residential care. Such a decision is really a matter for patient and family together, provided that they are funding the care themselves. Apart from providing advice and information, health care professionals would not take or bear responsibility for such a decision.

However, if governmental agencies supported by taxation will be required to pay the greater cost of residential care, then clearly social workers, as agents of the government, must be involved in the decision. They are responsible for allocating the budget available to fund residential care, and must ensure that this limited budget is used to obtain maximum benefit, and that such benefit is distributed justly. In this situation social workers often have conflicting obligations.

The following example is common in clinical practice and does pose genuine problems. A mildly demented patient would be happier at home in familiar surroundings, but the frail elderly relative might find the care of this patient mentally and physically exhausting and therefore harmful. Assuming that this couple have little money and only a limited amount of help is available at home, care at home will mean considerable and continuing input from the

relative. But care at home is much cheaper than residential care for the state because the relative is not 'paid' much via state benefits for looking after the patient. The social worker's budget for residential care is too small to fund every patient who would ideally be in residential care.

The social worker has conflicting obligations; an obligation to prevent harm to the relative, an obligation to benefit and prevent harm to the patient (both as a general and as a special promissory obligation) and obligations to make the best and fairest use of scarce state funds. The social worker has to make a judgement about which obligation is the most pressing in the circumstances, and also about the balance of good to harm achieved for both patient and relative. The patient is likely to be incompetent to make such a complex decision, but may well be able to express a simple preference, usually for being at home! The patient is the subject of a special relationship to the social worker, who in this case is functioning partly as an advocate for the patient.

In this situation there is no clear rule which can be applied to decide whether the social worker should place and fund the patient in residential care. This decision will depend upon the patient's care needs, the relative's ability to meet those needs without exhaustion, and the competing needs of other patients for state funded residential care.

There is also a complex interaction between the well-being of the patient and that of the relative. For example, an exhausted relative is less able to give adequate care to the patient. On the other hand, if the patient is unsettled in residential care the relative may feel guilty or distressed. A patient who feels secure in the environment of his home may be less agitated and distressed and may require less medication than when in an unfamiliar institutional environment. But if the patient is at home, with only a single carer day and night, then night sedation for the patient may be essential if the relative is to be able to sustain supervision and care.

It must be noted that this scenario is not really about 'treatment', but it is about where mentally infirm patients should receive the health care benefit of treatment and continuing care and supervision. Health care professionals, especially social workers, will take part of the responsibility for such decisions for incompetent patients (their relatives will share responsibility, for they must decide what they are willing and/or able to do for the patient).

There will be some circumstances where the risk of mental and physical exhaustion to the relative outweighs a risk of harm to the patient arising from residential care. The latter risk is small, and is probably confined to the requirement for sedation initially because of disorientation and agitation. The risk to the relative from exhaustion may also outweigh the patient's preference for being at home (where the patient is moderately demented and so not competent to make a considered decision). If the patient is incompetent to make the decision regarding place of care, then care needs are likely to be much greater, and to constitute a real risk of exhaustion for the relative.

At other times, where dementia is mild and the patient is able to bear in mind the welfare of the relative in making a choice regarding place of care, and where care needs at home are very limited, then clearly placement in residential care against the wishes of the patient could not be justified. This is because the patient is largely competent to decide to remain in his own home, and also because the care needs of the patient are small.

As the population ages and the incidence of dementia rises this problem will become increasingly common. Health care practitioners will have to make judgements in each case regarding competing obligations to patients and relatives, and will have to make a just use of state funds. Unfortunately, owing to the scarcity of state funding for residential care, some patients will remain at home when the ideal solution from a moral perspective is residential care. Their relatives may be harmed by exhaustion.

2.1.vi The obligation of beneficence to relatives.

The general obligation of beneficence, which we owe to people to whom we do not stand in a special relationship, might require health care professionals to benefit the relatives. As has been argued above, this general obligation could not override the special obligations owed to patients, and so benefits to relatives could not be pursued if this resulted in compromised care for patients.

Health care professionals might benefit relatives in four ways, which may or may not be morally justifiable. Firstly, they might give them information about the patient's illness. Secondly, they might offer 'counselling' or other emotional care to the relatives. Thirdly, they might assist relatives to achieve the relatives' goals in respect of the patient's treatment. Fourthly, they might assist relatives to achieve other life goals not related to the patient's care.

With respect to benefiting the relatives by divulging information about the patient's illness it was clear from the preceding discussion [2.1.iv] that there is no such obligation unless there is a significant risk of serious harm to either the patient or relative. It was also clear that when health care professionals are obliged to make best interests judgements regarding treatment for incompetent patients, and so divulge information, the justification for so doing is the obligation to benefit the patient, not an obligation to provide information for the benefit of relatives.

With regard to giving counselling or some other form of emotional care to relatives, conflicts almost inevitably arise between obligations to the patient and possible obligations to relatives. Two factors are very important in judging which obligation should override the other.

Firstly, it should be noted that 'counselling' normally entails giving explanations and answering questions about the nature of the illness, its likely progress and prognosis, and the patient's care needs in the future, all of which is information confidential to the patient. Health care professionals have a

natural desire to assist and please the relatives by answering their questions, and it can be difficult for them to remember their obligations in respect of patient confidentiality. In this context it is clear that counselling the relatives is not possible without the consent of the competent patient. If the patient is incompetent, then health care professionals have to consider whether divulging the information would benefit the patient, and whether the patient would have wished the information to be shared with family members.

Secondly, emotional care and counselling require time, and since professional time is often the most scarce and valuable health care resource it must be apportioned justly. It is widely recognised that the illness of a loved one is traumatic, and health care professionals therefore feel obliged to try to support relatives by giving the latter time to air their feelings and obtain realistic reassurance, thereby assuaging to some extent the relatives' distress. But there must be limits to this obligation, for the time required is necessarily taken from the time provided for the care of patients because health care teams are not provided with resources of time to care for relatives.

Clearly, relatives who are less distressed are more able to be supportive to the patient, and to care for the patient. But this factor cannot justify time given to the relatives at the expense of time essential for adequate care of the patient. The obligation to benefit patients overrides the obligation to relatives. The problem for health care professionals is not the moral judgement here - they are very likely to consider that their primary obligation is to the patient - instead it is the fact that the relatives are usually far more assertive than the patients in requesting the time of practitioners, so it is much easier to give in to the relatives' demands at the expense of patient welfare.

Moreover, health care practitioners have fears regarding litigation, and such litigation is frequently instigated by relatives of patients. So professionals may consider that there is a moral obligation to spend time with relatives in order to reduce the possibility of distress and financial cost to the health service

resulting from litigation. Since the financial cost of litigation to the UK NHS is now considerable, and consumes a significant proportion of the resources gathered for patient care, then perhaps there is an obligation to try to avoid or forestall litigation. But surely this obligation should not override that to provide direct patient care.

It might be objected that the relatives may themselves be mentally ill, or verging on mental illness. If this is the case, then they are patients in their own right. Care should be provided for them from the appropriate source, usually the primary care team or perhaps the psychiatric service. There is a risk in this situation that the team caring for the original patient find themselves devoting most of their time to the disturbed relative, so that patients lose out on the care they can reasonably expect. The benefit to the relative does not justify the harm to the patient. The solution to the relative's problems should be sought from the appropriate health care team, who then have a promissory relationship to the relative.

With regard to any possible obligation of health care professionals to benefit relatives by treating patients according to the relatives' interests, it is clear from the preceding discussions that a general obligation to benefit relatives could not override the promissory relationship of practitioner to patient plus the general obligation not to harm patients. One might try to imagine situations where the benefit to the relatives of complying with their wishes might be so great as to outweigh the special obligation to the patients.

It might be argued that where a patient is incompetent, and relatives wish the health care team to institute a treatment which the team considers to be of no benefit to the patient, it is just possible that administering the treatment might be justified if the harms to the patient are so small as to be almost negligible, and if the resource consequences are so small that there will be no appreciable opportunity cost to other patients. In this situation it is undoubtedly easier to give the treatment, thus pleasing the relatives, and it may be justifiable

on the grounds that no harm is done to the patient or to other patients, and perhaps a costly complaint or litigation may be avoided.

The problem with these justifications is that they may still not outweigh the obligation based on the promise to provide health care in the best interests of the patient. In UK law, and according to the BMA guidance, treatment given without the consent of the patient must be justified by an expected balance of benefit over harm. In this case, administration of the useless treatment cannot be justified because there is no benefit to the patient and there may be some harm.

It should be noted that the 'benefit' to the relatives of providing the treatment they want may be very small or non-existent. When the treatment is ineffective they still have to face the reality of the situation, and they may feel guilty for having been partly responsible for the administration of the ineffective treatment. This is particularly likely if the treatment has associated harms, such as chemotherapy or side-effects like diarrhoea or nausea from antibiotics.

In some circumstances the benefits of a treatment to a patient, for example antibiotics, may be uncertain. In this case the views of the relatives regarding the patient's wishes are very important. If the balance of benefit to harms and risks is very unclear but there is a reasonable possibility of overall benefit, and the patient is not thought to have been opposed to the treatment, then clearly it is quite acceptable to provide the treatment. However, in these circumstances the justification for doing so is the best interests of the patient, not the benefit of the relatives.

It remains very difficult, if not impossible, to imagine a clinically realistic situation where it is justifiable to conclude that an obligation to benefit the relatives outweighs the obligations of the health care professionals towards the patient. It is therefore not surprising that professional codes and the law stipulate that health care professionals must make health care decisions only on the basis of the interests of patients.

2.2 Is the moral situation sufficiently different in palliative care from general health care to justify different obligations to relatives from those of general health care?

The philosophy of palliative care, in describing attainment of the best possible quality of life of the relatives as a goal, effectively establishes a promissory relationship between the health care practitioners and the patients' relatives. Once the quality of life of the relatives has been accepted as part of the remit of specialist practitioners in palliative care, and has been accepted publicly and professionally by them, then a specific obligation towards the relatives has been established. By accepting this philosophy and enacting it in clinical practice, practitioners implicitly and often explicitly promise to try to improve the quality of relatives' lives. By so doing they enter the moral realm of specific obligation - the special relationship between the agent who makes the promise and the beneficiary of that promise.

Not only have specialists in palliative care accepted this philosophy, but they have also advocated its adoption by all health care professionals in the context of palliative care. It has become known as part of 'the palliative care approach', and has been advocated as an essential part of the care of patients who are terminally ill. Indeed, it has been held up as an example of excellent care in context of terminal illness. But is it morally acceptable as a model of care, let alone morally preferable to the model of general health care where obligations to relatives are considered as limited to those of general obligation, as described in section 2.1.i.?

The establishment of a promissory relationship between practitioners and relatives in specialist palliative care requires justification, and such justification entails several steps. Firstly, it must be shown that there is some sort of benefit to relatives from the care promised. Secondly, that benefit should really be a health benefit in some way, otherwise health care funds are being

expended to attain a goal not related to health. At worst, this constitutes a misuse of public funds, at best it is a deception of the public regarding the use of taxes gathered to fund health care. Thirdly, the health benefit to relatives must be considerable, for it is resourced at the expense of some health benefit to patients, for an opportunity cost is attached to all health care. Fourthly, a promissory relationship between professionals and relatives should not compromise patient care, but rather should enhance it.

2.2.i Is there some sort of benefit to relatives from the care promised?

In trying to ascertain whether there is a benefit to relatives from the promissory relationship it is necessary to have some idea of what sort of benefit specialists in palliative care consider that the relatives might gain. Benefit is closely related to the concept of need. Specialists in palliative care speak of the 'needs' of family members. In so doing they are meaning both that there will be certain benefits for the family (and perhaps patient) if those needs are met, and also that there is a moral obligation to try to meet those needs. The use of the term 'need' in the context of health care implies a moral obligation on somebody to try to satisfy that need.

The suggested benefits of meeting those needs are that the relatives will be less distressed by the experience of the patient's illness and death, and will be less likely to suffer abnormal bereavement reactions, and will be better able to give love and care to the patient.

The relief of distress and prevention of abnormal and severe bereavement reactions are the most obvious benefits to relatives, and thus constitute goals for the specialist palliative care team. Attainment of such benefits is often referred to as satisfaction of a 'need'. The 'needs' of the patient's family members have been studied, and results are quoted by Mary Vachon in her chapter on the emotional care of patient, family and professional

in the Oxford Textbook of Palliative Medicine.²⁴ Where patients are at home family members have felt stressed, have perceived the patient's suffering as a personal discomfort, have had difficulty coping with the uncertainty about the course of the disease and have worried about their inability to provide care for the patient and to handle the patient's depression and anger.²⁵

Vachon accepts the results of a study by Hampe in 1975 which identified eight needs of family members of dying patients; to be with the dying person, to be helpful to the dying person, to receive assurance of the dying person's comfort, to be informed of the dying person's condition, to be informed of impending death, to ventilate emotions, and to receive comfort and support from family members and health care professionals.²⁶ Vachon comments that in this study only three of the needs were met in more than half the sample.

With reference to this (and other) studies, Ilora Finlay, concludes 'These studies suggest that the relatives have very specific needs related to the process of loss....'²⁷ She goes on to say that 'The family members each need information to make decisions about their future and to develop ways to cope and adjust to their loss'. Whilst she notes that this need for information may sometimes conflict with the patient's right to confidentiality, she does not suggest how health care professionals ought to act when this conflict of obligations occurs.

In a paper which questions the extent to which 'we' (presumably health care professionals) are achieving the WHO goals of palliative care, Gail Johnston and Charles Abraham state that 'Research to date indicates that carer's needs can be identified, but that they are often unmet'.²⁸ But what does meeting those needs mean, and is it always a proper goal for health care practitioners?

No-one could reasonably doubt that the close relatives of patients would find the experience of the loved one's illness and death very stressful and distressing. It is also normal to find uncertainty difficult to deal with, whether it

be with regard to one's own abilities to cope with a new major physical challenge or to cope with a new emotional situation. But do these normal reactions in some way indicate a 'need' - something which can be satisfied and which ought to be satisfied? What are the clinical implications of describing these emotions and anxieties as potentially 'unmet needs'? The use of this terminology suggests both that health care practitioners can somehow satisfy these needs, and secondly that they ought to do so.

But is it possible to 'meet' these needs? It is implausible to suggest that anything the health care practitioners could do would abolish the emotional distress. Indeed, it would be rather a sinister undertaking to try to abolish normal human anxieties and sadness surrounding the death of someone much loved. Perhaps meeting these needs means simply to diminish the distress, but if this is the case, and relatives still speak of their remaining distress, then have the health care professionals failed to 'meet' the relatives' needs?

Furthermore, it may often be impossible for practical reasons to meet some of the relatives' needs. For example, the health care practitioners are not in control of either the time of the patient's death or times that relatives choose to come and go, so they are hardly in a position to ensure that the relatives are present at death. Relatives can sit with patients for hours, but then the patient dies when they slip out for a shower or a meal break! Have the health care team then 'failed to meet the relatives' 'need'?

On those rare occasions when the patient has not wanted information about the illness divulged to relatives it is not possible to give relatives the information they apparently 'need' unless the professional codes of confidentiality are breached. In such circumstances practitioners ought not to divulge the information, so ought not to meet the relatives' needs. It is perhaps surprising that in discussing the giving of information to relatives the obligation of confidentiality to patients is not mentioned in the Oxford Textbook of Palliative Medicine, but this is not uncommon in texts on palliative care. Most

accounts of relatives' needs mention 'support' but do not describe what is meant by this. It must include information and reassurance, where possible. Since it will not always be possible to provide that information and truthful reassurance it is not always possible to 'meet' the need for support.

Even if it is possible to 'meet the needs' of relatives, it may not be just in terms of allocation of scarce resources. Johnston and Abraham note that 'Clearly, further investment is required in this area if this final WHO guideline is to be implemented across palliative care settings.'²⁹ The implication here is that more resources are required, and ought to be provided, to meet the various needs reported by relatives and written up in studies. If no more resources are available, as is usually the case, the implication is that resources provided for patient care should be used, thus potentially disadvantaging patients in order to 'meet relatives' needs'.

It is interesting that the relevant WHO guideline is not itself questioned in this paper. The guideline states that palliative care 'Offers a support system to help the family cope during the patient's illness and their own bereavement'. It would be possible to spell out exactly what giving support entails, the ethical limits (such as patient confidentiality) to that support, the practical limits, and the limits imposed by a just allocation of scarce resources. Yet no attempt is made to consider such moral limits.

Ilora Finlay concludes that resources should be allocated for the care of relatives in the context of palliative care. She argues 'The allocation of health care resources must take account of situations, such as intensive care and palliative care, where demand by relatives is high because it reflects an underlying need.... When difficult decisions are taken, the continuing care of the patient must also encompass continuing professional care of the close relative..... Time spent with relatives is not assessed in estimates of workload, yet the needs of families as secondary patients must be recognised in resource allocation.'³⁰

Three points arise from her conclusions. Firstly, since she admits that resources are not allocated for the care of relatives, it follows that if that care is given then resources provided for patient care will be expended on relatives and lost to patients. Secondly, the use of the term 'secondary patients' definitely implies that she is committed to the idea that the promissory relationship of professional to patient should also exist between professionals and the relatives of patients. Thirdly, she admits that relatives 'demand' care from professionals, she claims that they do this because of an underlying 'need', and she concludes that because of this need resources *must* be provided. But it does not follow that because a need, (in the sense of something which would benefit relatives if it were satisfied), is shown, that the need should be satisfied. For it is not possible to satisfy all needs within available health care resources. This paper illustrates the problems of asserting that simply because something has been declared a 'need' it ought to be satisfied.

It is important to consider the type of benefit that has been described by following the WHO philosophy in the context of specialist palliative care. Johnston and Abraham comment that when patients have been cared for within a hospice programme, the relatives received the following benefits; decreased feelings of guilt, dependency, loss of control, despair, numbness, shock, and disbelief.³¹

Whilst it initially seems to be a good thing that these distressing emotions were experienced less, one must ask what the cost of achieving these benefits was in terms of patient care. One must also ask to what extent it is desirable for health care professionals to try to diminish the normal emotional pattern, albeit distressing, of grief in bereavement.

The perception that the patient had 'a good death' is considered by Johnston & Abraham to lessen the relatives' distress and so benefit them. However, these authors point out that it has been shown that patients and relatives may differ in the factors considered important for a good death, so that

patients and their relatives may have different agendas or goals for the last phase of the illness.³² This poses problems for health care professionals, for if they wish to pursue the relatives' agenda in order to alleviate their distress, then factors important to patients may be overridden, or worse still, completely ignored.

Whilst it may seem improbable that health care professionals could knowingly fail to consider the patient's wishes and interests, unfortunately this situation does occur. Indeed, in the Oxford Textbook of Palliative Medicine, in the chapter on domiciliary care, Dr Derek Doyle discusses 'treating the patient for the sake of the relatives'. In this section he considers that doing what is in the interests of the relatives (rather than the patient) may be justified, and in one example he completely fails to mention the factor of the interests of the patient.³³

In the example given he states that if a patient develops status epilepticus as a result of cerebral metastases from a recently diagnosed bronchogenic carcinoma, then it is justifiable to commence high doses of dexamethasone 'so that in the following weeks as the doses are gradually reduced, the family may enjoy the patient's final days with him'. In his example Dr Doyle omits to mention any consideration of the patient's interests. Instead, he advocates striving for a temporary improvement in the patient's condition (hopefully with a return to consciousness), followed by a slow decline, with the *sole aim* of giving the relatives time to come to terms with the patient's death. Clearly, a very temporary revival in an uncertain state of consciousness, followed by a steady decline as practitioners reduce the steroid dose, may not be a benefit to the patient at all! One might argue that the patient's dying is protracted for the sake of the relatives.

The presence of the above example in such a prestigious textbook illustrates the important clinical implications of considering that there is a promissory relationship between the health care professional and the patient's

family. The results of considering the relatives as 'secondary patients' are clear. The patient's goals, which may be different from those of the relatives, may be completely ignored in favour of the relatives' goals. Whilst there is not a promissory relationship between health care professionals and the patient's family, unfortunately palliative care effectively establishes a fictitious promissory relationship by including as a goal of such care the improvement of quality of life for relatives.

It is possible to argue that the fiction that there is a promissory relationship between health care practitioners and the relatives of patients may diminish the relatives' distress, although it could not abolish it completely. In particular, the relatives may benefit if their interests are pursued even when they conflict with those of the patient. On the other hand, it is equally possible that relatives may feel guilt in bereavement if they judge that the patient suffered in some way because of the pursuit of their own interests. In such cases their overall distress will not be diminished and may even be increased. So it cannot be concluded that establishment of a promissory relationship between health care professionals and the patient's family will inevitably decrease the relatives' distress.

It must be noted that giving information and realistic reassurance (within the constraints of confidentiality) to relatives who are helping to care for the patient will very often assist the family to continue to provide effective care. Indeed, there are occasions when such explanation and encouragement may enable relatives to continue to care for a patient at home, so achieving the patient's goal of avoiding institutional care. The point is made by Robert Twycross and Ivan Lichter that 'Much of the support that the dying person needs can be given only by the family. Their love and attention are of paramount importance to the well-being and psychological comfort of the dying patient'.³⁴ They go on to say that 'They in turn need support at this critical time, and should have easy access to those providing care for the patient'. The

problem with this latter conclusion is that easy access for relatives to those providing care for the patient can sometimes mean that care for the patient necessarily suffers!

Clearly, a sense of balance is required by health care professionals. Giving time to relatives to provide explanations and realistic reassurance is likely to diminish relatives' distress and at the same time enable them to continue to give love and attention to the patient. However, excessive amounts of time devoted to the relatives are likely to have a detrimental effect on patient care. It is also possible that spending a great deal of time with the relatives may not achieve much extra benefit for them in terms of relief of distress or avoidance of severe bereavement reactions. Furthermore, pursuing the relatives' interests at the expense of the patient's interests may later result in feelings of guilt on behalf of the relatives, exacerbating their distress.

2.2.ii Is the benefit to relatives a health-related benefit?

Alleviation of emotional distress and avoidance of abnormal bereavement reactions are health-related benefits, since they are both likely to lessen physical and psychiatric morbidity. However, the fictitious promissory relationship established between relatives and practitioners by the palliative care philosophy entails that the practitioners strive to achieve goals not related to health for relatives. Indeed, the practitioners are bound by that philosophy to try to achieve for the family 'the best possible quality of life'. This might entail suggesting that they plan a holiday, or make alternative career plans, or take any number of measures which could enhance their lives.

It seems totally unreasonable to suggest that health care practitioners should have an obligation (via a promissory relationship) to pursue non-health goals for the relatives of their patients, especially as many of these goals could conflict with the interests of the patients. Moreover, using community health care resources to pursue non-health-related goals of relatives does seem a

misuse of these scarce resources which were collected specifically for the care of the sick.

2.2.iii Is the health related benefit to relatives sufficient to justify the expenditure of resources?

It is impossible to answer this question in the absence of research comparing the benefit to relatives with the benefits patients could receive if those resources were devoted instead to patient care. What is interesting is that within the field of palliative care there seems no interest in pursuing such research. In the context of scarce resources, where evidence of benefit is increasingly required in order to secure funding for services, it is surprising that such studies have not been done. Perhaps it is because health authorities allocating resources are assuming that they are expended on patient care, rather than on the care of relatives.

At a very simple level it would be interesting to measure the time spent with relatives, and to work out how many more patients the specialist team could care for if varying proportions of that time were used for patient care. Obviously a comparison of the benefit to relatives and to patients would have to be conducted and considered in parallel.

This work may not have been undertaken because a considerable proportion of the funding for specialist palliative care services (more than 50% in many areas) actually comes from charitable sources, not the NHS. Where palliative care services are not under NHS management the benefit derived from resources may be less closely scrutinised, and charitable trusts are able to use their funds in whatever way they consider best.

In the absence of evidence it is impossible to make a judgement about whether the health-related benefits to relatives could justify the expenditure of resources which are withdrawn from patient care. However, since it is clear that time spent with relatives is lost to patient care it seems reasonable to argue that

excessive time should not be spent with relatives. The resource of time must be rationed between relatives and patients.

It may be objected that health care professionals in the course of their clinical work already ration the resource of time between patients, even though they have a promissory relationship and associated obligations to each patient. The rationing process entails an obligation to distribute benefit justly, as well as to maximise benefit. This raises the question of whether giving benefit to relatives instead of patients represents a fair distribution of resources. It can and should be argued that patients have a prior claim to health care resources over relatives. So where time is scarce, priority should be given to patients. This is not to say that absolutely no time should be given to relatives, but only that patients ought not to be deprived of care essential for their comfort in order to benefit relatives.

2.3 What should be the basis of decisions when professionals perceive a conflict between their obligations to the patient and to the relatives?

I have concluded from the above discussion that obligations to relatives should be those of general incidence, and not those of a promissory relationship. Since obligations to patients are those of a promissory relationship (plus those of general incidence) then they will normally override obligations to relatives if there is a conflict between the two.

I am not suggesting that the professional's attitude or behaviour towards relatives should be inhumane, but only that they must balance carefully their obligations to both parties, and constantly be aware of the moral requirement to consider which is the most pressing duty.

Clearly, members of the health care team will need to weigh up the nature, magnitude and likelihood of the benefit (or the avoidance of harm) to

relatives, against the nature, magnitude and likelihood of the benefit (or avoidance of harm) to the patients, bearing in mind that the special relationship of promising pertains in their bond with the patient, and is absent from their links to the relative. The concepts of a bond to the patient but a link to the relatives might be useful as a way of using language to remind the professionals of the difference in their relationship between the two.

It is possible to argue that a benefit to relatives could be so large as to outweigh a very minor harm or forfeit of a small benefit to the patient. Health care professionals may use this argument to try to justify pursuing the interests of the assertive relatives at the expense of the often vulnerable and unassertive patient. But even if the harm to the patient is considered small it cannot be justified by a benefit to the relatives because of the overriding obligations of the promissory relationship to the patient and lack of similar obligation to the relatives. If health care professionals, following careful consideration, decide that what the relatives seek would constitute any sort of harm to the patient, then they should not accede to the relatives' wishes.

2.4. What, if anything, should the philosophy of palliative care say about obligations to relatives of patients?

Whilst it may be best to say nothing about our obligations to relatives, the idea that their well-being is part of the specialist's remit is so entrenched that it is very unlikely that a new philosophy statement without any such mention would be accepted. Granted this situation, then the statement about any obligation to relatives must be explicit about the nature of the obligation and its limits.

It would be possible to state that relatives should be given information and explanation about the illness within the constraints of confidentiality to patients, that they should be given realistic reassurance, encouragement and

advice when they are participating in the patient's care, and that such support should be given with due regard to the time required and the opportunity cost to patients. Furthermore, when patients are incompetent the relatives should be asked what they think the patient would have wanted, and if possible, their agreement should be reached with the treatment plan, but the patient's interests should not be significantly compromised in order to reach such agreement.

Many specialists in palliative care would not want to accept the above statement, preferring to extend a promissory relationship to relatives, as is illustrated by referring to them as 'secondary patients'. Within clinical contexts of health care in general, but particularly in specialist palliative care, assumptions regarding this topic are being accepted without question, despite absence of mention in professional codes of conduct. A discussion at undergraduate and postgraduate levels about professional obligations to relatives is long overdue.

2.5 Conclusions.

1. Whereas a special relationship, founded on an implicit promise and associated with specific obligations, exists between professionals and patients, there is no special relationship, and no implicit promise, between professionals and the relatives of patients.
2. Improvement in the quality of life of relatives of patients is not an intrinsic aim of palliative care.
3. Pursuing the relatives' interests at the expense of the patient's health interests cannot be justified, even in the palliative care setting.

4. Patients should not be deprived of the care essential for their comfort in order to devote time to relatives. Achieving a benefit for the relatives cannot justify inflicting a harm on the patient.

5. The philosophy of palliative care should not state that the aim is to achieve the best possible quality of life for the relatives of patients.

References to Chapter 2

¹ British Medical Association. *Withholding and Withdrawing Life-prolonging Medical Treatment*. London: BMJ Books 1999. pp. 21-57.

² Beauchamp T, Childress J. *Principles of Biomedical Ethics*. New York: Oxford University Press, 1994.

³ Ross W. D, *The Right and the Good*. Oxford: Oxford University Press, 1930.

⁴ as 3, p. 21.

⁵ as 3, p. 41.

⁶ as 3, p. 39.

⁷ as 3, p. 22.

⁸ as 3, p. 38.

⁹ as 3, p. 29.

¹⁰ as 3, p. 18.

¹¹ as 3, p. 30.

¹² as 3, p. 32.

¹³ Raphael D. *Moral Judgement*. London: George Allen and Unwin Ltd. 1955.

¹⁴ as 13, p. 115.

¹⁵ as 13, p. 120.

¹⁶ as 13, p. 122.

¹⁷ as 13, p. 125.

¹⁸ as 13, p. 111.

¹⁹ as 13, p. 112.

²⁰ Franks P. J. et al, The level of need for palliative care: a systematic review of the literature. *Palliative Medicine* 2000; 14: 98.

²¹ Lewis F. M, Deal L. W, Balancing our lives: A study of married couples' experience with breast cancer recurrence. *Oncology Nursing Forum* 1995; 22 (6): 943-53.

²² Almond S, A lesson to be learnt, A word out of place. *BMJ* 1999; 319:1105

²³ British Medical Association. *Withholding and Withdrawing Life-prolonging Medical Treatment*. London: BMJ Books, 1999.

²⁴ Vachon M. Emotional Care of the patient, family and professional. *Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press 1993, p. 592.

²⁵ Hinds C. The needs of families who are caring for patients at home: are we meeting them? *Journal of Advanced Nursing*, 1985; 10: 575-81

²⁶ Hampe S. O. Needs of the grieving spouse in a hospital setting. *Nursing Research*, 1975; 24: 113-19.

²⁷ Finlay I. Families as secondary patients. *Palliative Care Today*. Vol VIII, no III 1999.

²⁸ Johnston G, Abraham C. The WHO objectives for palliative care: to what extent are we achieving them? *Palliative Medicine* 1995; 9: 130.

²⁹ as 27.

³⁰ Finlay I. Families as secondary patients. *Palliative Care Today*. Vol VIII, no III 1999.

³¹ as 27.

³² Higginson I. The support team assessment schedule (Thesis). London: University of London, 1992.

³³ Doyle D. Domiciliary Care. *Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press 1993, p. 645.

³⁴ Twycross R, Lichter I. The terminal phase. *Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press. 1993 p. 652.

Chapter 3

Quality of Life

Thesis 3: that quality of life as a global concept should not be used.

Introduction.

The concept of quality of life is central to the philosophy of palliative care. The WHO definition cites the quality of life of patients and their families as *the goal* of such care. If health care professionals, patients, their families and the community are to have some shared understanding of the philosophy and aims of palliative care, then a clear and shared concept of 'quality of life' is essential. The first question is whether such a clear and shared concept exists now or could be developed.

The achievement of explicit goals is the measure of success of a health care service or treatment. When decisions regarding either the funding of services and treatments or the appropriateness of treatments for individual patients are made, the evidence regarding success of those services and treatments must be considered. If the success of palliative care services or palliative treatments in achieving their explicit goal is to be assessed, then it must be possible to assess whether the best quality of life has been achieved for the patient and family. The second question is whether it is possible to assess quality of life, and in particular to measure it.

Since the goal of palliative care is achievement of 'the best possible' quality of life, success depends upon achieving a better quality of life than conventional services and alternative treatments. Thus in order to assess success it must be possible to compare the outcome, in terms of quality of life, of palliative care services and treatments with the outcome of conventional

services and alternative treatments. Quality of life studies then appear essential for the function of resource allocation. It has also been suggested that quality of life data might improve decision making for individual patients. The third question is how quality of life data are currently used and whether it successfully fulfils those functions, together with consideration of whether qualitative information would also fulfil those functions.

