ETHICS FROM THE GROUND UP
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EMERGING DEBATES, CHANGING PRACTICES AND NEW VOICES IN HEALTHCARE

EDITORS: J. WINTRUP, H. BIGGS, T. BRANNELLY, A. FENWICK, R. INGHAM AND D. WOODS
For Eloise Megan Land

Every day her generous, courageous, loyal and beautiful self
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What does doing ‘everyday ethics’ mean for healthcare practitioners?

This is an example of a day-to-day dilemma that will be familiar to many.¹

Eric is a 72-year-old man who was diagnosed with colorectal cancer at the age of 70. He has been treated by radiotherapy, surgery and a temporary ileostomy. He has just had the ileostomy reversed and was expecting a hospital stay of two or three days. Unfortunately, it took some time for his bowel to start functioning again, and since it did he has been experiencing distressing, frequent and violent attacks of diarrhoea. He has now been in hospital for eight days.

Eric is the type of patient who tries to put a brave face on things, and tends to joke around with his consultant, the foundation doctors and nursing staff. But you got to know Eric well when he first had a stoma, and he is a bit more honest with you when you stop by to see him. ‘My tail end is so sore’ he tells you. ‘I can’t sit; I can’t lie on my back – it is really painful. I seem to have no control over my bowel now. It’s just awful. But I’m desperate to go home; my friends can’t feed the cats forever. I said that to the doctors. The hospital is so busy, I don’t think I ought to stay here if I can be at home.’

The youngest survivor of several siblings, Eric doesn’t have any close family. He lives alone in a rather out-of-the-way cottage he bought with his partner, Frank, who died two years ago. They were intending to do it up but ran out of money. You know it has no central heating and that the tiny bathroom has six steps leading up to it. All winter the hospital has been running at close to 100 per cent bed occupancy.

¹ It was first developed to stimulate discussion among practitioners working with Macmillan Cancer Support, who recognise it as immediately relevant to their concerns.
One of my favourite ways of starting a study day or conference or meeting with care professionals is to ask them to talk about what gave them the greatest satisfaction in their last week at work. After a common initial reaction – that the entire week has been an unmitigated disaster and they can’t think of anything about it that was remotely good – and given permission to reflect on the whole past month if necessary, a moving conversation ensues. Three themes frequently emerge: (i) the delight in seeing a patient, or someone important to the patient, getting a benefit from something you have done for them; (ii) the pleasure in drawing on your expertise, and using it to good effect; and (iii) the gratification to be found in relationships with colleagues, perhaps those whom you have helped, or who assisted you, or a colleague with whom you have had a better than expected interaction. When we then move on to discussing the ethical challenges that paid caregivers encounter in their work, we discover that they often threaten to disrupt these important sources of fulfilment.

Eric’s unenviable situation doesn’t present professionals with an ethical dilemma because it is new, unusual, or requires special ethical expertise. Quite the opposite. It happens frequently in a care system running at full capacity, is immediately recognisable, and contributes to the day-to-day moral distress that can accompany care work. (Pauly and colleagues have examined the various meanings attributed to the term moral distress: centrally, it refers to the feelings that arise from ‘difficulties navigating practice while upholding professional values, responsibilities and duties’ (Pauly et al., 2012). For me, this scenario is an ‘ethical’ one because it goes directly to Bernard Williams’ question, ‘how should one live?’(Williams, 1985). And it presents a ‘dilemma’ because bringing it to a satisfactory conclusion will require both careful scrutiny of different parties’ interests, and also the exercise of great skill in negotiating the outcome.

Moreover, Eric’s situation severely tests all three of the cherished motivations: doing good, being an expert and getting on with colleagues. The resources to do good appear to be unavailable (and frustratingly, if Eric is sent home and suffers harm, it will undo much of the good that has already been done). Being an expert hasn’t necessarily helped. This practitioner’s expert assessment differs from that of her colleagues (whether

Having heard from the doctors treating him, the bed manager is of a view that, despite the continuing diarrhoea and his general frailty, Eric is medically fit for discharge. You cannot imagine how Eric will cope with the minimal support that can be offered by community-based services. What ethical issues does this raise for you?
this puts her in an awkward situation depends on whether the team she works with values hearing different views). But unless she can do something about Eric’s situation, the expert listening that elicited his doubts and anxieties merely serves to accentuate her difficulties. And finally, there is her interaction with the bed manager to worry about. Each of them has a different focus, the practitioner mindful of Eric’s well-being and the bed manager mindful of the population of patients waiting for a bed. Whether this different focus turns into a conflict depends on how well they manage their interaction.

