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978-0-521-73470-7 - The Cambridge Medical Ethics Workbook, Second Edition

Donna Dickenson, Richard Huxtable and Michael Parker

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Cambridge, New York, Melbourne, Madrid, Cape Town, Singapore,
São Paulo, Delhi, Dubai, Tokyo, Mexico City

Cambridge University Press
The Edinburgh Building, Cambridge CB2 8RU, UK

Published in the United States of America by Cambridge University Press, New York

www.cambridge.org
Information on this title: www.cambridge.org/9780521734707

First edition © Cambridge University Press 2001
Second edition © D. Dickenson, R. Huxtable and M. Parker 2010

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First edition published 2001
Second edition published 2010

Printed in the United Kingdom at the University Press, Cambridge

A catalogue record for this publication is available from the British Library

ISBN 978-0-521-73470-7 Paperback

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Preface to the second edition

Why call this book a ‘workbook’? Isn’t it more than that? In length and coverage alone, this is a full-fledged textbook, not what might seem a mere auxiliary teaching item. We are all experienced teachers of medical ethics and law, and this book embodies the pedagogic methods and strategies in which we believe. And while we are committed above all else to helping readers make up their own minds, we also have our own positions on the issues we raise, along with our own ‘take’ on the theoretical underpinnings of medical ethics. It is fair to say that we are much less utilitarian in our approach than the dominant trend in British bioethics, for example. So aren’t we selling ourselves and the book short by trivializing it with the title of ‘workbook’?

What might seem a pedantic issue of nomenclature has preoccupied the authors since we began planning for a second edition of the *Cambridge Medical Ethics Workbook* as long ago as 2004. At least one reviewer of the first edition made the point we set out above, which provoked us into some very profitable discussions about our overall purpose, going well beyond the title issue. In the end we chose to retain the original name, on the principle that the book has enjoyed a very favourable reception under that title; but here at the start of the second edition, we want to point out that our ambitions and the book’s ‘mission’ are considerably broader than the title ‘workbook’ may imply to some readers.

We have tried to provide an innovative method of learning and teaching medical ethics and law from the ‘bottom-up’, beginning with actual cases and challenging readers to develop their own analysis and recommendations. Medical and nursing educators have praised the first edition because it felt ‘real’, but as with ‘realistic’ fiction, it takes some doing to create that effect. We are aware that we have not always succeeded, but we strongly feel that the attempt is worth making. For many years the dominant trend in medical ethics education was ‘principlist’ or ‘top-down’, with a number of overarching deductive

principles introduced to the reader and then applied to particular cases. Our approach is ‘bottom-up’, presenting cases – taken in many instances from real-life clinical examples, with adjustments for confidentiality – and working with the reader to derive from them maxims or principles that can apply more generally. For the philosophically minded, our approach is more inductive and empirical: less like the Cartesian method than like Aristotle’s method of *phronesis* or case elucidation. Two of us are in fact philosophers by training, one a lawyer, although we have all taught for many years in medical schools and collaborated with clinicians as research partners. All three of us view our book as no less theoretically weighty than the more dominant strand of principlism, but as an alternative – one which, in the Quaker phrase, ‘speaks to the condition’ of healthcare professionals.

We do present the major ethical schools of deontology, utilitarianism, feminism, communitarianism and virtue ethics – particularly in the final chapter, where we examine the philosophical and legal basis of the key concept of autonomy, along with challenges to the previous dominance of this concept in Anglo-American bioethics. Here the theoretical depth of the book – its claim to be more than just a ‘workbook’ – is most apparent, as we elucidate the importance of autonomy in medical ethics but also present alternatives to its dominance from European law and other conceptual models. Michael Parker’s article in that chapter, ‘A deliberative approach to bioethics’, can be read as an example of the way in which the workbook as a whole moves carefully from practical matters to critical analysis of key ethical concepts such as rights and community.