If, following discussion, the thesis that quality of life as a global concept should not be used is accepted, then a fourth question is posed - what should be the goal or goals of palliative care? We have, then, four questions, and they will be discussed in order.

3.1 Is there a clear and shared concept of quality of life, and if not, could such a concept be developed?

3.1.i The context of quality of life.

At the outset it should be noted that the concept of quality of life makes sense only in the context of human mortality, and our acceptance of that mortality. R. S. Downie comments that 'whatever its quality, human life by its very nature is a transient affair. Indeed, it can be argued that what makes the very idea of quality possible, is that death comes to us all in the end; death supplies the framework or the parameters within which we can talk of value and quality'.¹ Campbell et al comment that 'A longing for some form of human immortality is a longing for more of the same: a longing for a prolonged earthly life, which itself has profound limitations. Once we acknowledge and accept our finitude, we can devote our attention to living well and establishing important priorities for the time that remains to us as mortal and finite human beings.'²

Awareness of mortality is heightened in the context of a terminal illness, and it is perhaps this inescapable and inevitable link between the fact of mortality and ideas of 'living well' that contributes to the importance placed on

quality of life for patients and their families in palliative care. When it is clear that little life remains, and loss of opportunity now cannot be compensated by future actions, patients and all around them become focused on achieving the ideal of the best possible quality for the remaining life.

3.1.ii The use of the term.

The term 'quality of life' has become part of the English language, and is now commonly used both within health care and also in daily life. The ways in which the term is used lead to conclusions regarding what it might mean. In the context of health care, it is often used to mean 'health-related quality of life'. This is the sense in which it was used when unpleasant life-prolonging treatments first became available for illnesses such as cancer - one often heard patients and health care professionals say that in the context of a terminal illness it is 'quality of life that matters, not quantity'. Similarly, some authors have noted that the most appropriate aim for health care is 'not to add years to life, but life to years'.³ Such statements arose from the realisation that prolonging a life characterised by pain and other symptoms, plus perhaps disability and dependency, without hope of restoration of health, might not constitute an overall benefit to the patient.

In contrast the term quality of life is also used more broadly outside the context of illness and in this sense applies to various characteristics of life as people perceive it. For example, people may speak of the quality of life in inner cities as compared with a rural environment, or of differences in quality of life of people living in different cultures or with differing incomes. It is in this broader sense that the term is discussed by Professor Storrs McCall in the Oxford Companion to Philosophy⁴ where the following three alternative meanings are described. Firstly, it may be defined in terms of social indicators such as nutrition, educational services, health care, crime rates etc. but it is noted that it is very difficult to rank or weight each factor in importance. Secondly, it may be

defined as a subjective measure of perceived satisfaction or dissatisfaction, summed over the members of the population. Thirdly, it may be defined as perceived happiness or availability of the requirements for happiness.

In the following discussion 'health-related quality of life' and the broader interpretations of the term are described separately, although there is of course a degree of overlap of factors which are considered important or relevant to each.

3.1.iii Health-related quality of life.

Since disease and subsequent health care have major effects on physical and mental functioning, but disease and health care are not the only factors which affect the many possible components of quality of life, it seems reasonable to assume that those providing health care should concentrate only on 'health-related quality of life'.

This assumption is based on two premises. Firstly, whatever health care is provided, the patient's (and family's) overall quality of life is outside the control of the health care team, and so that team cannot take responsibility for it. It may be argued that many of the factors of quality of life in the broader sense, such as satisfaction in employment or relationships, are not determined by health, which is neither necessary nor sufficient for their achievement. These factors are outside the remit of health care. Secondly, it may be argued that those providing and funding health care should recognise the responsibility of patients and their families for their own quality of life, and should respect their privacy in governing their own lives. Thus those involved in health care should not endeavour to interfere in those factors related to overall quality of life which are not directly determined by or strongly influenced by health.

This position is controversial, and further discussion arises in chapter 4 in relation to psycho-social care, and chapter 2 with regard to care of the relatives. However, it is a justifiable position in a cash-limited health service

funded by taxation. Moreover, it may be easier to describe the narrower concept of health-related quality of life, and perhaps to assess or measure it, rather than to achieve the same for the broader concept.

Ann Bowling, a medical sociologist, in her book 'Measuring Health, A review of quality of life measurement scales' on quality of life measurement scales, acknowledges that the conceptualisation and measurement of the outcomes or consequences of health care are controversial. However, she states that 'There is now a recognition that meaningful measures of health-related quality of life should be used to evaluate health care interventions'.⁵ Her book is about the measurement of health-related quality of life as the outcome of health care.

She further states that 'In order to measure health outcome a measure of health status is required which in turn must be based on a concept of health.'

She notes that health status should take into account two concepts; firstly, that of 'disease' which is a pathological abnormality indicated by a set of signs and symptoms, and secondly, the person's 'ill health' which is indicated by feelings such as pain or perceptions of change in usual functioning and feeling. A general statement about the importance of the patient's subjective experience follows: 'What matters in the 20th century is how the patient feels, rather than how doctors think they ought to feel on the basis of clinical measurements. Symptom response or survival rates are no longer enough; and, particularly where people are treated for chronic or life-threatening conditions, the therapy has to be evaluated in terms of whether it is more or less likely to lead to an outcome of a life worth living in social and psychological, as well as physical, terms.'

The latter statement illustrates a current confusion in health care. Bowling begins by stating that 'what matters...is how the patient feels' implying that this is what really matters. She further states that how the patient feels matters 'rather than' how they might be expected to feel on the basis of

objective clinical measurement, implying that the latter evidence is irrelevant. However, she later concedes that symptom response and survival rates must be relevant in health status, for she says that they alone are 'not enough', which implies that they are necessary in assessing health status.

There is a current fashion in health care and health care ethics for considering that the *only* factor of importance in health status or in the outcome of health care is how the patient feels, and that other evidence, even that which is uncontroversial such as whether the patient is alive or dead, is simply irrelevant. This makes little sense. Moreover, the term 'feels' is ambiguous and might refer to bodily sensations of discomfort or to unhappiness at one's lot in life. Bowling's initial implication that what matters is only how the patient feels must be rejected.

Returning to her model of the derivation of health outcome measures, it is apparent that such measures depend on measures of health status, which in turn depend on a concept of health. She goes on to note that there is no satisfactory definition of health. This would appear to pose an insoluble problem for health outcome measurement if the latter depends on our being able to describe concisely what we mean by health. She rejects as insufficient the typical indices of health status which are built around negative concepts of health such as illness, disease and disability, and which measure biochemical factors, symptom rates or role performance.

Her proposed solution is to approach the problem from the opposite direction of health outcomes, and to work backwards from those factors which influence health outcomes to construct a model of health:

'There are multiple influences upon patient outcome, and these require a broad model of health. The non-biological factors which can affect recovery and outcome include patient psychology, motivation and adherence to therapy, socio-economic status, availability of health care, social support networks and

individual and cultural beliefs and behaviours. Outcome should thus be measured more comprehensively in relation to people's value systems.¹⁶

In this statement Bowling makes it clear that her model of health, constructed so as to serve as the basis for health outcome measurement, is very broad indeed! Based on that model of health, health-related quality of life must include many aspects of life including one's beliefs.

Furthermore, ambiguity marks her final statement regarding people's value systems. It is not clear whether she means that the outcome of health care must be measured in terms of the patient's own value system, or in terms of some value system which is shared broadly among 'people'. In the light of her reference to individual cultural beliefs and behaviours it seems likely that she believes that health-related quality of life as an outcome should be measured in relation to each individual's value system. This returns us to the earlier confusion about whose assessment of outcomes in health care is relevant - is it just the subjective view of the patient in the context of his own value system, or are there some objective aspects of outcome which are also relevant and essential?

This discussion on Bowling's approach to the measurement of health care outcomes illustrates the problems created by trying to solve conceptual issues by providing a list of definitions which effectively stand one upon the other leading logically to a definition of a concept such as health-related quality of life. Her proposed solution is essentially circular - finding no generally accepted definition of health to serve as a basis for health status and health related quality of life, she uses a selection of factors relevant to the latter as a basis of the definition she then creates for health. She has resorted to defining health in terms of some notions of health-related quality of life, which is the concept she was trying to define in the first place. The problem here is that there simply is no generally accepted and comprehensive description of the concept of health, so that there can be no generally accepted and

comprehensive description of health-related quality of life. Ann Bowling concludes that there are essentially two parts to the concept of health-related quality of life. The first includes functional ability, which is to do with being able to carry out the acts of self-care and domestic activity, as well as functional status which is directly related to the ability to perform social roles. The second part is a concept of positive health, which implies 'full-functioning' or 'efficiency' of mind, body and social adjustment, plus related concepts such as social well-being and quality of life which she sees as components of a broad concept of positive health.

Whilst functional ability would seem to be a straightforward measure of what a person can actually do, and can be evaluated subjectively and objectively yielding a verifiable result, the idea of functional status is less easily assessed and more loosely connected to health. For example, one's ability to fulfil a social role such as parenting is dependent on many factors other than health.

The second part of her concept of health-related quality of life, that of positive health, is problematic. She recommends the following description of positive health: 'the ability to cope with stressful situations, the maintenance of a strong social-support system, integration in the community, high morale and life-satisfaction, psychological well-being, and even levels of physical fitness as well as physical health.'⁷ She also states that social health is a matter of whether people function adequately as members of a community, and notes that there is no consensus definition of quality of life, which she has also included as an aspect of positive health and which includes 'perceptions of well-being, a basic level of satisfaction and a general sense of self-worth.'⁸

In a later discussion on measures of life-satisfaction and morale, Bowling mentions happiness and self-esteem and states that 'indicators of these concepts are useful in assessing the mental health or well-being of people.' Happiness is generally considered a mood-state, whereas self-esteem and

morale are more cognitive in nature. The inclusion of a mood-state, as opposed to the psychiatric state of depression, further extends her concept of health-related quality of life.

One must conclude from her description of these two parts of the concept of health-related quality of life that it is a very broad concept indeed. It includes many characteristics of life which are not solely or principally determined by health, as well as concepts for which there is no generally accepted comprehensive definition or description.

This apparently unsatisfactory conclusion is inevitable, for there simply is no comprehensive and coherent description of the concept of health-related quality of life, with clear boundaries between it and non-health-related quality of life. Such an account is not achievable, since the concepts which are part of quality of life in a broader sense are fundamentally incoherent and possibly in conflict with each other, as the following discussion illustrates.

3.1.iv Quality of life in the broader sense.

Those funding and providing health care have recently become persuaded that the impact of health care on overall quality of life is what matters (and what must therefore also be demonstrated and measured). Thus, increasingly clinical trials include some evaluation of the impact of a service or treatment on the quality of life of the patient. Yet there is no agreement on the components of this concept, their relative importance, or how they are linked to each other.

Lesley Fallowfield, a lecturer in psychology also qualified as a nurse and counsellor, published her book 'The Quality of Life, The Missing Measurement in Health Care', in 1990.⁹ Her purpose was to stress the importance of looking at the overall effects of treatment on the patient, especially in those circumstances where the benefit of prolonging life may be outweighed by the unpleasant aspects of treatment and continued existence in a state of disease

or disability with no prospect of restoration to health. Her book was not written with the aim of influencing resource allocation, but in order to make health care professionals and the public more aware of the overall effects of treatment so that better individual treatment decisions might be made. Her book is particularly relevant to palliative care, not least because her inspiration for studying the subject was her observations of the adverse effects of palliative chemotherapy on a close friend, which stimulated her to look particularly at quality at the end of life.

At the outset she says of quality of life 'Trying to define it, explicitly, in a fashion which would permit objective measurement, is another matter.'

It is important to note that implicit in this statement is the assumption that if one can only define a concept, objective measurement will be possible. This assumption is questioned in section 3.ii.

Since explicit definition is considered to be a pre-requisite for measurement, she is committed to producing a definition which is the following: quality of life is a 'complex amalgam of satisfactory functioning in essentially four core or primary domains' which are then listed as psychological, social, occupational and physical. The following table is reproduced from her book,¹⁰

Quality of Life

<i>Core Domains</i>	<i>Typical items</i>
1 Psychological	depression anxiety adjustment to illness
2 Social	personal and sexual relationships engagement in social and leisure activities
3 Occupational	ability and desire to carry out paid employment ability to cope with household duties
4 Physical	pain mobility sleep appetite and nausea sexual functioning

One must ask whether the importance of the above factors alters in the context of a terminal illness. It is possible that some factors, for example pain, have a greater influence on quality of life in palliative care than in chronic illness.

Fallowfield considers psychological function to be very important. She states: 'Healthy psychological functioning, that is freedom from anxiety and depression and the ability to adapt and adjust to different illness states, is crucial for maintenance of quality of life. It may even sustain life.' In the context

of terminal illness one must ask whether even the most adaptable patient could remain free of anxiety or frustration, and most people would consider sadness, perhaps even depression, to be a normal human response. It is difficult to interpret Fallowfield's idea of healthy psychological functioning in the context of palliative care.

In the social domain she mentions the importance of the continued support and company provided by friends and family, noting particularly the fears expressed by some patients that their friends may abandon them, especially if the illness is prolonged. She states that these factors are 'immensely important contributory factors to quality of life'.¹¹ The comments of patients bear out the importance she attributes to close loving relationships - many say that they could not have coped with their illness without the sensible and constant support of close friends and family. On the other hand, those close to the patient can be unhelpful, for example by 'smothering' attention, putting undue pressure on the patient to be positive, to strive to get better, or by burdening the patient with their own distress. Conversely, the family may find the illness more distressing if the patient is not considerate towards them. Love and well-intentioned efforts will not alone improve quality of life for patient or family. Some people seem to know how best to help the patient and to lessen distress, others unintentionally add to it! The mere presence of friends and family does not mean that they are necessarily helpful to the patient.

The importance of paid employment is stressed in Fallowfield's account. She notes that 'Part of an individual's concept of self is derived from the various social roles he or she engages in, such as work.... Any forced retirement due to ill-health severely threatens self-image, self-worth and self-respect, which can produce considerable psychological distress.' She also notes that being dependent on others for everyday household tasks may lessen self-esteem. These comments introduce the idea of self-respect into her concept of quality of life. She does acknowledge employment is 'not always particularly satisfying',

especially if it is stressful or excessively time-consuming, when it actually detracts from quality of life. She thus introduces the concept of satisfaction in one's job. In the context of palliative care the majority of patients are not physically fit enough to continue in their paid employment, and so this factor becomes less relevant in quality of life. Strangely, Fallowfield does not mention the financial consequences of reduced income, which can definitely cause physical hardship and anxiety.

In summary one might say that Fallowfield, like Ann Bowling, comes up with a list of many factors which impact on quality of life and are relevant to it. Their lists combined would include satisfaction in one's job and with one's life, self-respect and self-esteem, morale, happiness, the love and company of family and friends, the freedom and ability to pursue leisure activities, freedom from anxiety and depression and ability to adapt to life changes. All of these are thought to be necessary for a good quality of life, in addition to good physical health. When speaking of the outcome of health care Fallowfield concludes that 'Clearly, many covariates in any given patient's world must be considered, and if possible their contribution evaluated, when the therapeutic effects on quality of life are being assessed.'¹²

3.1.v A coherent concept of quality of life?

One must ask whether the many factors considered relevant to quality of life are compatible with each other, and whether together they form a complete and coherent model of quality of life. One must further ask whether this model is applicable in the context of palliative care.

Prof. Robin Downie addressed the first question in a lecture and subsequent paper for the Royal College of Physicians.¹³ . He noted that 'While the term 'quality of life', is used frequently in everyday discourse, perceptions of what it might actually mean differ greatly and are often incompatible.'

Prof. Downie described the various models of quality of life. In addition he argued that the factors which health care researchers have considered relevant to quality of life are those same factors which they consider give value to life, hence 'a typical medical view of the value of life seems to be that life, or a life, has value to the extent that it exhibits certain qualities.'

Using the legend of Sisyphus as an illustration, he described models which represent the various factors which may make life valuable or worthwhile. They are the 'significant toil' model, the 'happiness or well-being' model, the 'choice' model and the 'social factors' model.

The significant toil model portrays Sisyphus (following the intervention of Asklepios) enduring punishment but able to pursue a worthwhile job building cairns or shelters out of boulders, and occasionally assisting mountaineers, in a healthy and aesthetically pleasing environment, with time for leisure pursuits and able to meet friends who encourage and support him. This model is based on ideas of realising our essential human nature, which has its roots in Greek mythology and later in Christianity, where the pursuit of our work for the glory of God and the benefit of others, and the development of our nature in the image of God is emphasised.

The happiness model is based on the idea that 'your quality of life is just how you happen to be feeling', where happiness or well-being are states or moods in which pleasant feelings dominate. This is reminiscent of Ann Bowling's statement that what matters is how people feel. The problem with this is that it implies that so long as a person has predominantly nice feelings they have a high quality of life, even if they are constantly confused or demented, or if their mood state is dependent on anti-depressants and lack a satisfying occupation or even good health.

The choice model is currently very popular, for it is based on the idea that what is most valuable in life, what gives it an essentially human quality, is our autonomy or ability to choose our way of life. This model uses Kant's term

'autonomy', but not in the sense that he used it. Modern usage, certainly in health care ethics, focuses simply on what the patient wants, rather than Kant's ideal of a choice based on universalisable maxims. The problem with the choice model is that possessing choice does not necessarily yield lives which would be considered to be of high quality, for example if people choose to lead a life of crime, substance abuse or even poor relationships.

The social factors model stresses 'human inter-relatedness or solidarity, and the quality or the worthwhileness of the life of one person has a bearing on that of another'. As Professor Downie points out, this model is particularly relevant in a society with a publicly funded health care system and other publicly funded benefits. In this context an adequate discussion of quality of life must be based on an equitable distribution of the resources which give important benefits to everyone. The problem with this model is that one may have a financially impoverished society where benefits are distributed equitably, but where standards of nutrition and living are so poor that quality of life would not generally be judged to be good.

The point which is being made is that these four models are actually in conflict with each other and represent incompatible positions. Thus from these common and plausible accounts of factors which give value and quality to life it is not possible to construct a coherent account of quality of life. As Professor Downie states 'This makes it impossible to combine all the models into a single measure for evaluating health care, still less any wider social dimension.'

It is interesting to note that Ann Bowling, Lesley Fallowfield and Robin Downie have all described a similar list of factors which give value or quality to life. The first two authors agreed that there is no generally accepted definition or account of quality of life, while Downie's account provides a convincing argument that this is the case simply because it is not possible to construct a coherent account from our various everyday notions about what quality of life means.

Having reached this conclusion, one must return to the question of whether any of the models or accounts of quality of life is applicable to palliative care.

The life of significant toil, where one's contribution brings about self-development, self-respect and a satisfying life, is often inapplicable to those terminally ill who become increasingly incapable, because of ill health, of working either outside or within the home. According to this model, their quality of life would, on the whole, be very low.

Similarly, on the happiness model, they will also appear to have a very low quality of life because of the low moods which most experience because of natural sadness, anxiety or periods of depression. Whilst some patients report interludes of an elated or happy mood state, it is unlikely that the predominant state would be one of pleasant feelings.

On the choice model patients who are terminally ill would also seem to fare badly, for the illness removes from them so many of the choices in life - they have not even a choice to go on living, for medical science cannot prolong their lives indefinitely. Whilst enabling them to participate in treatment choices does restore a measure of control over their lives, the inexorable progress of the illness fundamentally and severely limits choices for them and their families.

Ironically, the social factors model perhaps provides the background against which such patients may have a moderate or even good quality for life. For if death is seen and accepted as a natural end to life, and good care is provided for those terminally ill, so that they still feel valued by the community and know that they are receiving a fair share of resources, then self-respect, satisfaction with their lot and perhaps even contentment are possible.

It should be noted that in all the previous discussion about factors important in quality of life none of the authors has mentioned the matter of dignity, a factor which patients and their families quite often mention spontaneously.

3.2 Is it possible to assess quality of life, and to measure it?

Professor Downie concluded that since quality of life is multifactorial, and its component factors are inherently incommensurable, any attempt to produce a quality of life scale is bound to fail, no matter how sophisticated the mathematical techniques applied. This is a convincing argument.

However, there is a prevailing view in health care that however difficult the project we simply *must* provide measurement of the impact of health care on quality of life. The motivation behind this perceived duty is basically good - it is considered that if scarce resources are to be expended to best effect and distributed justly, then we need to be able to compare the outcome of one service or treatment with another. At the level of the individual patient, some authors, such as Lesley Fallowfield, consider that measurement of quality of life outcome of treatments will enable better decisions to be made for each patient. Added to these primarily good motivations is a current enthusiasm for expressing everything as a number or statistic, which is associated with a lack of regard for the results of qualitative research not presented numerically. The consequence of these strong trends is an overwhelming drive to establish quality of life measurement techniques and scales. The use of such a scale in every clinical trial of a service or treatment is now considered essential.

It is interesting that this drive has persisted despite obvious problems in measuring quality of life in terms of the theory of measurement. These problems are grave, and appear insurmountable. It is surprising that despite acknowledgement of this difficulty sociologists, statisticians and health care professionals persist in the belief that it is possible to overcome them, and they continue to try to measure quality of life.

3.2.i Theory of measurement and quality of life.

Measurement tools must meet certain criteria in order to be considered acceptable for research purposes. These criteria include validity and reliability. These are widely accepted concepts and tests to demonstrate validity and reliability have been established. Conclusions drawn from invalid measurement tools are themselves invalid. Therefore measurement tools failing to meet these criteria should be rejected.

Validity is the extent to which a tool measures what it purports to measure. The following factors are important for overall validity.

Face validity is the extent to which the items in the tool are relevant to the purpose of the test. In the case of quality of life there are obvious problems here - is a mood state like happiness relevant, or choice, or self-esteem, or ability to work?

Content validity is the extent to which the tool covers all the aspects of the attribute to be measured. Considering the very large number of factors thought relevant to quality of life, and the fact that some are perhaps in conflict, it seems very unlikely that a clinically useful quality of life scale could be created which would meet this criterion.

Criterion validity is the extent to which the variables can be measured with accuracy - the considerable difficulties with this criterion will be mentioned below when scales are discussed.

Construct validity is to do with underlying theories and assumptions about what is being measured and how items relate to each other. The arguments raised by Professor Downie illustrate the apparent impossibility of satisfying this aspect of validity.

A crucial question pertaining to validity is the identity of the person completing the assessment. The subjective nature of many of the items in quality of life measurement tools, such as pain and other symptoms, mood and self-esteem, make it essential that the patient completes his or her own

assessment. Both Fallowfield and Bowling make this point strongly, and are of the opinion that neither the patient's family nor health care professionals are able to assess the items sufficiently accurately. Research on cancer patients by Slevin et al showed poor correlations between professionals' and patients' scores.¹⁴ In the context of palliative care, where patients may be weak and weary, any measurement tools must not be too long, since it would clearly be morally unacceptable to use tools which are burdensome to patients.

Reliability is the extent to which a tool consistently produces the same results, particularly when applied to the same subjects at different times. There are three common tests of reliability.

The first, termed 'multiple form reliability' is carried out by using two tools in parallel on the same subjects. A high correlation of results between the two tools is said to indicate reliability. This test would not seem applicable for quality of life tools, where different tools may be measuring or giving more weight to different factors.

The second test, termed 'split-half reliability', entails dividing the items in the tool into two equivalent halves and comparing the scores obtained by each half. The higher the correlation, the greater the reliability. The problem for quality of life tools is that it is very difficult to divide the items into two equivalent halves, as the items are too disparate. Any questionnaire which could be divided into two equivalent halves would be too long.

The third test, termed 'test-retest reliability', entails using the same tool on the same subject on two separate occasions. If the tool is reliable, the results will show a high correlation. The problem with this test in the context of palliative care is that the patients' condition changes with time and it would not be reasonable to expect a high correlation between results obtained on different occasions. Thus it seems very difficult, if not impossible, to devise a quality of life measurement tool which meets standards of reliability.

It is therefore not surprising that authors such as Ann Bowling and Lesley Fallowfield, who are both committed to the pursuit of establishing quality of life scales, admit that currently there is no satisfactory scale of quality of life in terms of validity and reliability. Whilst they may hold out the hope that such a scale may be developed in the future, the problems inherent in the goal appear insurmountable.

3.2.ii Scales and numbers.

Measurement is the act of attaching a number to an entity which is not itself a number. In using tools which measure quality of life a number is used to represent the patient's quality of life. We use numbers in three distinct ways, as described by Downie and Macnaughton in their book on clinical judgement.¹⁵

The first is as a method of identification or labelling. For example, after a clinical trial the state of the patient could be identified as either alive or dead and a number, such as 1 or 2 could be used to identify that state. The number in this case is simply serving as a sort of short-hand label, and this is not really measurement as is commonly understood. However, Bowling calls this a 'nominal' or 'classification' scale and describes it as the weakest form of measurement.¹⁶ She asserts that there are methods of data transformation which permit even this use of numbers as labels, 'nominal data', to be made quantitative for the purposes of analysis. Yet as Downie and Macnaughton point out, the numbers used as labels have no relationship with each other and they are assigned in a totally arbitrary fashion. For example, 'dead' could be 1 and 'alive' 2, or any other numbers we choose. It is simply not plausible to assert that numbers used simply as labels can be made into quantitative data, since the numbers put into the initial calculations do not represent a quantity - they are serving only as identifying symbols. It is not reasonable to suggest that from numbers used as labels any quantitative data can ever be obtained.

The second use of numbers is to indicate the position of something in a series. Bowling calls this an 'ordinal' or ranking scale, and points out that many health-status measures are strictly of this type. For example, the Karnofsky Performance scale rates physical ability between 0 and 100. On this scale 0 is dead, disabled requiring special care and assistance is 40, normal activity with effort is 80, and 100 is normal with no complaints. These numbers are simply placing the patients' abilities in order; rating a patient's ability at 40 does not mean that the ability rated 40 is half as good as that rated at 80, or that being normal is one hundred times as good as being dead! The points on this scale are identified with numbers which happen to be separated by intervals of 10. This gives the impression that one state is ten units of something better than the state below, and that the difference between each state and its neighbours is the same. This is misleading, as the numbers are simply ranking disability (or ability).

Downie and Macnaughton point out that 'when qualities are arranged in a series and identified with numbers, the use of those numbers to perform calculations like averages or percentages is meaningless, as the relationship between points 1 and 2 and between 5 and 6 in the series may be completely different. Distinctions between qualitative entities can very often only be expressed through descriptions like 'more and less' or 'better and worse' as they have no true numerical meaning.'

Despite this convincing argument attempts have been made to convert descriptions of entities into numerical scores on ordinal scales which are then subjected to statistical analysis. For example, a patient might be asked 'Do you feel depressed?' and the patient ticks one of four possible response categories, such as 'very much', 'moderately', 'somewhat' or 'not at all'. These responses are each given a score from 0 to 3 or 0 to 4. Offering too few response categories, for example just yes and no, produces too crude a scale and insufficient opportunity for the patient to express his opinion accurately. On

the other hand offering too many categories makes it difficult for patients to discriminate between categories.¹⁷

When the measurement tool requires patients to answer a number of items grouped into subsets, and the scores for all the subsets are added together, this is called a Likert scale. It must be noted that such a scale is at best producing an ordinal or ranking result. The patients have not assigned any number to their response - this is done by the test scorer - they have instead chosen a statement which most agrees with their own view. It cannot be assumed that a score of 4 for 'very much' is twice as bad as a score of 2 representing 'somewhat', or that the distance between 0 and 1 equals that between 3 and 4. All one can really say is that the patient is indicating progressively more depression from the 'not at all response' to the 'very much' response. The same comments apply to Guttman scales in which patients make a 'yes' or 'no' response to various items grouped together in degrees of severity, and the responses are scored 0 to 3 or 0 to 4.

Bowling is aware of the problems of subjecting data from ordinal scales to statistical analysis. She notes that the most appropriate statistic to draw from ordinal scales is the median, where the number of scores above and below the median is the same and the median itself is not altered by what those scores actually are. She notes later that summing up scores from two or more ordinal scales 'erroneously converts what is at best ordinal data into interval levels of measurement when applying statistical techniques. Statistical caution is required'.¹⁸ Unfortunately quality of life measures require the scoring of several sorts of entities (such as mood, symptoms, self-esteem) on ordinal scales and then adding together the results and subjecting them to statistical analysis. This is clearly an invalid process and it is difficult to see how even 'statistical caution' could render the results valid.

The third use of numbers is to describe a quantitative relationship between entities. Bowling calls this an 'interval' scale. The items on the scale

are arranged in a series, as on the ordinal scale, but in addition it is known that the distances between any two numbers on the scale are of a known size. Usually they are the same size - the exception would be logarithmic scales. On the interval scale there is a constant unit of measurement, and so we can assign a 'real number' to the entity being measured. It should be noted that zero may be arbitrary, for example the Centigrade and Fahrenheit temperature scales have arbitrary zero points since on neither scale does zero represent the complete absence of heat. Downie and Macnaughton describe entities which can be measured in this way as 'additive'.¹⁹ A 'ratio' scale is like an interval scale but there is a true zero point, such as in weight when zero is scored when there is, in theory, no mass at all. A measurement of blood sugar or the entities of a full blood count are ratio scales as it is possible (in theory) to have no white blood cells or no blood glucose.

The interval scale is truly quantitative and can be used for entities whose scores can be added together. All the common statistics such as means and standard deviations are applicable.

The obvious problem for quality of life tools is that the entities being measured, such as physical performance, role performance, mood, social support etc. can be represented on an ordinal scale but cannot be represented on an interval scale, since it cannot be said that a constant unit of measurement separates each point on the scale. As Bowling says 'The most rigorous methods of data analysis require quantitative data. Whenever possible, measures which yield interval or ratio data should be used, although this is often difficult in social science. Measures of functional disability and health status never strictly reach a ratio- or interval-scale of measurement.'²⁰ Yet she goes on to assert that methods of data transformation permit even nominal data (and by implication also ordinal data) to be made quantitative for the purposes of analysis. If an entity is such that it simply cannot be measured on an interval scale, but only on an ordinal scale, surely no method of 'data

transformation' can enable one to obtain the valid statistical data that can be derived only from data which can be legitimately represented on an interval scale.

Information about the domains of life thought relevant to measurement of quality of life is inherently qualitative (as opposed to quantitative) in nature. This gives rise to two problems relating to the use of ordinal scales. The first is that it is open to question whether such information can even be represented on an ordinal scale. The second problem is that in trying to represent it only by a number the information is diluted, weakened or impoverished in some way. These problems arise persistently when attempts are made to represent entities such as mood or acceptance of dying on an ordinal scale.

The first problem is well illustrated and acknowledged by John Hinton in his paper on the awareness and acceptance of dying.²¹ His research was conducted by interviewing patients and relatives and scoring their level of acceptance between 1 and 9 depending on the phrases they used to describe their thoughts. He states that "Acceptance ratings of 1- 4 represented degrees of troubled rejection of a fatal outcome, five for noncommittal and 6-9 indicated increasingly positive acceptance....Examples of brief quotations with the ratings for the full interview were:

Rated 2 'I'm frightened he won't get better' (said with agitation and tears).

Rated 3 'I feel depressed, lonely at night. I cry if I talk about it.'

Rated 5 'I want to stay hopeful and don't want to look much farther.'

Rated 7 'I'm rather resigned to the situation.'

Rated 8 'I've got no fear of death, I've had my life - what happens after that who knows?'

Rated 9 'We both know all about it, it's accepted as God's will.'"

