

Book review



David Sigel, LMSW, CCM

***The Cultures of Caregiving: Conflict and Common Ground among Families, Health Professionals, and Policy Makers* edited by Carol Levine and Thomas Murray**

187 pp. Baltimore: The Johns Hopkins University Press, 2004.

In this book, the editors successfully blend viewpoints and experiences of caregiving from medical professionals, governmental officials, and caregivers. Each chapter eloquently states the viewpoint of its author, with vivid examples and detailed statistics. The foreword by Christine Cassell, MD, president and chief executive officer of the American Board of Internal Medicine, presents a poignant vision of the interface between family relationships and the patient/physician relationship. Families come to the situation with years of a historical relationship—functional or dysfunctional. Physicians arrive with the knowledge and skills they have been trained to master. This mastery, according to Dr. Cassell, is based on certainty, which at times is not feasible, thus creating frustration and uncertainty in all involved. Creating collaboration among the patient, caregivers, and medical professionals is the goal of this book as each contributor points to areas of common ground and continuing challenges.

This book originated from a project of the United Hospital Fund (UHF). In 1996, UHF began focusing on family caregiving and cultural diversity, creating a series of meetings, focus groups, and other projects. Grants and further studies branched from this original project and continue to give voice to caregiver issues.

Part I of this book focuses on various perspectives of family caregiving. Chapter 1, written by David Gould, PhD, senior vice president for UHF, reviews the outcome of a 1998 national survey involving over 1000 caregivers. Dr. Gould provides excellent statistics on costs, relationships, and demographics. He addresses the types of responsibilities caregivers have, their training or lack of training, and expectations placed on them by others. Chapters 2 and 3 are personal narratives. In the first, social worker Gladys Gonzales-Ramos addresses the struggles related to her parents' declining health and the cultural and language barriers they faced when dealing with a variety of health care environments. In the second narrative, New York nephrologist Jerome Lowenstein recounts a personal experience when a patient's wife asked him not to disclose to the patient the terminal nature of his illness.

Part II focuses on home care in the present and past. Chapters 4 through 6 explore home care in 19th-century New England, which involved not just family members but entire communi-

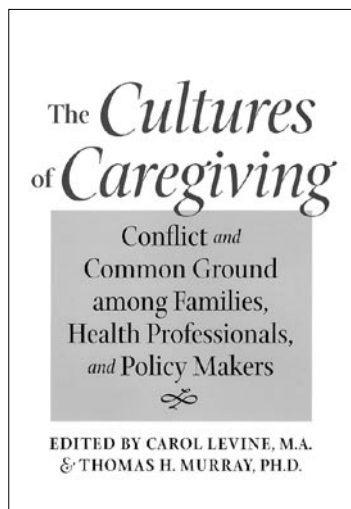
ties. The role of the home care nurse and home health aide are spotlighted, and an interesting account is given on the way these professions are weaved into the family caregiving model. Part II also addresses Medicare and Medicaid funding of some home care needs. The chapters of part II were written by a professor of public health; the founder/president of a nonprofit, Medicaid-managed, long-term care organization; and a nurse educator specializing in geriatrics. The blending of these three authors' viewpoints gives a concise and informative approach to a paramount component to caregiving.

Part III, "The Societal Context," highlights two cultures. The policy culture is reviewed by Judith Feder, dean of public policy at Georgetown University, and Carol Levine, director of the UHF Family and Health Care Project. They clearly describe the evolution of payment for home care—by Medicare and Medicaid and by third-party payers. Popular culture, in which views of caregiving are shaped by the media, is reviewed by Carol Levine and social worker Alexis Kuerbis. They poignantly describe five types of caregivers—invisible, gothic, saintly, eroticized, and realistic—and refer to recent movies that exemplify each type.

Part IV, "Bridging the Gap Among Cultures," is a critical component of the book. Without this piece, the common ground between health care providers and caregivers cannot be established. Jeffrey Blustein, PhD, professor of bioethics at Albert Einstein College of Medicine, explores the common values shared by the physician and the family and explores how tensions can be reduced. He advocates a partnership between medical professionals and caregivers that clarifies roles and allows each to rely on the other while maintaining mutual respect. Hospice is also discussed as a collaboration between medical and family values.

Chapter 10 was written by Maggie Hoffman and Donna Jean Appell, who have children with special health care needs. Hoffman and Appell cofounded Delivery of Chronic Care (DOCC), a parent-directed program providing training and education. Examples include pediatric grand rounds presented by parents, hands-on assessment and training in the homes of ill children by medical professionals, and other collaborative methods to build the bridge between medical providers and family caregivers. DOCC is an amazing illustration of willing partners attempting to share knowledge and gain additional knowledge from one another.

The final chapter, "Changing Institutional Culture," was written by Judah Ronch, PhD, founder of an institution that develops mental health programs. Dr. Ronch addresses the conflict that appears in a variety of scenarios and explains how to change the conflict into an opportunity. He describes five principles to this new pathway. He also points out how the environment shapes the



situation. The practitioner holds more authority in an institution than in a home. When the family yields to the expectations of the care setting, they may experience stress and guilt. Dr. Ronch suggests a collaborative process and provides a passionate explanation supporting his recommendation.

The book's conclusion superbly links the chapters. It identifies research, education/training, and policies/programming as ways to further the goal of "the best possible care for ill or disabled people and the best possible quality of life for both them and their caregivers."

The collaboration and talents brought together to write this book are phenomenal. Varied viewpoints allow the readers to empathize and learn from others. Each vantage point is presented in a manner that respects other opinions. This book should be considered an instrument in building and solidifying the bridge between caregivers and the medical community, focusing on the patient's needs and comforts along with the medical talent and care available.

The reviewer, David Sigel, LMSW, CCM, is a practice administrator and social work supervisor for the Baylor Senior Health Network.