Caregiving: Research · Practice · Policy
Series Editor: Ronda C. Talley
An Official Publication of The Rosalynn Carter Institute for Caregiving

Ronda C. Talley
Rhonda J.V. Montgomery
Editors

Caregiving Across the Lifespan

Research • Practice • Policy

Series Foreword by
Former First Lady Rosalynn Carter

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To my grandparents, Jim F. and Vela Booher McCoy, and Curtis Edward and Mary Ashmore Talley, whose loving care and support have meant so very much to me.

Ronda C. Talley

This book is dedicated to my husband Mike, who remains my constant source of support.

Rhonda J.V. Montgomery

Editorial Board

Series Foreword

From its inception in 1987, the Rosalynn Carter Institute for Caregiving (RCI) has sought to bring attention to the extraordinary contributions made by caregivers to their loved ones. I grew up in a home that was regularly transformed into a caregiving household when members of my family became seriously ill, disabled, or frail with age, so my interest in the issue is personal. In my hometown of Plains, Georgia, as in most communities across our country, it was expected that family members and neighbors would take on the responsibility of providing care whenever illness struck close to home. Delivering such care with the love, respect, and attention it deserves is both labor-intensive and personally demanding. Those who do so represent one of this nation's most significant yet underappreciated assets in our health delivery system.

When the RCI began, "caregiving" was found nowhere in the nation's health lexicon. Its existence was not a secret but rather simply accepted as a fact of life. In deciding on the direction and priorities of the new institute, we convened groups of family and professional caregivers from around the region to tell their personal stories. As I listened to neighbors describe caring for aged and/or chronically ill or disabled family members, I recognized that their experiences reflected mine. They testified that while caregiving for them was full of personal meaning and significance and could be extremely rewarding, it could also be fraught with anxiety, stress, and feelings of isolation. Many felt unprepared and most were overwhelmed at times. A critical issue in the "field" of caregiving, I realized, was the need to better understand the kinds of policies and programs necessary to support those who quietly and consistently care for loved ones.

With the aging of America's Baby Boomers expecting to double the elderly population in the next 20 years, deinstitutionalization of individuals with chronic mental illnesses and developmental disabilities, a rising percentage of women in the workforce, smaller and more dispersed families, changes in the role of hospitals, and a range of other factors, caregiving has become one of the most significant issues of our time. Caregiving as an area of research, as a focus and concern of policy making, and as an area of professional training and practice has reached a new and unparalleled level of importance in our society and indeed globally.

As we survey the field of caregiving today, we now recognize that it is an essential component of long-term care in the community, yet also a potential health risk for those who provide care. The basic features of a public health approach have emerged: a focus on populations of caregivers and recipients, tracking and surveillance of health risks, understanding the factors associated with risk status, and the development and testing of the effectiveness of various interventions to maximize benefits for both the recipients of care and their providers.

The accumulated wisdom from this work is represented in the volumes that make up the Springer Caregiving Series. This series presents a broad portrait of the nature of caregiving in the USA in the twenty-first century. Most Americans have been, are now, or will be caregivers. With our society's increasing demands for care, we cannot expect a high quality of life for our seniors and others living with limitations due to illness or disability unless we understand and support the work of caregivers. Without thoughtful planning, intelligent policies and sensitive interventions, there is the risk that the work of family, paraprofessional, and professional caregivers will become intolerably difficult and burdensome. We cannot let this happen.

This volume's chapters make explicit that those who receive caregiving support range across the entire span of life, from infants through the later years. Caregivers range from new parents whose newborn enters the world with a developmental disorder through those in childhood or adolescence to individuals across the adult years who suffer from a disabling disease or accident. With little warning or extended forewarning, individuals find themselves responsible for someone they love who needs a range of emotional, physical, and other forms of support and caregiving. Caregivers provide support to those whose needs may arise at any point in the life span. For that reason, caregiver support services must be designed in alignment with the point in human development at which the need for care arises. This volume, perhaps more than any other in this series, gives evidence to the longstanding message from me that the world is made up of two kinds of people: those who are currently giving care to others and those who will become caregivers at some point in their life.

Readers of this series will find hope and evidence that improved support for family and professional caregivers lies within our reach. The field of caregiving has matured and, as evidenced in these volumes, has generated rigorous and practical research findings to guide effective and enlightened policy and program options. My hope is that these volumes will play an important role in documenting the research base, guiding practice, and moving our nation toward effective polices to support all of America's caregivers.

Rosalynn Carter

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About the Editors

Ronda C. Talley, PhD, MPH, is Professor of Psychology at Western Kentucky University. Dr. Talley's professional experience includes providing national leadership on caregiving issues and organizational development as Executive Director of the Rosalynn Carter Institute for Caregiving and the National Quality Caregiving Coalition; working with federal government groups to promote caregiving issues as Associate Director of Legislation, Policy, and Planning/Health Scientist for the Centers for Disease Control and Prevention, U.S. Department of Health and Human Services, in Atlanta, GA; and promoting the science and practice of psychology in the schools as Associate Executive Director of Education and Director of School Policy and Practice at the American Psychological Association in Washington, DC. Dr. Talley taught ethics and legal issues in school psychology at the University of Maryland, College Park, and clinical, counseling, and school psychology students at Spalding University in Louisville, KY. Dr. Talley worked as teacher of students with special needs and as school administrator for almost 20 years in the Jefferson County (KY) Public Schools. In addition, she supervised a multidisciplinary private practice.