While it was widely praised for being consciously practice-oriented, distinguishing itself from the top-down principlist approach, the previous workbook did embody a theoretical perspective based on respect for everyday ethics, experience, relationships and narratives. We have tried to avoid the use of the clever

Preface to the second edition

hypothetical cases beloved of moral philosophers, in favour of common situations that may not even appear at first glance to raise moral issues. Why our ‘moral antennae’ pick up certain situations as ethical dilemmas and ignore others is itself a question worthy of ethical analysis.

At the same time, ‘workbook’ still seems an appropriate title: we are committed to challenging readers to ‘work through’ their own initial responses and thoughts on the profound questions this book raises. The addition of an entirely new component, the CD-ROM of six case studies, demonstrates that process. After watching an initial clip setting out an ethical dilemma from the areas of genetics, reproductive medicine or research, readers are asked what they would have done in the situation. They are then directed down one of two or more branching paths, given further information and asked whether it would make them change their minds, and finally presented with the likely outcome of their decision. At the end they are asked to reconsider or justify their original choice in the light of the further information and consequences. So we also stand by our statement in the introduction to the first edition that ‘this is very much a workbook’, and we have devised new ways of working for and with the reader in this second edition.

Acknowledgements

The former BBC producer Alison Tucker, who scripted and directed the video sections for the CD-ROM, lived to see the CD-ROM produced as a separate entity

but died before it came out as an integrated component of this workbook. She was the most professional colleague and most imaginative collaborator any author could wish for. Professor Heather Widdows and Dr David Lloyd developed the structure of the CD-ROM, the extensive glossary and the teaching strategy associated with it, working along with Donna Dickenson. We owe deep gratitude to all of them.

Nick Dunton, Nisha Doshi and Jane Seakins of Cambridge University Press have seen this project through a number of difficult stages, with calm and encouragement. We hope they are as pleased as we are that it has come to fruition.

Ron Berghmans of the University of Maastricht deserves special thanks not only for expanding his original contributions to Chapter 1 on death and dying, but also for volunteering a personal account of his own serious illness. Our thanks to him for his courage. Other contributors are listed under individual chapter headings. The use of their articles, many written especially for this edition, has allowed us to create a book with many different ‘voices’, many more sonorous than our own, all in what we hope is close harmony.

Richard Huxtable would like also to thank Genevieve Liveley for her encouragement, plus his colleagues and students for their support for – and input (both explicit and implicit) into – the book, which he dedicates to his Nan, Alma Huxtable.

Donna Dickenson would like to dedicate this book to Elsie Vernon Hart, who is herself a case study in courage, endurance and laughter.

Preface to the first edition

The *Cambridge Medical Ethics Workbook* is a practical, case-based introduction to medical ethics for anyone who is interested in finding out more about and reflecting on the ethical issues raised by modern medicine. It is designed to be flexible; suitable both to be read in its own right and also for use as a set text in group teaching or in open learning. It is aimed at the interested general reader, at practising healthcare professionals and at medical and nursing students studying ethics for the first time.

The workbook is able to be flexible in this way because it is based around the reading of and reflection upon real cases. It uses a variety of structured activities to introduce and to explore the major ethical issues facing medicine today. These activities are clustered around: (a) *cases* (which were provided by healthcare professionals from many countries); (b) *commentaries* on those cases by healthcare professionals, ethicists, lawyers and so on; and (c) *short papers* by experts in the area concerned. This is very much a *workbook*, designed to help readers think about, reflect upon and to work their own way through ethical problems, by deliberating on the issues raised by them either alone or together with others. In this way, the reader is guided through the core themes in medical ethics in a way which is appropriate for them and which is relevant to their own experience.

While a glance at the workbook's contents page shows that it covers most of the major themes in medical ethics, it does not aim to provide in itself a comprehensive survey of every issue. Our aim is rather, through the active and structured exploration of core themes and key cases, to develop skills of independent study and research in ethics. This is an increasingly important requirement of healthcare professionals. For a measure of good practice in medicine today is increasingly coming to be seen to be the extent to which such practice is 'evidence-based'. An understanding of the ethical issues involved and of the way to balance and assess the validity of ethical arguments

in relation to particular cases is a core skill in the development of an analytical approach to medicine. Good quality healthcare is ethical healthcare and a consideration of the ethical dimensions of decision-making in healthcare practice must form a cornerstone of good evidence-based practice. This workbook helps practitioners and students to develop these skills and to have confidence in their use, not only in the context of research but also of teamwork within clinical practice.

