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CARE ETHICS AND SOCIAL STRUCTURES IN MEDICINE

Ruth E. Groenhout

Care Ethics and Social Structures in Medicine

This book examines the central structures in medicine—medical knowledge, economics, technological innovation, and medical authority—from the perspective of an ethics of care. The author analyzes each of these structures in detail before considering the challenges they present to end of life care. The perspective of an ethics of care allows for a careful focus on how these structures affect the capacity of the health care system to provide the care patients need, on the impact they have on the relationships between patients and caregivers, and on how they affect the caregivers in terms of their own sense of identity and capacity for care. This book offers one of the first focused discussions of an ethics of care across a wide range of social issues and structures in contemporary medicine. It will be of keen interest to advanced students and scholars in bioethics and health care ethics who are interested in these important issues.

Ruth E. Groenhout is the Distinguished Professor of Health care Ethics at the University of North Carolina at Charlotte, USA. She is the author of *Connected Lives: Human Nature and an Ethics of Care* (2004) and co-editor of *Philosophy, Feminism, and Faith* (2003).

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This book is dedicated to my kids—Ben and Kelsey, Tessa and Caleb, Annemaria, and Gordon—with the hope that they will be enmeshed in structures of care that provide for them for their whole lives.


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Introduction
Care and Social Structures

The central premise of this book is that an ethics of care offers substantive resources for ethical analysis of contemporary medicine. We are told, regularly, that contemporary medicine is in crisis, whether an economic crisis (Blazheski and Karp, 2018), or a crisis of care (Himmelstein et al., 2018), or a crisis of too few caregivers and too many prospective patients (Kirch and Petelle, 2017; Haddad and Toney-Butler, 2018). But while there is widespread agreement that medicine needs to make changes, it is difficult to know where to begin to think through the complex challenges in a productive way. This book proposes to begin thinking about some of the central issues in medicine by offering a consideration of how a framework developed from within an ethics of care might offer helpful considerations in this process. We do need to think about what the criteria are that we use to evaluate what expenses are too high, or what sorts of care ought to be provided to citizens (or residents of a country, citizens or not), and so on. A basic ethical framework cannot resolve every problem in health care, but it can provide a set of criteria for debating specific issues, as well as a general framework for making decisions about what policies are within a generally acceptable range.

An ethics of care is a theory that makes care central to any consideration of ethical matters, and it seems particularly apt for providing a framework for thinking about contemporary health care practice. This book does not try to provide a complete overview of all the various ethical viewpoints one might consider for such a task, but instead offers an analysis that develops the resources of an ethics of care and considers the potential it offers for thinking about the many challenges we face. And it focuses this analysis on a specific set of issues, namely, the large-scale social structures that structure the delivery of care in medicine today. An ethics of care is a theoretical approach particularly suited to the health care context. It focuses on the relationships that shape our lives and on the social structures that support (or fail to support) those relationships, and it works within a framework that recognizes the fact, so obvious in the context of health care, that people are not equal in power, knowledge, or authority. Physicians and nurses stand in positions of differential authority and power, patients usually don't

stand at all, but sit or lie down (visually mapping their situation vis-à-vis those who do stand), and so on. The primary purpose of medicine is care, making an ethics of care particularly apropos for this context. Further, so many good theorists are currently working in an ethics of care framework that the resources it offers in terms of approaching issues from a variety of perspectives is tremendous. Working within an ethics of care framework, then, promises to be a worthwhile method of approaching issues in health care. But much of contemporary medical ethics focuses on individual cases and decision-making by particular individuals. Individual decisions are important, to be sure, but ethical issues in the health care context go far beyond the choices of particular patients or medical professionals.

Because an ethics of care makes caring practice itself central to any ethical evaluation, this provides the over-arching consideration for this evaluation. But just noting that providing care is a good thing doesn't get us very far. This book offers a brief history of an ethics of care, and the methods of evaluation and moral analysis that care ethicists have developed. In the course of that explanation, I will argue that an ethics of care provides resources for evaluating social structures in terms of the following four sets of considerations:

First, how does the structure under analysis provide care, and what sort of care does it provide? In the case of health care, the aim, clearly, is to provide for the restoration of health when possible, to alleviate pain and restore function, to cure illnesses, and so on. But for different types of health care practices, the specifics that define good care will differ. More than this, for the particular structure at issue, the measure of good care will depend on what that structure ought to provide. So, in the case of economic structures, for example, one main consideration, from that perspective of care as well as many other theories will be the question of access—do the economic structures of health care generate an adequate level of access for the population as a whole?

Second, how do these structures fit into the rest of the social systems within which they are contextualized? Economic issues intersect with the development of new technologies, for example, complicating the provision of care and the very notion of adequate access. Likewise, caregivers' authority rests, in part, on their role as gatekeepers for access to health care, and this depends, in turn, on the economic structures.

Third, how do the structures themselves function in terms of providing, facilitating, or obstructing the care that they are designed to offer? This is a central concern for care theory, since relationships of care are, as noted earlier, central to any care analysis. Here the criteria for evaluating better and worse care need to go beyond health outcomes (though clearly these matter) to include the experiences of patients and caregivers alike. Structures that give rise to deep frustrations on the part of caregivers, for example, contribute to burnout and failures of care, and need to be addressed. Structures that make it harder to maintain interpersonal relationships, such as the over-technologization of end of life care, likewise deserve critique.