It is clear that this data can be presented only on an ordinal scale, for it is not possible to assert that there is a standard unit of difference of acceptance between each state. Indeed, one might consider that such descriptions are not always amenable to an ordinal scale, for it is surely a matter of opinion whether the statement rated 3 above actually shows more acceptance than that rated 2. Hinton acknowledges this difficulty, for he says 'Certain phrases about ways of accepting death became familiar and fell into clusters which help describe the ways that people saw their situation. These clusters were not clearly demarcated one from another.' If the clusters are not clearly demarcated one must question whether the descriptive phrases can be represented on an ordinal scale at all. Perhaps, if one must use numbers, all one can legitimately achieve is to attach a number as a label to each cluster of phrases, yielding only a nominal scale.

Despite the ordinal nature of the data Hinton still subjected it to statistical analysis. For example, he states that the mean weekly score for acceptance increased from 7.0 eight weeks before the patients' deaths to 7.5 in the week before death, and quotes a $P < 0.05$. In so doing he has definitely (and erroneously) converted what is at best ordinal data into interval data, (the problem identified by Bowling and mentioned above).

The second problem, that of trying to represent a statement said in a certain way and in a context by a single numerical score, is also appreciated by Hinton. In the same paper he says 'During interviews, measuring acceptance by quantitative ratings alone could seem as incomplete as estimating illumination in candlepower. Most people indicated or explained the nature and quality of their acceptance.' The analogy with illumination is powerful, for who would consider that the quality of moonlight could be represented by the numerical value of its candlepower!

The attempt to reduce the meaning of the patients' phrases to a numerical score greatly impoverishes our understanding of what they were

trying to communicate. Thus much can be lost in the drive to obtain quantitative results from studies of entities which can be adequately represented only in language. Hinton does realise this, for he writes 'The shaping of questions and measurements to give standardised and more reliable answers is necessary for research, but it may limit or distort people's self-descriptions and free accounts of feelings. This particular study aimed to explore and elucidate people's progress, so it was decided to rely on observed weekly changes assessed by the same interviewer and compare different occasions or different groups. This choice means that the 'absolute' values are questionable (when are they not).' Hinton is so committed to the ideal of producing quantitative data that he persists in doing so, despite being aware of these major shortcomings in his method, whilst commendable honesty compels him to remark on the shortcomings of this method.

3.2.iii Weighting and summing scale items.

The simplest way to obtain a final score from a measurement tool is to sum the scores obtained from each item or subset of items. Thus in order to obtain a score for the patient's quality of life one would simply sum the scores from the physical, social, emotional and symptom domains. However, some items or subsets of items may be more important in quality of life than others. For example, it is possible that freedom from pain and nausea may be more important in quality of life in terminal illness than ability to perform one's social roles. If this is the case then the more important items should contribute more to the overall score. Weighting certain items deemed to be very important is often suggested or carried out. The problem in quality of life scoring is to know which domains should be given more weight, especially as certain domains will be more important to one individual than another. If quality of life is really just how the individual feels, and a score must represent that individual's value

system, then the weighting would have to vary from one individual to another. It is doubtful if such a scoring system could work in practice.

Summing scores from the various domains to obtain a final quality of life score also hides information about the differences in quality between one domain and another. Fallowfield noted this problem in relation to quality of life studies comparing lumpectomy for breast cancer with mastectomy.²² She notes that several studies showed no difference in quality of life outcomes between the two treatments. She comments that 'The impact that a diagnosis of cancer has on quality of life is not necessarily ameliorated by sparing women the trauma of breast loss'. The reason for the lack of difference in quality of life outcome may be that women who have a mastectomy have more physical trauma due to a larger operation, so that they score worse on the physical domain, but they may have a lower score on anxiety because they may have fewer fears of cancer recurrence. Telling patients only that the quality of life outcome of the two treatments is the same does not really give adequate information; patients should be told how the different domains of quality of life are affected by each treatment, since this knowledge is likely to have an impact on their decision.

The summing of domain scores and subsequent disclosure only of the total quality of life score might well be used by drug companies to conceal the adverse effects of chemotherapy. For example, recent advertising material for the drug irinotecan²³ indicated that quality of life and performance status were maintained for longer (about 2 months) when irinotecan was used in combination with standard chemotherapy as compared with standard chemotherapy alone. The advertising material also states that the toxic effects of Campto are 'generally reversible, manageable and non-cumulative'. However, the prescribing information for doctors indicates that Campto can cause delayed diarrhoea, and 'if not properly treated, diarrhoea can be life-threatening, especially if the patient is concomitantly neutropenic.' The use of

quality of life information in the advertising effectively hides the existence of this severe side-effect which may make a difference to both doctors' and patients' willingness to use the drug.

3.2.iv The use of the mean and other statistics.

The presentation of qualitative data by reduction to numbers and statistics can hide important information or mislead readers to erroneous conclusions. For example, John Hinton in his paper on the progress of awareness and acceptance of dying, stated that awareness of dying rose from a mean of 7.6 eight weeks before death to 8.1 at the last available assessment, (paired $t = 2.45$, $P < 0.05$).²⁴ However, he goes on to say that many individuals did not follow the group's average path in the final two months. Out of 154 scores from 77 patients and their relatives, 72 patients and relatives showed that awareness may follow any direction. This important message is completely lost by focusing only on the mean score which leads to the erroneous conclusion that the average patient or relative increases awareness in the last eight weeks. Hinton goes on to explain that progress in awareness actually increased in only 15% of patients and relatives, and the change in this groups' awareness caused the increased mean score. An important lesson for clinicians from this paper should be that nearly half of the patients and relatives did not increase their awareness of dying despite the increasing evidence of the last eight weeks of life. Unfortunately this message is obfuscated or perhaps completely lost to most readers because of emphasis laid on the rise in mean scores. Understanding of progress in awareness of dying may actually be impeded by presentation of this important qualitative data in a quantitative form.

3.2.v Utility rating scales.

Economists have devised a series of scales which are attempts to assign a numerical value to health states and thus to quality of life. Bowling describes these as utility rating scales. Five types of scale have been used.²⁵

The first is a version of a visual analogue scale (VAS) which is a line, usually 10cms long, one end of which represents health or the most desirable state and is scored as 1 and the other end of which is death or least desirable state and is scored 0. The scorer, usually a member of the public and less commonly a patient, marks points on the line corresponding to the desirableness of various health states. Since the distances along the line of the various points is measured to obtain a score between 0 and 1 for each health state it is assumed that results can be presented as an interval scale. Bowling comments that subjects find this method difficult, and it cannot be assumed that in using any VAS the subject is using an interval scale - it might actually be closer to a logarithmic scale.

The second method is the standard gamble. In this case the subject is asked what probability of getting the desirable (or least desirable) outcome will make him indifferent between taking the gamble as opposed to choosing the certainty of one option. For example, he may be asked to consider whether he would prefer to continue in a poor health state or to undertake a risky but curative operation. He would be asked what probability of success in the operation would make him equally disposed to either continue in poor health or take the operation choice. If the health state is considered very poor he will choose operation even when the risk of intra-operative death is high. From subjects' responses to this type of question a score is allotted to the poor health state described.

The third method is equivalence studies. Subjects are asked whether they would choose to keep alive a group of fairly well people or a larger number of less well people. Each subject is asked to identify the numbers at which they

are indifferent or feel the choice is morally equivalent. From their number equivalences a score relating to the health states is allotted.

The fourth method is the time trade-off. Subjects are asked to judge how long a period in one health state could be traded for a different period in another health state. Bowling states that this is the method which subjects find easiest to use.

The fifth and most widely discussed method of assessing health outcomes is the quality adjusted life year or QALY. Members of the public are asked to consider life in various health states and rate the value of that state between 0 and 1. The number of QALY's gained by a health intervention is the number of years gained or spent in the new health state multiplied by the value (between 0 and 1) of that state. Since QALY's have been used in discussions regarding resource allocation a more detailed discussion of the moral problems inherent in that use follows in section 3.3.i on the use of quality of life scales.

Bowling comments that none of the utility scales has been tested adequately for reliability or validity, and subjects very rarely have experience of the illness state they are being asked to value. It is difficult to maintain that people who have no experience of an illness state can evaluate that state.

Bowling further comments that all the utility rating scales assume that 'people are being rational when assessing quality of life, and that individual value judgements are not interfering with their ratings.' This statement returns us to the initial problem of whether your quality of life is just what you think it is, i.e. it is entirely subjective, or whether there are entities which we all consider important so that it is possible and legitimate to derive an objective opinion on someone's quality of life. At the beginning of her book Bowling comments that quality of life should be evaluated according to each individual's values, yet at this point she seems to be saying that individuals should not allow their own value judgements to interfere or influence their scoring of the quality of a health state. This fundamental confusion is inherent in discussions of quality of life

because it is inherent in our somewhat diffuse and incoherent concept of quality of life.

Bowling also comments that it is also difficult to quantify quality of life, which is a multi-dimensional concept, in terms of one figure. One must conclude that she considers that subjects should score each domain separately. It is not clear whether she considers it is then useful to sum or otherwise combine those scores to obtain a single score, as most quality of life scales do. Fallowfield is aware that acceptance of combining all the domain 'scores' to establish a single score 'implies that a patient with a lowish score in one domain can be compensated in some way by high scores in other areas.'²⁶ It seems absurd to conclude that a patient's quality of life really improves because a package of care is put into the patient's home to compensate for increasing weakness and exhaustion.

In the conclusion of her book Lesley Fallowfield acknowledges that it has not been possible to create a satisfactory tool with which to measure quality of life, and she also notes that 'in taking the straight statistical route we may forget or artificially invalidate some other interesting and important paths and byways. The immeasurable aspects of life which give colour, meaning or purpose may be subtly altered or affected by different treatments; they should not be ignored because we cannot yet find a suitable number with which to tag them.' This last comment suggests that she believes that if we keep trying we will find a way to represent as a number the many qualitative entities which are part of our incoherent concept of quality of life. She is committed to this ideal and says 'No one seriously involved in the scientific measurement of quality of life can doubt the need to develop and refine our assessment tools; if we really want clinical medicine to embrace quality of life variables as valid outcome measures then we must produce good quantitative tools.'²⁷

Despite appreciating the problems of quantitative assessment of quality of life Fallowfield remains convinced that it is possible and desirable to create

and use relevant quantitative tools in clinical medicine. Yet the preceding discussion has shown that it is very questionable whether it is possible or desirable to use quantitative tools to create numerical representations of quality of life.

3.2.vi Should quality of life be represented as numerical data?

I have concluded that research data on quality of life is essentially qualitative, not quantitative data. Downie and Macnaughton ask whether researchers involved in qualitative research should use numbers to present their findings - they concludes that they should not.²⁸ There are five problems associated with presenting qualitative data on the entities relevant to quality of life as numerical scores with attached statistical analysis.

Firstly, since we have no shared and coherent concept of quality of life we are not really sure what we are measuring. For example when people say they are satisfied with life, we cannot say quite what they are satisfied with, and there is no clear concept of happiness or even dignity - the latter being a relevant but little discussed entity of importance at the end of life.

Secondly, on the ordinal scales which researchers have tried to develop from questionnaires it is difficult to identify discrete points on what is usually a continuum of experience or meaning.

Thirdly, since the scales used are basically ordinal rather than interval they are not amenable to statistical analysis (apart from identifying the median score). Statistical analyses are often carried out on such ordinal data but are misleading. Such analysis is often presented because the researchers believe that only statistical knowledge will be generalizable outside the study context and might therefore be useful in clinical work and worthy of publication.

Fourthly, whether an interviewer is used or the subject fills out his own questionnaire it is possible that the act of thinking about the questions and dwelling upon one's diagnosis, prognosis, mood, social support and physical

performance may have an effect on the results. When an interviewer is used, he or she is part of the measurement tool and may have a major effect on the score allotted to the patient's response. As Downie and Macnaughton say in their previously mentioned discussion of scales 'the measurement tool might distort what is being measured.'

Fifthly, the results of a quality of life study in a particular clinic or by a particular team may well be context-specific, and care must be exercised in extrapolating from them to other settings. C Salisbury et al make this point in their review of the evidence of the effect of specialist palliative care on quality of life, where they comment that the generally rapid but variable process of the patient's decline makes comparative studies across different settings and models of organisation very difficult.²⁹

One must conclude that research on quality of life is qualitative in nature. It cannot be satisfactorily quantified. Therefore it is not generalisable to other clinical settings in the way that quantitative research is. This is not to say that qualitative research in this context is useless. It is important to review the ways in which people are currently attempting to use quality of life tools, and to ask how the relevant qualitative data which we can gain might be useful in those areas.

3.3 How is quality of life data used, would qualitative data suffice?

The plethora of studies on quality of life has developed because those providing and funding health care have come to consider that data on quality of life is essential for two main functions. The first is the allocation of resources for treatments and services, and the second is to improve decision making for individual patients.

For each of these functions it is important to ask whether quantitative quality of life assessment tools are really essential, and whether the qualitative data we can obtain could be used instead.

3.3.i Allocation of resources to services and treatment.

The first function is assessment (usually measurement is considered essential) of the outcomes of health care services and treatments for the purposes of allocating scarce resources so as to gain maximum benefit and distribute that benefit justly. A new body, the National Institute for Clinical Excellence (NICE) has been set up in the United Kingdom to assess the outcomes of new and existing treatments and it will require quality of life data for those assessments. Already Health Authorities are asking for evidence of the outcome and quality of life impact of treatments for cancer.³⁰

Many studies have attempted to assess or measure the impact of specialist palliative care services on patients' and relatives' quality of life, in order to provide the information which those allocating resources require, and in order to justify the present existence of such services. No-one would wish to work in a specialist service which was clearly of no more benefit to patients overall than the conventional care provided.

It may be thought surprising that attempts have been made to assess the effects of a whole service - usually it is the outcome of individual treatments which is assessed. For example, it is not thought necessary to assess the impact of the orthopaedic service as a single entity on quality of life, but instead the outcomes of individual treatments such as hip and knee replacements are evaluated. No-one seriously disputes the benefits of availability of orthopaedic surgery. In contrast, palliative care is a relatively new specialty which feels it has to justify its continued existence by proving that it provides a greater overall benefit to patients than good conventional care by non-specialists. For, unlike orthopaedic surgery, palliative care can be carried out by non-specialists.

Assessing the impact of specialist palliative care teams is comparable to assessing the impact, on quality of life, of a specialist diabetic or stroke rehabilitation service. But if one were evaluating a diabetic service one might look for outcomes in terms of the various complications of diabetes, such as condition of feet and eyes and cardiovascular complications rather than global quality of life.

Since palliative care philosophy states that the aim of such care is the best possible quality of life for patients and their families it appears essential to evaluate outcome in terms of quality of life. Whilst pain and symptom control are important, evaluating these factors alone will not suffice to prove that palliative care services are capable of achieving their stated goal. Palliative care services are committed, via their philosophy, to evaluating their effect on quality of life. This becomes particularly important in the context of a service which explicitly states that it will not increase quantity of life. If that specialist service has no impact on quality of life its justification for existence and funding is removed.

In 1999 a systematic literature review of the impact of specialist palliative care services on patients' quality of life was carried out by Salisbury et al, and was published in the journal 'Palliative Medicine'.³¹ Eighty-six relevant papers were reviewed but the overall conclusion was that 'there is little robust evidence that any form of organisation of specialist palliative care offers significant advantages in terms of the impact on patients' quality of life.' The reviewers offer several possible interpretations of the findings.

Their first suggestion is that the models of specialist palliative care do not in fact benefit patients in terms of well-being more than conventional care.

Their second suggestion is that the research methods may have been inadequate to answer the relevant questions, and the tools used may not have been sufficiently sensitive or may not have been truly relevant to the values and aims of palliative care in terms of quality of life. They admit that whilst

measurement tools have been developed to assess quality of life 'all have problems and none have yet achieved widespread acceptability.' They acknowledge that in some circumstances, particularly regarding quality of life in palliative care, it is impossible to carry out randomised controlled trials. They conclude that 'Outcome measures should assess separate components of quality of life, particularly pain control, as well as allowing global assessments. Researchers should use measures which have been validated among terminally ill patients in similar settings.' They note the considerable difficulties of using relatives or health care professionals as proxies for patients, since some studies have shown a poor correlation between patients' and proxies' assessments.

Despite these monumental difficulties Salisbury et al still assert that 'Although the methodological difficulties must not be under-estimated, there remains a need for rigorous comparative research (both randomised and non-randomised) to evaluate all models of specialist palliative care, if expansion of these forms of care is to be justified by evidence of improvement in patients' quality of life.'

The philosophy of palliative care appears to have chained researchers to the wheel of a task which is unachievable. It would be preferable to conduct qualitative research, of a comparative nature, on the impact of specialist palliative care on separate domains of quality of life. This would be difficult but is not logically impossible. If such qualitative studies indicated benefit to patients, then those allocating resources would have to make value judgements, using qualitative data from the research, regarding the amount of resources that should be expended to improve patient's well-being.

It would be unhelpful to try to combine the evaluation of the domains of quality of life because they are so different in nature that they are incommensurable - they cannot logically be weighed against each other or added to make a single global assessment. A global assessment, even in

descriptive terms, would simply hide the important changes in separate domains - a service which improved pain control but also managed to increase psychological distress would not be very helpful.

The problem that remains for those funding and providing health care is that using the available measurement tools the evidence suggests that specialist palliative care is not achieving its goal. I would suggest that this result has occurred because the goal is unattainable - it simply is not possible to measure quality of life. If I am correct, it will never be possible to produce evidence to suggest that palliative care achieves its goal, so funders and providers of health care will have great difficulty justifying its provision. (They might argue that it is more cost-effective than other forms of care, or that patients prefer it, and the first of these arguments might justify its provision. Patient preference alone cannot justify provision of a costly service which has no demonstrable benefits.)

The lack of evidence of improvement in quality of life from specialist palliative care is crucial if the gain in terms of Quality Adjusted Life Years is considered when funding decisions are made. If it were possible to demonstrate a quality of life improvement resulting from palliative care it is likely that the change would be small, especially as the patients' condition is deteriorating anyway. Moreover, an improvement in quality score, say from 0.5 to 0.6, would be of very short duration since patients usually receive such specialist care for only a short time - perhaps only 3 to 6 months, and sometimes only a few weeks. The combination of an increase in quality of 0.1 for only 3 weeks to 3 months would yield a very low QALY score. Yet the public, who annually contribute millions of pounds to specialist palliative care services, consider pain control and excellent nursing care to be very important at the end of life. They would be outraged if, on the basis of low QALY scores, a decision was made not to fund such care.

The concept of QALY's, which depends on a concept of global quality of life and its 'measurement', is here to stay. It is likely to give rise to more problems in resource allocation in health care than it ever solves, and gives rise to counter-intuitive results in terms of resource allocation. Even if the QALY itself is abandoned, some global assessments of outcome in terms of quality of life will be attempted. It seems that there is an unshakeable commitment to measuring the unmeasurable. In the darkness of this reality the moral problems created by QALY's (and similar outcome measures) are important, and they are discussed in chapter 5.

The best way forward seems to be the abandonment of quantitative and global assessments of quality of life, together with abandonment of quality of life as the goal of palliative care. Qualitative studies on the separate domains, with presentation of results in descriptive terms, should be accepted as the most valid and applicable data that can be achieved. Health care providers and administrators, with input from the public, must then use this information to make the difficult but inescapable choices required in resource allocation.

3.3.ii Decision making for individual patients.

Fallowfield suggests that filling in a quality of life questionnaire might aid in the process of choosing the best treatment or management with the patient.³² She considers that this use of the measurement tools produces few problems. Quality of life assessment might help in clinical decision making in two ways. Firstly, knowledge about the impact of various treatments on the domains of quality of life would help patients, together with their health care team, to make better informed treatment choices. Secondly, it is possible that quality of life assessments might enable better identification of physical, psychological, emotional or social problems in the individual patient.

With regard to the first possibility it seems plausible that qualitative research on the effects of treatments and services on the various domains of

quality of life would serve to inform people's choices. The results of qualitative research would be helpful in the clinical context (and would be more helpful than invalid results of quantitative research). Of course, clinicians would always have to exercise judgement in applying the information from such studies to an individual patient - but this is also true of the generalisation of results from quantitative studies.

Fallowfield considers that future research and measurement techniques might tell us 'about the changes in quality of life variables which might cause any given patient to accept or reject a particular treatment.'³³ It is inconceivable that any statistical result from quality of life scales could possibly tell us which patients might accept a particular treatment. Moreover, even if such a predictive power were demonstrated, the moral and legal requirements for discussion of all suitable treatment options and for informed consent would remain, so that it is difficult to see how any such predictive power would be helpful either to patients or their doctors. Assuming that quantitative results from quality of life scales could predict patients' choices is analogous to assuming that knowledge of average life expectancy from a given cancer will tell us how long a particular patient will live!

With regard to the second possibility, it seems that clinicians are increasingly convinced that the use of questionnaires or structured interviews relating to the domains of quality of life is the best way to identify patients' physical symptoms, emotional and social problems and psychiatric morbidity. This method of assessments contrasts with the traditional method of taking a history, listening carefully, and asking some open questions. This traditional method allows the patient much more freedom of expression and ability to communicate what he or she feels is important than does a questionnaire. Of course, taking the traditional history takes time and can be frustrating for the doctor or nurse, especially when the patient persists in mentioning or dwelling upon aspects of the story which appear irrelevant to the professional.

I suspect that the enthusiasm for measurement tools may be based partly on the idea that they are more cost-effective in that they obtain the answers the professional seeks in the minimum of time, and partly for the less good reason that they place the professional firmly in control of the interaction. It is ironic that workers in specialist palliative care, who have long been advocating a 'patient-centred' approach, should show enthusiasm for methods which are very 'professional-centred'. It should also be noted that the trend towards structured interviews and questionnaires runs completely contrary to the ideal of the patients relating their own narratives, and to the associated ideas of narrative-based medicine. Some examples of papers published in the journal *Palliative Medicine* in 1999 illustrate the growing enthusiasm for tool-based diagnosis as opposed to traditional history taking and allowing the patient to tell the story.

Peter L Fevre et al published their paper on 'Screening for psychiatric illness in the palliative care inpatient setting: a comparison between the Hospital Anxiety and Depression Scale and the General Health Questionnaire - 12'.³⁴ In this study they compared the performance of the two questionnaires against the 'gold standard' of a semi-structured psychiatric interview. They concluded that the Hospital Anxiety and Depression Scale (HADS) 'was found to be an effective screening tool' with acceptable sensitivity and specificity. They suggest that the HADS should be used to confirm a diagnosis of anxiety or depression, and furthermore that 'the provision of a validated screening tool opens the door for future 'treatment validation' studies.' This latter comment suggests that they consider that a study to assess the outcome of a treatment cannot be carried out unless there is a tool to confirm the original diagnosis. Whilst this is plausible in the case of physical examinations to diagnose a physical pathology, it is less plausible in the context of emotional, psychological or social problems.

Similarly, Peter Maguire et al in 'Physical and psychological needs of patients dying from colo-rectal cancer', reported on the use of a semi-structured interview, a concerns checklist, and the Psychiatric Assessment Schedule to determine patients' physical complaints.³⁵ They compared the patients' scores with those of their proxies, both informal carers and their GPs, and found poor correlations between the patients' scores and those of the proxies. This group concluded that whilst the use of systematic assessment schedules has been advocated as an effective way of assessing patients' and family problems, 'there is probably no substitute for better training in assessment skills of health care professionals involved in palliative care.' One can only hope that such training emphasises the importance of allowing the patient to divert from the semi-structure that the professional has imposed on the interview!

Sheila Payne et al, working with the informal carers (usually family members) of patients, used a semi-structured interview and the General Health Questionnaire - 30 and the Carer Strain Index to assess the psychological distress and strain experienced by carers.³⁶ They stated that the purpose of this study was 'to identify the perceived support needs of informal carers (family and friends) of cancer patients receiving palliative care in the community.' It is interesting to note that whilst the questionnaires yielded results showing above normal levels of psychological distress and strain, the most informative part of the paper is the section giving direct quotes from the carers' interviews. This section actually allows the reader some insight into what the carers were experiencing. It is difficult to see how a score on a questionnaire could be helpful in comparison with the carer's own description of the problems. The latter information is essential in drawing together possible assistance and solutions, whereas a questionnaire indicating distress and strain is no help in identifying solutions.

Lastly, it should be noted that some questionnaires are highly judgemental in their scoring. This is illustrated in the paper by Ruth Powazki

and Declan Walsh who describe psychosocial assessment of patients and primary caregivers in a specialist palliative care unit using a questionnaire.³⁷ The purpose of this questionnaire was to identify patients' and caregivers' psychosocial 'needs'.

However, the scoring system in this paper is highly judgemental; a low score was taken to indicate 'high psychosocial risk and need for further intervention, e.g. education and counselling'. Patients would be accorded a low score if they said they indicated they were unaware life was threatened (but some patients actually cope best by not confronting this issue), or if they asked or allowed others to make decisions, or if they avoided conversation with professionals or were regarded as being in denial.

The danger of this sort of questionnaire is that it is identifying some characteristic of the patient as a 'need' for intervention when that intervention is not necessarily a benefit and may be harmful. Perhaps some patients fare better if they do not acknowledge that life is threatened, if they allow others to make decisions, and if they avoid conversations with professionals. Perhaps, rather than this questionnaire, a conversation with the patient might have yielded more information about and acceptance of the patient's chosen way of adjusting to the illness and coping with it.

With regard to decision making for individual patients it seems that the hazards of using quantitative questionnaires and structured interviews outweigh any benefits. Questionnaires which permitted recording of the patient's actual description of the situation, or less structured interviews, might best serve to bring to light patients' concerns and point to the possible solutions.

3.4 What should be the goal or goals of palliative care?

Since there is no shared and coherent concept of quality of life attempts to measure it are bound to fail. Whilst it may be possible to agree about which factors may be important in quality of life, a quantitative assessment of those

factors either separately or together is not possible. Quality of life a global concept should not be used as a goal of palliative care, and it follows that attempts to quantify it should be abandoned. Instead, qualitative studies of pain and other symptoms, of physical functioning, of mood and emotional distress, and perhaps of perceived social support and self-esteem should be attempted.

The relief of pain and other symptoms and the maximisation of physical functioning should be goals of palliative care. Giving people the information they seek about their illness and so enabling them to take part in decisions may also lessen emotional and psychological distress. The treatment of depression and anxiety are also appropriate goals.

Whilst competent and humane care in these areas might increase self-esteem and life-satisfaction, these entities are dependent on many factors which are unrelated to health care and which lie outside the influence of health care professionals. Increasing patients' self-esteem, life-satisfaction, happiness or morale are not appropriate goals for palliative care, even though such care may contribute in some small way to their achievement.

Although health care professionals may come to know patients quite well in the context of the illness those professionals are not actually the patients' friends or family, and cannot substitute for them as a social support for the patient. I have argued elsewhere (chapters 2 and 4) that psychosocial care and care of the family should not be put forward as goals of palliative care, even though they may such care may sometimes be of benefit to the patient.

Specialist palliative care may improve aspects of our patients' lives. We should begin by carrying out more qualitative studies on those entities which are legitimate goals of palliative care, and of health care in general.

3.5 Conclusions.

1. It is not possible to construct a coherent account of quality of life from our everyday notions about what it means.

2 Quality of life is multi-factorial, its component factors such as happiness, significant toil, well-being, choice and social factors are incommensurable, so it is not possible to construct a quality of life scale.

3. Research data on quality of life is essentially qualitative and not quantitative - it cannot be rendered quantitative.

4. The quantitative and global assessment of quality of life should be abandoned, and global quality of life should be abandoned as a goal of palliative care.

5. Qualitative studies on the impact of specialist palliative care on the various domains of quality of life should be undertaken.

6. The hazards of using quantitative questionnaires and structured interviews for individual patients outweigh any benefits for those patients.

References to Chapter 3

-
- ¹ Downie R. S, The value and quality of life. *Journal of the Royal College of Physicians of London* 1999; vol 33 p. 379.
- ² Campbell A, Charlesworth M, Gillett G, Jones G, *Medical Ethics*. Auckland: Oxford University Press, 1997, p.138.
- ³ Campbell A, Charlesworth M, Gillett G, Jones G, *Medical Ethics*. Auckland: Oxford University Press, 1997, p. 138.
- ⁴ *Oxford Companion to Philosophy*, ed by Honderich T, Oxford: Oxford University Press, 1995, p. 736.
- ⁵ Bowling A, *Measuring Health, A review of quality of life measurement scales*. Milton Keynes: Open University Press, 1995, p.1.
- ⁶ Bowling A, *Measuring Health, A review of quality of life measurement scales*. Milton Keynes: Open University Press, 1995, p. 4.
- ⁷ Lamb K. L, Brodie D. A, Roberts K, Physical fitness and health-related fitness as indicators of positive health state. *Health Promotion*, 1998 3: 171-82.
- ⁸ Bowling A, *Measuring Health, A review of quality of life measurement scales*. Milton Keynes: Open University Press, 1995, p. 9.
- ⁹ Fallowfield L, *The Quality of Life, The missing measurement in health care*. London: Souvenir Press (Educational and Academic) 1990.
- ¹⁰ as 9, p. 20.
- ¹¹ as 9, p. 25.
- ¹² as 9, p. 32.
- ¹³ Downie R. S, The value and quality of life. *Journal of the Royal College of Physicians of London*, 1999; vol 33 p. 378-81.
- ¹⁴ Slevin M. L, Plant H, Lynch D, et al Who should measure quality of life, the doctor or the patient? *British Journal of Cancer Care* 1998 57: 109-12.

-
- ¹⁵ Downie R. S, Macnaughton J, *Clinical Judgement*. Oxford: Oxford University Press, 2000 p. 27.
- ¹⁶ Bowling A. *Measuring Health, A review of quality of life measurement scales*. Milton Keynes: Open University Press, 1995 p. 12.
- ¹⁷ Fallowfield L. *Quality of Life, The missing measurement in health care*. London: Souvenir Press (Educational and Academic) 1990, p. 42
- ¹⁸ Bowling A. *Measuring Health, A review of quality of life measurement scales*. Milton Keynes: Open University Press, 1995 p. 13 & 19.
- ¹⁹ Downie R. S, Macnaughton J, *Clinical Judgement*. Oxford: Oxford University Press, 2000 p. 28
- ²⁰ Bowling A. *Measuring Health, A review of quality of life measurement scales*. Milton Keynes: Open University Press, 1995 p. 13.
- ²¹ Hinton J. The progress and acceptance of dying assessed in cancer patients and their caring relatives. *Palliative medicine*, 1999 13: 19-35.
- ²² Fallowfield L. *Quality of Life, The missing measurement in health care*. London: Souvenir Press (Educational and Academic), 1990 p. 100.
- ²³ Rhone-Poulence Ltd., Sept 1999, re *Campto*.
- ²⁴ Hinton J. The progress and acceptance of dying assessed in cancer patients and their caring relatives. *Palliative medicine*, 1990 13: 19-35.
- ²⁵ Bowling A. *Measuring Health, A review of quality of life measurement scales*. Milton Keynes: Open University Press, 1995 p. 20.
- ²⁶ Fallowfield L, *Quality of Life, The missing measurement in health care*. London: Souvenir Press (Educational and Academic), 1990 p. 70.
- ²⁷ Fallowfield L, *Quality of Life, The missing measurement in health care*. London: Souvenir Press (Educational and Academic), 1990 p. 221.
- ²⁸ Downie R. S, Macnaughton J, *Clinical Judgement*. Oxford: Oxford University Press, 2000 p. 32.

²⁹ Salisbury C. et al, The impact of different models of specialist palliative care on patients' quality of life: a systematic literature review. *Palliative Medicine* 1999; 13: 3-17.

³⁰ Dorset Health Authority. Dorset Plan for Cancer Prevention, Diagnosis and Treatment 1999/2000.

³¹ Salisbury C. et al, The impact of different models of specialist palliative care on patients' quality of life: a systematic literature review. *Palliative Medicine* 1999; 13: 3-17.

³² Fallowfield L, *Quality of life, The missing measurement in health care*. London: Souvenir Press (Educational and Academic), 1990 pp. 70, 108.