Medical ethics is increasingly coming to be seen as an essential element of the education of any healthcare professional (GMC, 1993) and this is increasingly reflected in the medical and nursing schools themselves. Recently teachers of medical ethics in UK medical schools published a joint statement on the core themes and topics which ought to form the basis of any ethics curriculum (Consensus statement by teachers of medical ethics and law in UK medical schools, 1998). Similar work is also currently being done by the Association of Teachers of Ethics in Australasian Medical Schools and developments are also proceeding apace in other countries. Whilst recognizing these developments and being to some extent a reflection of them, this workbook does not follow any of these curricula rigidly. (We do however provide a useful grid in appendix two, showing how the UK national core curriculum maps onto the chapters and subtopics of this workbook.)¹ This workbook is intended to be a flexible educational resource which will enable those who teach medical ethics in any of these or any other educational setting to explore the core themes and issues in the ethics of medicine using cases and activities which will resonate with and be engaging for both medical and nursing students and those healthcare professionals who wish to develop their skills in this area. We would encourage teachers of medical ethics to pick and choose cases, activities and themes from the workbook in order to construct courses, workshops or training days appropriate to those they are

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teaching. The workbook is intended to be both a coherent approach to medical ethics and also a toolkit of resources for teachers and lecturers.

The workbook is divided into three parts.² In part one we explore some key ethical themes arising as a result of recent and ongoing technological developments in medicine. The first chapter is on ethical decisions at the end of life and explores ethical issues relating to the withholding and withdrawing of life-prolonging treatment and other ethical issues at the end of life. The chapter's focus is the extent to which the application of modern medicine at the end of life demands a reconsideration of the goals of medicine itself. When healing is no longer possible what ought to be the goals of medicine and of the healthcare professional? The second chapter in part one looks at the ethical issues raised by genetic testing and by the use of genetic information in clinical practice. The third chapter investigates the ethical implications of developments in reproductive technology. The fourth looks at the ethics of medical research itself and investigates the extent to which the research which is driving advances in medicine itself raises ethical issues – for those who organize and fund such research, for those clinicians who enrol their patients in research and for those of us who participate as research subjects.

In part two of the workbook we look more specifically at four themes which permeate medical ethics: vulnerability, truth-telling, competence and confidentiality. We do so by looking at the ethical issues raised by medicine and healthcare with three particularly vulnerable groups of patients. In keeping with the UK national curriculum in medical ethics, we also consider the vulnerabilities of clinicians. In chapter five we investigate the ethical issues that arise in long term and daily care. In chapter six we look at the ethics of mental health and of the treatment of psychiatric patients. And in chapter seven our attention turns to the ethics of work with children and young people. In each case the key issues are competence, vulnerability, truth-telling and confidentiality.

In part three of the workbook we explore some of the generic ethical issues relating to healthcare. In chapter eight, still by means of real cases, we investigate the ethical issues relating to the allocation of healthcare resources, questions of priority setting and just distribution. It hardly needs saying that these issues are increasingly important in all healthcare systems and across all clinical specialties. Finally, in

chapter nine we reflect on a theme which emerges at several points throughout the workbook, the extent to which we ought to see autonomy and patient choice as the key measure of whether healthcare provision and treatment are ethical. What exactly are the limits of such patient-centredness? To what extent is an ethical approach based on the concerns of individual patients capable of addressing the role of relationships and the duty of care which appear to be central to ethical healthcare practice?

The existence of the workbook depends a great deal upon the willingness and enthusiasm of those who have provided us with cases, papers and commentaries and so on. We feel that this makes the workbook both up to date and vibrant as a way of learning about medical ethics. But times change and so do the ethical issues in medicine. It is our intention to update the workbook in the future and in order to do that we will need new cases and papers. If you have any comments on the workbook or any suggestions for how it might be improved, or if you have cases which would work well as educational tools we would be very pleased to hear from you. You can contact us on michael.parker@ethox.ox.ac.uk.

