The Ethics of Palliative Care: European Perspectives


A welcome addition to the “Facing Death Series” makes an important contribution to palliative care ethics. The contributors, from seven European countries, debate the tension created between viewing ethics as a way of giving answers to end of life issues and the practice and philosophy of palliative care contributing to the development of medical ethics—that is, ethics “in” and “of” palliative care.

Philosophical discussion requires a historical perspective; the early part of the book addresses this by describing the work of the “Pallium” project. This European collaboration of ethicists, clinicians, philosophers, and social scientists, explored and analysed conceptual and ethical issues in palliative care.

The study describes the differing way in which palliative care services have evolved and relates this to ambiguities in the palliative care movement. The question arises as to whether palliative care should be integrated into medicine or should be a new discipline? Should it complement existing services? Palliative care philosophy emphasises care and communication rather than intervention and treatment, which dominate mainstream medicine. Where palliative care has been integrated into mainstream services, there has been a lack of clarity about its scope and boundaries. The study revealed dramatically different levels of palliative care provision, both nationally and locally, raising ethical questions of distributive justice.

The project also examined ethical “hot topics” such as withholding and withdrawal of treatments, terminal sedation, and euthanasia. The authors challenge the current prioritising of respect for individual autonomy by including the interests of the family, carers, and professionals.

The Pallium project concluded that the role of professional ethicists should be to identify morally relevant issues rather than provide answers.

In an analysis of the goals of palliative care, which “occupies a space between hope of cure and fear of dying”, the contributors conclude that quality of life, relief of suffering, a good death, and prevention of euthanasia are the most important goals.

Issues of cure and caring, “which has never been the goal of medicine”, are discussed in a thought provoking way, linking concepts with the charitable origins of hospice care and social changes in family structure.

The second part of the book looks at moral values and explores existing concepts of autonomy. Respect for autonomy in palliative care is examined in depth. Its general importance in health care is not questioned but whether it should have pre-eminent importance is explored. The medicalisation and secularisation of palliative care has created a tension within the specialty. The apparent paradox of acceptance of death but denial of a right to die is explored from an “autonomy” perspective, which distinguishes between respect for autonomy as a liberty claim and as a rights claim.

Terminal sedation is discussed in a helpful chapter, which redefines the topic. Convincing arguments are put forward for replacing “terminal sedation” with “palliative sedation” as the latter is a more helpful term, combining both the proportionality and the adequacy of sedation in response to symptom control. Further chapters on research ethics provide ethical and practical insights such as the suggestion that observational studies may be as appropriate as random controlled trials in the palliative care context. The authors also argue for a benefit based model of research ethics rather than an evidence based model.

The concept of futility and its limits in palliative care raise the question: who determines what is the proper goal of treatment. Palliative care can benefit from bioethics but ethics can learn from the experience of palliative care practitioners. We need to create interest in alternative concepts of ethics in order to explore the moral experience of patients and professionals. Narrative ethics, responsibility ethics, and virtue ethics, can all contribute to our understanding.

Respect for autonomy may isolate the patient and neglect issues of vulnerability, fragility, and dependency. This book will be of interest to all those responsible for promoting palliative care. It also contributes to the development of bioethics itself.

D Jeffrey
david.jeffrey@egnhst.org.uk