for the first time, is a timely contribution to the identification of, and debate around, the fields of ethics and health informatics. As befits the multidisciplinary nature of its subject matter, standing as it does at the intersection of health care, computing and ethics, its contributors include specialists in public policy, social research, nursing, computing, ethics, and law. While at times making for a less than entirely cohesive tone, this approach has the advantage that important areas are addressed rather than ignored.

The editor is at pains to inform the reader that the collection aims at going beyond mere identification of already recognised problems, and seeks both to re-map the landscape, highlighting hitherto unrecognised areas of ethical concern, and also to suggest answers to some of the problems. He is benignly dismissive of the question-raising that for him characterises much contemporary bioethical debate: "To write, 'Lo, an ethical issue' is doubtless to make a contribution, often an important one. But it is inadequate" (page 3).

A multi-authored collection, the book exhibits both the strengths and the weaknesses of such a collaborative enterprise. Two important themes emerge, one of which is highlighted by the editor in his opening chapter, but there is also significant disagreement between the contributors around a central issue in the field. Depending on one’s own perspective, of course, this might be seen as a creative tension that reflects a dynamism of thought at the leading edge of research: or not.

Goodman’s central theme, which he describes as emerging, is the adoption of a stance that he labels as "progressive caution". This via media seeks to steer a middle ground between the Scylla of reactionary Ludditism and the Charybdis of an unreflective embrace of the next big technological thing. James Anderson and Carolyn Aydin’s chapter on system evaluation, for instance, argues that developments in health informatics should be seen as analogous to progress in other areas of health care provision, and that there is a corresponding duty to evaluate information systems in practice before the practice becomes too firmly rooted to be overturned. This suggestion fits well with the doctrine of primum non nocere (first do no harm), although whether the already hard-pressed members of local research ethics committee (LRECs) would be pleased at the prospect of all new health informatics systems coming under their remit is at best an open question.

A second theme of the collection, particularly of the chapters on “Medical informatics and human values”, “Outcomes, futility, and health policy research” and “Meta-analysis: conceptual, ethical and policy issues” is the idea that while there are no individual tasks of medicine that should be ring-fenced for humans only to perform - for instance certain operations might be performed less well by a fallible human than a machine - none the less the second-level questions and tasks, such as determining the goals of medicine, and evaluating the worth or futility of a particular intervention are matters that can be considered properly only by humans. Goodman’s conclusion that we should be wary of being "so enthralled by the medium that we get the wrong message" (page 161) might be taken as the motto of the whole collection, holding that as tools, information systems and machines may be useful, but that there is a conceptual limit to their application, and we should greet each new possibility with scepticism and look for the harm that it could do rather than the novelty it provides.

The contributors, however, cannot agree so easily on the slippery if central issue of the moral status of medical information systems. John Snapper argues that expert systems should be held to be morally accountable because they are potentially legally liable for their decisions. This view is challenged by Randolph Miller and Kenneth Goodman, who implicitly reject the idea that medical decision-support systems (MDSSs) can be seen as morally accountable, and instead locate moral responsibility with the personnel operating the systems. While not every reader will share Snapper’s intuitions that morality ought to follow behind legal principle, the disagreement is clearly important, and is set to become central to the area of both ethics and law if, as Goodman predicts in his opening sentence, “the future of the health professions is computational” (page 1).

Ultimately, the collection’s failure always to live up to its promise of providing answers rather than questions should perhaps be seen as a strength rather than a weakness, reflecting the ongoing uncertainty around not just the new area of health informatics, but also around such issues in the underlining ethics as privacy, confidentiality, non-maleficence and the review of research. Goodman’s achievement in bringing together specialists from each of the areas at the interface of the ethics of health informatics lies not in solutions adduced but in consciousness raised and methodology explored.

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Managing Death. The First Guide for Patients, Family Members, and Care Providers on Forgoing Treatment at the End of Life


I found this book, which has been promoted as “the first guide for patients, family members, and care providers on forgoing treatment at the end of life”, interesting, well-presented and readable.

The author deals with this very difficult emotive subject with both sensitivity and warmth. The preface leads you nicely to the introduction and sets out a USA consensus of four principles which apply as death approaches: (1) Patients should be able to make any decisions they choose about what medical technology they will accept or refuse (whether they are terminally ill or not); (2) If the patient is unable to make decisions for him or herself, surrogates - family members or close friends - should be fully empowered to step in and make decisions based on what they think the patient would want or what they believe would be in the patient’s best interests; (3) There should be no distinction between withholding and withdrawing treatment; it should be just as acceptable to stop treatment once started as it is not to start treatment in the first place; and (4) Artificially provided nutrition and hydration - tube-feeding - should be thought of as a medical procedure that patients or their surrogates cannot decide to accept or forgo like any other medical treatment.