Fourth, how do the structures affect the capacity of those working within them to actually care for others, and how do they shape the characters of agents in terms of supporting (or destroying, or facilitating, or otherwise affecting) the development of the character traits essential to acting as a caring person? As discussed earlier, the structures within which professionals function shape them in deep and profound ways. The power and authority which accrue to the role of caregiver, for example, are both crucial to the caregiver's job and represent challenges for providing care in situations where patients refuse to accept the caregiver's recommendations.

In Chapter 1 the basic features of an ethics of care that provide the context for this analysis are explained and detailed. The account focuses on the resources of an ethics of care for understanding large-scale structural issues.

The social structures that form the focus of this book are ones that have direct bearing on the provision of care. In Chapter 2, I start with the issue of knowledge and the way different conceptions of knowledge structure the provision of health care. Medical knowledge makes for a particularly interesting case for ethical analysis because the very concept of knowledge has recently undergone a substantial revision, moving from a primarily clinical judgment model to one that bases knowledge claims on evidence-based practice. The shift from clinical judgment to evidence-based practice changes both who is considered an expert and how knowledge is constructed. These changes, in turn, have changed the way that care is given, the standards for what counts as good care, and the self-understanding of caregivers.

Knowledge is not the only structure in medicine that determines the way care is given. In Chapter 3, economic forces and their impact on the provision of care and the character of caregivers are analyzed. In the current politicized climate surrounding economic structures and health care, it is easy to get carried away by rhetoric, proclaiming one's own preferred economic structure to be a moral requirement, one's opponent's to be deeply wrong, evil, and muddle-headed. But my sense is that any economic structure in medicine will have both positives and negatives: some keep costs down more than others, but perhaps at the cost of certain kinds of care. Others may provide a greater range of services, but fail at providing the most basic kinds of care to the most vulnerable, and so on.

Both medical knowledge and medical economics are driven by technological factors. The increasingly sophisticated technology that health care currently offers has changed the delivery of care and the ways that caregivers function. Chapter 4 focuses on the increasingly technological structure of contemporary medical care and the way that technology functions in positive and negative ways in the provision of care.

Knowledge, economic factors, and technology all represent forms of power in medicine. Social structures track this power, for the most part, making those who have the most knowledge, those who control the economics, and those who provide and control access to the technology the ultimate authorities in the medical field. But power and authority are never

absolute, and the complexities of modern life are such that knowledge and economic control, or technological control, do not always coincide. So medical practice involves with competing structures of power, and Chapter 5 turns to the complexity of power and authority in the medical context, looking at how it supports (or sometimes frustrates) caregivers.

Finally, Chapter 6 turns to some of the deepest questions in medicine—namely, questions about what the ultimate aims of medicine really are. If we are to care well in the medical context, we need to have some shared sense of what we are trying to achieve when patients come seeking care. But contemporary medicine has some deep conflicts in its understanding of what good care consists in. One place where these conflicts are particularly apparent is in the realm of end of life care, where conflicts between those who argue for fighting against death as long and as hard as possible and those who argue for a good (i.e., painless) death have become quite strident in recent years. These issues get to the heart of what medicine is and ought to be, and of what it means to provide the sort of care that we should ensure for all members of our communities.

An ethics of care is a good fit for thinking about the ethics of health care precisely because of the overlap between many of the central concerns of medicine and the resources offered by an ethics of care. First, care is central to medicine. A famous debate of a number of years ago focused on whether medicine should focus on care or on cure—that is, whether the primary ends of medicine should be assumed to be the correction of conditions identified as diseased, abnormal, or dysfunctional (that is, primarily cure), or whether medicine, while including a concern for curing illness, needed to have a broader focus on care for the whole patient, care that encompassed both cures for illness and care for conditions that either need not be cured (pregnancy and childbirth) or cannot be cured, amelioration of suffering, preventive care, and health promotion. The general consensus today is that medicine encompasses far more than just cures, and it is common to find discussions that advocate for both cure and care (see, for example, De Valk et al., 2001; Glouberman and Mintzberg, 2001), or identifies both as central values in medicine (Giordano, 2018). Medical practice as a whole encompasses more than simply cure, and a single-minded focus on cure can increase patient suffering (Cassell, 1998). Care, then, is the over-arching goal of medicine.

More than this, because patients enter the world of medicine when they are vulnerable, sick, and sometimes dying, what they look for from their caregivers is more than simply diagnosis and prescription of treatment. There is an existential aspect to the medical encounter because patients so often are facing conditions that could either change their lives drastically or signal the end of their life altogether. Caregivers find themselves asked to respond to needs that go far beyond merely the need for treatment of physical conditions; they are asked to provide emotional and psychological support for individuals facing death, or watching a family member die.

While emotional support is possible in these cases, caregivers often cannot fully respond to the deepest existential questions patients pose. These are existential questions, after all, precisely because each of us must face our own death, and that is a burden no one can take from us. While an ethics of care cannot resolve these questions, it provides space for addressing them and recognizing their importance in a medical context.

An ethics of care offers an ethics focused on practices of care, so it is not surprising to find that many care ethics discussions emphasize medical practice as either one central component of care (Engster and Hamington, 2015; Sevenhuisjen, 2004; Tronto, 1994) or as a central focus of their analysis as a whole (Petersen, 2008). Because medicine is a set of practices that provide physical care aimed at protecting health, providing alleviation of suffering, and supporting people's abilities to live well, it is a central part of the care that allows us to live and flourish in the contemporary world. Its central role makes it a natural focus for an ethics of care. Care ethics also has much to offer medicine. It is a theory designed to examine complex relationships of care, one that recognizes the vital importance of the work that goes on in medical facilities, and a theory that emphasizes the centrality of embodiment and the physical world, as well. This book, then, is an exploration of the intersection between these two.

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