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40 funded regional and national studies focused on public policy, the role of family, and the role of staff in providing long-term care. Most recently, Dr. Montgomery completed two multisite randomized trials to assess the impact of a comprehensive care management protocol (Tailored Caregiver Assessment and Referral (TCARE®)) for working with family caregivers.

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Deryl F. Bailey, PhD, is an Associate Professor at the University of Georgia. He earned his B.S. and Master's degrees from Campbell University, and his Education Specialist and Ph.D. degrees from the University of Virginia. He believes strongly in the power of education and is committed to providing equitable opportunities to promote the betterment of societal existence for everyone. Dr. Bailey is an accomplished professional in the areas of school counseling, diversity, multicultural education, adolescent development, and African American adolescent male development and is a published scholar.

Dr. Bailey specializes in designing professional development opportunities that are in safe and engaging environments that allow participants to stretch in order to achieve positive personal and professional growth. Dr. Bailey is a highly trained facilitator and trainer. He uses humor and sincerity to deliver practical training in an exciting manner. Participants often comment that they did not want the workshop to end and always find the messages to be effective and inspiring. His expertise lies in the areas of exploring assumptions, welcoming diversity in the workplace, and leadership for diversity. His specialty in multicultural education includes Secondary School counseling; group work; mentoring African American adolescents; engaging parents; and development and implementation of enrichment and empowerment interventions for adolescents.

During his career, Dr. Bailey has consulted for school districts, churches, businesses, colleges, and universities, as well as, presented at state, national, and international conferences on a variety of topics as well as received numerous local, state, national, and international awards for his work with children and adolescents.

As a distinguished community leader and educator, he has served as a member on the local school district's diversity task force, University of Georgia's Board of Regents African American Male Initiative, National School Counselors Advisory Team for the College Board, consultant for the Education Trust and the College Board, Membership chair and Executive Board Member for the International Association for Counseling, Past-President of the Association for Counselor Education and Supervision (ACES), and the 2011–2012 William Allan Boeing Endowed Chair and Distinguished Professor of Education at Seattle University.

Jan Blacher, PhD, received her A.B. in Psychology from Brown University in Providence, Rhode Island, and her Ph.D. in Special Education/Developmental Psychology from the University of North Carolina at Chapel Hill. She is currently Distinguished Professor of Education and former Faculty Chair of the Graduate School of Education, at the University of California, Riverside. She is known nationally for her research on developmental disabilities and for her expertise in special educational programming and autism. Dr. Blacher is frequently asked to appear as an Expert Witness in contested cases involving right-to-education suits for children with autism, intellectual disability, or other learning disorders. Over the years, Dr. Blacher has served as reviewer for the *Journal on Autism and Developmental Disorders,* as consulting editor for the *American Journal on Intellectual and Developmental Disabilities* and *Intellectual & Developmental Disabilities;* she is the North American Editor and Associate Editor of the international *Journal of Intellectual Disability Research*.

Dr. Blacher is the Founding Director of SEARCH, a Family Autism Resource Center newly established at UC Riverside. Dr. Blacher's research, which is longitudinal in nature, focuses on the family context of children and adolescents with and without developmental disabilities, including predictors of later psychopathology. She has published on family coping in Anglo and Latino families, and is currently studying the cultural context of autism and the transition to early schooling for children with autism (*Smooth Sailing*, funded by the Institute for Education Sciences).

She was recently appointed to the National Research Council of The National Academy of Sciences, and the Johnson & Johnson/Rosalynn Carter Institute Caregivers Program. As of February, 2002, she wrote a column for EP, *Exceptional Parent Magazine* (www.eparent.com). She is a Fellow of the American Association for the Advancement of Science (AAAS).

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William E. Haley, PhD, is a clinical psychologist and Professor in the School of Aging Studies at the University of South Florida. His research has focused on the problems faced by family caregivers of older adults with stroke, Alzheimer's disease, cancer, and terminal illness. He is currently on the Editorial Boards of four major journals in the field of gerontology, and is President-Elect of the Division of Adult Development and Aging of the American Psychological Association.

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David A. Mrazek, MD, joined Mayo Clinic in September of 2000 as Chair of the Department of Psychiatry and Psychology. His specialty is in the area of Child and Adolescent Psychiatry; however, his research interests and publications cover a broad range of psychiatric illnesses that occur in patients of all ages. Most recently, Dr. Mrazek has begun several new research initiatives in genomics. He has collaborated with other investigators in studying various links between genomic variability and psychiatric illnesses such as depression, bipolar illness, and attention deficit hyperactivity disorder. Mayo's Genomic Expression and Neuropsychiatric Evaluation (GENE) Unit is directed by Dr. Mrazek.

