

# KNOWLEDGE CENTRAL

**Barbara D. Powe, PhD, RN**  
Associate Editor

## B O O K S

**Culture and Clinical Care.** *Juliene G. Lipson and Suzanne L. Dibble\* (Eds.). San Francisco, CA: University of California, San Francisco, Nursing Press, 2005, 512 pages, \$33.95.*

🕒 ✓ 👤👤 Softcover



*Culture and Clinical Care* offers an excellent overview of the provision of culturally appropriate health care to 35 different cultural groups. The editors, both nurses, are careful to avoid using the phrase “cultural competence” because it implies mastery when caring for a broad range of culturally diverse populations. Instead, the book is designed to enhance awareness, sensitivity, and knowledge (ASK) among healthcare providers caring for culturally diverse populations. Using this framework, ASK can enable healthcare providers to offer more effective, culturally appropriate care. The de-emphasis on cultural competence is a unique and interesting perspective as providers strive to offer quality and appropriate care to diverse groups of individuals.

In the introduction, the editors briefly describe the various sources of diversity (e.g., immigrant or refugee status, race or ethnicity, socioeconomic status, sexual orientation, gender identity, disability status) and conclude with a discussion on the aspects of communication, as well as the Health Insurance Portability and Accountability Act of 1996 and its relevance to providing interpreter services. Although broad, the information on communication is applicable to all groups, regardless of cultural back-

\* *Oncology Nursing Society member*

ground. A detailed cultural assessment is preferable when caring for patients, but five key questions are offered that can be used when conducting a cultural assessment for any cultural group.

All contributing authors for the 35 chapters follow a consistent format addressing the following categories: cultural or ethnic identity, spiritual or religious orientation, communication (oral, written, nonverbal), activities of daily living, food practices, symptom management, birth rituals or care of a mother and baby, developmental and sexual issues, family relationships, illness beliefs, health issues, and death rituals. Populations are alphabetized and range from Afghans to former Yugoslavians.

Strengths of the book are its easy-to-read and consistent format and its inclusion of a wide range of cultural groups that is not limited to racial and ethnic minority groups (i.e., groups with a population of more than 100,000 according to the U.S. Census and those with limited published information). A strong feature of the text is its inclusion of each contributor’s brief biography and photograph. The contributing authors and editors are either members of the respective cultural group about which they are writing or have some affiliation or experience working with their respective group. This information serves to enhance the book’s credibility. The authors are careful to acknowledge limitations of the book in the first chapter, thus orientating readers upfront to the book’s intent, which is to offer guidance and hopefully stimulate further inquiry related to providing culturally appropriate health care. The authors clearly achieve this goal, with a focus on using guidelines versus a cookbook approach when caring for a growing number of culturally diverse populations.

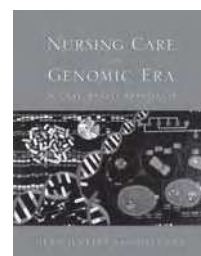
Given the increasing need and challenges associated with caring for diverse populations, healthcare providers, regardless of their area of practice or specialization, will find this book user-friendly, timely, and

a must-have when caring for patients in today’s healthcare arena.

*Janice Phillips, PhD, RN, FAAN*  
*Nurse Researcher*  
*University of Chicago Hospitals*  
*Chicago, IL*

**Nursing Care in the Genomic Era: A Case-Based Approach.** *Jean F. Jenkins and Dale Halsey Lea\*. Sudbury, MA: Jones and Bartlett Publishers, 2005, 411 pages, \$49.95.*

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In 2003, the completion of the human genome sequence occurred in tandem with the 50th anniversary of the discovery of the structure of the DNA molecule by James Watson and Francis Crick. We are living in an era of unprecedented scientific discovery that promises to bring an understanding of human disease at the genetic level, as well as medicine that is, in the words of Leroy Hood, preventive, predictive, and personalized. The power of genomics rapidly is changing the understanding of the pathophysiology of cancer and, hence, its management. Oncology nurses of the 21st century must have a basic understanding of genetic principles and resulting implications for the care of patients. The authors of this book are well-recognized leaders in the field of genetics and have shared their knowledge and expertise with the nursing profession in a creative way in this insightful text.

The goal of *Nursing Care in the Genomic Era: A Case-Based Approach* is to relate the principles of genetics and genomics and the resulting implications for nursing practice through stories. Each chapter highlights a story of a particular genetic condition and the related biologic, personal, and psychosocial issues. Chapters then discuss the required knowledge, skills, and attitudes that nurses and all healthcare professionals should possess to provide optimal care. The core set of skills is based on the work of the National Coalition for Health Professional Education in Genetics (NCHPEG) ([www.nchpeg.org](http://www.nchpeg.org)).

