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978-0-521-53025-5 - Essential Values-Based Practice: Clinical Stories linking Science with People

K. W. M. (Bill) Fulford, Ed Peile and Heidi Carroll

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accepted standards and practice at the time of publication. Although case histories are drawn from actual cases, every effort has
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Review quotes

As a primary care physician who has spent over 25 years in the USA caring for patients, teaching, and developing curricula, I am continually searching for strategies to help patients, medical students, and physicians get “unstuck” and get on with the business of healing and health. *Essential Values-based Practice: Linking Science with People* provides coherent tools and frameworks that I am eager to use as a provider, a teacher, and a carer. The values-based practice framework outlined in the premise, the process, and the point offers information that can be used to support self-awareness, reflective practice, and exploration of values – the provider’s and the patient’s. Alicia D. H. Monroe, MD Vice Dean Educational Affairs, University of South Florida College of Medicine.

“*Essentials* is an outstanding example of clear writing, essential references and useful clinical reasoning.” Professor Giovanni Stanghellini, Co-Chair of the World Psychiatric Association (WPA) Section on the Humanities and Chair of the Association of European Psychiatrists (AEP) Section on Philosophy and Psychiatry.

“Constantly reinforce(s) the reality of value issues in everyday practice.” Dr Roger Neighbour, Past President Royal College of General Practitioners and author of *The Inner Consultation* and *The Inner Apprentice*.

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Foreword

Julia Samuel
Founder Patron and Trustee of the Child Bereavement Charity

This is truly brilliant book. In the twenty-first-century medical environment, driven by the dual pulls of high costs and cost effectiveness. Patients can get submerged in technology, protocols, and paperwork, to the extent they lose their humanity and experience themselves as a case number, not a person. This book highlights the challenge medical teams, having a plethora of scientific knowledge, encounter every day when faced with the uniquely human problems of each individual patient. Its guidance puts the heart back into medicine.

My experience with families whose children have died has taught me that, even when medicine fails as tragically as when a child dies, how the family is responded to at the time has a life-long impact on that family, for good or ill. Every conversation, every decision, every gesture is burned in their memory for life. Often the unforgiveable errors are more to do with the lack of attuned care than with medicine: not enough proper reflection on the needs of this family, careless assumptions made, insensitive communication, which might be appropriate for another family, but is received with fury by this particular family, too much haste to get “it over with.” Any medical professional

reading this book is given both a map and a way of thinking which protects against these all too frequent irrevocable mistakes, and ensures the family receives the best possible care at such a difficult time.

The coherence with which the authors unpick complex and usually intangible, as well as explicit, situations is extraordinary. They keep the same themes running throughout the text, linking and reinforcing them with each case study, giving their arguments a lot of weight. I was fascinated by the different scenarios, which echoed some of my own experiences with patients and made the text come alive and easy to read. They intentionally didn’t describe the “nightmare” examples where bad practice, bad stories, and bad outcomes come together, recognizing that it is the more subtle everyday situation that is the key learning in this book, because it is from them that individual patients receive genuine person-centered care.

This book is a hugely welcome clarion call back to the essential values in medicine, that keys into the natural motivation of most doctors, to reach out to the individual patient and make a difference. It is a very impressive book, and I couldn’t be more delighted to endorse the importance and value of its messages.

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Acknowledgments

The development of values-based practice has been a strongly collaborative enterprise involving a wide range of stakeholders, including patients, carers, clinicians, managers and policy-makers, in the UK and internationally. We are grateful to all these and to the many individual colleagues whose particular contributions are acknowledged in the body of this book or in the website supporting the series (see Prologue).

Early work on developing values-based practice in mental healthcare was generously supported by a number of institutions including the Mental Health Foundation, the Sainsbury Centre for Mental Health, Turning Point, the UK’s Department of Health and the World Psychiatric Association. Much of the thinking behind this book was developed through two Warwick-Wellcome conferences, and we gratefully acknowledge the support of both the Wellcome Trust and the Laces Trust in assembling experts from the UK and around the world interested in developing values-based practice in all areas of clinical practice and policy.

The stories at the heart of this book have taken us into areas of practice beyond our respective areas of personal experience and clinical expertise. While the

responsibility for any errors remains our own, we are very grateful to the many colleagues from other specialty areas at Warwick Medical School and elsewhere who have given generously of their time and expertise in reviewing either individual chapters or the book as a whole: Gillian Bendelow, Kamaldeep Bhui, Mark Bratton, Matthew Broome, Amanda Burls, Iain Chalmers, Graham Clarke, Janet Cooper, Annabelle Crauford, Jeremy Dale, Peter Gilbert, Christopher Heginbotham, Jeremy Howick, Sally Johnson, Jane Kidd, Malcolm King, Sudhesh Kumar, John Launer, Judith Lees, Alicia Monroe, Daniel Munday, Roger Neighbour, Alec O’Rourke, Vimmi Passi, Mila Petrova, Hanna Pickard, Christopher Poole, John Sadler, Julia Samuel, Ajit Shah, Suzanne Shale, Janet Smith, Anne-Marie Slowther, Lanre Sorinola, Giovanni Stanghellini, Jill Thistlethwaite, Philip Thomas, Jan Trott, Werdie van Staden, Tom Viggiano, Malcolm Walker, Veronica Wilkie and Sue Ziebland

Finally, we want to acknowledge the late Yvonne Carter, who, as the first Dean of Warwick Medical School, worked with and supported us in extending values-based practice from mental health into other areas of health and social care.