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Dr. Talley received the Outstanding Alumni Award from Indiana University and the Jack Bardon Distinguished Service Award from the Division of School Psychology of the American Psychological Association. She serves on the national board of the American Association of Caregiving Youth, the Indiana University School of Education Board of Visitors, and the Western Kentucky University National Alumni Advisory Board. Dr. Talley is Editor-in-Chief of the Springer CARE book series on diverse caregiving issues. Dr. Talley may be reached at 1906 College Heights Boulevard, GRH 3023, Bowling Green, KY 42101; by telephone at (270) 745-2780; or via e-mail at Ronda.Talley@wku.edu.

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Formerly the director of mental health services, crisis intervention and suicide prevention at the Los Angeles Unified School District (LAUSD), she is identified by the White House as one of the "pre-eminent experts in school crisis and recovery" and an "architect of school safety programs" by the Wall Street Journal. A frequent consultant to the US Department of Education and the Department of Defense (Educational Directorate/Pentagon and DoDEA/Department of Defense Dependent Schools), she has helped develop recovery programs for schools and train educators impacted by violence, school shootings, terrorism, and natural disasters in the United States, Canada, Israel, Japan, and China.

Dr. Wong served on the Institute of Medicine (IOM) Board on Neuroscience and Behavioral Health, which was charged with assessing national priorities and approaches to public health and medical practice, public policy, research, education, and training. She also worked on the IOM Committee which produced the publication: "Preparing for the Psychological Consequences of Terrorism".

She is one of the original developers of the Cognitive Behavioral Intervention for Trauma in Schools (CBITS) and Psychological First Aid: Listen, Protect Connect, Model and Teach. Both interventions have been implemented extensively in schools in the United States and in Asia.

In July 2011, Dr. Wong was appointed to a 3-year term to the Substance Abuse and Mental Health Services Administration (SAMHSA) National Advisory Council.

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Part I
Caregiving from Birth Through Adolescence

Chapter 1
Caregiving: A Developmental, Life-Long Perspective

Ronda C. Talley and Rhonda J.V. Montgomery

From the moment I was born, I have been learning to care. From the time I moved from my mother's womb, I felt care. There was a mother eager to see me and excited relatives in the hospital waiting room, those family caregivers who I would learn to know so well and who would learn to know me even better. There were professional caregivers, the doctor and nurses who were with us through delivery, birth, and the important aftercare that is given to a newborn infant. There was physical care, the cleaning and swaddling all new babies get and the food they receive, and there was emotional care, the touches, the strokes, the warm feelings of new-found baby-love that a new parent experiences. There was someone there who cared about me and counted to see if I had ten fingers and ten toes.

And that is how it started. Care was given to me and laid the foundation for a lifetime of giving back. In the early parts of our lives, we are the recipient of care that is unidirectionally given from mother to child. As we grow, we learn to express our feelings, to smile, to laugh, to cry when we want something, and to say "no!" These important steps help us challenge our environment and allow us to run to the secure base of our primary caregiver when in doubt about why lies ahead.

The findings and conclusions in this chapter are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

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While we are first learning to care, most of our needs are taken care of by others. Our father helps us stand up as we are learning to walk, our older sister gives us a bottle, and our grandmother helps us get dressed. Gradually, we are introduced to others outside the immediate family. Our next-door-neighbor brings their grandson over to see the new baby or to play. The babysitter is a new caregiver we are introduced to, and then we start day care. And so it goes as an ever-widening circle of new people populate our lives.

The individuals who come into our lives become our teachers. The care they give, the consideration they show, the kindnesses they perform are quietly, but powerfully embedded in our minds and our experiences; they model for us the ways care is shown. As we learn to hold our heads up, sit up, scoot, stand up, and walk, we are learning care in parallel form. As we develop physically, we are developing emotionally. As we become able to reach for care, we put ourselves in physically proximity to deliver a kiss or a hug. As we develop, we seek to please those who have cared for us by showing affection or doing things for them. If you have ever observed a kindergarten teacher with her class during the early morning greetings or the afternoon good-byes, you see unadulterated affection and a group of youngsters who will do most anything to please their teacher. The children are learning to care.

Most scholars do not consider the long-term nature of care, but rather focus on a specific age, such as old age, or a specific disability, such as cancer. Yet the most important care lessons in our lives are taught and given at every age and regardless of disabilities or other limitations. Care as a personal experience is continuously evolving. We get care, we learn care, we give care.

Care is also developmental. While the care process starts out in a one-way fashion, that is, baby gets all, it gradually evolves into a bi-directional, then multi-directional process that involves both the receipt of care and the delivery of care to others. While the primary caregiver, usually the mother, may be the child's first love, as they experience additional important individuals, such as father, brother, or grandfather, they are able to use the care lessons they first learned from mother, then shared with mother, to other significant persons with whom they come in frequent contact. Gradually, as the child grows, this expands to include friends of the family; children in the neighborhood; members of the church, synagogue, or mosque the family attends; schoolmates; long-distance relatives; and others in the community.