We think the case-based approach, supported by activities and guided reading exercises has several advantages over other approaches to medical ethics. Firstly, such an approach cuts across disciplinary and cultural boundaries. Everyone can 'relate' in some sense to an actual case, even if they come from very distinct religious or cultural traditions which dictate different principles of ethical conduct. The cases we have chosen are wherever possible 'everyday' cases. Similarly, different healthcare disciplines have increasingly evolved their own forms of healthcare ethics: nursing ethics, for example, sees its concerns and approach as quite distinct from those of medical ethics proper. But in a case-based approach, the different slants of different disciplines can be explicitly built in. Secondly, such an approach requires little previous knowledge of ethics and reassures students who think of philosophy as abstruse and difficult. It is at the same time an approach which is capable of facilitating the development of the skills necessary for a rigorous and consistent analytical approach to the ethics of healthcare practice. Thirdly, a guided, case-based approach encourages students to think of comparable cases of their own, and thus to generalize what they have learned from one case to another, comparing similarities and differences. Finally, given the approach

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adopted by this workbook, the case-based approach allows students to learn from practice in other countries.

We hope that you will agree and that these chapters will give you the necessary motivation and support for doing the important tasks of learning about medical ethics, for students/practitioners, and of teaching students and practitioners, for medical and nurse educators.

Acknowledgements

We owe thanks to a great many people for their help and advice with this workbook over the three years it has taken us to write it. The cases and papers used have been gathered from all over the European Union, the United States and Australia. Many of them were collected at a series of workshops held as part of the European Biomedical Ethics Practitioners Education project (EBEPE) which was funded by the European Commission's BIOMED II programme. We would like to acknowledge the European Commission's Directorate General 12 for their support during this period and Hugh Whittal in particular for his support and encouragement. We would also like to acknowledge the role of Imperial College London who supported us through the later stages of the EC project.

Michael Parker would like to thank Julian Savulescu, the University of Melbourne Visiting Scholars Scheme and the Centre for Health and Society at the University of Melbourne for providing him with a Visiting Fellowship in summer 1999 which enabled him to work on this book and to write two additional chapters (and to see the Barrier Reef). Thanks too to Elena Iriarte-Jalle.

We would also like to acknowledge the contribution made by those who participated in the EBEPE workshops without whom this workbook would not have been possible. The success of the project was a result of the teamwork and support of our project partners. They are Ruud ter Meulen; Juhani Pietarinen, Raffaele Bracalenti, Carlo Calzone and Stella Reiter-Theil.

Many of the EBEPE participants and partners provided the commentaries, papers and cases which form the core of the workbook. Those who do not appear in print have influenced the workbook in other ways. Those who contributed papers or commentaries are acknowledged where their work appears in the workbook itself. Those who contributed cases are not