The decision-making principles above were agreed by bioethicists, medical clinicians, legal experts and religious leaders.
Each chapter explores medical, legal, ethical and religious beliefs, tackling issues of: forgoing treatment versus suicide; withholding versus withdrawing treatment; terminal illness; beyond the persistent vegetative state; severe dementia, and artificial nutrition and hydration.

The author has used various case studies and opinion polls to argue various points and to highlight ethical dilemmas faced by health care professionals. The book includes recommendations from various groups, including the American Medical Association, the American Nurses Association, the Catholic Health Association, and The President's Commission.

To clarify the findings the author has used tables and boxes: box 1, page 8, describes the persistent vegetative state. Table 1.1, page 9, looks at the persistent vegetative state and syndromes often confused with this. Table 3.2, page 72, explores attitudes about refusing life-sustaining treatment for oneself. Table 3.3, page 73, explores choices regarding the use of life-sustaining treatment if in a persistent vegetative state. Table 3.6, page 83, deals with attitudes versus behaviour regarding advance directives. Table 3.7, page 86, focuses on institutional objections to withholding and withdrawing treatments in hospitals, and table 3.8, page 87, looks at institutional objections to withholding and withdrawing treatments in nursing homes.

Good examples are given throughout the book to help explain what medical procedures are available and the advantages and disadvantages of their use. There is a full explanation of the methods by which artificial nutrition is given and the positive and negative aspects of the various procedures.

This would be a very good basic reference book for all health care professionals, clarifying as it does, certain concerns the primary health care team may have when considering the right path to follow, when meeting the needs of the dying patient.

Although it is promoted as a first guide to the patient, family members and care providers I am not sure if it would be too distressing for the patient to read, because of the complexity of the subject and the differing opinions held by so many health care professionals. Practices and policies vary too much at present, depending on where you are treated and by whom.

Since the book concentrates on the USA and uses its legal structure and procedures, I do not feel it would apply to the United Kingdom in the same way. Therefore, for the patient and his/her family in the UK the book is open to misinterpretation and could lead to misunderstanding.

The considerable power of the courts is described at the beginning of the book, in a case study. It is clear that the court decided in what it considered was in the patient's best interests, and it has to be accepted that if the relative's wishes are overridden by the court, yet another dimension of stress and anxiety is added to what the family has to bear, at a time when they are already emotionally vulnerable.

Finally, I dislike the cover and title of the book. The black/red lettering and the blue/yellow colours are cold and hard. White and pastel are warmer and gentler when dealing with the subject of death and dying.

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Ethical decision making in therapy practice


This book is the first in the UK to address ethical issues in the therapy professions. It is aimed at practising therapists and students and is both readable and stimulating. The focus of the book is on the ethics of clinical practice and it does not attempt to address the equally important ethical issues around research and therapy. The book covers a range of subjects in chapters on: Introduction to ethics; Ethical decision making; Truthfulness; Informed consent; Confidentiality; Death and dying; Resource allocation, and Codes of ethics and in less depth Advocacy; Suicide; Care of older people, and HIV infection. Each chapter has a summary that serves as a reminder of the key points in the chapter.

The first chapter, Introduction to ethics, is refreshingly simple, with a very clear explanation of the subject, in particular its description of ethics and why this is an important issue for therapists to address. The author is not afraid to tackle difficult concepts such as the relationship between morality and ethics and law and ethics.

The book continues to hold the attention and provoke interesting discussion, for example in the chapter on Death and dying. The author states that this may "not impinge significantly on professional practice in the therapies". However, it is important that therapists have a knowledge and interest in other areas of health care that impact on their colleagues in the multi-professional team.

The issues surrounding resource allocation appeared to give the author the most difficulty and there was a strong feeling of underlying anxiety and anger. He points out that therapists ignore such issues at "their professional peril". The chapter attempts to answer the question of how therapists can ensure that resource allocation decisions are made appropriately. He cites three main considerations for resource allocation: efficiency, effectiveness and equity (the three Es). He makes an excellent attempt to clarify this issue and provides the reader with both a taster on the subject and a sound base from which to enlarge on this particular area.

The author shows no bias towards any one therapy and the contents are as relevant for a physiotherapist, as for a speech and language therapist or for an occupational therapist, which is an indication of the quality of the writing and the content.

While being both readable and stimulating the book also contains some clear definitions which would be useful to the practising therapist. It provides an excellent starting point for therapists and for the multi-professional team considering these complex issues. As the author points out in the book it is important for all those in the business of health care to understand ethical issues "beyond the confines of their own professional activities".

The book should be included in the recommended reading list of multi-professional undergraduate training courses as well as available for all practising therapists. Julius Sims has addressed complex subjects with clarity and given therapists a useful tool. This book is long overdue and should encourage greater discussion amongst therapists.

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