Caring: A Life-Long Process

As noted previously, care is a life-long process. Care begins before birth and ends after death. Our care begins while we are in our mother's womb, continues throughout our lifetime, and ends after our death. Pre-conception care for the developing life and care for the pregnant mother are hallmarks of life's beginnings. We care for the expectant child and mother, and our own care and our care for others continue throughout life; our loved ones care for us until they die, and we express our final care for them until they are put to rest. Care for us after death by a spouse or partner, daughter or son, other family member, or friend marks life's ending. Life begins with care and ends with care. Care, the giving and receiving of it, is one universal hallmark in every person's life. Caregiving is an experience of all humanity.

The foundations for a caring personality are learned early in life from our primary caregivers, usually our mothers and fathers. They provide care by feeding us, taking care our daily needs, making sure we are clean, taking us for medical and dental appointments, and providing us with stimulation to encourage our development. The primary caregiver is the first person with whom the infant learns reciprocity: An infant's smile will evoke one from the caregiver, reaching out will usually result in being picked up, and crying will bring someone to the infant's side. Parents, or other primary caregivers, teach us how to engage with them and with others. They are our first teachers of giving and receiving.

Others we encounter along life's journey also teach us about care, both through modeling and direct teaching by both family and non-family members. We see caring all around us as we grow to adulthood. Sometimes we do not call it by that name, but examples of care abound. Care is demonstrated daily and given by persons who surround and influence us: daycare workers; teachers and other school staff, such as counselors, school psychologists, principles, cafeteria workers, custodians, and bus drivers; religious leaders, such as ministers, rabbis, mullahs, or priests; athletic coaches for basketball, archery, swimming, football, skiing, skating, or other sports; academic coaches for the debate club, the Latin club, the National Honor Society, the chess club, or the bridge club; and leaders for groups such as Girl and Boy Scouts.

When you are an infant, your primary caregiver feeds and changes you, and provides stimulation. The caregiver provides for you in every way. At the end of life, we also have caregivers. These caregivers ensure that we are provided for, that we are fed, helped with personal care activities, taken to the doctor when needed, and provided with environments that keep our minds and bodies engaged as long as we live. This is life's circle of care: we begin as a recipient of care and end life in similar fashion. However, a great difference in the two is that throughout life, and at the end of life, we are capable of providing care and love to others.

This book emphasizes caregiving as a process that occurs across the life span. It begins with infant care, changes to meet the development needs of children and adolescents, and continues as we enter adulthood and mid-life. This process concludes with end-of-life care, including bereavement care. When we look at caregiving across the continuum of life, it becomes easy to see why it is an issue that involves all people, regardless of race, gender, socioeconomic status, disability, developmental level, or age. As noted in *The Multiple Dimensions of Caregiving and Disability*, a recent volume in the CARE book series, "Caregiving is an activity in which we will all engage at some time(s) in our lives" (Crews and Talley 2012).

Genesis of the Rosalynn Carter Institute Caregiving Book Series

The efforts to develop this book began in 2000, when Johnson & Johnson, an international health care business leader, and Dr. Ronda Talley, Executive Director of the Rosalynn Carter Institute for Caregiving, began discussions that lead to the development of the Johnson & Johnson/Rosalynn Carter Institute Caregivers Program. In the program, a Science to Practice component was created that allowed the Rosalynn Carter Institute to convene a series of 10 expert panels over a period of several years to address a wide variety of caregiving issues (Talley 2000). The result of the collaboration with expert panelists, plus the addition of a caregiving book by noted psychologist Seymour Sarason, has culminated in an 11-volume book series on caregiving issues and a series of pamphlets on various caregiving issues (i.e., Talley 2004). With Springer as our partner, we launched the book series in 2010. Thus far, six volumes have been made available to caregiving professionals and family caregivers. These include *The Multiple Dimensions of Caregiving and Disability; Rural Caregiving: Research, Practice, Education, and Policy; Caregiving for Individuals with Alzheimer's Disease; Caregiving and Cancer; Education and Training for Family Caregivers; and Centers for Endings.* This volume, *Caregiving Across the Life Span: Birth Through End-of-life Care*, marks the seventh series volume. Future volumes scheduled for print in 2013 include *The Challenges of Mental Health Caregiving; Multi-disciplinary, Coordinated Caregiving Across the Professions; Intergenerational Caregiving; and Building Community Caregiving Capacity.*

Definitions Used in this Volume

To define *caregiving*, we turned to several well-known caregiving researchers and advocacy groups. The National Family Caregivers Association (n.d.) defines caregiving as the necessary physical and mental health support to care for a family member. One description of range of other tasks that support the caregiver and care recipient. In this volume, we will use the terms *informal caregiver* and *family caregiver* interchangeably and employ the comprehensive NFCA definition of *family caregiver* to refer to caring relatives, friends, and neighbors of all ages across the life span (see *Intergenerational Caregiving*, this series).