³³ as 31, p 216.

³⁴ Peter L Fevre et al, Screening for psychiatric illness in the palliative care inpatient setting: a comparison between the Hospital Anxiety and Depression Scale and the General Health Questionnaire. *Palliative Medicine* 1999; 13: 399-407.

³⁵ Maguire P. et al, Physical and psychological needs of patients dying from colo-rectal cancer. *Palliative Medicine* 1999; 13: 45-50.

³⁶ Payne S. et al, Identifying the concerns of informal carers in palliative care. *Palliative Medicine* 1999; 13: 37-44.

³⁷ Powazki R, Walsh D, Acute care palliative medicine: psychosocial assessment of patients and primary caregivers. *Palliative Medicine* 1999; 13: 367-374.

Chapter 4

Psychological, social and spiritual problems

Thesis 4 : There are constraints of expertise and propriety on attempts to influence the patient's psychological, social and spiritual well-being.

The WHO definition which summarises the philosophy of palliative care clearly states that practitioners should control psycho-social and spiritual distress:

'Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount.'¹

The definition assumes that control of such problems is possible, and then goes on to state practitioners have a professional responsibility to undertake the task. This raises two questions; firstly, should professionals be attempting this task at all as part of the remit of care, and secondly is it possible for them to achieve the resolution of such problems.

4.1. Should professionals be attempting to control the patient's psychological, social and spiritual problems?

4.1.i The nature of the goal.

In health care ethics in general there is little emphasis on professional responsibility for psycho-social care in the hospital sector, although recognition of the patient's emotional state has always been considered important in primary care. However, such recognition is different from assuming responsibility for altering the patient's psychological, social and spiritual state, as is suggested by the definition of palliative care.

In contrast, since the beginning of the modern specialist palliative care movement there has been emphasis on the importance of enhancing the patient's emotional, social and spiritual well-being. Dame Cicely Saunders, in her foreword to the first edition of *The Oxford Textbook of Palliative Medicine*, published in 1993, describes the development of palliative care. She says:

'The message was: "You matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die". These words together with the concept of "total pain" - a combination of physical, psychological, social and spiritual elements - were built into St. Christopher's and from thence into the modern hospice movement'.²

Two important points emerge from this description; firstly, it seems that the professional should be absolutely dedicated to the welfare of this particular person as a unique individual (and not just because this person is a human being and/or a patient), and secondly, that addressing the patient's psycho-social and spiritual distress was seen as necessary in order to control 'total pain'. The control of pain is uncontroversially part of palliative care.

The term 'total pain' can simply mean the physical pain which the patient complains of but which we know is influenced by emotional and mental factors via a very complex neurological network. Alternatively, it may be interpreted as including the patient's entire experience of distress resulting from terminal illness. During my time at St. Christopher's in the early 1980's I understood the term to mean the former - physical pain which has a very complex aetiology. There seems no moral problem in recognising that perceived pain has such a complex aetiology, but there are problems in considering that one should try to alter the patient's psycho-social and spiritual state in order to modify the pain.

Later in the same foreword Dame Cicely Saunders enlarges on the professional role:

'All the work of the professional team - the increasingly skilled symptom control, the supportive nursing, the social work, the home care, and the mobilization of community resources - are to enable the dying person to live *until* he dies, at his own maximum potential, performing to the limit of his physical activity and mental capacity with control and independence wherever possible. If he is recognized as the unique person he is and helped to live as part of his family and in other relationships, he can still reach out to his hopes and expectations and to what has deepest meaning for him and end his life with a sense of completion.'

Here she is setting out very high goals for the patient who is expected to achieve his maximum potential, physically, mentally, socially and spiritually - an achievement which few of us attain at any time in our lives, let alone when terminally ill. Moreover, the professionals involved are supposed to make it their responsibility to enable him to do so. The corollary of this is that their care is in some way lacking if the patient fails to achieve these lofty goals. It is important to ask not just whether such goals are attainable, but whether they are appropriate for both patients and professionals in the first place.

4.1.ii. The nature of the patient/professional relationship required to achieve the goal.

Given that the professionals are supposed to be able to enable the patient to reach out to his hopes and to end his life meaningfully, it is important that the nature of the patient/professional relationship required to do this is fully appreciated. Dame Cicely does state that this can be achieved *if* the patient is recognised as the unique person he is and is helped with his family and other relationships. This entails a relationship of a close personal nature between professional and patient, for the combination of recognising the patient's uniqueness and becoming involved in the way he conducts his closest relationships must logically require a close personal relationship.

The reasons for this conclusion are as follows. Becoming involved in the way a person conducts his relationships will entail making some critical comment (albeit constructive) as well as approbation, and only close personal relationships can stand this degree of honesty which serves as a marker of intimacy. Moreover, recognising the patient's uniqueness in the context of his terminal illness and life will entail feelings of sympathy and compassion which tend to connect the professional to the patient in a personal link. Dame Cicely Saunders seems here to be advocating a very genuine and personal concern for the patient. She states clearly that the patient as a unique individual *must matter* to the professional.

One might object that perhaps she means that the patient must matter to the professional simply because he or she is a *patient*, and it is a feature of the traditional professional/patient relationship that every patient's welfare must matter, or be important to, the professional. This sense of 'matter to' does not entail a close personal relationship. However, the stress put by Dame Cicely on the patient's uniqueness, the idea of helping the patient in his relationships, and the professional responsibility she describes for enabling the patient to attain the life and death most meaningful *to him* all imply a close personal relationship, not the traditional professional doctor/patient relationship. The latter would seem to have no prospect of achieving the goals that she (and many others in specialist palliative care) set for practitioners. Other writers outside the field of specialist palliative care are also beginning to advocate a more personal relationship with the patient. This may be because of the development, particularly in nursing, of 'an ethic of caring' which seems to entail a more personal relationship. Anne Scott, a senior lecturer in nursing and ethics writes:

'Health care professionals have a duty to engage actively at a level which allows them to gain sufficient insight into the personal world of the patient to perceive the likely implications of certain treatment decisions for *this*

particular patient. Engagement of this sort, I suggest, only comes through activating moral imagination. Without to some extent entering imaginatively into the world of the “person-who-is-the-patient”, it is impossible to achieve much of the understanding upon which compassion depends’.³

In declaring that professionals have a *duty* to try to gain insight into the patient’s *personal world* Anne Scott is clearly advocating that they try to establish a personal relationship with the patient, for surely such insight could not come from any less intimate relationship. She grounds this duty in the idea that without such insight professionals cannot have compassion, and compassion is seen as central to an ethic of caring in nursing.

Verena Tschudin regards caring as a basis for ethics in nursing.⁴ She states that ‘Nursing, however, is a practical, hands-on job, where experience, emotion, affection and relationship make up the bulk of everyday work.’ She stresses that in caring one person relates to another person. Her book starts with a description of caring, which is considered to comprise compassion, competence, confidence, conscience and commitment. The importance of compassion is stressed; Tschudin quotes Churchill who believes that in nursing ‘Compassion is the groundwork, competence the superstructure’.⁵ Thus compassion seems to be a foundation of caring, although Tschudin also asserts that caring can occur without compassion.⁶

Like Anne Scott, Tschudin feels that compassion requires a high degree of involvement with the patient. She quotes the following description of compassion by Nouwen:

‘Compassion asks us to go where it hurts, to enter into places of pain, to share in brokenness, fear, confusion and anguish. Compassion challenges us to cry out with those in misery, mourn with those who are lonely, to weep with those in tears. Compassion requires us to be weak with the weak, vulnerable with the vulnerable, powerless with the powerless. Compassion means full immersion in the condition of being human’.⁷

Later, Tschudin explains that caring involves receiving the other person into oneself:

'It is a question of understanding the sufferer in her or his own position. It is not a question of projecting oneself into the other; it is a question of receiving the other into oneself. This may sound contrary to much that has been written about caring. On deeper reflection though, it can be seen that caring based on relationship can only be received caring. One cares for the other; one receives the other.' She goes on to discuss Martin Buber's distinction between the I - It and the I - Thou relationship, asserting that the world of I and Thou is that of relationship and the one appropriate to caring.

At times in Tschudin's discussion the importance of the caring relationship is seen to override other professional issues. For example, she states that:

'The carer is in relation with the care-receiver. That is what care is all about. Anyone who has been at the receiving end of care will say that what matters most is how human the nurse or doctor - or any carer - is. Not how clever, how efficient, how good with the best equipment; no - but how able the carer is to receive the cared-for: that is what matters.'⁸

Having been on the receiving end of care myself I must say that I profoundly disagree with this statement. The technical skill of my surgeon was more important to me than his caring relationship with me, and the fact that the nurses on one occasion failed to perform an essential but basic nursing task thus causing considerable discomfort and a prolonged hospital stay mattered far more to me than 'how human' the nurse was who finally performed the procedure! In my view competence (as professional skills and knowledge) should be regarded as essential - neither an attitude of caring and compassion nor the establishment of a particular relationship with the patient will achieve the goals of health care, even in the context of incurable and fatal illness.

I have included these fairly long quotes to illustrate the depth of interaction and involvement, which according to these writers, the professional is supposed to seek with the patient. Anne Scott and Verena Tshudin are writing about nursing in general health care, which of course includes the care of terminally ill patients. They are certainly advocating a degree of knowledge and interaction with the patient which resembles a close personal relationship rather than the traditional patient/professional relationship.

Of course, the concepts of care, compassion and commitment and sympathy, which have been 'borrowed' for use in health care ethics, have their origins and a long history in personal relationships which pre-dates their mention in health care. As Christopher Cherry notes:

'they remain embedded in a realm of morals, and ultimately of ethics, which tends towards the personal as opposed to the impersonal, the individual as opposed to the collective, the partial as opposed to the impartial, and the unmanaged as opposed to the managed.'⁹

Clearly, in a managed system of health care such as the NHS, there must be impartiality and concern for the collective good, especially in the face of scarce resources. Christopher Cherry concludes that it is inconceivable and impossible for 'the partial and particular and personal to co-exist with and soften the impartial and the impersonal.' He is clear that the concepts of care and compassion, having their roots and meaning in personal relationships, cannot simply be transposed into a managed system of health care and into the patient/professional role.

4.1.iii. Is such a close relationship a good thing for the patient and the professional?

At first sight, if the establishment of this close relationship solves the patient's psychological, social and spiritual problems then it would appear to be a good thing for the patient. It must confer some sort of overall benefit on the

patient. But we must look at the process of building this relationship, not just at the outcome which it is claimed to achieve.

As mentioned above, a close relationship requires considerable knowledge of the patient. Mary Vachon suggests two ways 'of approaching an assessment of what causes most concern in a terminally ill person'. She asserts that the first approach involves inquiring into the following; health and well-being of every kind, family and marital attitudes, housing and money worries, sexual and social activities, job and daily life, self-image, and existential issues about illness, invalidism and death. The alternative approach which she advocates is 'assessing what patients want' and she states that this includes possibilities such as relief of symptoms, better support, firmer security, sustained relationships - both personal and professional, and stronger morale to face the future. She goes on to suggest a number of questions which might entice patients 'who do not want to speak about personal matters' to discuss the areas she is interested in. She adds that

'Using these approaches the interviewer can begin to assess the areas in which patients will be able to use practical assistance to help them cope more effectively. This will also allow the clinician to decide in which areas he or she is comfortable to intervene and which will require some outside assistance.'¹⁰

Vachon's description of the recommended professional approach to a patient in the context of palliative care is not unusual. It should be noted that this approach entails a number of assumptions. It assumes that the patient wants some intervention into his or her psychological, emotional, social and spiritual state, or it assumes that the process of intervention is justified by the benefit to the patient, and perhaps most importantly it assumes (without any evidence) that the patient *consents* to this type of questioning or to any intervention. Where patients are unwilling to divulge the information she seeks, Vachon actually suggests the questions which might cause them to reveal it!

Thus the establishment of this close relationship may not be a good thing for the patient - the latter may be exposed to intrusive or manipulative questioning without consent, and worse still, may perceive that he or she receives essential symptom control and treatment only if he or she acquiesces to such questioning and provides the answers.

In health care generally it is now widely accepted that treatment is not given to competent patients without their informed consent, and that any form of duress or coercion in the process of obtaining such consent is unacceptable. Yet consent in the context of psycho-social care in palliative care is hardly ever explicitly sought. It is the terminal illness of the patient which has caused the patient to seek help, so it is this illness for which the patient has given implied consent for health care. The scope of implied consent is difficult to define, but it suffices to say that we cannot assume that a patient implicitly consents to whatever care interventions the professionals consider would be beneficial. Someone asking for pain control does not necessarily want to explore feelings related to the diagnosis, let alone those related to previous life crises, close relationships, or sexuality. It is certainly disrespectful of patients to embark on personal discussions unless they have indicated a desire or at least willingness to do so.

Of course patients may want help with social, psychological, or spiritual problems, especially once physical distress has been alleviated. It is obviously appropriate to ask frequently what problems the patient wants to address. But there is a subtle and morally important distinction between encouraging patients to talk about their present concerns and asking searching questions which it is difficult to avoid answering. In the context of specialist palliative care patients are often placed in situations from which it is difficult to escape without making personal revelations. It is not morally acceptable to assume that patients want and consent to care for emotional, social and spiritual distress,

and on the basis of this assumption to instigate deeply personal assessments and interventions.

This is a difficult area in palliative care, where professionals (influenced by writings such as those quoted above) are so strongly motivated towards relief of all distress that they tend to assume that the patient, in consenting to give a history of the illness and in permitting physical care and examination, is also consenting to give a personal life history and is permitting the detailed assessment of psychosocial problems that is generally recommended in texts on palliative care. However, the belief that the relief of psychological distress is a morally good aim and a great benefit to the patient cannot justify attempting to 'treat' these problems without the patient's consent.

The situation in palliative care is confounded by the dependence of the patient on the team for physical care and symptom control. The assumption of consent to psychosocial assessment and intervention leads to the infliction of 'care' on the patient who may find it difficult to refuse this care or even to escape from it, especially if it is 'sold' to the patient in a package in which it is inextricably mixed with physical care and treatment which *is* wanted. It is clearly not morally justifiable to bind different aspects of care together in this way so that it is difficult for patients to select those which they want and to refuse those which they do not want. Yet in the drive for 'holistic' care specialists in palliative care have become almost unaware that they are binding symptom control and physical care together with psychosocial care.

Intrusive and potentially exhausting questioning in the name of assessment of psychosocial and spiritual needs may clearly be a *harm* to some patients. But it is not the only harm that may arise out of attempts to form this close relationship and to 'intervene' to solve the patient's problems. There are some other harms which may befall patients in the course of what is termed psychosocial and spiritual care.

It is true that all people have emotional, social and spiritual needs which if not met can give rise to suffering. However, such needs can be identified only by the patient, and not by professionals. There is a danger that professionals assume some unmet needs on the basis of their own experiences, values and beliefs, or on the basis of what they have been taught that patients need. They may then consider it necessary to explore in detail those perceived or assumed needs which the patient may hitherto be unaware of (and therefore not distressed by) or which the patient may not wish to discuss. For example, a nurse may suggest to a patient that she has an unmet need for continuing sexual contact. The patient, whose libido is reduced by hormone therapy and by her illness, may not perceive this need but may be very suggestible and may also think that as a normal woman she 'ought' to have this need. In fact it may be very difficult for her to have satisfactory sexual contact for many reasons. Thus an iatrogenic unmet need may be generated and give rise to distress.

The patient may also be harmed if the professional concludes, rightly or wrongly, that the patient's response to circumstances derives from some deep-seated 'hang-up' or unfinished emotional business which the professional thinks the patient 'needs' to sort out. In fact the patient may be too exhausted or simply unwilling to confront a long-term 'hang-up' which was not dealt with even in health. Specialists in palliative care often consider that their role is to help patients to achieve a peaceful and meaningful death (see Dame Cicely Saunders quote above). To this end they believe that patients should be encouraged and 'helped' to resolve some issues (often in relationships) that have troubled them for many years in life. As a result of this belief there is a definite risk that the patient may be distressed by being encouraged or persuaded to confront a traumatic issue or relationship. There is a further serious risk that the patient's condition may deteriorate whilst this issue is unresolved and the patient is in a transitional state of even greater distress,

confusion or anxiety. A traumatic death amidst re-awakened and re-lived distress may result. This outcome is clearly a significant harm.

Denial of the diagnosis or prognosis by the patient may be perceived by carers as a need to break down that denial in order to enable the patient to make more realistic life plans and move on towards acceptance of death. As John Hinton remarks that 'peaceful acceptance has remained the seldom questioned common aim' of professionals in palliative care.¹¹ But since denial is known to be a protective mechanism, and thus a coping mechanism, there is a significant risk that the patient may be harmed if it is broken down. This risk is justifiable only if the denial is causing the patient to refuse highly beneficial treatment or if the denial itself is causing emotional distress.

Sometimes it is suggested that distress which the patient is experiencing as a result of family relationships can be relieved by getting the family together in a situation of 'family therapy'. If such therapy is not conducted by someone highly skilled and experienced there is a great risk of harm to all concerned. Even case conferences about the patient's future care can give rise to expression of strong emotions and suppressed family strife may come to the surface. When this happens it can be destructive to all concerned. In the context of palliative care there may simply not be sufficient time and energy from the patient and family to resolve relationship difficulties, so that encouraging people to air their differences may result only in distress.

A more difficult philosophical question is whether sadness, anxiety and a sense of loss in a terminal illness constitute or represent any sort of unmet need or problem which should be 'treated'. It seems more sensible to suggest that they are simply natural and appropriate human responses. If this is the case then it is doubtful that the patient would benefit from their abolition, even if that was wanted and was possible. It makes little sense to say sadness, loss and realistic anxiety are 'needs' which should be met, or that they are

inappropriate responses which should be manipulated in some way into alternative responses that professionals believe are more beneficial.

On the other hand conditions such as depression, which is common, can and should be recognised and treated. Furthermore, anxiety and guilt based on misunderstandings about the aetiology of the illness or about its future progression should be assuaged by giving accurate information and truthful (but not false) reassurance.

In summary one might say that a delicate balance has to be struck between the harms, risks and benefits for patients resulting from the assessments and interventions for relief of psycho-social and spiritual distress.

Whilst professionals may gain a great deal from rewarding close relationships with their patients, especially in terms of job satisfaction and enjoyable and stimulating human contact, there are clearly associated harms for them as well as for patients.

The most obvious is the emotional trauma resulting from repeated losses of patients to whom they have become personally attached. Doctors and nurses are able to maintain emotional well-being in specialist palliative care partly because they do not become personally attached to the vast majority of their patients. This is not to say that the patients do not matter to them, nor that they fail to recognise that each person is unique. Rather, it is to say that they matter because they are patients and only as patients - the relationship remains in the realm of the traditional doctor/patient or nurse/patient relationship, rather than becoming a bond of personal attachment. The formation of relationships with patients which are close and personal enough to solve the patient's psycho-social problems, or 'meet the patient's psycho-social needs', is likely to result in repeated grief and bereavement experiences for professionals. Such frequent and repeated losses would be unsustainable.

Furthermore, there is a great emotional cost in suffering-with the patient to the extent recommended by those who ascribe to the descriptions of

compassion quoted above. Emotional distress and exhaustion are likely to result. Anne Scott disputes this and claims that the more the professional focuses on and becomes imaginatively involved in the patient's circumstances the less the professional will focus on his or her own distress. She claims that such a 'patient-directed' practice will allow an enriching and enlarging of the practitioner's perspectives.¹² But this claim does not take into account the exhausting nature of trying to absorb and understand the distress of another. However much one is concentrating on the patient's distress, this does not decrease the personal impact of witnessing at close quarters the pain and suffering of others. Indeed, concentrating only on the patient may simply submerge the practitioner's distress so that it goes unrecognised until it manifests itself later in mental or physical exhaustion or illness.

Professionals are also likely to suffer feelings of guilt and failure if patient's psycho-social distress is not relieved. The assumption that the role and responsibility of the professional is to enable the patient to attain a meaningful death will inevitably lead to feelings of failure and guilt if patients die apparently still emotionally or spiritually distressed or with continuing strife in relationships. Since it is easier to relieve physical symptoms such as pain than to enable patients to achieve this meaningful death, much more stress and even depression and guilt are likely to result from perceived failure to achieve the goals of psycho-social and spiritual care.

Finally, there is a real possibility that in immersing themselves in their patient's lives and problems, and in forming close relationships with them, health care professionals cease to develop their own lives and talents, especially those outside the work environment. They may increasingly try to meet their own emotional needs at work. The tendency to do this is aggravated by spending long hours at work and little at home. However, the main reason is the emphasis which the philosophy of palliative care puts on responsibility for

the patient's psycho-social well-being which entails close involvement with the patient.

4.1.iv Do the potential benefits to patients justify the potential harms to both patients and professionals?

One must conclude that there are significant harms for both patients and professionals in forming this close personal relationship. Yet one might argue that the benefit of the relationship (for the patient) might justify those harms. In reply to this two points must be made.

The first is that the close relationship required to solve the patient's psycho-social and spiritual problems cannot be achieved. It requires resources of professional time which are not available except for a small minority of patients. It is the case that only a minority of people dying, even in the United Kingdom where specialist palliative care is well-developed, receive care from a specialist team. If it is the professionals' duty to solve patients' psycho-social and spiritual problems, then they are bound to fail. In reality, it makes no sense to say that doctors and nurses have obligations and responsibilities which they cannot possibly fulfil.

The second point is the one mentioned above and made by Christopher Cherry. He explains that, in the context of a managed health care system, the patient matters simply because he or she is a human being. The patient does not matter in a personal sense to the professional, for the personal attributes and qualities of the patient, which he calls 'the particularities of identity', are valued in the context of personal relationships, rather than in the patient/professional relationship necessary in such a system. He states:

'Ideas such as love, devotion, caring for, suffering with, feeling compassion for and empathising with are most at home where there is minimal abstraction from identity, where alleviation of misery, deprivation, sickness and suffering falls within the frame of a pre-existing relationship which has started

and developed independently and of which it cannot therefore be the point. Where such issues are the sole reason for a relationship the moral epistemic concepts are significantly modified; a modification which amounts, in essence, to an abstraction from identity....

Carers and writers on caring often give themselves a bad time because they mistake what is a logical impossibility for a shortfall in compassion. They do not adequately distinguish between the relief of suffering as something called for within the course of a relationship of which that suffering is just one feature and the relief of suffering as the essence of a relationship, as the only reason why it should be there at all. With this goes a failure to distinguish between the logics of "non-abstracted" and "abstracted" caring, and hence a sense that if only they tried hard enough they could offer the first and not merely the second.' He goes on to state that

'This value (non-abstracted caring) cannot conceivably exist within a managed health care system, although it can of course co-exist - in the community, for example - with other values the system incorporates or generates. At the same time, many who believe in the centrality of this non-transferable value believe also that its unavoidable sacrifice is a price regularly (and increasingly) worth paying for the institutional goods and professional skills the system makes possible.'¹³

His argument is convincing. From it and the above discussion one must conclude that the close personal relationship which the philosophy of palliative care advocates to the end of relieving psycho-social and spiritual distress is neither achievable nor desirable. 'Non-abstracted' caring, which is caring on a personal level with the degree of intimacy which it requires, is not an appropriate end in a managed health care system.

The very provision of palliative care services carries an emotionally important message to patients about their value to the rest of the community. Christopher Cherry makes this point in a footnote, where he comments that

people want to know why it should be thought worthwhile to try and make them better, and that they may also care about who makes this happen.

Experience in palliative care shows that patients are touched by the fact that the community continues to provide for their needs, even if inadequately, when clearly there is no prospect of recovery or return to what might be regarded as a useful and productive life. It matters to them, and in some way consoles them, that members of the community are willing to fund their care, either charitably as an extra to the NHS provision, or by taxation via NHS services. Charitable provision is arguably an even stronger indication to patients that their community still considers their welfare important, and it is interesting to note that even NHS specialist palliative care services are reliant on charitable provision to some extent.

It may be that the provision of care for these patients by the community demonstrates to them that they are in some way valued, even if that is an 'abstracted' value in the sense that the community must value them as human beings and cannot value them in a personal sense. It seems to follow that being valued by one's community enables one to retain a sense of self-respect in illness, which must be essential to well-being. Howard Brody, in his book 'Stories of Sickness', comments that self-respect is fundamentally a social concept - it relies on social reciprocity. He further explains that self-respect is an attribute of persons that figures centrally in how they respond to sickness. In order to maintain their self-respect they need affirmation of their altered life-plans by others, and those chronically sick or handicapped 'need a very strong and repetitive symbolic reassurance from the state that their lives are viewed by their fellow citizens as being worth living.'¹⁴ The provision of specialist palliative care provides this reassurance from the community.

Returning to Dame Cicely's comments as initially quoted - 'you matter because you are you, and you matter until the last moment of your life.'; if we interpret these words as meaning that the patient matters to the community and

so is cared for via health care professionals, then this interpretation makes sense in the context of the NHS. The patient, abstracted from his or her actual identity, matters to the community which demonstrates this by providing care. The health care professionals are the agents of the community's care for its members. In contrast it is much less plausible to say that the particular patient is cared for in a 'non-abstracted' sense by the particular health care professional. This latter interpretation, popular as it is amongst specialists in palliative care, is unrealistic, and if it were lived out in practice would probably lead to harm both to patients and staff.

The first question of 'thesis 4' on psycho-social care was whether doctors and nurses should seek to control the patient's psychological and social and spiritual problems as part of their remit. Since this requires the establishment of a close personal relationship which I have concluded is morally undesirable, then either an alternative way to achieve the goal must be achieved, or I have to conclude that the goal as stated is unacceptable, and so must either be abandoned or be modified in some way. Rather than modifying or abandoning the goal, it is often suggested that the patient's psychological and social problems can be resolved by the introduction of another kind of professional who tries to establish a different but still special relationship with the patient. This different kind of relationship is that which is said to occur between 'client' and 'counsellor'.

4.2. An alternative: the client/counsellor relationship.

The last twenty years has seen a rapid rise in the popularity of 'counselling' as a way of dealing with human distress, traumatic life events, or difficulties with relationships. As such, it has everything to do with psycho-social care, and perhaps something to do with spiritual care if the latter is taken as helping a person in a search for meaning. Thus it is often advocated as a way of helping the dying.

Counselling occurs in the context of a well-defined relationship which has a contractual basis. It is now said to be a set of skills which can be (and it is argued should be) taught. It is not a relationship which naturally evolves between people, so that counsellors have to be trained to fulfil their role (and clients have to agree to their role). Thus courses for professional counsellors are available, and increasingly similar courses are recommended for health care professionals.

The meaning of the term 'counselling' has become blurred by its many different uses. The British Association for Counselling states that the counselling task is to give the client a chance to explore, discover, and clarify ways of living more satisfyingly and resourcefully. This goal is achieved via the special relationship between counsellor and client.

The counsellor sees the client for pre-arranged sessions lasting for a set time. This is not an open-ended, flexible relationship, but is clearly contractual. Whereas in health care a patient is frequently permitted to take more time than the allocated outpatient clinic allocation, and patients are free to ask for help when they feel they need it, in counselling the schedule of meetings is agreed in advance and the client is expected to adhere to it as a foundation of the relationship. Access to the counsellor is certainly not based on client-perceived need.

The idea of the relationship is that the counsellor will help the client find the solution to the client's problems, or will help the client to resolve the issue which is causing distress. However, the responsibility for working on the problem definitely lies with the client - the counsellor is regarded as having a facilitative role only. This means that the counsellor cannot be held responsible for the outcome of the relationship. This is in contrast to health care, where a professional is held accountable for the outcome of treatment.

Four concepts lie at the heart of counselling. They are empathy, congruence and unconditional positive regard, and a non-directive approach, all of which are morally problematic.

Empathy may be described as the ability to understand and share the emotions of the other person so as to enter their perceptual world, and to live in that world without making judgements. The moral problems of empathy are closely linked to those of compassion as described above. By listening to the client's story and interpretation of events, the counsellor is expected to empathise with the client. But empathy entails understanding the meaning that emotions and experience have for the other person. It is doubtful if even very close friends or marital partners can achieve this level of understanding, so it seems literally incredible that it could be achieved by a counsellor listening to the client for a few fixed and often fee-paying sessions.

In the context of palliative care it seems particularly unlikely that the counsellor can really understand the client's feelings regarding the terminal illness. Understanding usually requires having had a similar experience. The counsellor is very unlikely to have had any personal experience of receiving a fatal diagnosis, nor of the reality of confronting death in the near future, nor of the weakness and exhaustion the illness may bring, nor of the depression which afflicts many patients at some time. Without such understanding the counsellor cannot possibly enter the perceptual world of the patient. So perhaps the goal of empathy, even if desirable, is unattainable.

Despite this obvious problem, it is thought to be important that the client is convinced that the counsellor is listening and empathises. To this end the counsellor is told to adopt certain non-verbal behaviours such as postures towards the client, positions for chairs, level heights for conversation and even amounts of eye contact. Verbally, the counsellor is expected to keep reflecting back to the client the last phrase of sentences or a paraphrase of what the client has said. This is intended to demonstrate that the counsellor is listening,

and also allows the client to clarify his statement, and perhaps to think about it again. The counsellor is also expected to demonstrate empathy by statements such as 'that must have been difficult for you'.

The problem with such trained behaviour is that it is easily recognised as such, and when so recognised the client may (quite reasonably) lose faith in the genuineness of the counsellor. The client may also feel that talking to the counsellor is like speaking to a rock face and hearing the echo, whereas those supporting counselling would say that the counsellor is more like a soft reflective mirror.

The aspects of counselling associated with achieving empathy have, perhaps unfortunately, been described as a set of skills called 'listening skills', or 'communication skills' which many health care professionals have now been taught. Those professionals who were good communicators would have encouraged and enabled the patient to tell his story naturally. Those who were not would definitely have inhibited the patient in this respect. The latter group may or may not be helped by being taught such skills - the worst possibility is that they sound to the patient like a patronising computer program.

The concept of offering only unconditional positive regard is even more problematic, for it means being non-judgmental. If the counsellor is truly intellectually non-judgmental as well as verbally non-judgmental then the counsellor must hold no personal values, or at least must not believe that any particular way of living and dying is any better than another. The counsellor must be a post-modernist. But most health care professionals working with terminally ill patients do believe that some ways of living and dying are better than others. For example, they do seem to believe that peaceful acceptance of death (see Hinton quote in section 4.1.iii.) is better than bitter striving against it or denial. They tend to regard healing fraught relationships as preferable to dying with ongoing family tensions and strife. Health care professionals from their experience will know that some ways of living the end of one's life seem to

give rise to greater distress than others. Thus health care professionals, and even professional counsellors, are very unlikely to be non-judgmental intellectually.

Of course it might be argued that whilst they will inevitably have their own views and values regarding better and worse ways of dying they should not express those views verbally. Certainly in the traditional doctor or nurse/patient relationship the professional inhibits any desire to tell patients what they may think of the way the latter conduct their relationships and religious lives. On the other hand they have a professional duty to inform patients of life-styles which are injurious to health, and they may even have a duty to try to get patients to change those life-styles.

Yet in the context of the special relationship of counselling the counsellor should not be verbally judgmental of the patient's way of living and dying, however injurious to himself or those around him. This is in contrast to both the professional/patient relationship and close personal relationships. The counselling role is, in this sense, very passive. Moreover, since in this regard it does not resemble any relationships which have evolved naturally in society it is also artificial. People will not behave naturally in a totally non-judgmental way - they will have to be trained to do so.

Consistency requires that the non-judgmental counsellor should also be non-directive towards the client. This concept is a cornerstone of counselling. The counsellor must not tell the client what he or she 'ought' to do. Indeed, the counsellor must guard against giving any such hints to the client, leaving the latter to work it out for himself.