Ease of Reference and Usability	Content Level	Media Size
🕒 Quick, on-the-spot resource	✓ Basic	👤 Pocket size
🕒🕒 Moderate time requirement	✓ ✓ Intermediate	👤👤 Intermediate
🕒🕒🕒 In-depth study	✓ ✓ ✓ Advanced and complex, prerequisite reading required	👤👤👤 Desk reference

Digital Object Identifier: 10.1188/06.ONF.159-161

The book is targeted toward a general medical/surgical audience, although many specific examples relate to oncology. The text would be especially useful for nursing faculty and hospital nursing educators.

The book starts with the story of a woman diagnosed with cystic fibrosis and relates genomics to biology. Subsequent chapters connect genomics to practice through collecting family histories and present an overview of the health benefits of genomics, with a focus on prevention, risk assessment, genetic testing, pharmacogenetics, and pharmacogenomics. The next five chapters focus on practice issues, such as making a genetic referral, qualifications of healthcare professionals providing genetic counseling services, and the effect of genetic information on the lives of patients, families, society, spirituality, and religion. Additional chapters discuss genetic research, the future of genetics, the use of genomics to improve health, and genomic resources for nurses.

Chapters are organized with an introduction, a personal story that highlights the concepts of the chapter, and didactic information. Each chapter ends with a summary, resources, activities, and references. The activity section is particularly creative and stimulates readers to undertake programs for learning or discussion to further explore the concepts presented in the chapter.

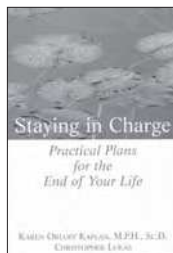
Strengths of the text include basing the content on the NCHPEG recommendations; the innovative use of titles and stories to illustrate concepts; a thought-provoking range of issues on the effects of genetic information on society, practice, patients, and families; and experiential learning through patient stories. However, the text does have several limitations. The titles do not always clearly relate the content of the chapter, and the chapters overlap and repeat information. The text has a considerable number of diagrams and tables, as well as text boxes, that highlight key points, but the pages can be text intensive in some areas. The included Web resources are outstanding. The text appears best positioned for use in a classroom or in-service setting or for personal learning about genetic principles and is not intended as a quick reference for questions related to genetics.

Overall, *Nursing Care in the Genomic Era* is well worth considering for a personal library or a hospital or university reference collection. It contributes in a significant and unique way to the existing nursing literature in genetics. The book serves to bring the human element of genetic discoveries to those involved, but not specializing, in this emerging field.

Paula Trahan Rieger, RN, MSN, CS,  
AOACN®, FAAN  
Director of International Affairs  
American Society of Clinical Oncology  
Alexandria, VA

**Staying in Charge: Practical Plans for the End of Your Life.** Karen Orloff Kaplan and Christopher Lukas. Hoboken, NJ: John Wiley and Sons, Inc., 2004, 240 pages, \$14.95.

ISBN 0 818 61111 1 ✓  Softcover



*Staying in Charge: Practical Plans for the End of Your Life* uses a commonsense approach to decision making regarding issues important to end-of-life care. In chapter one, the authors, using their personal experiences, explain their reasons for writing the book. The next two chapters address obstacles to receiving quality end-of-life care and the difficulty individuals may have when thinking and talking about mortality issues. A study done in 2003 by Last Acts Partnerships, a national coalition striving to make end-of-life care better for all, is cited to illustrate the need for individuals to make their wishes known. Throughout the book, the authors stress that no one else can determine what an individual's quality of life is or should be. Each individual must define his or her own quality of life.

Chapters four and five discuss palliative care and hospice. Symptom control, including pain (physical and emotional), shortness of breath, nausea, and dry mouth, are mentioned. Emotional and spiritual comfort and the legitimacy of seeking professional help when necessary are encouraged. The role and importance of the nurse are discussed. In addition, the authors cite the results of a 2003 Hastings Center think tank that extolled the benefits of hospice care.

In a chapter related to advance directives, the authors define the concept, discuss how to receive assistance, and describe the importance of excellent communication with an agent. To ensure individual wishes are followed, personal physicians should be informed of the existence of an advance directives document and provided a copy; the patient should review the document with the physician on an annual basis. The authors also discuss how to choose an agent or be an agent for someone else. Other chapters contain valuable information related to caregivers, children and serious illness, nursing homes, do-not-resuscitate orders, assisted dying, funerals, grief, and living with a terminal illness. Throughout the book, personal stories and case studies are used effectively. A list of suggested readings and resources is included at the end of the book.

*Staying in Charge* has several limitations that could be misleading to lay audiences. For example, lymphoma is defined as cancer of the blood. In another instance, the authors state that if a person is not insured by Medicare (which covers hospice), private insurers will pay for it. From this reviewer's experience, this is not always the case and could

be confusing to readers. One other statement was bothersome. The authors refer to "cancer victims" rather than patients with cancer. Overall, the book is appropriate for the lay public and healthcare professionals not familiar with palliative care, hospice, and advance directives. It is basic but informative.