Among the various descriptions of informal or family caregiving, one originally proposed by Amy Horowitz (1985) has been widely accepted. Horowitz proposed that informal care involves four dimensions: *direct care* (helping to dress, managing medications); *emotional care* (providing social support and encouragement); *mediation care* (negotiating with others on behalf of the care receiver); and *financial care* (through managing fiscal resources, including gifts or service purchases). The challenges of actually providing informal or family caregiving have been attributed to the level of intensity and physical intimacy required to provide care (Montgomery et al. 1985); the amount of burden, distress, and role strain that care engenders for the caregiver (Aneshensel et al. 1993; Berg-Weger et al. 2000; Seltzer and Li 2000); and the skill required to master care tasks (Schumacher et al. 2000).

Relatedly, the Administration on Aging (n.d.) defines a *caregiver* as "anyone who provides assistance to another in need." The National Alliance for Caregiving and the AARP (2004) define caregiving as caring for an adult family member or friend. However, most definitions of caregiving adopt a life span perspective that includes children and youth as both caregivers and care recipients.

More specifically, *family caregiver* is defined by the Health Plan of New York and NAC (n.d) as a person who cares for relatives and loved ones. Metlife and NAC (2006) expanded on this definition by specifying additional qualifiers, stating that a family caregiver is "a person who cares for relatives and loved ones who are frail, elderly, or who have a physical or mental disability." Similarly, the NFCA (n.d.) added that family caregivers provide a vast array of emotional, financial, nursing, social, homemaking, and other services on a daily or intermittent basis. The NFCA advocates for the term *family caregiver* to be defined broadly and to include friends and neighbors who assist with care by providing respite, running errands, or doing a

Throughout the book, we use the term *professional caregivers* to refer to paid care providers such as physicians, nurses, social workers, psychologists, case managers, hospice workers, home health aides, and many others. The designation as professional caregiver excludes family caregivers who may receive funds to provide care from new and emerging sources, such as the Medicaid Cash and Counseling Demonstration Program.

Contents and Organization of this Book

As noted previously, in *Caregiving Across the Life Span: Birth Through End-of-life Care*, we explore care from a development perspective. We believe that care can take different forms and follow different paths to the end of life, but the development of care and our ability to caregive is grounded in life's beginnings. We begin with a discussion of caregiving in infancy, move through care in childhood and youth to care in young and middle adulthood, and illuminate pathways of care. We conclude by considering the dynamics of care at life's end. In the first section, we address caregiving issues from birth through adolescence. Section two addresses caregiving from young adulthood through the end-of-life.

Caregiving in Birth Through Adolescence

Mrazek. In Chap. 2, David Mrazek explores *Caregiving in Early Childhood.* He notes that during this period, parenting and caregiving are traditionally linked since young children are completing dependent on parents or other adults in their immediate environment. Family forms the center of the caregiving process. In most cultures, Mrazek notes, women bear the primary caregiving responsibilities and are responsible for direct care that meets the young child's direct physical and psychological needs that lay the foundations for care and security. Mrazek explores the concepts of emotional availability, guidance and control, parental mental health, understanding of the young child's needs, and emotional commitment as critical variables in successful early childhood caregiving.

Blacher & Feinfield. In Chap. 3, Jan Blacher and Kristin Feinfield explore *Caregiving in Middle Childhood: Coping with Typical and Atypical Development.* In the chapter, the authors discuss core caregiving issues, practice considerations, and future research opportunities in providing care for the middle years children. They explore both normative caregiving and issues in providing care for families raising children with disabilities. The authors also begin to explore the school as a care setting and note services that school-aged children may receive in that environment.

Wong & Nadeem. In Chap. 4, *Responding to the Challenges of Preadolescence: Roles for Caregivers,* Marleen Wong and Erum Nadeem provide information on developmental caregiving milestones for children from ages of 9 through 12. At this time, when children begin to establish their identities as independent social beings outside the home setting, major caregiving challenges can emerge. These issues are particularly germane in light of the increasing importance of peer acceptance and pressure, more unsupervised time away from home and parents, and the ever-growing exposure to social and technological media during this critical developmental period. Wong and Nadeem explore the continuing importance of caregiving issues as the young child moves through preadolescence and prepares for the challenges of adolescence.

Bailey & Bradbury-Bailey. In Chap. 5, Deryl Bailey and Mary Bradbury-Bailey explore *Caregiving Across the Lifespan: Adolescence.* The authors note that adolescence can be divided into two age groups: early adolescence, which encompasses the years from 10 to 14, and mid-adolescence, which refers to children and youth adults from 14 to 18 years of age. Bailey and Bradbury-Bailey focus their chapter on the school as a caregiving environment and discuss school personnel as caregivers who are positioned to promote adolescents' intellectual growth, mental health, social connectedness, and physical development. In their chapter, the authors describe specific school programs to promote care at this critical developmental period. Research and policy implications are explored.