In contrast the idea of congruence, which is linked with genuineness, seems quite inconsistent with being non-judgmental and non-directive. For a person is said to be congruent when he is accurately aware of what he is experiencing, and when he communicates to another fully and honestly exactly what he is experiencing. In counselling congruence is thought to be a good

thing for people. It is seen as a goal for the client, and so presumably also for the counsellor.

There are several difficulties with this idea. Firstly, it is not always possible to be sure what one is thinking or experiencing in a given situation because our motives and emotions can be complex and inaccessible. Secondly, if congruence is 'being what you are' at all levels of feeling and awareness, and then communicating that to another, then there is surely a risk of bringing a relationship (of whatever nature) to an abrupt, unsatisfactory and possibly destructive end. People would need to be deeply attached at a personal level to withstand the full blast of congruence! In the context of the relationship between the patient and the health care professional it would not be acceptable to be congruent, since this might entail expressing strong disapproval, inappropriate affection, or worse still sexual attraction!

Finally, it must follow that it is impossible to be both non-judgmental, non-directive and yet congruent at the same time. One would have to be a true post-modernist, fully committed to the view that no one way of living and dying is any better than another, in order to be genuinely non-judgmental and non-directive with a client. This view is not compatible with being a health care professional, for the latter certainly do (and should) have views about ways of living and dying which are most compatible with health.

This brief description of the central precepts of counselling leads to two conclusions. The first is that it seems logically impossible to combine these concepts and associated 'counselling skills' in any human relationship. The second is that it is morally unacceptable to attempt to introduce them into the professional/patient relationship of palliative care. Indeed, patients would probably be harmed by health care professionals becoming enmeshed in role conflicts through attempting to be a counsellor. In order to pursue counselling both the patient and the health care professional would have to change roles, and this is simply not a practical possibility. Therefore, the artificial relationship

of counselling should be rejected as a method for health care professionals to solve the psychological, social and spiritual problems of their patients. Counselling should not be regarded as a way to achieve this goal.

4.3. Should the goal of controlling the patient's psycho-social and spiritual problems be abandoned or modified?

The concept of *controlling* the patient's psychological, social and spiritual problems should certainly be abandoned, for it would entail controlling the patient's emotions, relationships and values. This latter idea is deeply counter-intuitive, principally because it hints of brainwashing and is certainly destructive and disrespectful of the patient's autonomy.

Furthermore, it is exceedingly unlikely that health care professionals could ever attain this undesirable goal, since they cannot personally meet the patient's psycho-social and spiritual needs, and the participation of patients themselves is essential in relieving such problems - no technical solution administered by professionals and received by patients could ever be successful.

This leaves us with the question of whether the goal should be completely abandoned. In that case a policy could be adopted whereby health care professionals see the patient's emotional, social and spiritual state as strictly the patient's affair, and they cease trying to address any problems which patients might raise. Obviously, answers to enquiries about the illness and its likely progress, together with realistic reassurance to counter fears should always be given.

This solution seems excessively restrictive. For professionals will always want to try to alleviate the emotional distress of patients, and from their experience they will have learned that certain approaches of other patients and families proved helpful in similar circumstances. This is not to say that there is a professional skill in alleviating the patient's emotional distress, but simply to say

that professional experience combined with ordinary human contact can be used to alleviate such distress. In other words, professionals can use their common humanity to comfort the patient, through companionship, in combination with giving advice based on the relevant professional knowledge of similar situations.

Thurstan Brewin has termed this sort of professional contact 'friendly professional interest' or FPI. He says the following:

'In a 'hopeless situation, tender loving care is not enough, concern and compassion are not enough. Somewhere along the road between old-fashioned TLC and new-fangled counselling, lies something as old as Medicine itself, which I have called here friendly professional interest. For the doctor - whatever else is said or done - FPI is the basic minimum. It need not take up a lot of time; and it does not need special training beyond what ought to be given in every Medical School. Lack of it is a common cause of low morale and misery.'¹⁵

He recommends a regular but informal visit, probably lasting only a few minutes, and perhaps as little as once a week. He stresses that the professional's approach should be easy, friendly, yet interested and professional. He is not recommending that the professionals step out of role, but rather that they should strive for certain qualities. Of professional friendliness he says the following:

'The ability of one person to lend strength to another (not just in medicine, but also in the way that a good leader does, for example when men or women face possible death in some other kind of threat or disaster) is a mystery that nobody entirely understands. But, for my money, in medical situations - especially advanced cancer - just being natural and friendly has a lot to do with it. Look at the way some hospital cleaners and porters boost the morale of frightened patients. Do they have special understanding, spiritual inspiration, or powers of leadership? Not usually. How many communication

and counselling courses have they attended? None. They are just natural and relaxed, with friendly good humour and no awkwardness or embarrassment....

Professional friendship is not quite the same as ordinary friendship, but much that applies still holds true. A friend is warm and welcoming at each meeting. A friend pays small compliments. A friend has at least some idea of how the patient feels; some idea of what she has been going through; understands how her moods may vary (maybe hope one day, despair the next). A friend listens; knows the value of a little praise; asks how she can help. A friend is just as ready to talk seriously (if that is what the patient wants) as to joke or gossip. A really supportive friend doesn't go over the top emotionally, but is always concerned; doesn't stay too long; knows when to be silent; doesn't ask too many questions. A doctor should follow suit.¹⁶

This powerful extract really says it all. Patients want doctors who are genuinely concerned and understanding, as a friend might be, not those who have simply been trained to look concerned and understanding. Courses on counselling and communication skills cannot teach the attitude and qualities that Thurstan Brewin is describing.

At the same time the patient must be able to remain confident in the professionals' competence. Dr. Brewin stresses the importance of continuing to examine patients rather than relying exclusively on investigation results. For gentle and respectful but business-like and efficient examination, besides yielding clinical information, stresses to patients 'that they have not been abandoned, that the doctor is still anxious not to miss anything that could be corrected or prevented. And there is also a chance to lay firm, calm, caring, unhurried hands on all parts of the body, blending professional efficiency with the age-old power of touch to give comfort; at the same time giving a clear signal to the patient that we don't think of him as in any way repugnant, unclean or infectious.'

On the subject of interest it is important to stress that doctors ought not to be less interested in patients because a diagnosis has been made and the prognosis is very poor, so that cure cannot be offered. Dr. Brewin also suggests that professionals should be interested in the patient as a person - most have some events in their lives which are of importance and general interest, and interests in patients as people often leads to increased respect for them.

Howard Brody, in 'Stories of Sickness', explains further how ordinary professional contact in listening carefully to the patient's story can help patients and professionals to understand the meaning of the illness for the patient. For the meaning of the illness has much to do with spirituality, and peace of mind for the patient and self-respect. He explains that:

'being sick includes experiencing a special and generally very frightening sort of disruption in the unity of body and self, and it also includes undergoing an alteration in one's social role and in the way one relates to others and vice versa. It is unlikely that these essential features of the sickness story will be elicited by the standard medical history, but they may be better understood if the patient is asked to relate the meaning he attaches to the illness.'¹⁷

In his foreword to 'Narrative Based Medicine', he states that 'Some of medicine works very well precisely because it treats people as being all the same; and some of medicine works very well because it treats people as being all equal.'¹⁸ His point could be expanded as follows. In both clinical medicine and ethics we must appreciate both the similarities between cases and the differences between them. Hence the relevance of casuistry. Working out in what way cases are the same and also being aware of their uniqueness and the differences between them is crucial to both casuistry and clinical medicine. The patient's unique story is part of the case history. It is evidence. It goes beyond straight factual evidence because it usually contains insights into the meaning of the illness for the patient.

Howard Brody explains that doctors, in the course of their normal work, can make the meaning of the illness more positive for the patient in three ways:

'First, the illness experience must be given an explanation of the sort that will be viewed as acceptable, given the patient's existing belief system and worldview. Second, the patient must perceive that he or she is surrounded by and may rely upon a group of caring individuals. Third, the patient must achieve a sense of mastery or control over the illness experience, either by feeling personally powerful enough to affect the course of events for the better or by feeling that his or her individual powerlessness can be compensated by the power of some member or members of the caring group (such as the physician).'¹⁹

He is sceptical that courses on ethics can make doctors more compassionate, and considers instead that doctors should be taught always to listen to the patient's story with 'the air of one trying to recognise - trying to make a link between their own humanity and the humanity of the anguished individual before them'.²⁰ He suggests that this practice should be encouraged in ordinary medical education, and should be integral to clinical work.

4.4. Conclusions.

1. Patients' consent should be sought to in depth questioning and interventions regarding their psycho-social and spiritual welfare.
2. A close personal relationship between patient and professional is potentially harmful to both, unachievable and not sustainable. It is morally undesirable.
3. The requirement for the development of a close personal relationship between patient and professional should not be part of the philosophy of

palliative care, nor should the development of the client/counsellor relationship be advocated.

4. The goal of controlling the patient's psychological, social and spiritual problems should be abandoned.

5. It should be replaced by the idea of alleviating those problems within the context of the traditional professional/patient relationship, using ordinary human interaction, sensitive explanations and advice based on professional knowledge and experience, and friendly professional interest.

References to Chapter 4

-
- ¹ World Health Organisation. Cancer Pain Relief and Palliative Care. Report of a WHO Expert Committee. Technical Report Series 1990 No. 804
- ² Saunders C. Foreword to The Oxford Textbook of Palliative Medicine. Oxford: Oxford University Press, 1993.
- ³ Scott A. Nursing, narrative and the moral imagination. Narrative Based Medicine. ed. by Greenhalgh T. and Hurwitz B. London: BMJ Books, 1998, p. 152.
- ⁴ Tschudin V. Ethics in Nursing. London: Butterworth/Heinemann, 1993, p. 1.
- ⁵ Churchill L. Ethical issues of a profession in transition. American Journal of Nursing, 77 (5) pp. 873-5.
- ⁶ Tschudin V. Ethics in Nursing. London: Butterworth/Heinemann, 1993, p. 4.
- ⁷ Nouwen H. J, Mcneill D. P, Morrison D. A, Compassion. London: Darton, Longmand and Todd, 1982.
- ⁸ Tschudin V. Ethics in Nursing. London: Butterworth/Heinemann, 1993, p. 10.
- ⁹ Cherry C. Health care, human worth and the limits of the particular. Journal of Medical Ethics 1997; 23: p. 310-314.
- ¹⁰ Vachon M. Emotional problems in palliative medicine: patient, family and professional. Oxford Textbook of Palliative Medicine. Oxford: Oxford University Press, 1993. p 586.
- ¹¹ Hinton J. The progress of awareness and acceptance of dying assessed in cancer patients and their caring relatives. Palliative Medicine, 1999; 13: 19-35.
- ¹² Scott A. Nursing, narrative and the moral imagination. Narrative Based Medicine. ed. by Greenhalgh T. and Hurwitz B. London: BMJ Books, 1998, p.153.
- ¹³ Cherry C. Health care, human worth and the limits of the particular. Journal of Medical Ethics 1997; 23: p. 310-314.

¹⁴ Brody H. *Stories of Sickness*. London: Yale University Press, 1987, pp. 540 & 132.

¹⁵ Brewin T. *The Friendly Professional*. Bognor Regis: Eurocommunica Publications, 1996, p. 74-79.

¹⁶ Brewin T. *The Friendly Professional*. Bognor Regis: Eurocommunica Publications, 1996, p. 76.

¹⁷ Brody H. *Stories of Sickness*. London: Yale University Press, 1987, p. 184.

¹⁸ Brody H. *Foreword to Narrative Based Medicine*. ed. by Greenhalgh T. and Hurwitz B. London: BMJ Books, 1998, p. xiii.

¹⁹ Brody H. *Stories of Sickness*. London: Yale University Press, 1987, p. 6.

²⁰ Brody H. *Stories of Sickness*. London: Yale University Press, 1987, p. 183.

Chapter 5

Rationing

Thesis 5: that within health care there ought to be a just distribution of resources to palliative care, and then among terminally ill patients regardless of their illness.

Introduction.

This thesis comprises two separate assertions which relate to the two processes which occur in the distribution of health care resources. The first, 'that there ought to be a just distribution of resources to palliative care as a whole', relates to the process of macroallocation, whereby the available resources are distributed between different areas of health care. Resources are allocated to different specialties and for different treatments.

Macroallocation requires differentiation between services and treatments.

The second assertion, 'that there ought to be a just distribution of resources among terminally ill patients regardless of their illness', relates to the process of microallocation, whereby the benefits of a service or treatment are distributed between individual patients. Assuming that the capacity of patients to benefit exceeds the available supply of the service or treatment, then health care providers must decide which patients should receive the service or treatment, and which should not. Microallocation requires differentiation between patients. In the following discussion these two areas will be considered separately.

5.1 Macroallocation and palliative care.

Specialist palliative care services currently compete with other services for their share of National Health Service resources. Judgements are currently made by Health Authorities, and in the future perhaps by Primary Care Trusts, regarding the proportion of their funds which should be spent on providing specialist palliative care. The NHS is cash-limited since it is funded from taxation and so constraints of financial and human resources will always exist. Despite promised increases in health care spending, resources will remain insufficient to provide all services and treatments from which patients could benefit. Indeed, the costs of health care are likely to increase as life-prolonging treatments enable patients to live longer, but frequently in a dependant condition and reliant on continuous health care input. So now and in the future services must compete with each other for a share of limited resources.

5.1.i Evidence of benefit.

In order to compete successfully evidence of benefit from the palliative care service is required. Researchers have found it difficult to prove and demonstrate the benefits of specialist palliative care as compared with conventional care, both in the context of comparative studies and randomised controlled trials.¹²³ Despite the failure of numerical scales used in such studies to demonstrate a clear benefit from specialist palliative care services over conventional care, there is a widespread belief that specialist services do provide better care.

This belief is probably based on shared experiences of those dying in specialist care - the reputation of specialist services for providing excellent care, as judged by patients and families, has led directly to great charitable support for the specialist services. In contrast it is obvious that the environment and priorities in busy acute medical or surgical wards are not

conducive to calmness and conscientious, meticulous symptom control and careful explanation of the disease process. It may also be the case that health care providers and the commissioners of care recognise that the benefit sought from specialist palliative care is very difficult to demonstrate by numerical scales. They have therefore to date accepted at face value the benefit from specialist services.

Duncan Keeley in an editorial on the problems of rigorous assessment of palliative care services⁴ comments that 'wisdom and compassion are needed when evidence is lacking'. He notes that randomised trials in palliative care are fraught with problems and that this may be why assessment by such trials has not provided conclusive evidence of the superiority of specialist services over conventional care. He asks 'Can we insist on evidence of effectiveness from randomised controlled trials for support services which are of such evident human desirability as to render their deliberate withholding difficult or unethical? If we want to know whether five years of pill taking for high blood pressure will reduce our risk of stroke we are unwise to rely on our own or our doctor's common sense impression and want evidence from randomised controlled trials. But if our loved one is dying and wishes to die at home, how much evidence do we need that skilled home nursing available around the clock would be a good idea?' Dr Keeley is making a plea for commonsense in the commissioning of care, but he is also making a statement about the importance of wisdom and compassion and acknowledgement of a 'broad and inclusive conception of the role of health care services in reducing human suffering'. This statement is very much to do with societal values. In particular, it reflects the high value people tend to put on being comfortable at the end of life, and on being able to die where one chooses.

Richard Smith, editor of the 'British Medical Journal', makes a similar plea for recognition of the value judgements which are inevitable in the

process of macroallocation. In an editorial on rationing⁵ he notes that decisions regarding whether or not drugs or services should be made available via the NHS are often 'dressed up' as technical arguments, but are in fact value judgements. He states that 'The NHS has survived so long because it has been an institutional expression of deeply held values. But we cannot have universal access free at the point of delivery, comprehensiveness, and high quality on current resources. If the government wants to sustain the NHS then it needs to engage the public in deciding how to trade those values.' In this editorial, entitled 'Stumbling into rationing', he is calling for public debate regarding macroallocation. He is suggesting that the public should have some say on how health care resources are spent. This argument is compelling because the resources are derived only from the public via taxation and the service is for the benefit of the public.

In the area of specialist palliative care, it is largely public demand and approbation of the existing services which has led to pressure to increase their availability, rather than evidence from randomised trials or comparative studies. To date this pressure has been sufficient to increase public spending on palliative care, albeit at a gradual pace. But public demand due to perceived effectiveness of specialist care is unlikely to be sufficient in the future to enable specialist palliative care to compete successfully for resources. It is likely that bodies such as NICE, the National Institute for Clinical Effectiveness, will require evidence of benefit as a condition for funding of services and treatments, and specialist palliative care may then come off badly when its benefits, in so far as they can be demonstrated via trials, are compared with the benefits of other treatments. The difficulties of such comparisons are discussed below, section 5.1.vii.

5.1.ii The proposed future role of specialist palliative care.

Since specialist palliative care as it has been provided to date is considered to be beneficial it has been suggested that it should be made available for all patients.

Currently, specialist services reach a varying proportion of terminally ill cancer patients. The Calman-Hine report on cancer services⁶ has recommended that specialist palliative care should be available to all patients who need it. If all terminally ill cancer patients were to receive the service, clearly more resources would be required.

It has also been suggested that specialist palliative care should be available to all terminally ill patients regardless of their diagnosis. In 1992 a report from the Department of Health recommended the provision of palliative care services to all who need them⁷, and this was reiterated in a National Health Executive letter to Health Authorities⁸. As so often happens, these policy statements were not followed by provision of funding to provide the service for every terminally ill patient, nor even for a majority of such patients, but only for a minority. It is therefore not surprising that specialist palliative care is currently not available to the majority of patients dying from diseases other than cancer. Julia Addington-Hall noted in 1998 in a report for the National Council for Hospice and Specialists Palliative Care Services that patients with non-malignant but terminal diseases were very unlikely to receive specialist palliative care, even from a hospital support team.⁹

In a presentation on behalf of the Department of Health in February 2000, Sue Hawkett, specialist palliative care nurse advisor to the department, quoted the following aim 'Within the context of a Quality Improvement Framework, ensure that appropriate information, psychological and social assessment and subsequent support, with *access to specialist palliative care*, are provided to *all* those who are affected by cancer and delivered to those *who need it.*' [my italics].

It is clear that the Department of Health requires that specialist palliative care should be available for all patients 'who need it', but the funding available is sufficient for only a minority of terminally ill patients (regardless of diagnosis). This raises the important question of how it is to be decided that a patient 'needs' the service. Much turns on the meaning of the word 'need' in this context - policy statements using the term without any description of the sense in which it is used are meaningless. It will be tempting for service providers to describe the notion of 'need' so as to allow them to provide care for all the patients who fall into their defined category of need. The concept of need gives rise to considerable problems in health care rationing, both in macroallocation and microallocation. It is discussed more fully in section 5.1.vi.

5.1.iii The goals and moral necessity of rationing.

Rationing is an imposed distribution system which has two goals; firstly to ensure the best use of resources by using the most cost-effective treatments and secondly to ensure a just or fair distribution of treatment benefits. A rationing system for the NHS is required now and will continue to be required in the future. At present, there is no such system and the current resource allocation process could best be described, as Richard Smith comments, as 'muddling through'.¹⁰ This rather haphazard method results in resource allocation which is greatly influenced by political expediency, pressure groups, and the media. It is unlikely to achieve the goals of rationing.

It is clear to most people that financial constraints must be imposed on the expenditure of resources, and that because of those constraints rationing is necessary. Since rationing entails denying beneficial care to some patients, proposals for means to avoid it are sometimes made. Two mechanisms are

suggested: firstly, increasing public funding, and secondly, narrowing the boundaries of 'health care'.

The first suggestion entails finding ways of increasing the funding available for health care so that patients are not denied any intervention, especially life-prolonging treatment, from which they could benefit significantly. It is sometimes argued that there is an obligation to provide health care which overrides almost all the other obligations of a community towards its members. For example, John Harris argues that there is an obligation to provide health care which overrides almost all the other obligations of a community.¹¹ He states that:

'the obligation to provide health care, and in particular life saving health care, to each and every citizen, *regardless of its effect on the aggregate health status of the community*, takes precedence over the obligation to provide defence forces against external (and often mythical) enemies.' (my italics).

Harris seems to be suggesting that we should spend money on trying to 'save' the life of a person, perhaps even for only a few months, regardless of the effect of this expenditure on the health status of the rest of the community, and regardless of the other social benefits which must be foregone to fund that 'life-saving' care. Very few people would agree with him. Not only would his suggested policy be associated with serious social disadvantages in terms of paucity of education, defence etc., but it would also result in very little expenditure on palliative interventions because of the overriding priority status given to prolonging lives. Neither politicians, nor the public, nor health care professionals are likely to agree with Harris' argument and its consequences. Financial constraints on health care expenditure will continue.

The second suggestion, of narrowing the boundaries of health care seems a more promising mechanism. Setting limits to or re-defining what the

NHS should provide are necessary procedures whatever health service a country provides for its population. A process of continually narrowing the scope of health care to be provided would reduce health care costs. For example the elderly, even if terminally ill, who require 24 hr nursing care but not frequent medical intervention, are no longer entitled to that care free of charge in a long-stay hospital. Instead, they have to fund their own care in privately owned nursing homes if they have more than a modest amount of savings. Yet even this very significant narrowing of NHS provision has not enabled sufficient funds to be available to provide all the treatment and care from which patients could benefit. Even if there were a continuous process of setting greater limits to the scope of NHS provision financial constraints would still exist. Moreover, reducing the scope of the health service is itself a disguised form of rationing.

Financial constraints will inevitably cause some people to be denied care and treatment from which they could benefit. It is this fact which the public, patients and health care professionals find most difficult to accept and which causes them to try to deny the fact that rationing is morally necessary and to evade attempts at implementing it. When faced with the fact that we cannot have a particular treatment or aspect of care because of cost, or that we cannot provide what we consider a beneficial treatment for a patient, it seems that we all become aware only of what we cannot have or provide. We seem to become oblivious to the fact that judicious use of resources enables a decent minimum standard of treatment and care to be provided for everyone.

Health care professionals, the public and politicians need to be reminded frequently of the consequences of *not* rationing health care. Rationing is an externally imposed distribution system which endeavours to derive the greatest benefit from medical technology and care and to distribute that benefit in a way which is as just and fair as possible. If health care

rationing is not undertaken, then it is very clear that we will not make the best use of resources and unjust distribution of health care benefits will occur. Turning a blind eye to these outcomes is morally unacceptable. Failure to ration health care will lead to less than optimal use of resources and injustice.

Rationing is necessary so that each person has the best chance of obtaining optimal treatment when he or she becomes ill. People behind a 'veil of ignorance' would wish to dwell in a community where the best use was made of health care funded by that community, and where benefits were fairly distributed. Politicians, health care professionals and the public will need to be continuously reminded of this fact in order to bolster their determination and courage to formulate and implement rationing policies. The community as a whole needs firstly to believe in the practical reality of capacity-for-benefit exceeding supply, and secondly to believe in the importance of justice in the use of public resources for health care.

Unfortunately politicians have remained very reluctant to initiate and support the implementation of explicit rationing because denying people beneficial care and treatment is unpleasant and is not a political vote-winning activity. Therefore others in society, probably health care professionals, will have to take responsibility for it. This may be preferable to a situation where those unfamiliar with the benefits and harms of treatments have the authority and power to allocate resources. Health care practitioners working in palliative care should therefore participate in the rationing exercise, striving for optimal utilisation and just distribution of resources. Health care professionals and the public should be involved in formulating rationing policies. This would leave government with the role of ratifying the policies!

It is necessary to have a system of rationing, and one which produces just outcomes, or at least outcomes less unjust than those resulting from the present practice of 'muddling through'.

5.1.iv. Conflicts of responsibility perceived by doctors.

Whilst doctors may be able to accept the moral arguments in favour of rationing, they may still be uncomfortable with it because they consider that a duty to pursue the goals of rationing conflicts with their duties to individual patients. This moral discomfort arises because they think that to carry out the one duty they necessarily fail to carry out the other. This sort of unease is distressing for them and can also be demoralising and stressful. It is the sort of unease we all experience when, in order to fulfil one duty which we consider very important, such as preventing serious harm to a person, we have to renege on another important duty such as fulfilling a promise made to another person.

Doctors often consider that they have a duty always to do the best for the particular patient in front of them, or to act in that patient's 'best interests', and that they have (or ought to have) clinical freedom to carry out that duty. Professional codes of conduct reinforce this idea - they stress that doctors should act in their patients' best interests, and this is made particularly clear in the case of the incompetent patient. Two separate issues are at stake here; firstly, that of clinical freedom, and secondly the duty to do what is in the particular patient's best interests.

Clinical freedom is the notion that the doctor should be free to provide whatever treatment he or she considers to be in the best interest of the particular patient. It is a strongly held ideal, and some doctors might even regard it as some sort of right. Thus they might regard this right to prescribe as they consider best for the patient to override other considerations, such as the welfare of other patients or the community. For example, in the context of palliative care they would prescribe bisphosphonates for bone pain without the extra funding needed to support these expensive but effective drugs. This would result in overspending, which would have to be compensated for by

cut-backs in other parts of the palliative care service, or from other departments in an NHS Trust.

Clinical freedom obviously can never be absolute; it must always be constrained by law. Clinical freedom can be considered similar to the idea of freedom in a democratic society. In such a society it is considered right that people should be free to pursue their own ideals and life plans provided they function within the law, which exists to protect the interests of all members impartially. Even in a democracy there are limits to personal freedom. These limits may be imposed by law. For example, we must pay taxes, wear seat belts and obey speed limits in cars. These limits are necessary if we are to live together successfully and safely in a community. There are also moral limits to personal freedom. We should not do things which harm others, even if such actions are not proscribed by law. Such limits are 'imposed' by the moral law. In a similar way, the freedom of clinicians ought to be limited by the law and by the majority opinion of their informed colleagues in other specialties and by team members. I shall later develop the communitarian idea of the team as a constraint on individual clinical freedom. At this point I am by no means suggesting the removal of clinical freedom but only its responsible use in a team spirit.

Sometimes the notion of clinical freedom is described in terms of autonomy of physicians. But it should be noted that 'Granting physician's clinical autonomy is justified by reference to the patient's interests, not the physician's'.¹² Thus the foundation of the concept of clinical freedom or autonomy is the good of patients, not physicians. So the interpretation of the meaning of clinical freedom must be made in the context of the good of patients, which means patients in a general sense rather than just one particular patient in front of just one particular physician. In other words, the 'clinical freedom' argument against rationing is really secondary to the 'patient's best interests' argument, which I shall now consider.

Doctors who believe that they have a single or overriding obligation to do the best for the patient before them, regardless of the resource consequences, tend to argue that the nature of the special relationship between them and that patient requires that they do not in any way compromise that patient's interests, even in the interests of other patients.

The 'special relationship' argument can be interpreted in two ways. In terms of the first way, which I shall call the 'advocacy' interpretation, the doctor should be loyal to his individual patients and advocate their best interests. It should be noted that one acts as advocate for someone to someone else. To whom is the doctor advocating the patient's interests? If the doctor is pleading the cause of his patients to the commissioners of health care, for example by arguing coherently and honestly for more resources for specialist palliative care on the grounds of its benefits for patients, then clearly this is a professional duty. On the other hand, if the doctor is using the advocacy argument to expend resources without agreed provision of those resources, so that other patients must be deprived of some other benefit to fund his treatment, then he is judging that the duties of advocacy override the duties of general justice. Such a judgement cannot be justified. There are analogous cases outside health care. For example, a mother has duties of advocacy towards her own children, but if she happens to discover that her child is bullying others at school then the duty of general justice, to strive to stop her child bullying others and thereby protect other children, overrides the duty of advocacy.

The second interpretation of the 'special relationship' argument is based on the idea that the foundation of the special relationship between doctor and patient is an implicit promise by the doctor to the patient. I introduced this idea and argued for its validity in chapter 2. If the doctor implicitly promises to do the best for his or her patient, as opposed to the

generality of patients, then it is not at all obvious that a duty of general justice will override this.

Clearly there are elements of both advocacy and the promissory relationship in the doctor-patient relationship. Arguments about which is the more important are unhelpful. Instead the discussion should be moved on by asking the question: who is the doctor's patient? To put it another way, to whom does a doctor have positive duties to act 'in the patient's best interests'. Do doctors have a special relationship and obligations to benefit just the patient in front of them at an instant, or equally to all their patients? Do specialists in palliative care have duties just to the patient in front of them at an instant, or equally to all those currently under their care, or even to those who in the future will come under their care? Do they owe obligations to all the people from the community who are patients of that NHS Trust, or in the community they serve?

No one contests the fact that the doctor-patient relationship confers on the doctor a responsibility to do the best possible in the circumstances for the patient in front of him. But what of all the other patients to whom he will have the same obligation during the rest of the financial year? They are also his patients, present before him on a different occasion, so surely he must have an equal obligation to do the best possible for each patient at whatever point in the year the referral takes place. So, if the doctor's budget is a fixed constraint and is to be respected as such, and assuming insufficient resources are available to provide all the care and treatment which would be beneficial, then care and treatment must be rationed at the level of the individual patient in order to ensure that patients are treated equally no matter the timing of their referral during the financial year.

In other words, since all patients referred to a single consultant or service are owed a fair share of that doctor's resources, rationing is essential at the level of the individual patient. Thus rationing is required between

patients even though there is no doubt that the doctor has a special responsibility towards all of them arising from the professional relationship with each.

This is the same as pointing out that there is a necessity to ration treatment and care provision amongst current patients, a policy which is generally accepted. For example, if on a particular day there is only one specialist palliative care bed available, but there are two patients who would benefit from it, then rationing at the individual patient level is required and this form of rationing is widely accepted. One patient will receive a higher standard of treatment than the other, and usually doctors react to this decision dilemma by giving the specialist bed to the patient who is likely to derive most benefit from it, taking into consideration also the harm sustained by not receiving specialist care. Rationing in this case is accepted because of the concrete and fixed nature of the resource of in-patient specialist beds - it is clear that only one bed can be available, since the total number is fixed, and that two patients cannot share the bed.

Difficulties of acceptance of rationing occur when doctors and others do not consider the resource to be truly constrained, or when they think it can be shared so that each patient can benefit. This latter situation sometimes occurs when the resource of a single specialist palliative care nurse is considered 'flexible' so that she can be expected to look after sixty patients rather than an average number of thirty-five. It also occurs when doctors overspend their drug budgets and imagine that the deficit can somehow be made up without compromising the care of other patients.

It must be admitted that doctors who fail to respect the constraints of resources, and who thus expend more than their service's agreed share, are not generally acting maliciously. They may simply be taking what they consider to be the easiest way out, and be blameworthy on account of lack of moral courage to face up to a responsibility that is onerous and often

unpleasant. A few cannot accept that when the resources are gathered either via taxation or charitable giving then the duties of general justice override those of special relationship with an individual patient.

All health care staff will find it difficult and distressing to have to withhold beneficial care from patients. Their 'moral distress' can be alleviated only by the conviction that they are doing the most right action in the circumstances. In order to be able to maintain their integrity and self-respect it is essential that they judge that they are meeting their obligations to all their patients in the best way possible, and that they personally are not blameworthy on account of the paucity of resources.

The arguments surrounding the obligations of rationing versus those towards individual patients can be summed up in terms of the use of the apostrophe 's': doctors ought to base their treatment decisions not on the basis of the '*patient's* best interests', but on the '*patients*' best interests'. This position leads on towards a consideration of the responsibility of a specialist palliative care team towards the community they serve.

5.1.v Team responsibility for the health care of a community.

Specialist palliative care is funded by NHS resources, but also substantially by charitable giving from the community. Whilst some units and teams are an integral part of NHS care and are managed by NHS staff they are still dependent on charitable funding for a significant part of their service provision. The other units and teams are managed by independent charities, and have a variable contribution from their local NHS Trusts. These independent units have some autonomy, but this is limited by the constraints imposed by the agreement or contract they have with the NHS locally. Thus virtually all specialist palliative care teams are funded jointly by NHS funds and also by charitable giving from their local population.