What is the everyday ethical expertise that the practitioner will need to call upon here? It is both epistemic and performative (Weinstein, 1993, 1994). First, there is the epistemic expertise: she must draw on her ability to make a clinical assessment (including Eric’s psychosocial needs and the risk of harm to him) and appreciate the implications; but she must also be able to explain and justify her assessment to her colleagues. Next is the performative expertise: she will need the know-how and skill to navigate the system, to have a constructive negotiation with colleagues, to change the bed manager’s mind to prioritise Eric or change her own mind to prioritise other patients’ claims, and to do all of this in a timely fashion. Further elements will be necessary to sustain her. She will need the emotional expertise to manage her own response to the situation and to deal with the residue of distress she may feel if things don’t go Eric’s way. Perhaps she will seek guidance, wondering what a real expert would do in these circumstances. (But who is she to ask?)

This collection is concerned with ‘surfacing the ethical issues implicit in everyday health and care, and in exploring the questions and concerns that emerge’ (page xii). The opportunity to do so is vital. Only through attending to the reality of everyday ethics in care work will we come to understand its challenges; comprehend the nature of the expertise that enables such challenges to be overcome by professionals seeking to realise citizens’ interests; and begin to appreciate what we need to do to sustain care professionals in ethically demanding roles. And it is by attending to the voices of those less heard in ethical texts – as we have the opportunity to do in the third part of this collection – that we come to realise the intimate connections that exist between professionals, learners and citizens in the care enterprise. The diversity of issues and of voices captured in this collection enriches our approach to the question of how we should live, not just as professionals but as fellow human beings.

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Bibliography

INTRODUCTION

Julie Wintrup

Exploring ethics from the ground up

The purpose of this collection is to introduce new ways of thinking about healthcare work as a moral and collective endeavour. It is part of a wider initiative to explore the ethics of everyday health and care that includes dedicated conferences (e.g. On Everyday Ethics, 2016\(^3\)) and draws on the work of practitioners who write and blog (see, e.g., Tomlinson, 2018\(^4\)). A group of contributors go on to explore more explicitly theoretical perspectives in the chapters that follow, each sparked by experiences, conversations, analysis and research. The collection examines ethical work, both practice and policy, that is often tacit in nature, what Lambek (2010, p. 2) describes as ‘grounded in agreement rather than rule, in practice rather than knowledge or belief, and happening without calling undue attention to itself’. Although chapters differ in style and focus, they share the educational goal of surfacing the ethical issues implicit in everyday health and care, and in exploring the questions and concerns that emerge. Such close analysis tends to raise new and even more difficult issues, which seems at odds with the urge to find answers and resolutions and can be experienced – in particular by those who feel unfamiliar with ethical concepts or outside decision-making arenas – as frustrating and even deskilling. However, we propose that realising complexity and seeking answers are the central elements of ethical reasoning. Dewey (1910, p. 12) described the ‘demand for the solution of a perplexity’ as the ‘steadying’ factor that provokes learning. In other words, and to summarise our educational stance: not knowing, being open to new information, indeed being prepared to be more perplexed, while remaining committed to seeking solutions, however imperfect, is the basis of learning healthcare ethics. Such learning occurs when working with and learning from other

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\(^3\) Everyday ethical dilemmas in healthcare: power, politics and practices, http://2016.oneverydayethics.co.uk/.

\(^4\) Jonathon Tomlinson, A better NHS: exploring the relationships between doctors and patients and health policy, https://abetternhs.net/about/.
INTRODUCTION

people, in unique situations and during testing times, and with the people and in the places they live and manage health conditions. Chapter authors, in very different ways, offer their own experiences of not knowing, questioning, and using ethical concepts to generate and appraise ways forward.

Although this is not a book that begins with moral philosophy, thinking philosophically is encouraged throughout and is necessary to get the most from several chapters. It purposefully offers alternative routes into foundational ethical theories, offering the interested beginner and those more familiar with the subject opportunities to examine and critique some taken-for-granted health and education practices. It does not compartmentalise ‘types’ of ethics or promote specific concepts such as biomedical, legal or research ethics, and it does not foreground policy, procedures, rules or professional codes – although those are variously discussed in contextual terms. Neither is it following in the tradition of disciplinary-based ‘ethics for x’, x denoting whichever professional group is the intended audience. This is because many texts already cover those narrower interests more than adequately, and though the collection reflects authors’ specialist interests, our purpose in writing this book is different. It is designed to be of broad interest and accessible to the non-specialist, including students, practitioners, people using services, health educators, managers and interested others. Chapter topics are diverse, our hope being that interests are piqued in new readers who associate healthcare ethics only with more traditional medical decision-making.