Caregiving in Adulthood

Givens & Givens. In Chap. 6, Charles and Barbara Given and their co-authors focus on early adult caregivers. *Caregivers in Early Adulthood: The Challenges* underscores the prevalence of women as caregivers and highlights the challenges that caregivers face as their relationship to the care recipient is transformed from one of adult child or spouse to a caregiver. In particular, they note the isolation, the role conflicts, added role responsibilities, and the common need to use a "trial and error" approach to acquiring necessary care skills. The authors provide important insights into the changing nature of the caregiving experience that is associated with fluctuations and change in the patient status. They describe a process that is linked to changes in the types and intensity of support that caregivers need as the patient's disease and problems progress.

Gonyea. In the next chapter, Judith Gonyea explores *Midlife, Multigenerational Bonds, and Caregiving.* She addresses common themes as she describes caregiving experienced by middle-aged adults, most of whom care for aging parents. After providing an overview of the demographic trends that have transformed family structures and functioning, she discusses the role conflicts that often emerge for caregivers in this stage of life. In particular, she explores the demands of caregiving in the context of work obligations and other familial obligations, which can include responsibilities for grandchildren. She gives special attention to the significant differences that are associated with gender, race, and income. Finally, Gonyea turns her attention to both public and organizational policies that could potentially reduce role conflicts and address the gender bias that is now inherent in public policies.

Montgomery & Kosloski. In *Pathways to a Caregiver Identity and Implications for Support Services*, Rhonda Montgomery and Carl Kosloski offer a theoretical model that has implications for practice and policy. Building upon the vast research on caregiving and interventions, they have drawn on both social and psychological literature to create a vision of the caregiving process. The model highlights the dyadic nature of the caregiving role and describes caregiving as a dynamic process wherein the caregiver oscillates between periods of identity change and identity maintenance. The model provides insights into the sources of caregiver stress and mechanisms for identifying interventions to effectively alleviate stress. After describing five phases of caregiving, Montgomery and Kosloski illustrate the way that the model can be used by providers to effectively target services to support family caregivers. Together, the chapters in Part II complete the portrait of caregiving across the life span.

Haley. Finally, in Chap. 9, William Haley provides a disturbing description of the experience of dying in America and addresses the special situation of caregivers who are attending to the needs of persons at the end of life. A significant emphasis of this chapter is on the grief and emotional work that takes place as the dyadic relationship is transformed from a familial relationship to a caregiver relationship. While emphasizing the fact that family members are often forced to do the work alone, the chapter also provides a glimmer of hope as Haley describes the many benefits of hospice. As a model for developing support services, hospice may be the beginning of an effective policy to support families.

References

Administration on Aging. (n.d.). *Resources: Common caregiving terms.* Retrieved from http://www.aoa.gov/prof/aoaprog/caregiver/careprof/progguidance/resources/caregiving_terms.asp

Aneshensel, C. S., Pearlin, L. I., & Schuler, R. H. (1993). Stress, role captivity, and the cessation of caregiving. *Journal of Health and Social Behavior, 34*(1), 54–70.

Berg-Weger, M., Rubio, D. M., & Tebb, S. S. (2000). Living with and caring for older family members: Issues related to caregiver well-being. *Journal of Gerontological Social Work, 33*, 47–62.

Crews, J. E., & Talley, R. C. (2012). *The multiple dimensions of caregiving and disability*. New York: Springer.

Health Plan of New York & National Alliance for Caregiving. (n.d.). *Care for the family caregiver: A place to start.* Retrieved from http://www.caregiving.org/pubs/brochures/CFC.pdf

Horowitz, A. (1985). Family caregiving to the frail elderly. In C. Eisdorfer (Ed.), *Annual Review of Gerontology and Geriatrics, 5*, 194–246.

Metlife & National Alliance for Caregiving. (2006). *2006 MetLife Foundation family caregiver awards program.* Retrieved from http://www.asaging.org/asav2/caregiver/index.cfm?CFID=12644792&CFTOKEN=19400852#definition

Montgomery, R. J. V., Gonyea, J. G., & Hooyman, N. R. (1985). Caregiving and the experience of subjective and objective burden. *Family Relations*, 19–25

National Alliance for Caregiving & American Association of Retired Persons. (2004). *Caregiving in the U.S.* Washington, DC: Author. Retrieved from http://www.caregiving.org/data/04finalreport.pdf

National Association of Area Agencies on Aging & Metlife. (2007). *The maturing of America: Getting communities on track for an aging population*. Washington, DC: Authors.

National Family Caregiver Association. (n.d.). *What is family caregiving?* Retrieved from http://www.thefamilycaregiver.org/what/what.cfm

Schumacher, K. L., Stewart, B. J., Archbold, P. G., Dodd, M. J., & Dibble, S. L. (2000). Family caregiving skill: Development of the concept. *Research in Nursing & Health, 23*, 191–203.

Seltzer, M. M., & Li, L. W. (2000). The dynamics of caregiving: Transitions during a three-year prospective study. *The Gerontologist, 40*, 165–178.