NHS funding is very important to all such services. Under the present politically driven re-structuring of the NHS the responsibility for deciding what health care should be provided is being devolved increasingly to groups of general practices called Primary Care Groups. Currently Health Authorities are still commissioning most secondary care, including specialist palliative care. The problem with rationing at the level of the primary care group is that it seems very difficult for members of different practices to agree on treatment priorities and rationing policies. Moreover, it is very difficult for members of one practice to alter the behaviour of members of another practice who are not adhering to the rationing policy agreed by the majority and are therefore overspending. No-one seems to know what will happen if a primary care group becomes significantly overspent. Unfortunately it seems likely that in order to remain in budget for the financial year treatment which is clearly beneficial and normally routinely available would have to be denied to some patients. Whilst the authority and responsibility for rationing seems gradually to be passing to primary care groups, they do not appear to have a mechanism for enforcing inevitable and necessary rationing policies on their members. This situation is likely to lead to low morale and bad feeling between practitioners, and could result in the group giving up attempts to constrain costs with disastrously unjust consequences for some patients.

If treatment priorities are decided by Primary Care Groups it is very likely that different groups will assign different priorities to different treatments and services, including palliative care. It then follows that whether a service is available, plus the extent of the service, will depend on the opinion of the patient's primary care group, and thus ultimately on where the patient lives. The same result occurs where health authorities have to decide on treatment priorities. This has been referred to as 'rationing by post code' and is widely accepted to be an unjust outcome in a publicly funded health service. The only solution would be to decide at national level the 'illnesses' which the

NHS will treat, and also to decide at national level which drugs will be available and purchased by the NHS for certain conditions. The National Institute for Clinical Excellence (NICE) has been set up to fill this latter role. However, rationing criteria will have no success unless there are very strong incentives, be they legal or moral or preferably both, for doctors and other health care professionals to implement the rationing system once it has been agreed, and even if they personally feel that some patients will be disadvantaged in order that others can benefit.

If this policy were followed, similar NHS provision for specialist palliative care would occur nation-wide. Persisting differences would be due to additional funding from charitable sources to improve basic services.

At present, specialist palliative care services managed by the NHS are usually located within a Hospital Trust, the latter being the functional economic unit of secondary health care. Each consultant in that Hospital Trust is a member of a team of consultants (and other health professionals) caring for a community as a joint responsibility. The team of health care professionals within the Trust, with the organisational assistance of management staff, have the task of providing the best possible care for the people living in the catchment area within the allocated budget. The budget is currently provided largely by the Health Authority, but in the future it may increasingly be controlled by Primary Care Groups.

Consultants in the NHS are all team members, not isolated doctors whose only responsibility is towards the patient in front of them. This is because no single consultant could provide the patient's care without the involvement of a host of colleagues in a variety of departments in the Trust. Since consultants can fulfil their function only in the context of team functioning, it follows that there is a responsibility to work as a member of that team. This entails not exploiting other departments by regarding them as a

means to obtain extra funding to bail out an overspend in one's own department.

Thus consultants (including those in palliative medicine) should be good team players in terms of co-operating with their professional colleagues to make the most just use, and the best use, of the resources available for the community served by the NHS Trust. There is a moral obligation to strive for this goal. Rationing is essential to achieve it. So rationing activities are not simply justifiable, they are morally required of NHS consultants.

Refusal to take joint responsibility for the implementation of agreed rationing policies within the Trust is very likely to result in an unjust distribution of resources, which consequence is morally unjustifiable. However great the benefits one might personally consider one's own service to convey, maverick overspending so that another service must be cut back so as to meet budget constraints cannot be justified. Consultants should argue constructively and truthfully for the benefits of their care, whilst at the same time acknowledging that the overriding criteria in rationing are the most cost-effective use of resources with a just distribution of the benefits.

One might argue that as a team member a consultant should implement a rationing policy which has been agreed within the Trust team even though he or she believes the policy to be less just than could be achieved. Teamwork requires respect for team decisions, even though the individual may at times disagree with them.

Implementing a rationing policy may mean rationing at the level of individual patients (micro-allocation), so that some patients are given the expensive treatment which is denied to other patients, or it may mean agreeing not to provide an expensive treatment which the Trust team or the Health Authority has decided cannot be made available to any patients following a cost/benefit analysis (macro-allocation).

However their service is funded health care professionals in specialist palliative care teams should regard NHS and charitable resources as having been given to them in trust for the health care of the community. They are like trustees of a charity, whose responsibility is to make the best use of the charity's resources and distribute the benefits justly. In effect all health care professionals, administrative and management staff are trustees of the funds provided charitably and through taxation.

A more detailed account of how health care, including palliative care, might be rationed requires a development of the distinction I have already made between macro-allocation and micro-allocation. Macro-allocation requires us to decide which services and treatments a publicly funded health service should provide. Micro-allocation requires us to decide which patients should receive these treatments or services. They are best considered separately.

5.1.vi Concepts of health, need and efficiency.

A publicly funded health service exists to provide health benefits. However, virtually all treatment and care options entail some harms (side-effects and inconveniences) and some risks. Decisions regarding which treatments and care facilities a publicly funded health service should provide require consideration of the benefits, harms and risks of each treatment or care option, and also the costs of those options. Some concepts have been central to discussions regarding which treatments and care should be provided. I shall discuss the concepts of health and health care, of need, and of efficiency.

There have been many attempts to define 'health'. However, a universally acceptable definition of health - even if it could be established - would not decide those benefits which a publicly funded service should

provide. Such a decision is essentially a moral judgement and the act of choosing a definition of health does not in itself make clear which services should be provided. Difficult moral choices about what sorts of benefits the health service ought to provide still have to be made.

The following benefits ought to be included within the remit of health care (including palliative care):

Prolongation of life

Relief of distressing symptoms arising from physical and mental illness

Nursing care when necessary because of physical disability or mental infirmity.

Should the remit of health care services (including palliative care) be limited to the above goals? This is an important question. It has already been noted that the philosophy of palliative care includes the psychosocial and spiritual welfare of patients and the 'quality of life' of relatives as a goals, whereas other services for patients do not explicitly include these goals within the remit. Clearly, there are major resource consequences arising from the inclusion of these aspects of care.

It is debatable whether a publicly-funded health service should be committed to providing interventions which enhance the psycho-social well-being of patients (as distinct from the treatment of psychiatric illness). It is very doubtful that a health service ought to provide interventions which enhance the psycho-social well-being of those who are not ill, for example counselling services for bereaved relatives. It is impossible to limit the services which a publicly funded health service ought to provide if one considers that everything which enhances psycho-social well-being, even in the context of terminal illness, should be provided. Indeed, if such a view is

taken it appears that the requirements from the service would be virtually infinite.

Rather controversially, especially in the sphere of palliative care, and in the context of very limited resources, I would suggest that the benefits expected from the service should be *limited to* the prolongation of life, relief of distressing symptoms arising from physical and mental illness, and care and assistance with the activities of daily living when necessary because of physical disability or mental infirmity.

It might be suggested that an analysis of the purpose of health care would provide a basis for deciding which benefits the service should provide. But what is the purpose and ideology behind health care? Is it to enhance autonomy? Is it to uphold the dignity of each individual? Is it to try to even out the injustices of life's lottery in terms of health so as to strive for the 'level playing field' of life opportunity based on good health? Is it to ensure that each person has the capacity for effective interaction with others? Is it to alleviate suffering? It is very unlikely that agreement would be reached on this matter, and given the diversity of views it will not be possible to derive answers to questions about which benefits the health service ought to provide from a debate about the purpose of health care.

The concept of need is one which is often discussed in the context of decisions about the provision of health care. Three aspects of the concept of need are important in resource allocation; firstly, it is intended to convey a moral 'ought' to meet that need, secondly, need is an instrumental term - we always need something in order to achieve a goal, and thirdly, different definitions of need have different meanings and consequences in terms of resource allocation.

The concept of need in terms health care is generally taken to imply a strong moral 'ought' or duty on behalf of an affluent society to meet that

need. Thus it may be thought that if we could adequately describe what we mean by 'need' we would achieve a description of those benefits which the health service ought to provide. When used in the context of health care, the term 'need' is simply being used as a substitute or short-hand for that which the publicly funded health service ought to provide.

What do we mean when we speak of 'the needs' of patients and their families for palliative care, or of a 'needs assessment' for palliative care? Research yields evidence regarding interventions which provide benefit, and assertions that patients and their relatives 'need' those beneficial interventions usually follow. Such assertions in turn imply that there is a moral obligation to provide those interventions. But neither research, nor the assertion that patients and relatives have certain needs, tells us which of those 'needs' ought be met by the service, or how to balance apparently competing needs when there are insufficient resources to meet them all.

In the context of health care it is important always to appreciate that 'need' is an instrumental term. Patients always need something in order to attain a particular goal, although that goal itself is often not explicitly stated. For example, we may say that patients need information (in order to give informed consent), or that relatives need bereavement counselling (in order to reduce emotional and physical morbidity). When deciding which of two or more competing needs should be met, practitioners in palliative care must consider the goals giving rise to the needs. They then have to choose which goals ought to take priority over others in the circumstances. Rationing of scarce resources means that low priority goals and their associated needs will not be met.

Macroallocation requires the prioritisation of competing needs and goals. For example, resources might be allocated to provide expensive chemotherapy (thousands of pounds per patient) which has a 30% chance of prolonging life for six months. Alternatively, those resources could provide a

specialist palliative care team to improve symptom control throughout the district general hospital. The goal of prolonging life competes with the goal of alleviating suffering.

Microallocation requires that practitioners differentiate between patients. For example, there may be only one available specialist palliative care bed, but two patients who need it for different reasons - one may be in the midst of a family crisis and the other may be imminently dying. The goals are different in the two cases. In order to allocate the bed the health care practitioner must take a view about which goal is more important in this instance.

The way people choose to describe the concept of need also varies. For example, if one takes a narrow view of the concept of need one might say that a need is 'something without which one will be fundamentally harmed', as has been suggested by Childress and Beauchamp¹³. In the context of health care this definition would imply that we might need health care which would prolong life significantly, or alleviate incapacitating suffering or disability. It is less clear that a desire to die in a particular place constitutes a need which if not satisfied will fundamentally harm a patient. It is even more debatable that counselling after the loss of a 'significant other' constitutes a need in this case.

Some have suggested a much broader definition, and have defined need as 'capacity to benefit'¹⁴. According to this use of the term patients and their relatives 'need' anything from which they could benefit. Clearly there is a problem if the term 'need' is used in this way. The association of need with a moral obligation to meet such needs leads to the conclusion that the NHS ought to provide everything from which patients and relatives could benefit. It would entail providing every intervention which would benefit people in terms of their health. It would also entail the idea that everyone ought to be assured of good housing, lack of deprivation, rewarding employment and a healthy

lifestyle, and that such benefits should be provided as part of a health care package. If we were to provide everything which would benefit the health of each individual the responsibilities of the health service, let alone palliative care, would be infinite. Moreover, it is interesting to note that with regard to other public services such as education and housing we do not consider that the publicly funded service should provide everything from which each individual could benefit.

It is also important to note that there cannot logically be a moral obligation to do that which is impossible - it is impossible to provide all the housing and education services from which each individual could benefit. Similarly, it is impossible to provide all the health care, or palliative care, from which patients and relatives could benefit. So the association between a need and the obligation to meet it must break down if 'capacity to benefit' is accepted as a description of 'need'.

Yet another definition of 'need' was used by Franks et al when they conducted a systematic review of the literature regarding the level of need for palliative care¹⁵. They used an epidemiological definition where need refers to 'specific indicators of disease or premature death which require intervention because the level is above that generally accepted within a particular society'.¹⁶ This definition does make it clear that need is an instrumental term, that a person can need an intervention only if the intervention is effective in achieving the goal, and that a problem is declared a need only if the indicator is above a level deemed acceptable and tolerable in the society. As the authors acknowledge, the use of this definition requires evidence and judgements about the ability of the intervention to control the problem, and also about the level of the problem considered acceptable within society. In the context of palliative care the indicators would presumably be symptoms such as symptoms and psycho-social distress, or the requirement for increasing care for patients terminally ill and unable to look after themselves.

A need for palliative care (and specialist palliative care) would be declared if, and only if, the service was shown to alleviate the symptoms and distress, and the symptoms and distress were considered to be above the level considered acceptable. It would be difficult to decide how much pain and distress society considers 'acceptable' in terminal illness. Furthermore, the implication of this definition is that if the pain and distress is considered to be acceptable, then there is no 'need' for health care at all, let alone palliative care.

The range of meanings intended by people using the term 'need' in health care easily gives rise not only to confusion, but also to feelings of guilt or resentment among health care practitioners and the public. Because of the strong association between the concept of a health care need and the moral obligation to meet it, health care practitioners are likely to feel guilty if they cannot provide those interventions that they consider their patients need. This guilt is likely to persist whether they consider a need to be something from which a patient might benefit, or something which if not met will lead to a fundamental harm. Health care practitioners may also resent being placed in the situation of having to decide which patients should have their needs met and which should not.

Members of the public, especially if themselves ill, are likely to consider that they 'need' those treatments or services from which they would expect to benefit. They are likely to feel resentment or anger when they do not have access to such care, even if the benefit thus denied them is relatively small.

I have said that a need arises from a desire or aim to achieve a certain goal, but that there is no clear agreement about the goals of a health care service. Achievement of explicit goals is central to discussions regarding efficiency. Unfortunately, 'efficiency' is a term often used very loosely in discussions about rationing and health care policy.

Economists discuss the meaning of efficiency at great length, but a more pragmatic approach is required for use by those who must ration health care in the clinical context and who have no background in economics. Uwe Reinhardt has suggested such a pragmatic interpretation: 'among several policies - *with all of them designed to achieve exactly the same goal* - the most efficient policy is the one that reaches that same specified goal with the least expenditure of real resources (human labor, energy, materials, land and so on).'¹⁷ His use of italics here emphasises that efficiency is always directed towards a goal, and that policies or processes can be compared in terms of efficiency *only if* they are all directed towards the same specified goal.

The problem in health care is that the goals appear varied, even though I have suggested that they should be limited to prolongation of life, relief of suffering, and essential nursing care. Moreover, the goals are often not explicit, even in the minds of health care professionals, and many treatments or services aim to achieve more than one goal. Thus confusion arises firstly because people do not recognise that when efficiency is discussed it is essential to specify the goal which the policy or process aims to achieve, and secondly because patients and professionals are basically unclear about the goals that the treatment or care package is aiming to achieve.

Even when the goals are made explicit, assessing the extent to which they are achieved may be very difficult. This is particularly true in palliative care. It can be very difficult to assess the success of a specialist palliative care service in achieving symptom relief, let alone alleviation of psychological distress. It is then even more difficult to decide whether the specialist service achieved such goals more efficiently than conventional primary and secondary non-specialist care. It is (relatively) easy to sum the human and financial resources entailed by a service or treatment, but much more difficult

to assess the extent to which the goal(s) of that service or treatment were met.

Given that it is difficult to assess the achievement of health care goals (other than length of prolongation of life), it is very difficult to compare the efficiency of one treatment or service versus another in achieving specified goals. But one of the aims of rationing is to ensure the best use of resources by using the most cost-effective treatment or service. Cost-effectiveness is closely related to efficiency. A treatment or service can become more efficient either by decreasing costs or by increasing effectiveness, or both. It is very unfortunate for those who have to ration health care that effectiveness (the achievement of goals) is so difficult to assess, for it follows that efficiency is also very difficult to assess.

Macro-allocation must entail the comparison of efficiency of services and treatments, but until we have established more explicit goals, and more reliable methods of assessing, even qualitatively, the achievement of those goals, then comparison of services in terms of efficiency is at a very primitive stage. At present, 'efficiency' is said to be assessed by counting the number of patients treated by a particular service, and the financial and human resources costs of treating that number of patients. Here the number of patients treated is being used as a substitute for effectiveness. In fact, the effectiveness or outcomes of the treatments, and the quality of care provided, are currently not well assessed, leading to the conclusion that current 'efficiency' assessments are almost meaningless.

Awareness of this problem is increasing, hence recent emphasis on achieving better quality of care (as opposed to simply higher numbers of patients cared for). New initiatives under the umbrella title of 'Clinical Governance' aim to improve outcomes or effectiveness of treatments and services. Improving effectiveness is just as important in increasing efficiency as is cutting costs, although to date most emphasis has been placed on

cutting costs. A better understanding of the concept of efficiency, particularly its relationship to specific goals, is essential to the achievement of the first aim of rationing, and to the process of macro-allocation.

If the use of such essentially contestable concepts, such as health, need, and efficiency, cannot provide solutions to the problems of macro-allocation, then we must turn to direct consideration of the many benefits derived from available treatments and care packages. We must try to evaluate the net benefits from treatment and care options by weighing up the magnitude and likelihood of the benefits against the magnitude and likelihood of harms and risks of those options. We must also consider the forfeit of benefit that patients will sustain if the treatment and care options are not available.

When a treatment or care package is evaluated it is usually only the *outcome* which is assessed. Unfortunately this practice fails to take into account the benefit (or harm) that may be entailed in the *process* of treatment or care itself. The process of many treatments is actually harmful, for example in terms of side-effects. On the other hand the actual process of some treatment and care packages are beneficial, and these benefits should be considered alongside any beneficial overall outcomes of the care. For example, in the context of palliative care excellent physical care and symptom control performed compassionately may allay patients' fears, and the reduction in anxiety may significantly reduce symptoms such as pain and dyspnoea. It is clearly morally unsatisfactory to consider only the outcome of a treatment or care package, and to omit the value or disvalue of the process itself. When comparisons of treatment and care packages are required for macro-allocation it is essential to consider the benefits, harms and risks of the process of health care.

Having considered the net benefits of various treatment and care packages, in terms of process as well as outcome, we are left with the task of deciding which of those benefits ought to be provided by the publicly funded service. Some sort of comparison has to be made between the values of the goals that are achieved by the many possible treatment and care packages. One of the most important attempts to achieve that comparison by representation of benefit as a single number was the concept of the QALY.

5.1.vii The concept of the QALY.

The development of the QALY is the most sustained and serious attempt to express all the outcomes of health care in common numerical units called QALYs. As Edgar et al state in 'The Ethical QALY'¹⁸

'The basic thinking behind the QALY is that health has two main dimensions: length and quality. Effective health care must either extend life or improve its quality or preferably both, so in theory all effective health care will produce Quality Adjusted Life Years or QALYs...'

The use of the QALY calculation to represent health care benefit entails the assumption that improvements in length of life and quality of life can be traded off against each other.¹⁹ In turn, this assumption is built on a belief that quality of life can be represented numerically.

Of course evidence can and will demonstrate the time-span by which a treatment prolongs life, be it days, months or years. There is no moral or practical problem with the concept of added time to life, measured in our standard units of time. However, there are both moral and practical problems with the idea of assessing the *quality of life* change which results from treatment, and then with expressing that quality as a numerical value on a metrical scale. Yet this is exactly what is central to the concept of the QALY. The quality of life of the health state before and after treatment is represented as a number on a scale. The scale used to represent the quality of the

patient's life before and after treatment ranges from 0.0 to 1.0, where 1.0 represents full health and 0.0 represents no quality of life, or death. According to the QALY concept it is possible to be in a health state whose quality of life is rated as worse than death (some may consider the persistent vegetative state, advanced dementia or quadriplegia to be worse than death). A quality of life worse than death would be measured as a minus figure, for example -0.5. The figures on the scale for each health state are derived by questioning either the general public, those living in the health states, or health professionals. It is apparent that it may be of crucial importance which group is assessing the quality of life in each health state.

To calculate the health gain or QALYs from a particular treatment the number of years by which life is prolonged is multiplied by the improvement in quality of life resulting from the treatment. For example, if a coronary bypass graft added 10 years to the patient's life, at a health state rated as 0.9, then the outcome of the treatment is 9 Quality Adjusted Life Years. Similarly, if a treatment prolonged life for 5 years but in a state of paraplegia rated as 0.5 on the quality of life scale, then the QALYs gained would be only 2.5. It can be seen that the underlying assumption of the QALY is that people are likely to prefer a shorter life of high quality rather than a longer life of low quality.

Whilst it is conceptually easy to calculate QALYs for treatments which do actually prolong life it is much less apparent how this can be done for treatments (such as palliative care) which do not prolong life at all but which improve its quality. The QALY score for such treatments is achieved by making an assumption about the patients expected length of life, say 10 years, and multiplying this by the improvement in quality. For example, regarding a hip replacement, if quality is improved from 0.7 to 0.9, and the patient lives for 10 years, the QALY gain as an outcome of hip replacement is 0.2×10 or 2 QALYs. If palliative care improves quality of life from 0.2 to 0.4 for 0.5 of a year the QALY gain is a mere 0.1 of a QALY!

Logically it would seem that the calculations must become more complex where a treatment impacts on both length and quality of life. For example, palliative chemotherapy may prolong life by 6 months, but it may either enhance or decrease quality of life from that which would pertain without the chemotherapy but with palliative care. I shall not focus discussion on the complexities of such calculations. Rather, I will question whether they actually give us a more accurate impression of the health gain than if the person's state before, during and after the treatment were just *described* to us, together with relevant *evidence* about the expected prolongation of life in years.

Once the number of QALYs gained from a treatment has been calculated it is a matter of simple arithmetic to calculate how much it costs to gain 1 Quality Adjusted Life Year by various treatments. This is known as 'the cost per QALY'. It is then possible to compare the cost per QALY of various treatments. It is clear that since specialist palliative care is a package available to a patient for perhaps only 0.25 of a year, and in view of advancing illness quality of life improvements (in so far as they can be assessed) are small, then a very small QALY gain is achieved, so the cost per QALY will inevitably be high.

The assumption behind the use of QALYs in macro-allocation is that there is a moral imperative to achieve the maximum benefit from resources - in other words, the maximum QALYs per pound. Specialist palliative care would achieve few QALY's per pound, so if cost-per-QALY were the major factor used in macro-allocation, then specialist palliative care might not be funded at all.

5.1.viii. Criticisms of the QALY.

Many criticisms have been made of the concept of the QALY and of its use in macro-allocation. However, the single and most important criticism is

that it simply is not possible to place a numerical value on quality of life of health states where the number is part of a metrical scale. There are two reasons for this.

Firstly, there is no clear and universally accepted concept of quality of life. We have already seen (chapter 3) that 'quality' may be thought to lie in happiness, in a life of significant toil, in the ability to choose, or in membership of a community, to name but a few candidates!²⁰ When people are asked to rate the quality of life of a particular health state on a numerical scale we have no idea what concept of quality of life is in their minds. If they rate the quality of life in a wheelchair as 0.5, we do not know if this is because they believe a paraplegic person cannot hold down a satisfying job, or have satisfactory relationships in the community, or have an adequate range of life choices, or is simply very unhappy for any reason.

Secondly, when they are asked to rate quality of life on a scale from 0.0 to 1.0, they are really placing health states in a series, or producing a 'rational ordering' of those health states. They are not necessarily saying that a quality of life of 0.6 is twice as good as one of 0.3. They are considering the rank ordering of health states. It is exceedingly unlikely that they are wondering whether all the intervals on the scale are separated by the same amount. It is possible that they are actually rating quality of life on a scale more like a logarithmic scale, such as the Richter scale used to measure earthquakes. There are simply no grounds for assuming that they are either able to rate quality of life on a metrical scale or that they are actually doing so. Since this assumption is not well founded, the entire logical and arithmetical foundation of the QALY concept fails.

If the use of the scale to describe quality of life is invalid, then the use of that measure in a calculation to describe the benefit of health interventions as a single figure simply confounds the errors. When data are being handled to achieve a goal, it is often said 'rubbish in, rubbish out'. In other words, if the

data put into the equation are invalid, so will the result be. The problem in the QALY system is that if rubbish is put in, something even worse than rubbish will be put out, for there is a real risk that the error in estimate of quality of life will literally be multiplied. This would lead to counter-intuitive if not disastrously misleading results in terms of QALYs gained by the majority of treatments.

Most of the other criticisms of QALYs are based on the judgement that they appear to produce conclusions regarding macro-allocation which are *intuitively* either unwise or unjust. For example, it has been suggested by a group funded by the European Commission to look into the ethical problems of QALYs²¹ that these problems can all be solved by 'weighting' the QALY score in a certain direction so as to make the result more intuitively acceptable. For example, a higher number of QALYs would always be obtained for curative treatment of life-threatening conditions in young people than for curative treatment of similar conditions for older people, since more years of life would be gained. If allocation of health care resources followed this conclusion the result would be pervasive discrimination against older people as a group. It has been suggested that the QALY result should be manipulated mathematically (referred to as 'weighting') in order to prevent this result.

A second counter-intuitive result of QALY calculations would be the very low priority given to palliative care when the patient is known to be terminally ill. Any treatment which does not prolong life, but which improves its quality for the short time remaining, will produce a very low QALY score (and high QALY per pound cost) and therefore will probably not be funded. Yet good relief of distress at the end of life, or 'dying well', is generally thought to be a high priority. The counter-intuitive conclusion of the QALY calculation could be altered mathematically by positively weighting the quality of life in

the last few days, weeks or months. However, the weighting required to make any palliative care available at all following QALY calculations would have to be very significant!

A third counter-intuitive result has been described by Prof John Harris as that of 'double jeopardy'.²² Certain patient groups already have a quality of life score of less than 1, perhaps as a result of mastectomy, a colostomy, or disability due to previous illness or accident. If the quality of life of such persons is rated at only 0.5, then life-prolonging treatment for them is likely to be denied, because the QALY score gained is necessarily less than if the same treatment were given to patients with a higher quality of life score. The QALY value of the years of life gained for a disabled person with a quality of life rating of 0.5 would be only half that of the QALY value of the same treatment given to a patient whose quality of life score is 1. This results in 'double jeopardy'- those already disadvantaged by disability will be discriminated against in terms of life-prolonging treatment because the QALY gain from treating them is less than that achieved by treating people with no underlying disability.

Obviously it is possible mathematically to manipulate QALY scores in order to obtain results which are not counter-intuitive in terms of macro-allocation. However, one must ask what is the point? If QALY scores produce conclusions for macro-allocation which are deemed intuitively to be unjust, then it would be more rational to abandon the QALY concept because experiments using it have produced unacceptable results rather than to continue to massage the figures to obtain the results which we thought were just in the first place.

A fourth counter-intuitive result, and one which cannot be solved by mathematical manipulation of QALY scores, is that the utilitarian goal of maximising QALY's gained will often result in an unfair distribution of benefits. For example, if by palliative care one could improve the quality of life of one

person by 0.5 for 1 year by a treatment costing £ x.00, then this would be preferable to improving the lives of four people by 0.1 for 1 year at the same cost of £ x.00. According to the QALY concept we should do the former, thus denying 3 people any benefit at all. Yet improving the lives of four people is probably a more just distribution of the benefit than providing a larger gain for just one person. A utilitarian application of QALY's in macro-allocation yields counter-intuitive results in terms of fairness.

A further and important consideration is that QALYs present an oversimplistic view of the outcomes of health care. The criticism applies to measuring effects of treatment on both length of life and quality of the resulting health state. It is an overly simplistic idea to think that these two sorts of outcome arise independently of each other. For example, relieving a patient's pain may result in reduction of exhaustion and prolongation of life, but evidence gathered from trials on analgesics is unlikely to include any effect on length of life. The outcomes of health care arise from very complex interactions between the various effects of treatments, and our techniques for gathering evidence are unlikely to be sophisticated enough to assess overall outcomes comprehensively and reliably.

Moreover, whilst it is easy to ascertain whether the patient is alive or dead it is much more difficult to estimate the patient's quality of life after the treatment. This problem is confounded by the difficulties of deciding who should rate the quality of each health state, namely the public, health professionals, or those people who are actually living in that health state and so can be expected to have some knowledge of it. At first sight the last group, those actually in that state, seem best able to rate its quality. Groups of the public who are asked to rate various health states will probably have no knowledge of the health states occurring in terminal illness. On the other hand the public are paying for health care, and as a group also benefit from it, so if QALYs are to be used it can be argued that their judgement of the value of

the resulting health states is that which should be used for macro-allocation decisions.

This last point is crucial in debating the role of QALYs in macro-allocation. The problem with using the general public's evaluation of various health states in order to make macro-allocation decisions based on QALYs is that when people were asked to place a numerical value on those states they were doing just that. They were not agreeing, either implicitly or explicitly, to the concept of the use of those evaluations directly in resource allocation, and they were not evaluating health states with the use of QALYs in mind. They were certainly not producing numerical representations of the health gains produced by treatments - the QALY calculation does this. Nor were they making decisions about priorities in macro-allocation.

Some proponents of the QALY concept have argued that the role of QALYs in macro-allocation might have to be restricted, so that they are not the *only* factor considered. For example, McKie et al ²⁸ suggest that

'there is a principled way of governing the restrictions: the QALY method should be restricted when, and only when, it threatens to diminish social utility. Thus we do not think that health care should always be distributed so as to produce the largest possible number of health-related QALYs, and it is plausible to suppose that tilting the balance of health care towards the more disadvantaged members of society will reinforce feelings of concern and sympathy, and lead to a more compassionate society... So we would be prepared to restrict the application of the QALY method in particular circumstances if it threatened to have adverse consequences sufficient to outweigh any corresponding benefit it might have.'

In response to this sort of suggestion I would argue that since the QALY concept has major and fundamental flaws it is unhelpful and unreliable as a method or tool in macro-allocation. It is not possible to rate the quality of life on a numerical scale, as was discussed in chapter 3. Therefore, any form

of numerical trade-off between length of life and quality of life is not possible. If tried, it yields results which are not only meaningless but also lead to conclusions about macro-allocation which are counter-intuitive. The benefits of prolonging life and decreasing distress due to disease are incommensurable, and the latter cannot be evaluated numerically, either individually or on some sort of global quality of life scale. Thus they should simply be described qualitatively. In other words, economic or mathematical data are simply evidence to be used in a process of macro-allocation which must itself rest on humane judgement.

5.1.ix How should macro-allocation decisions be made?

Macro-allocation decisions are about what treatments and care the publicly funded health care service should provide, and how much of them. Such decisions entail discrimination between treatments or services. I have described the benefits of health care as confined to three categories: firstly, the prolongation of life, secondly, the relief of distressing symptoms arising from physical and mental illness, and thirdly, care and assistance with the activities of daily living when this becomes necessary because of physical disability or mental infirmity. Specialist palliative care probably has only a minimal effect on the length of life, but is concerned with the relief of symptoms and with provision of care and assistance with the activities of daily living as necessitated by the impairments caused by terminal illness.

When macro-allocation decisions are made the following are the most relevant considerations:

- 1 The characteristics of the population and the community to be served
- 2 The characteristics of the various treatments and services

3 Moral principles of equity, efficiency, respect for autonomy, beneficence and non-maleficence.

1 Relevant characteristics of the population and community.

The extent and characteristics of palliative care services must depend on the context within which the service is provided. For example, in the midst of a war associated with casualties and food shortages no-one would wish to argue that setting up a specialist palliative care service should be a priority in health care. Economically deprived nations will naturally prioritise provision of adequate food, warmth, shelter and hygiene to enable the population to survive, together with inexpensive vaccinations and antibiotics, simple and cheap preventative measures against infectious diseases etc.

In the United Kingdom at the beginning of the 21st century health care resources are inadequate to provide many treatments and care packages from which the population could benefit. Life-expectancy has increased mainly due to improved hygiene, nutrition and housing, but also due to the successful treatment of infectious diseases. Many more people are living into old age and this has two major consequences. Firstly, they develop incurable illnesses associated with ageing, and whilst life-prolonging measures are technically possible in many cases, they cannot be resourced for all who would benefit. Secondly, the natural history of the ageing process seems to include a tendency towards inability to function independently, due to deterioration in mobility and mental faculties. Therefore there is an increased requirement for basic care to enable people to eat, keep warm, move from bed to chair and walk short distances. In an affluent society there is a moral imperative to meet these most basic requirements for the survival and dignity of an increasing number of elderly people.

