ETHICAL ISSUES IN HOME HEALTH CARE

Second Edition

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For the many nurses who generously shared their stories with us. R.E.L. and S.L.S.

For my uncle, Olney Fortier, in gratitude of his continous support and deep and abiding commitment to intellectual pursuits.

L.P.

PREFACE

This book lets us listen to the voices of home health care nurses as they pose the ethical questions they encounter in their work. The cases presented in each chapter are fictionalized situations based on interviews conducted with home health care nurses in both hospital—sponsored and private agencies, in hospices, and in urban and rural settings. We have attempted to avoid the use of gendered pronouns, except in the discussion of cases, where their use reflects the fact that the majority of nurses in home health care are women.

Home health care is an increasingly important venue for nursing as advances in medical technology and cost-containing measures shift the ill population from hospital to home. The decrease in the length of hospital stays, with patients being discharged sooner and requiring more complex care, together with the aging of the population, has resulted in an increasing number of older, sicker, frailer patients being cared for at home. The rise of specialties such as geriatric case managers has also contributed to the possibility of more individuals being able to access services at home. As a consequence of these changes, home health care nurses may face a growing number of ethical questions and more complex ethical issues.

Not surprisingly, practicing nursing in the patient's home raises different kinds of ethical questions than are raised in hospital nursing. The general nursing literature addresses ethical issues, but little attention has been paid to the special circumstances of home health care and the fact that this kind of nursing requires different strategies for effective ethical responses.

Each chapter of the book is devoted to one of the main areas of concern for home health care nurses. Focusing on specific cases, it offers analysis and discussion of the ethical issues, cites legal requirements where relevant, and summarizes ethical criteria and practical strategies. Whether student or seasoned professional, the reader is afforded

the opportunity to gain increased sensitivity to what counts as an ethical question and a better understanding of the critical thinking process that leads to careful, reasoned decisions about what to do. At the same time, reflection on the issues and attention to the reasoning process can aid in communicating with patients and families about the often emotion-laden decisions that constitute the core of home health care ethics.

In this second edition, the text has been revised to reflect new developments in nursing ethics. The discussion of confidentiality and privacy incorporates the requirements for safeguarding confidentiality of medical records and patient information created by the Health Insurance Portability and Accountability Act. The ethical requirements for culturally competent nursing care have been addressed in the chapter on respecting cultural differences. There is also an updated discussion of the provisions of the revised American Nurses Association Code of Ethics, including the Bill of Rights for Registered Nurses. In addition, some cases have been rewritten to accord with changes in medical technology and the term "patients" has been substituted for the earlier references to "clients."

New material has been added in the form of two additional Appendices. One appendix includes ten new cases which may be used for discussion in groups or for individual practice in ethical analysis. The second appendix discusses how to develop and use Ethics Committees within home health care agencies. There are also a number of new cases introduced within the various chapters.

There is one change in organization. The cases which introduce the topic of each chapter are discussed and analyzed as the last section in each chapter rather than being analyzed in a separate chapter at the end of the book.

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ETHICAL ISSUES IN HOME HEALTH CARE

Chapter 1

ETHICAL DECISION MAKING

Ethical issues arise in home health care, as in human lives generally, in many diverse types of situations. Sometimes an issue arises because there is an important disagreement with others about what is right to do—a conflict that may have its origin in disagreement about fundamental moral values and principles. Perhaps the most confounding and most common issues, though, involve situations where it is initially unclear what is right, and individuals must resolve their own moral uncertainty in order to reach a decision. In all of these instances, ethical decision-making must have its foundation in a basic understanding of the nature of ethics and traditional moral ideas concerning right and wrong. Case 1 provides an example of a situation in home health care that raises a concern about what to do.

Case 1

I have a patient with cancer who is dying at home. Her two sisters are staying with her to take care of her. Because she is on morphine, she has experienced constipation, recently developed a partial bowel obstruction, and needs a colostomy. Last week she told me she didn't want the surgery because she didn't think her sisters could deal with it. As her condition has worsened, her sisters have noticed she is bloated and nauseated. They are pressuring me to tell them what is happening. Should I support her decision to spare her family?

General Issues

- What is ethics?
- How should claims about rights be used in making ethical decisions?

- What role should consequences have in ethical decisionmaking?
- · What other factors should be considered?

INTRODUCTION

In Case 1, the nurse faces a classic ethical dilemma, that is, a conflict between two moral ideals. One ideal holds that nurses should respect a patient's right to make decisions, but here that ideal conflicts with the responsibility nurses also have to promote a patient's health and well-being. The decision the nurse must make in this situation is different from the clinical decisions she confronts every day, for this involves the kind of question that goes beyond facts. The uncertainty about what it is right to do cannot be resolved by gathering more factual information or even through further assessment of a patient's clinical condition. Instead, answering ethical questions requires skill in identifying the significant moral factors in a situation and then reasoning to a conclusion about the best course of action.

This case illustrates three important features of the special challenges home health care nurses face when ethical conflicts arise: First, although they are part of an interdisciplinary team, home health care nurses are usually the only professionals in the home when a decision must be made. Second, the home setting itself may be the source of moral concerns, for example, if obstacles exist that prevent ideal nursing interventions on behalf of a patient. Third, though their primary responsibility is to care for patients, nurses must also respond to concerns about family members or others who are caregivers. As a result, the ethical dilemmas nurses face in home health care are not only complex but also in some instances unique to the home setting.

Ideally, home health care nurses will be adept at thinking through solutions to ethical problems, without the benefit of immediate advice from professional colleagues, and they will be able to assist patients and families in understanding and coping with difficult decisions. These skills can be developed through thoughtful reflection on ethics and practice in ethical decision-making.

WHAT IS ETHICS?

Ethics involves critical reflection on fundamental moral beliefs, that is, beliefs about how to live, what has meaning and value, and which actions are morally right. The ultimate goal of careful reflection on these issues is a decision or a claim about morality that is thoughtful and well supported by reasons. Thus, reasonable answers to moral questions and good ethical decisions will be the result of critical thinking.

Laws and nursing codes of ethics offer legal standards and moral ideals for the practice of nursing, but they cannot substitute for ongoing critical thinking about ethical issues. Laws, for example, are not very helpful in determining what is ethically right to do, because they state legal standards that are often vague and which need to be interpreted. Because legal standards are also subject to ethical evaluation, the laws themselves could possibly be judged immoral and thus fail to provide a reliable guide for ethical decisions. Moreover, many of the circumstances that present ethical dilemmas are not covered by the law. For these reasons, ethics requires going beyond the view known as legalism, the idea that right and wrong are fully determined by the legal requirements that apply to a situation.

Nursing codes of ethics outline the basic moral principles that should guide the professional practice of nursing and serve to inspire moral ideals for practice. However, codes of ethics, like laws, generally offer vague statements that require interpretation in a specific case to determine what to do. According to the American Nurses Association Code of Ethics, for example, "the nurse promotes, advocates for, and strives to protect the health, safety, and rights of the patient." The dilemma that arises when these moral requirements conflict is well illustrated in the situation described in Case 1. Referring to the Code of Ethics clearly does not resolve that dilemma. Instead, a resolution calls for weighing these requirements against each other to determine what should be done.

Finally, though religions are a common source of basic ethical principles, neither ethical thinking nor ethical behavior requires a basis in a religion or in religious beliefs. What good ethical thinking does require is reflection on moral values and principles, that is, critical evaluation of the reasons that support a decision.