Talley, R. C. (Ed.). (2004). *Caring for yourself while caregiving across the life span* (RCI Caregiving Pamphlet Series: Twelve Tips for Caregivers). Americus, GA: Rosalynn Carter Institute for Caregiving. Retrieved from http://www.rci.gsw.edu/RCIBookStore/Manuals_and_Booklets_files/Lifespan.final.pdf

Talley, R. C. (2000). Proposal for development of the Johnson & Johnson/Rosalynn Carter Institute caregiving program. Americus, GA: Rosalynn Carter Institute for Caregiving.

Chapter 2
Caregiving in Early Childhood

David A. Mrazek

Early childhood usually refers to the years that begin when an infant starts to use language, develops a sense of autonomy, and is emotionally able to establish a sense of separateness from her mother. It is at the end of this development period that children develop the ability to reason logically and are usually ready to learn, to read, and understand arithmetic processes. During these years, young children have a quite idiosyncratic way of making sense of the world that Piaget described as "preoperational thinking." For practical purposes, early childhood usually refers to children between the ages 2 and 5, despite the reality that some children must begin school at six or seven without having achieved all of the skills that they will need to progress academically.

During early childhood, caregiving is traditionally linked with parenting. This is particularly true for young children who are completely dependent on parents and other adults. Thus, much of the caregiving that is received during early childhood takes place within the context of a family. Here, the definition of family varies from culture to culture. However, in virtually all cultures, women care for young children. Furthermore, in most cultures, it is the mother of the child who takes the most direct responsibility for meeting the physical needs of the children and providing the emotional security that is necessary for her children to develop normally.

With the development of more recent economic pressures, more mothers are returning to full employment shortly after the birth of their children. Consequently, an entirely new class of caregivers for young children has developed. This change in social expectations has led to a serious intellectual reconsideration of the essential qualities of interpersonal relatedness that are required to successfully rear a young child. Subsequently, considerable debate related to the appropriate time for women to place their young children in childcare has taken place as well as discussions

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regarding how to organize this important caregiving in order to insure a good developmental outcome (Belsky 1984, 2001, 2002; Scarr 1992, 1993).

A potentially more beneficial approach to providing care for young children is to conceptualize the caregiving process as a partnership (Clinton 1996). While most caregiving arrangements still require the mother of a child to take the primary responsibility for orchestrating the coordinated arrangements, many more people are involved in actually providing care for the child. With this shift in the role of a parent, some of the key aspects of the process of caring for young children come into focus as each component of caregiving is considered.

What Basic Caregiving Needs Do Young Children Have?

The early caregiving of a young child must include the development of an appropriate emotional relationship. It is absolutely critical that children receive appropriate nutrition, that they have adequate shelter, and that they receive good medical and dental care. However, while some children in America do suffer from poor nutrition, unstable homes, and inadequate health care, much of the intellectual debate concerning caregiving in early childhood is focused on what aspects of childcare are required beyond basic survival considerations.

The concept of the “good enough” parent has a long history. Dr. D. W. Winnicott coined the term “good enough mother” years ago to describe women who did not have severe problematic parenting or overt psychiatric illness (Winnicott 1957). The “good enough” mother has adequate intelligence, insight, and relationship building skills to be able to provide satisfactory care for her young child. Within the context of this care, a normal child can be expected to make good developmental progress. The central question that arises in assessing young parents is “What are the characteristics that distinguish mothers who are not “good enough?” Research studies in child development have identified five important parameters (Mrazek et al. 1995).

Emotional Availability

The first key dimension is insuring appropriate emotional availability. This is sometimes described as providing sufficient emotional warmth. It is this parental quality that seems to be necessary for children to develop a sense of being loved and “cared for.” Children who do not experience this basic sense of interpersonal connectedness have been shown to have later negative psychological outcomes. Early studies looking at the parenting behavior of primates demonstrated that well-nourished baby monkeys developed severe disturbances of behavior if they were deprived of warm and reciprocal relationships with a mothering object (Ruppenthal et al. 1976). Furthermore, the classic studies of children raised in institutions addressed this issue. While many studies of institutions have been completed, Dr. Rene Spitz provided some of the most convincing descriptions of disturbed children in his classic investigations of “hospitalism” and “anaclitic depression” (Spitz 1946). More recently, prominent child psychiatrists, including Sir Michael Rutter (O’Connor et al. 2000) and Charles Zeanah (Smyke et al. 2002; Zeanah et al. 2002), have identified similar serious cognitive and behavioral deficits in children raised in Romanian orphanages. Young children who do not experience early emotional relationships seem to be unable to develop adequate relationships in later life.

Guidance and Control

A second key dimension of early caregiving is the provision of guidance and control. Historically, Baumrind (1971) described three styles of caregiving for parents of young children. One extreme style was described as the “authoritarian” form of parenting which was characterized by the principle that children must be directed to comply with parental expectations. The other extreme form of parenting she described was “permissive” parenting. Permissive parents place a high premium on allowing their children to have a maximal range of freedom of behavioral expression. The third category of parenting was labeled “authoritative” and this form of parenting was associated with better development outcomes. “Authoritative” parents provided direction, but they also gave their children guidance within the context of an empathic relationship that allowed more gratification of the impulses and desires of their children. In summary, the best parenting style provides guidance in a sensitive and supportive manner.