A bold claim to start this book

The aim of most patient–clinician consultations is to improve health outcomes. Most often they succeed, and patients are to a greater or lesser extent satisfied and empowered. However, some consultations are unsatisfactory and result in failure to improve health outcomes; dissatisfaction on the part of patients, carers or clinicians; complaints and litigation; and even unnecessary morbidity or mortality.

In our experience, when consultations fail to achieve the desired results, the cause is not usually a failure of evidence-based practice. Today’s clinicians are trained in evidence-based medicine, educated,

updated and appraised to a point where they can find most of the accurate scientific information they need to assist patients in decision-making. *The most likely reason why things go wrong is a failure of values-based practice* – not ascertaining the relevant values perspectives and acting on them in a coherent and purposeful manner, evolving individual patient-centered decisions that are informed by values as well as evidence.

This book aims to help clinicians acquire and develop the processes of values-based practice that support evidence-based practice in the particular situations facing individual patients.

Prologue: linking science with people

A young woman with schizophrenia finds a turning point towards recovery when a new member of the mental health team recognizes and acknowledges her aspirations.

A middle-aged car sales manager finally engages positively with evidence-based management of his hypertension when a cardiologist appointed through his firm’s occupational health scheme links the need for treatment to his ambitions as an amateur racing car enthusiast.

A young couple at risk of being torn apart by conflicting views over IVF are reconciled when their parish priest helps them to understand the real rather than fancied implications of the techniques being proposed by the local infertility clinic.

These are some of the stories – based on those of real people, although biographically disguised – that are at the heart of this book. Each story presents a familiar clinical problem; for each problem, there are a variety of possible evidence-based solutions, but in each case matching solution to problem depends critically on engaging with the *values* of those concerned.

Values, evidence and complexity

There is nothing new as such about values in medicine. The Hippocratic Oath, on which modern codes of practice still draw, goes back over 2000 years. There is similarly nothing new as such about evidence in medicine. David Sackett and his colleagues, in their early and still influential *Evidence-Based Medicine: How to Practice and Teach EBM*, to which we will be returning at several points in this book, locate what is possibly the earliest recorded use of evidence-based methods in ancient Chinese medicine.

What *is* new is the ever-growing complexity of modern health care, and it is this complexity that drives the need equally for values-based and for evidence-based decision-making. We need evidence-based

practice as a process for factoring *complex evidence* into individual clinical decision-making; and we need values-based practice as a process for factoring *complex values* into individual clinical decision-making. The actual processes involved are different of course. Values-based practice is different from evidence-based practice in that it relies primarily on learnable clinical skills working within a person-centered and multidisciplinary model of practice. But the essential reliance on good process to support clinical decision-making in the growing complexity of current practice is the same.

Linking science with people

Even before the processes for values-based practice were defined, there were several tools in medicine’s toolbox for working with values, including ethics, decision analysis and health economics. We will be returning to these and other tools and to how they fit together with values-based practice at various points in the book.

One of the skills needed by the workman with a plethora of tools is to know *how* to use *which* tool in which sequence to achieve the optimal result. To work the toolbox analogy, the problem facing the carpenter when the door is sticking is *how* to best reduce the size. He has at his disposal saws, chisels, planes and sanders, and the good carpenter will put his hand on the right tool for the job in the right sequence. Values-based practice adds a number of specific tools to the toolbox: for example, not many clinicians carry “dissensus” in their toolbox until they have learnt a bit about values-based practice. But what values-based practice adds above all is an approach or process that focuses on *the unique values of the particular individuals* involved (clinicians, patients and carers) in a given clinical situation.

This is why values-based practice links science with people. The power of science is that it produces knowledge that is generalizable across all relevant cases. But people are unique. Values-based practice thus links the generalizable evidence that we get from science with the unique values – the needs, wishes, preferences, expectations and so forth – of the individual people

Prologue: linking science with people

involved in the particular clinical decisions we make in everyday practice.

What this book covers

This book provides an introduction to values-based practice as a new skills-based approach to working with complex and sometimes conflicting values in health care. It is not a textbook of values. There is already much that has been written from both theoretical and practical perspectives about values in medicine. We cover much of this in Part 1. This book is about the values of particular individuals – individual patients and their family members, and individual clinicians – and the skills and other resources needed to support balanced decision-making where their (often very different) values come into conflict.