Our intention is first and foremost to shine a light on the tricky, sometimes ambiguous, almost always contingent circumstances that healthcare work requires of us every day: if this, then maybe that, but possibly the other – or neither. Problems that do not have easy solutions prompt deeper reflection and discussion, often (but possibly, not often enough) in the midst of action. They require flexibility and cooperation among and beyond professional clinical and care teams. Such rich, organic learning is by its nature contextual and dynamic, because ‘what it does is continually alter the context in which it occurs’ rather than simply alter the properties of the learner, as Beckett and Hager (2002, p. 146) describe. Yet broadening the scope of ethical work, from a care or treatment decision to managerial or political decisions, a lifestyle choice or sharing of risk, raises new ethical issues. For example, when alliances break down – between patient and health professionals, or among different disciplines within a team – divisions can develop and over time become entrenched. Distrust and feelings of betrayal may have damaging effects far beyond the immediate circle of people involved. In public discourse, we hear relatively little about successful day-to-day healthcare work with its negotiated solutions and compromises, because
in general this remains private and between individuals, and in most countries is protected by law. So our impression of ethical dilemmas is often shaped by the out-of-the-ordinary situations that also become known about and debated in the media, meaning newspaper editors or those with the greatest social media reach determine their framing. Many voices are drowned out in such arenas. Others cannot or choose not to speak, leaving us to speculate on how situations may have arisen or why judgements were made. In bringing this collection together, we seek to learn more about the many kinds of ethical work from voices rarely heard and alternative vantage points. Schön (1987, p. 3) memorably described ‘the swampy lowlands, where situations are confusing messes incapable of technical solution and usually involve problems of greatest human concern’, reflecting the messy, intimate, routine nature of health practice, where learning and change may be uncomfortable, traumatic even, and may leave emotional scars. So a central message of the book is that we need to work together to better understand the range of factors that enable ethical reasoning and evaluation to take place in imperfect realities, and we begin by examining experience. Such an examination crosses the practice and classroom divide. It acknowledges the problems with terminology and requires inclusive language, detailed description and perspective taking. It obliges us to rehearse and articulate new and often complicated ideas, and to struggle with conflicting goals. Bringing together a collection that describes many kinds of experiences is a step towards redrawing the boundaries of healthcare ethics and extending its scope of interest.

How might such diverse perspectives contribute to health education and practice?

It is our contention that people involved in the work of healthcare – by which we mean not only the workforce but also unpaid and precariously employed carers, and those who work every day managing long-term conditions, disabilities or illness – are part of realising and relating ‘the ethical’, in their relationships, actions and stories. Sometimes this will be cultivated in teams or families, or through training, or in the intimate and intersubjective spaces between carer and cared-for. Although it is unlikely to be articulated in philosophical terms or even thought through in more abstract, intellectual ways, concerns may centre on such things as fairness, kindness or, more recently, the ubiquitous notion of ‘compassion’. Bringing together a range of perspectives, although a small step in a continuous project, is part of beginning to broaden what we think
of as ethical care. Yet more perspectives are sorely needed; Ion et al. (2018, p. 99) assert ‘the ability to work with complexity, ambiguity and uncertainty in a culturally safe way may require considering ethical frameworks from other locations if we are to avoid the pitfall of assuming that the common ethical frameworks of Western Europe and North America make sense to populations whose belief systems were forged elsewhere’. Without expanding the scope of health and care ethics, we risk debating moral issues only in the midst, and heat, of crisis, from the more established points of view, and then in terms decided by those who may have a specific agenda. In the same spirit, we advocate moving on from understanding ethics as a top-down application of principles, or as a system of calculating uncertain future risks and benefits, often known as applied ethics. Such approaches, Lawlor (2007) asserts, do not serve those in health education programmes well, much less offer scope for a more inclusive approach. He suggests such abstractions may unwittingly alienate students who may otherwise have a lively interest in more philosophically oriented topics.