Currently in the UK the cost of providing this basic care is not met from the health care budget, and patients who have savings are required to fund

such basic care themselves. Recently a Royal Commission²⁴ has suggested that the basic nursing needs of such patients should be funded publicly, whatever their personal means. The argument that a decent minimum standard of such basic care should be publicly funded is compelling. It might also lead to a more effective use of hospital beds since patients would not be reluctant to leave hospital because of the adverse implications of funding their own continuing care. In the absence of the provision of even such basic care for the frail elderly it is difficult to argue that specialist services for the dying should be provided, other than at a level necessary to achieve reasonable symptom control and adequate physical care. It should also be said that perhaps the very expensive treatments used to prolong the life of people with incurable illnesses such as cancer for a few months should not be resourced until and unless a decent standard of basic care is available for all.

Against a background of information about the changing characteristics of the population in terms of ageing, attempts have been made to assess the 'need' for palliative care for the population. Two methods have been used. The first is to study the epidemiology of terminal illnesses and the symptoms they cause. Mortality statistics for various diseases are gathered from death certification, and research is done to assess the incidence of various symptoms in each disease, thus giving rise to figures representing the number of people who might require palliation of those symptoms. This method was used by Franks et al when they conducted a systematic literature review regarding evidence of need for palliative care. For example, their review suggested that 45-100% of patients with advanced cancer experience moderate to severe pain, and it was inadequately managed in 20-40% of those patients²⁵. Of course one cannot assert that such patients should ideally receive specialist palliative care unless there is evidence that such care would alleviate the pain better than conventional care. The authors of this review acknowledge that evidence of symptom prevalence will not identify

the type of care required, its effectiveness as judged by 'users' and professionals, nor its cost-effectiveness. The second method used to assess the need of the population for palliative care is to look at health service use. There are so many assumptions built into the notion that use of a health service indicates the service which should be provided that this second method would seem to be of little practical value.

Despite epidemiological evidence of the care requirements of an ageing population, and similar evidence of the incidence of distressing symptoms associated with terminal illness, it seems that priority is presently given to life-prolonging treatments over basic care and symptom control. As the population ages, and more control of secondary care is exercised by primary care, this priority structure might change. Until such a change occurs there will continue to be few NHS resources for specialist palliative care, much of which is provided by the voluntary sector and funded by charitable contributions.

The first thesis of this chapter is that there ought to be a just distribution of health care resources to palliative care as a whole. In view of the demographic changes in the population which have recently occurred and which are predicted in the future, a 'just distribution' of resources towards palliative care would require some redistribution of funds from life-prolonging treatments towards symptom control and provision of basic care for the increasing number of people who will develop the incurable and terminal illnesses associated with ageing.

2 The characteristics of the various treatments and services.

The costs and the benefits of each service to the community and to the individuals who receive it are central to decisions about macro-allocation. Unfortunately there may be considerable difficulty in deriving information regarding benefit from the existing evidence base and this applies to

specialist palliative care services as well as to many others. Literature reviews and individual studies have shown little impact on quality of life or pain control from specialist palliative care as opposed to general palliative care^{26,27}.

In assessing costs and benefits the number of people to whom the service is given is relevant - if a large number will receive it then the costs may be high but the total benefit is also likely to be large. In the case of specialist palliative care the number of patients receiving it at any one time may be relatively low, but since all people will ultimately die, the number benefiting from the services at the end of life will be very high. This situation is similar to that of obstetric services, which are serving a relatively small proportion of the population at any one time, but which benefit virtually everyone around the time of their birth!

Where treatments are concerned, roughly the same considerations apply. The benefits, harms and risks of the process of care during the treatment, which will include the possible side-effects and mishaps, should be described. The outcomes of the treatment should also be examined. The evidence from research will obviously be crucial in providing the information base for these assessments. I have already argued that attempts to quantify net benefit in quality of life and to represent it as a single numerical figure in a scale are invalid i.e. the scales cannot measure what they are said to measure. Qualitative descriptions of benefit are to be preferred. Harms and risks should be described qualitatively for the same reasons. The exception to this general rule would occur where there is evidence regarding the length by which life has been prolonged by a treatment, since this can be represented in units of time.

It is also possible, but very difficult, to calculate the financial implications of providing or not providing certain treatments. Where a person is enabled to be independent or even to return to work there is clearly a financial benefit to that person and the community. Conversely, where a

treatment prolongs life but in a very dependent condition, then the total costs of that patient's ongoing care must be considered. Currently the cost of the procedure is considered, but not the costs of provision of care during the life prolonged. It is puzzling that so much effort has been put into attempts to assess benefit and represent it numerically as compared with few attempts to estimate overall financial costs of treatment.

Treatments and care provided for individuals may also benefit the whole community, by reassuring members that when ill or dependent or dying they will receive compassionate and competent care and their dignity will be preserved. In this way the community demonstrates respect for all individuals regardless of their health state. Fostering ideals of compassion and acknowledging the importance of dignity enhance the environment of the community for everyone. Conversely, failure to provide such care tends to increase fear of dependence and illness, producing anxiety and perhaps encouraging an image of those who are unwell as simply a burden on others. Thus one may argue that availability of specialist palliative care services for those with major care requirements and symptoms which require specialist help for effective relief is a significant benefit to the community. Most people face the reality of their own mortality at intervals during their lives. Provision of adequate palliative care would do much to diminish the fears which surround the dying process.

3 Moral principles.

Equity is the principle of fairness or justice in the distribution of benefits and burdens in a community. It naturally and rightly comes to mind when considering the distribution of the benefits of publicly funded health care. Aristotle originally described equity in his formal principle of justice, which states that equals should be treated equally, and unequals, unequally in proportion to their relevant inequality²⁸. This means that we should treat

people in the same way (equally) unless there are relevant differences between them. Two problems arise when implementing this principle in health care. Firstly, we must decide in each case which criteria may justifiably be used to discriminate between people or groups of people, or what are 'relevant differences'. Secondly, we must decide what it means to treat people equally.

With regard to the first problem it can be very difficult to decide which characteristics of people constitute relevant differences when it comes to health care. Macro-allocation decisions effectively require us to discriminate between groups of people because certain illness-categories tend to occur in certain groups. For example, should we allocate more resources to the care needs of the elderly frail and dependent patients, or should we allocate more resources to those in middle life who can obtain symptomatic benefit and prolongation of life from techniques such as coronary artery bypass grafts and some palliative treatments for cancer.

The most important questions in relation to this thesis are firstly, whether specialist palliative care should be available to all patients or not, and secondly, if it is not available to all patients then should its use be limited mainly to patients with cancer, AIDS and motor neurone disease as at present,²⁹ or should a proportion of patients with other terminal illnesses also benefit.

The first question asks whether it is equitable to discriminate between patients at all, or whether everyone should be entitled to specialist palliative care in the same way that all are entitled to and receive obstetric care at birth. The political position is currently unclear. Sue Hawkett on behalf of the Department of Health said in a presentation in February 2000 entitled 'Palliative Care for All' that within the context of quality improvement frameworks 'access to specialist palliative care should be provided for all those who are affected by cancer and delivered to those who need it'. This

statement unfortunately has little practical meaning as it is unclear what access means if the care is not delivered, and there is no description of what is meant by need. In 1992 the Standing Medical Advisory Committee (SMAC) stated that all patients in need of palliative care services should have access to them.³⁰ This statement is similarly enigmatic.

Although there are far too few resources to provide specialist palliative care to all dying patients, the question remains as to whether this would be an appropriate goal. What benefits would specialist palliative care bring if available to all people? It is important to have one's expectations anchored in reality, and there has been a tendency to imply that specialist palliative care can enable patients and health care professionals to have very substantial control over the dying process, and control is assumed to entail benefit.

For example, Richard Smith in an editorial in the *British Medical Journal*³¹ in January 2000 quoted twelve 'principles of a good death' which were identified by the Debate of the Age Health and Care Study Group³². These 'principles' included some goals which are sadly unattainable, even with infinite resources, such as 'To know when death is coming, and to understand what can be expected', and 'To be able to retain control of what happens'. As Richard Smith says, the twelve principles stress the importance of control, autonomy and independence. He adds that they should be incorporated into 'the plans of individuals, professional codes, and the aims of institutions and whole health services'. I would suggest that it is unhelpful to any individual or community to enshrine unattainable goals in its aims for health care. Even specialist palliative care cannot enable everyone to know when death is coming, and no-one can control what actually happens since we have very limited control over bodily processes. The idea that everyone ought to be able to retain control, autonomy and independence until the moment that they die simply perpetuates the myth of total medical power over the body. It is important to retain realistic goals for specialist palliative care.

Given that specialist palliative care cannot assure control over the dying process, and since we are lacking evidence that it would benefit all patients, it does not seem reasonable to put forward its provision to everyone as a health care goal. This situation contrasts with that of obstetrics, where specialist ante-natal care and supervision during delivery undoubtedly improves maternal and foetal mortality and morbidity.

Richard Smith also makes the additional point that 'There is, however, something paradoxical about creating a specialty to cater for something that happens to us all.' He notes that there is now a trend for the practices of specialist palliative care to be adopted by all health care practitioners, rather than suggesting that everyone should die under specialist supervision. I would suggest that the practices of specialist palliative care ought to be adopted universally if, and only if, they are shown to be beneficial to the majority of patients known to be terminally ill, and this is not clear at present.

An alternative opinion is given by Duncan Keeley in an editorial in the BMJ of December 1999.³⁴ He argues that despite lack of evidence of the effectiveness of specialist palliative care from randomised controlled trials^{34, 35} home-based specialist palliative care ought to be provided because of its 'evident human desirability'. He suggests that withholding such specialist care may be unethical. The difficulty with this point of view is that it really seems irresponsible to commit large sums of money and health practitioner time to the provision of a specialist service which has not been shown (by trials and studies) to be of benefit compared with conventional care. The answer may be to use comparative and qualitative studies rather than to rely on randomised controlled trials which are notoriously difficult to carry out in the palliative care setting (for moral and practical reasons).

Provision of specialist palliative care to everyone would also require that we could identify with reasonable certainty those who are terminally ill. This is unlikely to be possible, since there are obvious problems in defining

the terminal phase of an illness. It is notoriously difficult to predict how long a patient may live, and doctors' inaccuracies in prognosis have been clearly identified.³⁶ If it is very difficult to determine when a patient is approaching death, then it is difficult to plan health care services so as to provide specialist palliative care for everyone who is dying.

It is reasonable to conclude that resources should not be committed for the provision of specialist palliative care to everyone who is dying. If, in the future, we have evidence (not necessarily from randomised controlled trials) that specialist palliative care generally provides benefits over and above those of conventional care, then universal provision should be considered. The costs and benefits of such specialist care would then have to be weighed against the benefits of other treatments and care packages for acute and chronic illnesses.

The second question in relation to equity was whether specialist palliative care ought to be provided almost exclusively for patients with cancer, AIDS and motor neurone disease, or whether it should be available to patients with other terminal illnesses who have particularly difficult problems. Alternative formulations of this question are; is it equitable to discriminate between patients on the grounds of the nature of their terminal illness; is the nature of the terminal illness a morally relevant and justifiable criterion to use for rationing specialist palliative care?

Discussion on this topic is currently characterised by the view that specialist palliative care ought to be extended to patients with a wide range of terminal illnesses. However, it is by no means clear to me that this conclusion is valid. Whether or not a patient group should receive a certain treatment or care package seems to me to depend on whether we are reasonably sure from the evidence that they will actually benefit from that care package. It seems reasonable (and essential) to discriminate between patients on the basis of whether or not they will benefit from the particular service or

treatment. Indeed, it seems to be morally unacceptable to provide a care and treatment package unless one has reasonable grounds for thinking it will be effective. Papers on the subject of equity of access to specialist palliative care seem to be based on the (presently uncertain) assumption that specialist care will benefit non-cancer patients, as the following examples show.

Michael Connolly argues that 'Palliative care expertise could and should improve the care of many more patients than it currently does', and he argues that the current provision of specialist palliative care mainly to patients with cancer is inequitable.³⁷ His argument rests on the assumption that because patients with end-stage diseases such as heart failure, lung fibrosis, renal failure, stroke, liver cirrhosis and chronic obstructive pulmonary disease have similar symptoms to patients with cancer,^{38,39} then the treatments which have been found to be effective in patients with cancer will be effective in those with these other diseases. This assumption must be questioned medically, for whilst a symptom due to one illness may be relieved by a certain treatment it does not follow that the same symptom caused by another illness will be relieved by the same remedy. He does advocate research to establish the extent to which symptoms caused by non-malignant disease are amenable to the remedies which are effective for the same symptoms in cancer patients. In the absence of such research, it seems strange that he asserts that 'it is ... obvious that much of what has been learned within palliative care for people with cancer is applicable in some way to those with other diseases'. It would seem most sensible to conclude that before resources are expended on extending specialist palliative care services to people dying of non-malignant diseases there must be some evidence that those services are effective for these other patient groups.

Katherine Wasson, a clinical ethicist in a palliative care centre, goes much further and claims that the present situation for non-cancer patients 'is unfair, unequal and inequitable'.⁴⁰ She asserts that palliative care

professionals have duties 'to provide care, non-maleficence, beneficence, protecting the patient's best interests and respecting patient autonomy....for all their patients, regardless of the diagnosis'. The problem here is that the question is whether those with non-malignant disease should be patients of specialists in palliative care, not whether they are owed the same obligations as others once they are patients. It makes no sense to assert that specialists have obligations to provide their particular brand of care to certain groups of patients in the absence of evidence that one's particular skills will benefit those groups.

Wasson further asserts that 'this duty to care is not limited to patients, but extends to caring for and supporting family members, colleagues and other professionals.' Her argument seems to be that specialists in palliative care have a 'duty to extend palliative care to people with a wide range of life-threatening diseases', plus all those other people associated with terminally ill patients! The difficulty with assertions of this kind is that obligations are claimed to exist where it is not humanly possible to fulfil the obligations.

Her arguments around justice are based on the incontestable notion that 'there should be a uniform standard of care for all dying people'. But a uniform standard of care does not imply that all people should have the same type of care or treatment when dying, regardless of their diagnosis. It seems unlikely that evidence will show that patients with diverse illnesses would benefit from the same type of care and the same treatments, even specialist palliative care!

Capacity to benefit is a criterion (and perhaps the only criterion) on which it is morally acceptable (and morally required) to discriminate between groups of patients. It seems likely that patients with non-malignant disease will benefit from some of the symptom control measures currently used in specialist palliative care, and they may also benefit from other aspects of the care package. But pilot studies and some research are necessary before it

would be morally acceptable to provide the care package to them, in order to prevent the possibility that they be subjected to ineffective strategies, and the possibility that resources might be wasted. Discrimination between patients on the grounds of their ability to benefit from a specialist palliative care service is not inequitable.

Where micro-allocation is concerned the task is to discriminate between individuals and this is discussed in section 5.2.

Efficiency (sometimes the concept of utility is used instead) is to do with attaining the maximum output from the input of resources. As discussed in section 5.1.vi, it is necessary to specify the precise goal of efficiency - in other words, exactly what output is to be maximised from the resources. When judging the efficiency of various macro-allocation strategies one must be specific about what the goal of efficiency or the output to be maximised is. Like many care packages, specialist palliative care has more than one goal. Thus the outputs to be maximised include relief of distressing symptoms for each patient, the largest possible numbers of patients treated, adequate physical care per patient, together with provision of this care for as many people as possible. It can be seen that goals of symptom control and adequate care compete with goals related to maximising the number of patients who benefit from the service. A compromise always has to be struck between these two sorts of goals. This may be achieved by establishing as one's primary goals benefit in terms of symptom control and physical care to the largest possible number of patients, using quality of care as a constraint rather than a goal.

The principles of equity and efficiency frequently constrain each other in clinical practice. For example, centralisation of specialist resources may make for their more efficient use in terms of the resources needed for a given

output, but such centralisation may be inequitable because of the burdens of travel for very sick patients.

Other moral principles frequently used in discussing health care, such as the importance of obtaining consent and respecting the patient's refusal of treatment, or beneficence and non-maleficence, are more relevant to the problems of micro-allocation, and their force will be discussed in section 5.2.

In concluding this discussion of macro-allocation, with particular reference to specialist palliative care, I am suggesting that access to a decent minimum of health care should be available to everyone. A decent minimum in terms of specialist palliative care would mean that advice regarding symptom control should be available to all health care professionals by education and telephone consultation. Patients whose symptoms are particularly difficult to control, or who have complex care requirements which are best met by specialist input, should be treated by a specialist palliative care team. However, the majority of patients would be cared for by primary and secondary teams not specialising in palliative care.

In order to fund this universal decent minimum level of care, efficient use of health care resources is required. Judgements about efficiency cannot be made unless one specifies the precise goal of the efficiency drive. Maximising the chosen health benefit per unit of resource will necessitate restriction of choices for patients and professionals.

The macro-allocation judgements that a community makes and the policies it follows reflect the relative values attributed by that community to the three major types of benefits gained from health care. Those relative values also tell us something about the attitudes of members of that society to those vulnerable people who are dependent on others for care, or who are terminally ill. Perhaps they also tell us something about attitudes towards

death and the degree of acceptance of our inescapable human mortality. It is possible that by influencing and altering macro-allocation policies those responsible for making them may be able to influence society's attitudes to vulnerable people, and perhaps also towards death itself. Thus it can be argued that macro-allocation strategies can be a force for either good or evil.

5.2 Micro-allocation.

5.2.i Micro-allocation is unavoidable.

The necessity to discriminate between individuals in order to determine who ought to receive some share, or a greater share, of scarce resources is an unpleasant and unavoidable reality. Unfortunately, however hard we try to establish macro-allocation policies which will diminish the necessity to discriminate between individuals, such discrimination will remain an inescapable and very difficult task for health care professionals. It is very unlikely that expensive life-prolonging treatments will be withdrawn altogether in order to fund symptom relief or basic care such as specialist palliative care. Thus palliative care practitioners will have to decide which patients should receive specialist in-patient or community care, and for how long.

This is a sphere in which judgement is necessary. In particular, just as in macro-allocation there had to be a balance between the moral principles of equity and efficiency or utility, so in micro-allocation there must be a balance between the principles of non-maleficence, beneficence, respect for the patient's consent or refusal of treatment, equity and efficiency.

For example, it will always be necessary for professionals to decide how to divide the precious resource of their time between patients (or increasingly, between patients and relatives). There is a natural tendency to give the most time to the patient (or relative) who is the most assertive in demanding or requesting that time. But a policy of dividing one's time

according to demand is clearly unjust, for less assertive or demanding patients may benefit more from professional time, and may be more seriously harmed by being allocated insufficient time. Similarly, it will always be necessary to discriminate between patients who would benefit from care in a specialist unit, such as a specialist palliative care unit. There will always be more patients who would benefit from such specialist care than there are specialist resources. Decisions here cannot mechanically follow 'guidelines'; qualitative judgements are required, and those making them must be prepared to take responsibility for them.

5.2.ii Adverse consequences of micro-allocation.

Even when morally justifiable methods of discrimination are used in micro-allocation the public, patients and doctors all tend to feel very uncomfortable with the whole exercise and the results. Patients tend to feel distressed, angry or bitter, and health care professionals often feel stressed by the responsibility and angry that shortage of resources requires that they choose between one patient and the next, often without any acknowledgement from politicians that this is necessary. There is particular distress when a treatment or care package which would alleviate suffering or prolong life for a terminally ill patient is denied to one patient in order to provide it to another, even when that other patient would derive greater benefit from it.

Most distress and adverse media publicity usually occurs when a patient is denied a life-prolonging treatment. This is partly because being forced to discriminate between patients with regard to life-prolonging treatment entails making a choice about who will live longer - the almost certain consequence for the patient denied the treatment is earlier death. For example, expensive life-prolonging chemotherapy regimes can prolong life for a few months, but may not be fully funded, thus requiring health care

practitioners to decide which patients will receive them and which will not. If the benefit from such treatments is to be maximised, then patients who are expected to gain the most benefit should receive them. But it might be argued that everyone has an equal desire or interest in staying alive, and that since this characteristic is the same then discrimination between patients on any other grounds is not justifiable. The argument that there is a moral requirement to maximise the health benefit from scarce resources is more convincing, and so the net benefit expected from the rationed treatment must be a highly relevant characteristic or criterion in the rationing process.

The language used to describe the rationing of life-prolonging treatments, particularly in the media, tends to exacerbate emotional reactions to discrimination between individuals. For example, such treatments are usually described as 'life-saving', which leads to the notion that if society does not provide them it has failed to 'save' a life. There is a strong general presumption of the rightness of trying to save lives in society, and it is generally considered a moral obligation to save a life if one can do so without risk to other lives. Therefore the use of the term 'life-saving' to describe a treatment entails a moral obligation to provide the treatment, whereas the term 'life-prolonging' is not associated with the notion of a moral obligation.

It can and should be argued that the term 'life-saving' with regard to medical treatment is misleading in most cases. If a curative treatment for an otherwise terminal illness can be given to a child or young person one might reasonably argue that such treatment 'saves' a life. But such treatments would be provided by a decent minimum of health care, unless they were extraordinarily expensive or themselves entailed severe suffering. In the context of resource allocation in health care it is important always to remember that ultimately all patients will die. For this reason it makes much more sense to speak of life-prolonging or life-sustaining treatments rather than life-saving treatments - for no life can be 'saved' forever. Furthermore,

most life-prolonging treatments actually extend life by only a 10 or 20 years, not a whole average life-span. Thus it is misleading to imply that such treatments have 'saved' a whole life. Indeed, in the case of many other life-prolonging treatments, such as palliative chemotherapy, life may be prolonged for less than six months.

5.2.iii Relevance of various criteria or characteristics in micro-allocation.

In discriminating between individuals there is general acceptance of the formal principle of justice previously mentioned - that equals should be treated equally, and unequals unequally. This means that people who are equal in all the relevant characteristics or criteria should be treated the same, whilst those who are different in relevant characteristics or criteria should be treated differently. The moral problem lies in deciding what are the relevant characteristics or criteria on which we should discriminate between patients in the process of micro-allocation. I have used some examples from general health care because they illustrate the use of the criteria in clinical practice.

The most obvious criterion, and one which is generally agreed to be morally justifiable, is what we might call *medical utility*, or the expectation of medical benefit from the treatment. Assessment of benefit must include assessment of the likelihood of benefit for each patient, as well as its magnitude. In general health care it is often apparent that one patient is more likely to benefit than another. For example, if one kidney is available and there are two potential recipients, the likelihood of success of the transplant is as relevant as the length of time that the transplant might add to the life of each patient. If one patient is a diabetic the chances of success of the transplant in that patient are less, so if other clinical features are similar then the transplant should go to the non-diabetic patient.

There are some treatments which appear to be associated with equal benefit for everyone. It is then impossible to differentiate between patients on the basis of medical benefit. For example, Viagra is an effective treatment for impotence. It appears to be equally effective regardless of the aetiology of the impotence, so the likelihood of the benefit is the same. The restoration of potency is a benefit of the same magnitude to all men distressed by their impotence. Therefore it is impossible to discriminate between men requesting this drug on the grounds of differences in benefit. In view of this fact it is probably preferable to avoid micro-allocation decisions pertaining to this drug altogether. Since it was judged financially impossible to make it available to all who would benefit, then the most appropriate rationing decision would have been to make it unavailable via the NHS. Such a decision would have been morally defensible also on the grounds that per tablet it is not a very expensive drug, so that patients could purchase it using a private prescription.

Most micro-allocation decisions are more complex than the Viagra example. Many care packages produce benefits which are actually different in nature, and those different benefits are incommensurable. For example, patients may derive different sorts of benefit from specialist in-patient palliative care - some will gain symptom relief, others essential intensive nursing care while dying, others may benefit from a life-prolonging treatment, and in other cases exhausted family members can recover and the patient can be relieved of feeling responsible for their weariness. These benefits are so different that they are difficult to weigh against one another. Rationed drug treatments may likewise have more than one effect. Bisphosphonates are relatively expensive and currently cannot be given to all who would benefit. Some patients will gain pain relief from them, whilst in others they may prevent pathological fractures, and in others they may prolong life by preventing hypercalcaemia. It is difficult to compare these different benefits in order to decide which patients should receive the drug.

The harm sustained when a treatment or care package has been withheld or withdrawn from a patient in the course of micro-allocation is clearly relevant, and should be considered under the heading of medical utility. For example, if two patients would both benefit from admission to a specialist palliative care unit but only one place is available, then it is necessary to consider the outcome for the patient who does not receive specialist care. If one patient is already settled in a hospital bed, albeit on an 'acute' ward, then that patient will suffer less harm by lack of a specialist facility than an alternative patient who is at home and if denied specialist care will pass through the accident and emergency department (enduring several hours on a trolley) before being admitted to an acute ward where the nursing team do not know him.

Thus the criterion of medical utility can be difficult to apply in practice - even if we think we can be reasonably sure which patients are most likely to benefit, and to achieve the greatest magnitude of benefit, weighing benefits (and harms) against one another is difficult.

The criterion of *age* has given rise to controversy regarding whether its use to discriminate between patients is justifiable. There is no doubt that providing a life-prolonging treatment to a young person is highly likely to result in more years of added life than if the same treatment were given to an older person. Of course the difference is dependent on the age difference between them, and when the age difference is small it becomes impossible to say with sufficient certainty which patient will live longest. Similarly, providing a single pain-relieving procedure (such as a hip replacement) with long-term effect to a young person is likely to yield greater total alleviation of suffering than giving the same treatment to a very old person who is expected to live only a few years. The use of age in this way as a discriminatory criterion has been

criticised as being unjust, because it means that the elderly will always lose out in the micro-allocation process.

On the other hand it may be argued that such discrimination against the elderly can be justified by appealing to the concept of a 'fair innings' for each human being. According to this line of reasoning, "a younger person should have a greater claim because he or she has not yet had the opportunity to survive for as long a period as an older person, or has had less of a 'fair innings'." ⁴¹ This argument seems to accord with our moral intuition. For example, if there is one bed in an intensive care unit, and a grandmother and a small child would each recover from their illness if it were provided for them, but would die without it, then most people (possibly including the grandmother!) would allocate the bed to the child. This accords with our idea that the grandmother has had a fair innings already, whereas the child has not. In such situations the use of age as a criterion for discrimination seems morally justifiable. However, the closer together the ages of the prospective recipients of care become, the less acceptable the use of the criterion of age appears to be. Unfortunately, where micro-allocation decisions are necessary, prospective candidates for the treatment are likely to be in a similar age range, and thus in practice age is usually not a morally justifiable criterion for discrimination.

Whilst the 'fair innings' argument seems persuasive when applied to allocation of life-prolonging treatments between patients of widely differing ages, it does not seem convincing or applicable in the context of palliative care. There seems no justification for allocating better symptom control to younger patients than older ones, simply on the grounds of age. Of course it is likely that other relevant factors such as available carers and the likelihood of benefit from the treatment will differ between young and elderly patients.

Age should not be confused with medical utility as a criterion. Age may be associated with greater harms and risks from many treatments. For

example, elderly people tend to tolerate chemotherapy very badly, so because of severe side-effects they are likely to derive less net benefit from palliative chemotherapy than a more robust younger person. Extensive curative surgery, such as oesophagectomy for carcinoma of the oesophagus, is exceedingly risky in the elderly, so that it may result either in death or in a prolonged period of illness. If in such cases a rationed treatment is given to the younger person because of greater medical benefit then the decision has been made on the grounds of medical utility and not age and this is justifiable.

Social utility may be described as the comparative value of the patients who may receive treatment to the community. It is sometimes suggested as a justifiable criterion for micro-allocation, especially of life-prolonging treatments such as renal dialysis and major organ transplants. For example, it might be suggested that a young mother of three children or a business man providing employment might both be given priority over a young drug addict with no dependants who supports his habit through crime. The public might support social utility as a rationing criterion, particularly as the NHS is publicly funded and the public may consider that rationed treatments should be given to those people who convey the greatest benefits to the community.

Social utility appears less relevant in the context of palliative care because symptom relief and provision of care at the end of life are very unlikely to enable patients to resume their normal social roles. If one considers the benefits of palliative care in terms of short term rehabilitation, then social utility appears a very difficult criterion to apply. For example, should one enable a young mother of three children to return for a time to her home where she can be with her children, or should one enable a frail elderly person to remain outside residential care for a while longer? The benefits in

terms of social utility are different and incommensurable, so social utility seems impractical as a criterion for micro-allocation in palliative care.

Moreover, social utility is readily misinterpreted as implying that one person is intrinsically more valuable than another. This suggestion is not compatible with the ideals of equity which must be of major importance in a publicly funded health care system. Judgements about a person's value to the community might easily be based on the prejudices of others, and this outcome might even be unavoidable. For this reason social utility should not be used as a criterion in micro-allocation even though there may be some public support for its use.

Queuing is a commonly used strategy in micro-allocation, the criterion being the length of time waiting for the treatment. Unfortunately, where demand for a treatment consistently outstrips supply the queue will just become longer and longer, so that patients may either die in the queue or their illness may progress past the stage at which it is amenable to the treatment. In the case of treatment such as specialist palliative care, coronary care or intensive care, then it is obvious that queuing is morally completely unacceptable as a discrimination policy, for patients simply die on the waiting list, and those who survive long enough to receive the treatment may never have needed it anyway.

Queuing is used extensively within the NHS as a rationing strategy, although it is often not recognised as such and so might be referred to as implicit rather than explicit rationing. The public assume that once in a queue they will eventually receive the treatment, but in the case of palliative care this assumption is false since patients would very often succumb to their illness whilst awaiting care. Moreover, queuing results in treatments being given to those who have waited the longest, rather to those who would derive most

benefit, and it can be therefore be argued that it is both inefficient and unjust as a method of resource allocation.

Prior commitment is sometimes used as a criterion to differentiate between patients who would all benefit from a scarce service or treatment. It may be justifiable in the case of life-prolonging technologies requiring major resource input, such as renal dialysis and artificial ventilation. On the other hand it is probably not justifiable for treatments or services which alleviate suffering or provide care, such as specialist palliative care services.

The example of haemodialysis for renal failure provides an illustration of where prior commitment may be a justifiable criterion for micro-allocation. Hospital dialysis facilities are strictly limited in terms of the number of patients they can each serve. Once dialysis has been commenced for a patient it is continued until a transplant or terminal illness intervenes. In practice this means that once the commitment to dialyse a patient has been made the treatment is not withdrawn, even if a patient who would derive greater benefit from the treatment presents and has to be turned down. This is because withdrawal of the treatment from any patient would result in certain death, and no doctor or team wish to take responsibility for withdrawing the treatment so long as its benefits outweigh its burdens and risks. They consider that they would have caused death in such a case. (This is understandable, but not rational, since the renal failure caused the patient's death, see chapter 1 for discussion.) Instead, it is considered preferable not to start the dialysis for the patient for whom there is no room in the dialysis programme. In this case withdrawing treatment is regarded as so unpleasant that it is considered justifiable to continue treatment in some patients when it is denied to others who would probably derive more benefit from it.

Graphic examples of the result of using prior commitment as a criterion in micro-allocation occur in palliative care. Sometimes dialysis is commenced

as an emergency measure and it later emerges that the renal failure is due to incurable and progressive carcinoma of the prostate gland. Teams commencing the dialysis will probably feel they must honour the commitment already made to that patient, even though this may mean denying dialysis to other patients who might derive more benefit in terms of length of life and return to normal activity. This scenario happened to a patient normally resident in Bournemouth, who commenced dialysis as an emergency measure in Oxford whilst visiting there, and was subsequently found to have locally advanced and incurable cancer of the prostate gland. His local dialysis centre in Portsmouth declined to provide dialysis because he was then known to be terminally ill. They considered, quite justifiably, that they should not provide dialysis for him because to do so meant they would have to refuse it to another patient who was not already terminally ill with cancer. When the Portsmouth team declined to provide dialysis, the Oxford team who had commenced it felt duty bound to continue to provide it, so the patient travelled twice a week to Oxford for the treatment.