Virginia Bourne, RN, MSN  
Clinical Nurse Specialist, Emeritus  
Thanatology/Oncology  
Oostburg, WI

V I D E O

**And Thou Shalt Honor.** Public Broadcasting System, 2002. VHS/DVD, Part I: 55 minutes; Part II: 68 minutes; VHS, \$29.95 for private use or \$285 for public use; DVD, \$39.95 for private use or \$285 for public use.

ISBN 0 791 06111 1 ✓  Video



This two-part series, *And Thou Shalt Honor*, is an enlightened Public Broadcasting System (PBS) film aimed at informing its audience about the complexities and challenges of caregiving in society today, particularly for people in later life.

Originally filmed for PBS television, the film has all of the pluses (and some of the minuses) of its original producer. Narrated by Joe Mantegna, the film contains numerous vignettes that beautifully, poignantly, and honestly expose the dilemmas of caring for loved ones who are totally dependent on someone else for their care. The film includes a cross section of ethnic, geographic, and economically diverse families. The challenge and curse of long-term caregiving are portrayed in story after story: a doctor with early-onset Alzheimer disease; a poet with multiple sclerosis; a daughter with aging parents and a blind, mentally challenged sister; and an older woman poststroke who sits for hours a day at her daughter's workplace because of a lack of appropriate care. The stories continue, and each is unique and touching.

Part II of the series focuses on potential services for caregivers, highlighting innovations in nursing home care, such as the role of a geriatric care manager, a mobile Veterans Administration clinic, comprehensive faith-based or ethnic older adult services, and a medical school training program in which students go through the "aging game."

The film's weaknesses lie in two areas. Although citing the limitations of nursing homes and financial support for caregiving at home, the film does not speak to existing ideas for a radical and comprehensive revision of the healthcare system. Despite the

condemnation of the current care system, the workers in the system are depicted correctly and in a positive manner, be it a skilled nursing facility's administrator who sympathizes with his patients' life changes or nursing home aides who express profound love for their patients (e.g., "You have to love this work because nobody else would do it."). *And Thou Shalt Honor* also deals only superficially with the area of hospice care and the process of caring through death and beyond.

The audience for this documentary is unclear. Some of its viewers may have already done what the film advocates (i.e., advance care planning). The film is accompanied by a study guide and resources; however, with a viewing time of two-plus hours, the film most likely would not fit into any current curriculum, even though it would be a strong visual reminder to medical and nursing students about the challenges of older adult and disabled care.

This film may be helpful for members of senior centers, caregiver groups (which are growing in the oncology field), and churches. Again, because it is beautifully filmed, edited, and narrated, *And Thou Shalt Honor* is an often-touching reminder that the U.S. medical system, with a few notable excep-

tions, has not developed a comprehensive program that truly honors the ill and older adults. This issue is relevant to all nurses and healthcare providers.

Janet M. Hooper, RN, BSN, OCN®  
Charlotte Hungerford Hospital  
Torrington, CT

## Worth a Look

**Assessing Quality of Life in Clinical Trials: Methods and Practice (2nd ed.).** Peter Fayers and Ron Hays (Eds.). Oxford, UK: Oxford University Press, 2005, 488 pages, \$75.

Quality-of-life assessment has progressed considerably since the publication of the highly acclaimed first edition of this book in 1998. Quality of life now has become an indispensable outcome measure in many randomized clinical trials and other studies. Thus, this timely and completely new edition reviews the current state of the science and also discusses topical issues such as areas of active research.

Within *Assessing Quality of Life in Clinical Trials: Methods and Practice*, expert authors explore key elements for assessing quality of life in clinical trials. The first two chapters focus on developing and evaluating question-

naires as well as adapting and using existing questionnaires. Chapters three through six focus on analysis, interpretation of data, and measures for clinical trials. The book is organized and easy to read, with graphs and tables that complement the text. For example, one table provides a list of generic and disease-targeted measures of health-related quality of life. However, most of the topics are covered only briefly and readers would need to seek additional resources to gain a more thorough understanding.

This book could serve as a stand-alone resource for individuals interested in measures of health-related quality of life at a basic level or as a companion resource to other, more detailed resources that address one or more aspect of health-related quality of life and clinical trials. *Assessing Quality of Life* also could be used as a supplement in a traditional nursing research course because many of its concepts can be applied to other measures, such as the discussion of reliability and validity or the purpose of focus groups. From this perspective, the book could provide practical, realistic research guidance for taking some of the global steps of the research process and applying them to the measure of health-related quality of life within the context of clinical trials. 