The project we are calling ‘ethics from the ground up’ is intended to engage, to spark an interest in the areas of health practice that are often out of sight or just seem too difficult, and to introduce the new kinds of questions posed by the ways we live our lives, in often imperfect circumstances and contradictory ways. The main interest throughout is in the ethical as encountered and described by people whose lives, work, families and interests are intertwined with healthcare in different ways. This is important for Tronto (1993, p. 178) because for her, the doing of ethical work is where ideas and dispositions become part of moral conduct, because ‘people must engage in both private and public practices that teach them, and reinforce their senses of, these moral concerns’. In a similar vein, Zacka (2017, p. 35) explores the importance of discretion in transforming policy intentions, by those working directly with people in receipt of public services, asking ‘how street-level bureaucrats inhabit these spaces of discretion, how they negotiate compromises among the plurality of goals and values they must remain sensitive to, and how they find the resources to do so in an environment that often makes good moral judgement remarkably difficult’. Our starting point, then, is not how to reach a decision in a given situation through mental reasoning processes, or by examining in detached and dispassionate ways the ‘hard cases’. We begin with the goals of seeking to recognise and become attuned to the moral aspects of everyday care while in the moment; of questioning and investigating the environmental influences that inform our actions and decisions in and beyond the personal encounter; and of realising the part played by the exercising of discretion and moral agency. By framing our goals in such a way, not only does the familiar become
more interesting – and in a fruitful way, more perplexing – but develops ways of thinking in preparation for more testing situations ahead.

Such a questioning, receptive disposition is only the beginning, however, of a necessary but far from sufficient attribute to cultivate. For Rest (in Bebeau, 2010) four developmental steps are involved: sensitivity, judgement, motivation and commitment to action, each of which develops over time and through practice. But progress may not be smooth or unidirectional – as the authors show in the chapters that follow, emotions provoked by unsettling events are sometimes repressed, justified or trivialised in some way, or we may seem to take a step backwards following a difficult experience. Developing judgement when alternatives are uncertain, and remaining motivated and committed in the face of opposition or a lack of resources, cannot be taken for granted simply as a feature of qualifications or experience. So the notion of ethics from the ground up has meaning in terms of beginning with what is in front of us: the people and places we know, the things that happen around us in familiar procedures and taken for granted routines, and with the unspoken and under-explored aspects of those common experiences. The book invites us to shine a light on less well-examined practices, debates and voices to learn more about their ethical aspects and implications for care.

But the notion of ethics being ‘ground up’ is not simply about ‘understanding the ethical issues occurring at ground level’ – it is a much bigger project. The expression was first used by Richard Ashcroft, at a conference dedicated to the ethics of the everyday, to describe an empirical approach to researching healthcare as a practice that aims to be, and is required to be, consistent with certain values and commitments. For Dewey (1910), such empiricism was central to experiential and experimental learning. In the UK, at its inception in 1948, the National Health Service (NHS) was founded on three core principles: that healthcare meets the needs of everyone, is free at the point of delivery and is based on clinical need, not the ability to pay (Delamothe, 2008). These were expanded recently to include, among other things, placing ‘the patient at the heart of everything’, best value and accountability to communities and patients (The Department of Health, 2015). Meanwhile, inquiries into failures or poor standards in healthcare reiterate the importance of a healthcare system founded on fairness, openness and equal treatment. Francis (2013) went further, asserting throughout his inquiry report into Mid Staffordshire Hospital that staff should put patients’ interests before their own. Indeed the government accepted this recommendation, stating that the expectation ‘staff put patients before themselves’ (Department of Health, 2015) ought to be enshrined in the NHS Constitution. Research into ‘resilience’ does not find such self-sacrifice to be necessary or advisable, however, and care for self is seen as central to responsible, sustainable practice: ‘Doctors
need to be able to care for themselves in order to offer the best care to their patients’ (Howe et al., 2012, p. 350). Similarly ideological stances are reflected in codes of professional conduct, which describe the ideal of the good professional. So given the plethora of explicit and detailed ethical principles embedded in policy, law and subsequently in commissioning guidance, an empirical approach to an ethics from the ground up might set itself the goal of discovering how such high standards, robust principles and commitments to action are manifested not only in professional behaviours but in every aspect of care and treatment. Whether at the bedside or homeless people’s shelter, in the boardroom or purchasing department, or in local and national political arenas, actions and decisions have moral antecedents and implications. An empirical approach invites us to begin to formulate research questions and consider methodological approaches, to consider what would constitute data and to seek a wide and diverse audience for findings. It would necessitate confronting the less visible effects of social behaviours and power imbalances; not only those we associate with traditional hierarchies or doctor–patient divides, but those exercised between and within workforce groups, or constituted through access to forms of knowledge or representation, or generated by informal networks and interest groups.

Where does ethics from the ground up take us?

In this book, we encourage healthcare education to embrace an interdisciplinary, patient and service user-led approach to constructing ethics as a shared set of interests, in which tacit knowledge and the expertise of lived experience sits alongside disciplinary and technical forms of expertise. In such a construction of the ethical, ‘roles’ are less important than contribution. Individuals bring multiple perspectives and different insights to ethical dilemmas or problems and are encouraged to discover and explore others’ views and priorities. Emotion, often seen as anathema to cool reasoning, is viewed as intrinsic to the human conditions that prompt ethical debate: injustices, vulnerability and life-and-death decisions. Concepts such as compassion and resilience are understood to be contingent, situated and emotional in quality.