It should be noted that the UK is very unusual amongst affluent Western communities in that it does not provide sufficient dialysis for all patients with end stage renal failure who are not otherwise terminally ill. Other European countries and the USA provide sufficient dialysis services, so that these difficult and publicly unpopular decisions are effectively avoided.

Prior commitment is often considered very important by health care professionals who institute other life-prolonging treatments, even artificial feeding and hydration. They often consider that they have made a commitment to provide care for the patient whose life they have prolonged. For example, if artificial nutrition and hydration are commenced on a patient who is very disabled but not imminently dying, then practitioners may judge that they have a duty to continue to provide that patient's care. Yet such care, which may be undertaken in a specialist palliative care unit, will continue for

many weeks, and so other patients will be denied access to the specialist in-patient facility. Knowledge of this 'opportunity cost' to several other patients, and the feeling of duty to the patient whose life has been prolonged, may combine to make practitioners unwilling to commence the life-prolonging treatment because its use will entail what they reasonably judge to be an inequitable use of the specialist palliative care facility.

In this case the principle of honouring prior commitments actually results in professionals withholding a beneficial treatment because they do not want to have to face the choice between two morally undesirable consequences - the first being care of the one patient but a major opportunity cost to other patients, the second being breaking the commitment to provide care personally and sending the patient to a nursing home.

It would seem morally preferable to offer the life-prolonging treatment to the patient but to explain that ongoing care as an in-patient in the specialist unit cannot then be provided. At least then the patient is informed about what life may be like if the treatment is accepted, and so is able to make an informed choice about whether or not to accept the life-prolonging treatment. This approach also has three other merits; firstly, it fosters openness and honesty between patient and professionals, secondly it avoids patient acceptance of the treatment under the misguided impression that ongoing care will be provided in the specialist facility, and thirdly it requires professionals to face the stark realities regarding the true 'costs' of some of these apparently simple life-prolonging technologies.

Sometimes the provision of a life-prolonging treatment medically requires ongoing care in the specialist unit, which itself is a scarce resource. This situation occurs when ventilation (via a tracheostomy) of a patient with motor neurone disease is considered. Such patients would require moderately long periods of care in the intensive care unit, where pressure on beds is often acute. Once ventilation has been commenced, anaesthetists

running the ICU will probably feel unable to withdraw the ventilation even when a patient who could derive more benefit from ICU care is awaiting a bed. Having commenced the treatment, they feel they have made a commitment to the patient to provide the necessary ongoing care. They also consider that if they withdraw ventilation, then the act of switching off the machine and giving sedation to alleviate distress appears to them to be an act which (intentionally) causes the death of the patient. They would not consider that the act was more accurately described as withdrawal of treatment with foreseen death of the patient due to the underlying illness, although this description is more rational (see chapter 1 for discussion).

Where the provision of a life-prolonging treatment entails an inequitable and inefficient use of a scarce specialist resource, whether it be specialist palliative care or the intensive care unit, then it would appear preferable not to commence the life-prolonging treatment and instead allow the patient to die of the underlying disease. It should then be considered that the immediate cause of the patient's death is the underlying disease, and that the scarcity of resources has meant that it has not been possible to prolong this patient's life.

Specialist palliative care services provide treatment to alleviate symptoms and give essential care far more often than they provide life-prolonging treatments. When hospices first began to accept patients, the general policy was for the patient to remain until death, or until the patient improved and wanted to go home. A commitment was made to care for the patients until death. As demand for these specialist beds increased, it became apparent that looking after a small number of patients for many weeks until their death, whilst denying care to others who would benefit to a similar or greater degree, was unjust. Most specialist palliative care units now operate a policy whereby they offer short-term care but not long-term care, thus giving many more patients the opportunity to benefit from the service. In

practice this has meant a change from the initial policy of honouring prior commitment, undertaken when the patient entered the hospice, to a policy of providing care to those patients most likely to benefit and asking those whose needs can be met elsewhere to move, either back home or into residential care. This change in policy was clearly morally necessary as the legitimate demand for specialist palliative care beds increased.

Similar problems are now being experienced with domiciliary specialist palliative care services. In my own unit for the first 25 years increase in demand for specialist palliative care support at home was met by gradual increase in the number of nurses and doctors in the team. Once a patient was taken on for home care, then a commitment was made to remain in contact until the patient's death (unless the disease clearly remitted). However, by the end of 1999 the number of appropriate referrals had risen to the point where the nurses felt they could no longer offer sufficient time to provide all the support they felt should be given to each patient and family. Some team members reacted by working longer hours (without financial recompense or compensatory time off) and felt stressed. Therefore it became necessary to limit the case load of each nurse numerically, in the same way as the number of beds is limited on an in-patient unit.

Micro-allocation then became necessary. There was a choice between caring for a fixed number of patients from referral to death continuously, or caring for a larger number of patients (those judged to be able to derive most benefit from the service) but not necessarily continuously from referral to death. Patients who were stable or with few symptoms could be discharged from contact for a period, liberating nurse time to care for those with more difficult problems. Ability to benefit from the service, plus harm sustained without the service, seems a more justifiable criterion to use in this case than prior commitment. It seems an inequitable and wasteful use of resources to maintain contact continuously with patients who are stable and whose

symptoms are controlled whilst having to refuse input to patients who are distressed or imminently dying. Clearly, patients and the primary care team had to be informed that continuous contact from referral to death could not be guaranteed because of the requirement to make the best use of the specialist resource and to distribute that benefit justly.

From a purely logical standpoint, and bearing in mind the requirements of equity and efficiency, prior commitment should not be used as a criterion for micro-allocation. Instead, continuous reselection of patients is morally required so that those who stand to benefit the most receive the treatment or care. This policy does require health care professionals frequently to discharge patients from specialist care, even when they are deriving some benefit from it and would prefer to remain in specialist care. Although morally the most just policy, it is difficult to implement because it entails withdrawing a beneficial service from terminally ill patients who have grown to feel secure, and who know that the alternative care packages, whilst adequate, are unlikely to be as good.

It is sometimes suggested that the degree to which the *patient's conduct* has caused the condition might be used as a criterion for discrimination in micro-allocation. For example, one might refuse liver transplants to alcoholic patients who have previously been warned that their alcohol abuse will irrevocably damage their liver, or one might refuse expensive palliative chemotherapy for lung cancer to smokers. It is important not to confuse such decisions with those based on medical utility. For example, if an alcoholic continues to abuse alcohol after a transplant the new liver will also be destroyed.

At first consideration it does seem reasonable to discriminate between those who have brought the illness on themselves and those who have not. But it is difficult to prove that the patient really understood that the damaging

life-style would result in organ failure. Moreover, there will inevitably be prolonged and probably unresolvable arguments about the patient's responsibility for the conduct.

Finally, *chance* can be used as a way of 'discriminating' between patients. When chance is used in micro-allocation the patient who is most lucky receives the treatment, which is allocated by a lottery system. This is seen by many people as being a fair method of allocation when it is used to choose amongst a group of people between whom there are no other relevant differences. This latter qualification is essential. It should be argued that as the stakes regarding health care are so high, micro-allocation by lottery is justifiable only when there is no morally preferable criterion. The arguments above support medical utility as the only criterion which is clearly a relevant difference between patients, although age might be, (according to the fair innings argument), if the age difference between potential candidates is sufficiently great.

Unfortunately there are practical problems with allocation by lottery. Firstly, if a lottery is to be held, then it should be held only between patients in the same age range and for whom the treatment holds the same medical utility. But patients appear serially for treatment, and it is very unlikely that a group of patients (or even two patients) who are equal in terms of medical utility will ever come forward at the same time. Secondly, since the stakes are so high attempts to rig such lotteries are very likely. Thirdly, a lottery system is associated with these very significant practical problems. Lastly, some people may consider that such important decisions should not be made by 'mere chance', and so a lottery should avoided. However, on those rare occasions where two patients in the same age range come forward and the treatment has the same medical benefit for both, then drawing lots would be the fairest solution.

Sometimes it is suggested that 'need' or 'quality of life' might be morally appropriate and practically applicable criteria for treatment, but preceding discussions (section 5.1.vi and chapter 3, section 3.1.v) have shown that the confusion surrounding such terms causes these concepts to be useless in the process of micro-allocation.

The conclusion of this discussion of micro-allocation is that the criterion of medical utility, although frequently difficult to apply, is the only clearly justifiable criterion for use in micro-allocation of scarce specialist palliative care resources. Since those resources will always be limited, this criterion will remain essential to discriminate between terminally ill patients (whatever their diagnosis) in order to determine who should receive the specialist resource.

5.3 Conclusions.

1. There is overwhelming evidence, deriving from considerations of finance and equity, that health care rationing, and rationing of specialist palliative care services is necessary.
2. Members of specialist palliative care teams are trustees of resources; objections that they may raise to rationing are based on misunderstandings.
3. Macro-allocation cannot be based on the QALY, but requires judgement about the relative benefits of treatment and care packages, about the characteristics of the population, and the use of relevant moral principles.
4. Resources should not be committed for specialist palliative care for everyone until and unless there is clear evidence of benefit over and above conventional care. Qualitative evidence may suffice.

5. Micro-allocation is unavoidable; judgement has to be made regarding patients' ability to benefit from specialist care. Other criteria are difficult to justify morally.

6. A decent minimum of palliative care ought to be provided, and entails education and telephone advice available to all health care professionals, and care by a specialist team only for patients whose symptoms are difficult to control or whose care requirements can be met only by a specialist team.

References to Chapter 5

¹Critchley P, et al, 'Are Some Palliative Care Delivery Systems More Effective and Efficient than Others? A Systematic Review of Comparative Studies', *Journal of Palliative Care* 15: 4/1999; 40-47

²Salisbury C et al, 'The impact of different models of specialist palliative care on patients' quality of life: a systematic literature review', *Palliative Medicine* 1999; 13: 3-17

³McWhinney IR, Bass MJ, Donner A. 'Evaluation of a palliative care service: problems and pitfalls.' *BMJ* 1994; 309: 1340-2

⁴Keeley D, 'Rigorous assessment of palliative care revisited', *BMJ* 1999; 319: 1447-8

⁵Smith R, 'Stumbling into rationing' *BMJ* 1999; 319: 936

⁶Calman-Hine report on cancer services

⁷Standing Medical Advisory Committee, Standing Nursing and Midwifery Committee (1992), *The Principles and Provision of Palliative Care*. Department of Health, London.

⁸NHS Executive. 'A policy framework for commissioning cancer services: palliative care services.' London: NIH Executive, 1996 (EL96); 85

⁹Addington-Hall J, 'Reaching Out: Specialist Palliative Care for Adults with Non-malignant Disease.' National Council for Hospice and Specialist Palliative Care Services, London 1998.

¹⁰Smith R, 'Stumbling into rationing', *BMJ* 1999; 319:936

¹¹Harris J, *BMJ* 1997; 314:669-672

¹²Daniels N. 'The ideal advocate and limited resources'. *Theoretical Medicine*, 1987; 8: 69-75.

¹³Beauchamp T L, Childress J F, 'Principles of Biomedical Ethics', Oxford University Press, 1994, p 330.

-
- ¹⁴ Edgar A, Salek S, Shickle D, Cohen D, *The Ethical Qaly*, Haslemere, UK, Euromed Communications, 1998, p4.
- ¹⁵ Franks PJ et al, The level of need for palliative care: a systematic review of the literature. *Palliative Medicine* 2000; 14: 93-104
- ¹⁶ Last J M ed. *A dictionary of epidemiology*, 3rd edition. Oxford: Oxford University Press. 1995 111
- ¹⁷ Reinhardt U E, Rationing health care. *Strategic Choices for a Changing Health Care System*, ed. by Altman S. Health Administration Press 1996 p.71
- ¹⁸ Edgar et al, 'The Ethical QALY' 1998 op cit
- ¹⁹ Williams A. Health professionals have an ethical duty... *Journal of Medical Ethics* 2000; 26: 85-88.
- ²⁰ Downie RS. The value and quality of life. *Journal of the Royal College of Physicians of London* 1999; 33: 378-81.
- ²¹ Edgar et al, *The Ethical QALY*, 1998.
- ²² Harris J, 'QALYfying the Value of Life', *Journal of Medical Ethics*, 13, pp. 117-23. 1987
- ²³ Mckie et al, *Journal of Medical ethics*, 1996; 22: pp 216-221
- ²⁴ Royal Commission on Long Term Care. *With respect to old age. Report*. London: Stationery Office, 1999 (Cm 4192-I.)
- ²⁵ Franks PJ et al, The level of need for palliative care: a systematic review of the literature. *Palliative Medicine* 2000; 14: 98
- ²⁶ Salisbury C et al, 'The impact of different models of specialist palliative care on patients' quality of life: a systematic literature review'. *Palliative Medicine* 1999; 13: 3-17
- ²⁷ Greer DS et al, 'An alternative in terminal care: results of the National Hospice Study'. *Journal of Chronic Disease* 1986; 39 (1): 9-26
- ²⁸ Aristotle, *The Nicomachean Ethics* Trans D. Ross. Oxford: Oxford University Press, 1980, Book V.

-
- ²⁹ Addington-Hall J 'Reaching Out: Specialist Palliative Care for Adults with Non-malignant Disease.' National Council for Hospices and Specialist Palliative Care Services, London 1998.
- ³⁰ Standing Medical Advisory Committee, Standing Nursing and Midwifery Committee (1992) 'The principles and Provision of Palliative Care. Department of Health', London.
- ³¹ Smith R, 'A good death' *BMJ* vol 320 15th Jan 2000 p 129-30
- ³² Debate of the Age and Health Care Study Group. 'The future of health and care of older people: the best is yet to come.' London: Age Concern, 1999.
- ³³ Keeley D, 'Rigorous assessment of palliative care revisited.' *BMJ* 1999; 319: 1447-8
- ³⁴ Smeenk FW et al, 'Effectiveness of home care programmes for patients with incurable cancer on their quality of life and times spent in hospital: systematic review.' *BMJ* 1998; 316: 1939-44
- ³⁵ Grande GE et al, 'Does hospital at home for palliative care facilitate death at home? Randomised controlled trial.' *BMJ* 1999; 319: 1472-5
- ³⁶ Christakis NA, Lamont EB, 'Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study'. *BMJ* 2000; 320: 469-72
- ³⁷ Connolly M, 'Patients with non-malignant disease deserve and equitable service.' *International Journal of Palliative Nursing*. 2000. Vol 6, no 2 p91-3
- ³⁸ Addington-Hall J, 'Reaching Out: Specialist Palliative Care for Adults with Non-malignant Disease.' National Council for Hospice and Specialist Palliative Care Services, London 1998.
- ³⁹ Lynn J et al, 'Perceptions by family members of the dying experience of older and seriously ill patients.' *Ann Int Med* 126: 97-106
- ⁴⁰ Wasson K, 'Ethical arguments for providing palliative care to non-cancer patients.' *International Journal of Palliative Nursing*. 2000. Vol 6, No 2

⁴¹ Edgar A, Salek S, Shickle D, Cohen D, The Ethical QALY. Haslemere, UK, Euromed Communications, 1998 p 55

Chapter 6

Conclusions: The way forward

The discussion in the preceding five chapters was intended to bring out the main weaknesses of the philosophy of palliative care as it is summarised in the WHO definition. At the same time the immense strength of the palliative care movement and its benefits for patients have not been minimised. In this way I hope to have carried out the main aim of the thesis - to offer a critique of palliative care in Kant's sense of establishing the strengths and weaknesses of palliative care. But if we grant the force of this critique there remains an important question: are we to end negatively with the conclusion that a philosophy of palliative care is not possible, or is it possible to end on a more positive note, with a very brief outline of a possible philosophy of palliative care?

I believe that it is both possible and desirable to indicate, at least briefly, a possible direction for palliative care to take. Whether we dignify this with the title of 'philosophy' is not a matter which need detain us. Let us begin with the question of the desirability of having such a philosophy.

Is it desirable to describe and use a philosophy of palliative care? Yes, for several reasons:

- 1) There is a current fashion for mission statements, philosophy statements etc., and so if a single officially recognised statement is not formulated each specialist palliative care team will draw up, display and attempt to live by its own individual philosophy or mission statement.

2) The word 'palliative' is not universally understood, and patients and the public do not know what palliative care is, so a philosophy statement is necessary in order to inform them of the aims and nature of such care.

3) It is important to produce a new philosophy statement which will influence the care and treatment of terminally ill patients for the better, and which avoids, as far as possible, the problems and adverse consequences inherent in the present statement.

If we assume that these reasons point to the desirability of attempting to formulate a philosophy we can move on to consider the question of the possibility of such a philosophy. In brief and general terms, what should the new philosophy statement say? It would need to satisfy certain criteria.

Firstly, the aims, values and assumptions described in the statement should be consistent with the aims, values and assumptions of health care in general. Secondly, these aims should be consistent with professional codes and the law. It is essential that a new philosophy should not influence health care practitioners to act contrary to their professional codes or the law. Thirdly, the aims and values of palliative care should not cause its practitioners to pursue goals which are unattainable within the current national health service.

Granted the acceptability of these criteria, I propose the following brief account of a philosophy of palliative care. It is intended to avoid the pitfalls I have identified in the existing philosophy, but to preserve the essence of palliative care as it is currently practised.

'Palliative care is the care of patients whose disease is incurable and is expected to cause death. The aims of treatment are to minimise pain and other symptoms and to prolong life, but with a minimum of burdens and risks as

assessed by individual patients and professionals working together. The informed consent of competent patients regarding treatment is sought by presenting information honestly but sensitively. Refusal of treatment by patients is respected.

Incompetent patients are treated in accordance with their best interests as judged by the health care team following examination of the medical circumstances and exploration with the family of what can be known of the patient's wishes.

Professionals provide support to patients:
by ascertaining how much information patients seek and providing it sensitively;
by listening to patients' views about their own goals and values;
by discussing the possible impact of various treatments on their lives so as to work out which treatment will most benefit the particular patient;
by providing advice based on experience.

Explanation, professional advice and encouragement are given to caring relatives within the limits necessitated by the rules of confidentiality towards patients.'

Appendix: Casuistry

Casuistry has had a bad name for several centuries, and has become synonymous with the drawing of fine distinctions or with quibbling and special pleading. Historically this came about because of the abuse of the method in order to salve the consciences of noblemen in the 16th and 17th centuries. As such it was effectively satirised by Pascal in his 'Provincial Letters'¹ and criticised philosophically by Adam Smith and others.² Oddly enough, Adam Smith is perfectly happy with reasoning about particular cases, but he calls it 'natural jurisprudence'. Whatever it is called I believe that it offers a way of reasoning in health care ethics which is widely practised by doctors, and has been used in this thesis. The method has recently been defended and extended in an influential book by Albert R. Jonsen and Stephen Toulmin called 'The Abuse of Casuistry', published in 1988, and in a paper entitled 'Casuistry as Methodology in Clinical Ethics'.³

In the latter paper Jonsen describes casuistry as 'the interpretation of moral issues, using procedures of reasoning based on paradigms and analogies, leading to the formulation of expert opinion about the existence and stringency of particular moral obligations, framed in terms of rules or maxims that are general but not universal or invariable, since they hold good with certainty only in the typical conditions of the agent and circumstances of action'.⁴

Jonsen and Toulmin also describe casuistry more simply as 'the art of analysing moral issues in terms of cases and circumstances'.⁵ They stress that moral choices in life are essentially practical in nature, in that we make those choices in the context of a particular set of circumstances at a particular time and a choice must be made as to what to do. Thus moral issues should be regarded as requiring *practical reasoning*.

They argue that such decisions are *concrete* in their context, and are *temporal* in that they may not apply at a future time where circumstances may have changed subtly, and they are *presumptive* in that future events or consequences may prove those choices to be less than the best.

Practical reasoning is contrasted with theoretical or *scientific reasoning* which they describe as being to do with the understanding or discovery of universal principles or laws such as those of physics or geometry, and the subsequent application of such principles or laws.

Neil Pickering, in company with Childress and Beauchamp,⁶ Raanan Gillon⁷, and many others writing on bioethics, presents an alternative view. In 'General Principles and Particular Cases',⁸ he argues that the way one describes a case in terms of the principles considered most relevant determines which principle is used to guide and justify one's action. The chosen principle guides and justifies one's action via a logical syllogism. For example, where a technically feasible treatment would probably result in overall harm to a patient, the principle of non-maleficence would justify not providing that treatment according to the conclusion of the logical syllogism which would be as follows:

Major premise: doctors ought not to harm their patients.

Minor premise: the treatment in this particular case would harm this patient.

Conclusion: I ought not to give this treatment to this particular patient.

On the other hand Jonsen and Toulmin state that faced with a particular case one must decide which paradigm case from a taxonomy of cases our problem case most resembles. This suggestion pre-supposes a taxonomy of

paradigm and other cases, which to my knowledge does not exist in health care, but for the purposes of the present discussion I shall assume it could be drawn up. The choice of which paradigm case to use for comparison is not only difficult but will also be highly influential in our decision. Examples help to illustrate this point.

If we take the example of a case of assisted suicide one would choose from a number of quite different paradigm cases for comparison with the particular assisted suicide case. One paradigm might be the rightness of preventing a young girl depressed by disappointment in a love affair from committing suicide - the maxim here would be a duty to prevent suicide when its causes are temporary. Another paradigm might be that of allowing a terminally ill patient to have a supply of drugs adequate to ensure pain control knowing that the patient might choose to take the medication with suicidal intent - the maxim here would be that of giving patients responsibility for managing their own lives. Alternatively one might consider a paradigm of 'medicalizing' aspects of ordinary human life, as suggested by Tania Salem in a paper entitled 'Physician-Assisted Suicide, Promoting Autonomy - Or Medicalizing Suicide?'.⁹

A second example concerns issues of confidentiality. Quite often in palliative care a relative caring for a patient seeks information regarding the patient's illness. Following the pathway of casuistry one would have to decide whether this case most resembles a paradigm where the patient's right to confidentiality clearly should not be breached, or whether it most resembles a paradigm where the carer has a clear 'need to know' in order to minister to the patient. The choice of paradigm case for comparison with the problem case is crucial, since not only will it determine our choice of maxim as a warrant for a claim that a certain course of action is right, but it will also clearly colour our attitude to the problem case.

Jonsen in 'Casuistry as Methodology in Clinical Ethics'¹⁰ describes the process of choosing our paradigm case and its associated maxim in more detail. He states that each case has a *structure* or *morphology*. This structure is composed of

the circumstances of the case,
special topics which are always relevant in the field of clinical ethics,

the maxims which might be considered relevant,
the form of argument one uses in applying the maxims.

The *circumstances* can be summarised as 'who, what, when, why how and by what means'. They are the features of this particular clinical case at this particular instant. I have already noted that how one describes a case, which includes the circumstances, has a major influence on the factors one considers in reaching a judgement and on one's moral perceptions of the case. Only those factors which one includes in the description of the case will be included in the ensuing deliberations - if a factor, such as the patient's stated reason for making a choice, is omitted from the description it will not feature at all in the process of making a decision. In order to ensure that all relevant factors are considered it seems best to include many details about the particular case. Unfortunately, rehearsing a very detailed account can be like searching through a garrulous patient's history for the relevant information, a process with which all clinicians are familiar and which is remarkably similar to describing a case for the purposes of casuistry. The important analogy to remember is that where a diagnosis has not yet been reached, features of the history which at first seem of no relevance may turn out to be important as alternative diagnoses are considered. So it is important not to omit features of the case which may be relevant.

Jonsen¹¹ states that there are some factors in clinical medicine which are always relevant to the clinical decision. He calls these *special topics*. Thus statements about these special topics should always be included in the description of the circumstances. He does not give a list of these topics, but suggests that the medical indications of the case, the preferences of the patient, the quality of the patient's life and social and economic factors external to the patient are examples of these special topics. He considers that these factors will virtually always be relevant to a decision in clinical medicine, and as such they are 'invariant', although of course their actual content will vary greatly as cases are necessarily individual.

Once the circumstances of the case have been described, including the special topics, certain *maxims* which he defines as 'brief rule-like sayings' will appear to have a bearing on the case. Jonsen states that 'These maxims provide the 'morals' of the story. For most cases of interest, there are several morals, because several maxims seem to conflict. The work of casuistry is to determine which maxim should rule the case and to what extent. To what extent means under what constellation of circumstances, for certain changes of circumstances will lead to another maxim emerging as more significant. 'Circumstances', say the casuists, 'make the case'. This appears to mean that the selection of the appropriate maxim to rule the case is profoundly dependant upon the circumstances.... For the classical casuist, a maxim would accumulate weight from the circumstances that hung from it in a particular case.'

It is important to remember that the maxims themselves have been derived from paradigm cases - those in which the right (or wrong) course of action is apparent to virtually all people and about which there is no significant difference of opinion. So having described the particular case, one chooses a paradigm case and considers how the maxim derived from that case might be applicable to the particular case. Thus a correct description of the morphology of the case, including a comprehensive description of the circumstances and

special topics precedes selection of relevant paradigm cases and their associated maxims.

Although Jonsen and Toulmin do not state that one should choose a paradigm cases (or cases) which are as similar as possible to one's own case in terms of the crucial moral problem(s), yet it seems that common sense would dictate that this must be so. For there seems little point in ignoring a relevant paradigm case, or in using one which has few features in common with the particular case. Of course, if one did ignore relevant paradigms, or used significantly dissimilar paradigms, one could be accused of 'bad casuistry'.

Jonsen suggests that cases fall into certain types, and gives the example of cases where the underlying issue is 'euthanasia'.¹² He proposes that cases of a certain type should be 'lined up' so as to form what he calls a taxonomy or classification of cases. He then suggests that 'the casuist seeks out those cases, within the type, that demonstrate the most obviously, unarguably wrong (or right) instance. This would be a case in which the circumstances were clear, the relevant maxim unambiguous and the rebuttals weak, in the minds of almost any observer.... Such cases can be paradigms'. Thus Jonsen is advocating that in order to choose paradigm cases one must first identify what type of case one is dealing with, and then place it in the 'line-up' of similar cases, where cases are progressively further and further away in terms of circumstances from the paradigm case.

In 'The Abuse of Casuistry' Jonsen and Toulmin liken the process of identifying what type of case the instant case is to the process of making a diagnosis in clinical medicine. They assert that diseases are recognised collections of symptoms and signs, and that there is a 'taxonomy' of diseases. Diagnosis is about deciding what collection of symptoms and signs recognised as a certain 'disease' our patient's symptoms and signs most resemble. They state that 'Given this taxonomy of known conditions and the paradigmatic cases that exemplify the various types, diagnosis then becomes a kind of perception,

and the reasons justifying a diagnosis rest on appeals to analogy'.¹³ Since diagnosis depends on perception and analogy, two physicians may reach different diagnoses for the same patient. Jonsen and Toulmin suggest that just as clinicians diagnose a disease, in the same way they should decide what type of case the clinical moral problem most resembles, and should use the appropriate paradigms.

Evidence that casuistry is actually practised in the sphere of health care provides strong support for the conclusion that it is possible as a method of moral reasoning. Health care practitioners faced with a clinical moral problem do classify it as one of a type, in the same way that they make a diagnosis, and they do compare it with cases in which the right (or wrong) solution is more obvious to them. They do not instinctively think of a principle and deduce the answer to their problem from it, nor do they attempt to reach a solution by considering what a 'virtuous' practitioner might do. Instead they think of the 'accepted' or consensus decision as to what is right in this type of case. In other words, they compare their case with a professional paradigm. Thus casuistry is a theoretical description of the thought processes of doctors faced with moral problems arising in particular cases. Moreover it is the most accurate description of the way health care practitioners resolve moral problems in clinical practice.

Since the moral problems of health care, and palliative care, are resolved by professionals using an embryonic form of casuistry one must conclude that it would be possible to use this method in a more developed form to resolve the moral problems of palliative care.

It should also be noted that the legal problems of health care, including those arising in the context of incurable illnesses, are resolved by the establishment of case law. Judges compare the particular case with paradigm cases and with the cases and associated legal judgements which have gone before and established precedence. They reach resolutions by this process of

practical reasoning which might also be described as jurisprudence. The process of establishment of case law and thus accepted practice in a legal sense is closely analogous to casuistry.

Moreover, doctors must always have regard to the law in relation to health care and they understand how case law, via legal judgements, influences moral judgement in health care. The existence of case law as an example of reasoning closely allied to casuistry, together with its influence on medical practice, support the argument that casuistry is possible as a method of resolution of the moral problems of health care.

References to the Appendix

- ¹ Blaise Pascal. *The Provincial Letters* (1657) Penguin Classics, Harmondsworth 1967.
- ² The Theory of Moral Sentiments, Sect. iv 6th edition 1790 ed. by D. D. Raphael and A. L. Macfie, Oxford University Press 1976.
- ³ Jonsen A. R. 'Casuistry as Methodology in Clinical Ethics', *Theoretical Medicine*, 12, 1991 pp. 295-307
- ⁴ As above, p 297.
- ⁵ Jonsen A. R. & Toulmin S. *The Abuse of Casuistry*, Los Angeles: University of California Press, 1988 p. 15.
- ⁶ Beauchamp T, Childress J. *Principles of Biomedical Ethics*. 4th ed. New York: Oxford University Press, 1994.
- ⁷ Gillon R. *Philosophical Medical Ethics*. Chichester: John Wiley & Sons, 1985. pp. 61-91.
- ⁸ Pickering N. 'General principles and particular cases', *Advances in Bioethics*, Vol. 4 JAI Press Inc. 1998 p. 202
- ⁹ Salem T. 'Physician-Assisted Suicide, Promoting Autonomy - or Medicalizing Suicide?' *Hastings Centre Report* Vol. 29, no 3.
- ¹⁰ Jonsen A. R. 'Casuistry as Methodology in Clinical Ethics', *Theoretical Medicine*, 12, 1991 pp. 295-307
- ¹¹ As above.
- ¹² As above.
- ¹³ Jonsen A. R. & Toulmin S. *The Abuse of Casuistry* Los Angeles: California University Press, 1988 p. 40

Bibliography

I have found the following books to be the most helpful and influential in forming my ideas. It does not represent an exhaustive list of all the books read during my studies.

Aristotle, *The Nicomachean Ethics* Trans D. Ross. Oxford: Oxford University Press, 1980

Beauchamp T, Childress J, *Principles of Biomedical Ethics* 4th ed. Oxford: Oxford University Press 1994

Bowling A, *Measuring Health, A review of quality of life measurement scales.* Milton Keynes: Open University Press, 1995

Brewin T, *The Friendly Professional* Bognor Regis: Eurocommunica Publications, 1996

Brody H, *Stories of Sickness* London: Yale University Press, 1987

British Medical Association, *Withholding and Withdrawing Life-prolonging Medical Treatment* London: BMJ Books 1999

Elliott C, *A Philosophical Disease* London: Routledge, 1999

Fallowfield L, *The Quality of Life, The missing measurement in health care.* London: Souvenir Press (Educational and Academic) 1990

Jonsen A, Toulmin S, *The Abuse of Casuistry* Los Angeles: University of California Press 1998

Oxford Textbook of Palliative Medicine. ed by Doyle D, Hanks G, Macdonald N.
Oxford: Oxford University Press. 1993

Narrative Based Medicine ed. by Greenhalgh T, Hurwitz B. London: BMJ Books
1998

Raphael D, *Moral Judgement.* London: George Allen and Unwin Ltd. 1955

Ross W. D, *The Right and the Good* Oxford: Oxford University Press. 1930