Story lines of the book

In line with the person-centered focus of the book, our core chapters, in Parts 2, 3, 4 and 5, are all built around the stories of individual patients and clinicians. Each story illustrates how a given element of the process of values-based practice sits alongside and complements evidence-based practice in the clinical encounter. We cover a range of different clinical contexts in both hospital and the community settings, with some of our case histories being overtly value-laden (for example, cross-cultural presentations of abdominal pain, and child protection and multidisciplinary team working) and others less so (for example, compliance in the management of hypertension, and avoiding chronicity with low back pain). But in each case, it is the values (whether overt and/or hidden, and of patient and/or clinician) that are vital to effective evidence-based management of the situation in question.

The five parts of the book

In Part 1, we give an overview of values and values-based practice in medicine, drawing in this instance on the story of a primary care physician or general practitioner (GP), Dr. Gulati, and how she works with a patient, Roy Walker, who is demanding a clinically inappropriate off-work certificate for low back pain. Parts 2–4 then pick up on the details of values-based practice with further stories illustrating each of the key process elements of values-based practice considered individually. Finally, in the two chapters in Part 5, we draw the elements of values-based practice together, first through a story of partnership in decision-making

in end-of-life care, and then by returning to Dr. Gulati from Part 1 and following how she and her colleagues work in partnership with their local Patients’ Forum to develop a shared framework of values for their practice.

The book and the series

This book is the launch volume for a new series from Cambridge University Press on values and values-based practice in medicine. The series will be edited by Bill Fulford and Ed Peile with the support of an international advisory board representing each of the main stakeholder groups in values-based practice including patients and carers, clinicians, policy-makers and managers. Although the stories in this book are mainly UK focused, we believe the issues they raise are important across healthcare in all parts of the world. Through the series as a whole, we will be exploring some of these issues further as they arise in other cultures and systems of healthcare and as they are perceived from the perspectives of patients, carers, managers and policy-makers, as well as from those of clinicians.

Ways of using this book

One way in which the book can be read is by working through sequentially from Chapter 1 and developing your understanding of values-based practice as you go. As a collection of stories, on the other hand, another way to read the book is by starting from whichever case study is closest to your own clinical or personal experience. Having explored that case in detail, you can then broaden your knowledge of values-based practice by going back to the introductory chapters and working through some of the other case stories in the book. Although not a textbook as such, the case studies and supporting materials can be used for Continuing Professional Development (CPD) and other teaching and learning activities. To this end, we have included in each of the case histories a number of brief reflection points at which the reader is invited to think about a key issue for themselves before reading on. Each chapter starts with a topic box setting out the main points covered in that chapter. The final chapter, Chapter 14, includes an example of a workshop in values-based practice. Appendix B gives a teaching framework with detailed learning outcomes for each element of values-based practice together with possible methods of assessment. A diagrammatic “map”

showing how the elements of values-based practice fit together, which first appears as Fig. 3.4 in the initial overview of values-based practice, is repeated at the start of each subsequent chapter to help you to orientate yourself within the overall approach. You may also want to turn to the end of the book for additional features that you may find helpful in navigating your way around the book:

- Appendix A gives a summary of values-based practice with brief definitions of its key ‘terms of art’
- These key terms are highlighted in blue for ease of reference in the index.

The index is backed up by a spreadsheet (the VBP Index Spreadsheet) on the VBP website (see below) showing how each element of values-based practice is introduced, explained and illustrated across the book as a whole.

The book is further supported by the series website jointly hosted by Cambridge University Press and Warwick Medical School at <http://www.go.warwick.ac.uk/values-basedpractice/>. This includes full-text versions of many of the key sources and resources noted in the individual chapters.

Our characters

In linking the theoretical points to clinical practice, some of our characters may at times seem overly conscientious and self-aware. Dr. Gulati, for example, the GP in our opening Chapters 1 and 2, takes time out to review what she knows about some of the resources from ethics, decision analysis and evidence-based practice that might help her in deciding what she should do about a patient who is demanding a clinically inappropriate off-work certificate.

We could have presented the theoretical points here discursively and, while taking time out might be good “reflective practice,” Dr. Gulati’s investment in this one case clearly goes beyond what would be possible on a day-to-day basis in a busy inner city general practice. But we hope nonetheless that our narrative presentation of the theoretical points will help to underline the reality of value issues in everyday practice and the strongly practical nature of values-based practice as a resource for responding to them.

It is important to add finally that our characters, although fictional, are all based on experience. As such, we hope you will find them realistic in the range and diversity of perspectives that between them they represent. It is by engaging with the diversity of real people that values-based practice aims to link science with people.

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