acknowledged for reasons of confidentiality but we would like to take this opportunity to thank them for their contributions. The EBEPE participants were: Ines Adriaenssen; Gwen Adshead; Steve Baldwin; Attilio Balestrieri; Loutfib Benhabib; Ron Berghmans; Dieter Birnbacher; Gunilla Bjorn; Stefano Boffelli; Paul van Bortel; Nico Bouwan; Raffaele Bracalenti; Masja van den Burg; Arturo Casoni; Carlo Calzone; Abram Coen; Anne Crenier; Paula Daddino; P. Dalla-Vorgia; Joaquin Delgado; Paolo Deluca; Dolores Dooley; Ralf Dressel; Holger Eich; Dag Elgesem; Bart van den Eynden; Eduard Farthmann; Luis Simoes Ferreira; T Garanis-Papadatos; Chris Gastmans; Wolfgang Gerok; Sandro Gindro; Diane. De Graeve; Marco Griffini; Harald Gruber; Anja Hannuniemi; Jocelyn Hattab; Jean Marc Heller; Eckhard Herych; Christian Hick; Wolfgang Hiddemann; Rachel Hodgkin; Tony Hope; Franz Josef Illhardt; Giuseppe Inneo; Antti Jääskeläinen; Winfried Kahlke; Aristoteles Katsas; John Keown; Valeria Kocsis; Kristiina Kurittu; Raimo Lahti; Veikko Launis; Kristiina Lempinen; Jerome Liss; Salla Lötjönen; Giuseppe Magno; Caroline Malone; Elina Männistö; Glauco Mastrangelo; Simonetta Matone; Anne-Catherine Mattiasson; Susan Mendus; Roland Mertelsmann; Ruud ter Meulen; Michael Mohr; Emilio Mordini; Maurizio Mori; Dimitrios Niakas; Marti Parker; Valdar Parve; Stephen Pattison; John Pearce; Filimon Peonidis; Juhani Pietarinen; Gideon Ratzoni; Marjo Rauhala-Hayes; Dolf de Ridder; Stella Reiter-Theil; Klaus Schaefer; Renate Schepke; Alrun Sensmeyer; Jaana Simula; Sandro Spinsanti; Karl-Gustav Södergård; Randi Talseth; Maxwell Taylor; Mats Thorslund; Ulrich Tröhler; Mauro Valeri; Maritta Välimäki; Kristiane Weber; Sander Welie; Vera Wetzler-Wolff; Hugh Whittal; Guy Widdershoven; Rainer Wolf.

First drafts of all the chapters were sent to critical readers in several countries for critical comment. Their comments and criticisms have been central to the success of the workbook. The critical readers were: Ann Sommerville; Tony Hope; Richard Ashcroft; Carmen Kaminsky; Mark R. Wicclair; Chris Milet; Mairi Levitt; Ruth Chadwick; Chris Barnes; Martin Richards; Julian Savulescu; Ainsley Newson; Udo Schüklenk; Peter Rudd; Judy McKimm; Dieter Birnbacher; Alastair Campbell; Rowan Frew, Don Chalmers, Ajit Shah; Corrado Viafora; Peter Kemp; Robin Downie; Dolores Dooley; Win Tadd; Margareta Broberg; Alan Cribb; John Keown and Richard Lancaster, along with many of the EBEPE participants listed above.

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Our thanks also to Richard Barling and Joe Mottershead of Cambridge University Press, who helped us to develop what may have appeared to them a rather unwieldy collection of materials into this present work. And, finally, the authors would like to acknowledge the administrative and other support of Yvonne Brennan and Helen Watson of Imperial College London and Caroline Malone of the Open University – and for always being calm and positive in a crisis.

Michael Parker
Donna Dickenson

Notes

1. In the second edition, we have replaced this with an appendix mapping a common system of keywords against the contents of this book. Readers interested in the UK core curriculum can, however, find a reference for the most recent version in the bibliography (Stirrat *et al.*, on p. 241).
2. The second edition is not similarly divided.

Cases in medical ethics and law: an interactive tutorial

Created by **David Lloyd, Heather Widdows** and **Donna Dickenson**

How to use the CD-ROM

1. Insert the CD-ROM into your PC's CD-ROM drive. Depending on the configuration of your PC, the program may start its installation routine automatically (after 5–10 seconds). If the process starts, go to step 5 below. If the process doesn't start automatically, go to step 2.
2. Click on: Start/Run
3. Then either type:
x:\setup.exe
in the Run dialog box, substituting the drive letter of your CD-ROM drive for 'x', e.g. if the drive letter of your CD-ROM drive is 'D', you should type d:\setup.exe
or

use the Browse button on the Run dialog box to navigate to the file 'setup'

4. Click the 'OK' box on the Run dialog box.
5. Follow the on-screen instructions to complete the installation.
6. When installation is complete, you will be able to launch the program from your Windows 'Start' button 'Programs' menu, or by using the 'Medical Ethics' icon on your Windows Desktop.

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Published by Cambridge University Press.
Manufactured in the United Kingdom. Not for sale separately.

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