Healthcare ethics, once firmly within the ivory tower of medical academia, is gradually being democratised. People take an interest in individual dilemmas shared publicly or in blogs, engaging radio programmes, documentaries and dramas look in detail at individual stories, and networks and communities use social media to open up debate. At the same time, new risks to privacy and confidentiality are posed by new ways of communicating. As things change and evolve, what is or is not ethical is
far from settled. Doctors using social messaging services to communicate patient information are breaking privacy laws, yet when understood as part of a life-saving intervention to perform surgery or in the context of the total shutdown of a network, such a response seems a rational, creative and even praiseworthy solution to a crisis. Beginning to think about who decides what constitutes the ethical is an exercise that invites us to think philosophically and so is a fitting place to begin a book that starts with the everyday work of healthcare. Such work requires that we think not only about the way we make decisions, or resource, organise and regulate health services, but also about ways to live our lives, and to respond to one another's needs.

It seems then that the concept of healthcare ethics as a somewhat dry and abstract topic is out of step with society. When courts of law are asked to decide between medical recommendations and a request to be assisted to die, or to access an experimental therapy, people across all sectors of society get involved; they discuss life-and-death issues in the workplace and on Facebook, and form opinions. Treatment and technological advancements mean new kinds of decisions have to be made by people using health services, often in cooperation with professionals, with those responsible for purchasing and commissioning services, and sometimes with numerous others. Often such decisions threaten a person's privacy or necessitate the sharing of familial knowledge, or need to be revisited throughout the course of a lifelong disorder or disability. Choices may involve imperfect predictions, incomplete information and complicated data, and answers may well be temporary or provisional. Ethics is no longer, if it ever was, the preserve of health professionals.

Why is the notion of ground-up ethics a stimulus for learning?

If the traditional idea of healthcare ethics is shaped by situations that arise in the public domain, the kinds of questions that arise in more private domains remain under-explored. Their importance is overlooked until, as happens for some, the issues become public, or those involved come to view them as morally problematic or important to share with others. As a result, we tend to learn about and from healthcare problems that become public. These tend to be rare and unusual – such as the separation of conjoined twins when one is bound to die from the operation, or a dispute between patient and doctor that has reached the law courts. This public–private dimension is not binary, but a continuum, and to a degree subjective. So this is by no means suggested as a fixed category,
but rather a loose and functional distinction. Those in the public arena, as in the examples above, tend to be high stakes, life-or-death decisions, reported in real time and generating boundless levels of interest and emotion. When what is at stake is how well someone is able to access (say) a form of therapy that will improve their quality of life but is not essential to live, the issue might seem to be on a different continuum; with life-or-death outcomes at one end, and routine, everyday health (and social) care needs at the other. Like the public–private continuum, situations may change and move between higher or lower stakes. Finding a new heart for a gravely ill 20-year-old may move from high life-or-death stakes after a successful transplant, to low stakes, everyday care when the cost of transport to a specialist unit 60 miles away has to be compared with paying for essential prescriptions, meaning one or the other may have to be forfeited.

Viewed in this way, it is possible to see a relationship between the way ethical or moral questions in healthcare and in social care simultaneously shape and are shaped by the ‘high stakes or public’ quadrant of these two spectrums. Private encounters are, necessarily, between individuals entitled to and obliged to respect privacy. Low stakes issues attract little attention, until or unless they become high stakes. The extraordinary, or the highly emotive, seems to elicit empathy, and so we risk overlooking the moral problems inherent in the private or routine aspects of healthcare. Yet because this is where we tend to work together, cooperatively most of the time, the ordinary has untapped potential for learning, as we appreciate one another’s priorities and sensitivities. Relationships, particularly those that are outside of the normal run of things, and the daily routines and sustaining features of lives, offer rich learning that might better prepare us as ethical social beings, for the high stakes or public encounters when they come along.

This book is interested in the variety of experiences that we can understand to have ethical dimensions. It offers insights into how awareness of ethical concerns is heightened and into the process of becoming familiar with the moral components of situations, rather than seeing problems as puzzles to be solved or arguments to be won. Most importantly, it directs our gaze to aspects of healthcare that have been neglected in more traditional biomedico-legal constructions of the ethical.

The structure of the book

It is helpful to consider how this text might be used, whether in formal ethics education by students and by educators, or to deepen and broaden a more general interest in healthcare ethics. The three parts