Parental Mental Health

The third key dimension related to adequate parenting is parental mental health. Parents with serious psychiatric disorders may experience intervals of illness when their ability to care for their children is impaired as a consequence of their psychiatric symptoms. Many studies have demonstrated that children who have even one psychotic parent are at increased risk for the development of psychopathology, despite the important consideration that the negative behaviors of one parent can be largely compensated by supportive care provided by the other parent. However, if both parents are psychiatrically impaired, there is a high degree of likelihood that the development of their children will be atypical (Rutter 1966). More recent studies have focused on maternal depression and demonstrated that the children of depressed women are at increased risk for developing a mood disorder. In recent years, new strategies have been created that were designed to prevent the negative implications of severe maternal depression (Beardslee 2002). One complication in the estimation of the degree to which the caregiving problems of psychiatrically impaired parents are linked to increased risk of their children developing these disorders is the obvious confound these children have inherited an increased genetic vulnerability for psychopathology as well as having experienced less adequate caregiving. The child of a mother with severe schizophrenia has a high likelihood of carrying several susceptibility genes for the illness as well as having an increased probability of experiencing a less contingent and responsive early emotional relationship with her mother.

Young Children's Needs

The fourth key dimension of early caregiving is related to parents achieving a basic understanding of the physical and emotional needs of their young children. While "maternal instincts" have been clearly demonstrated, there are many aspects of caregiving that must be learned in order to successfully raise a young child. Understanding the importance of immunizations and the need for consistency in child care cannot be achieved by simply relying on instinctual awareness. Similarly, understanding the developmental capacities of young children requires a parent to acquire a contextual understanding of what is normal and what is not. From the perspective of the child mental health clinician, one of the most frequently asked questions that is posed by young mothers continues to be, "Is my child's behavior normal?" Often the answer can be quite complex.

Emotional Commitment

The fifth key dimension of early caregiving is that the parents of a young child must have sufficient parental emotional commitment to spend adequate time to care of their child. While this can be a sensitive issue to address directly, it is critical to establish that at least one parent is committed to meeting the basic needs of their child. Children require not only quality time, but also a sufficient quantity of time with their caregiver. There must be some person in the life of a child who can provide them with a sense of direction and the assurance that they are safe and secure. Parents who do not spend an adequate amount of time with their children are faced with the reality that their children may well develop problems in forming reciprocal and rewarding relationships.

How Well Are Young Children Cared For?

It is quite difficult to provide a straightforward evidence-based answer to this important question. There are many lucky children who receive warm contingent parenting and go on to have successful experiences in kindergarten and beyond. Similarly, there is the sober reality that child abuse exists as a persistent problem and that it involves not only physical abuse, but also the sexual misuse of children, demoralizing emotional abuse, and the neglect of basic needs (Children's Defense Fund [CDF] 2005).

Being able to answer this question based on valid measurement of caregiving would be a major scientific step forward. A first step towards this goal would be developing a consensus on the range of parenting abilities that must be measured. A next step would be ascertaining the epidemiological distribution of these appropriate parenting behaviors and skills. Unfortunately, children who are doing "reasonably well" are rarely the focus of any systematic level of assessment or follow-up. Rather, it is those children who are clearly in major distress who become the focus of studies and interventions.

An undeniable reality is that there is a strong link between social class and access to resources. In affluent communities, parents with conflicting emotional demands or persistent interpersonal difficulties are financially able to purchase appropriate caregiving for their children. As a result, they are able to spare their children some of the negative effects that can result from disruptive breakdowns in caregiving during these early years. In contrast, most parents struggling in underserved communities have few personal resources and cannot afford alternative childcare. In families with inadequate resources, failures in parenting become the primary responsibility of the extended family. In the worst case scenario, when severe breakdowns occur within a family system, an overextended social service network is challenged to provide surrogate caregiving. It is rarely adequate and all too often proves to be pathogenic.

While the concepts of "child abuse" and "child protection" are relatively new, the study of the epidemiology of child abuse provides an important perspective on the extent of serious breakdowns that exists in the care of young children. In affluent communities, well-organized and vigilant child protection teams are usually available. Consequently, intervention can occur early in the development of a problematic parent/child relationship. Children are evaluated by health care professionals as well as having opportunities to participate in early, well-organized educational and community programs. In these more affluent communities, child protection teams have a low threshold for disturbance. A nursery school teacher may identify a child that she perceives has an insecure attachment and is excessively fearful and subsequently is able to request help for the family. Similarly, overt hypersexual behavior in young children will be noted and acted upon by daycare staff and nursery school teachers.

In contrast, in the heart of impoverished city communities, child protection teams must face an almost impossible challenge. Many young children are without consistent caretakers and the incidence of identified overt abuse is very high. Unfortunately, there are few resources available to address these caregiving problems. Specifically, it is well known that the foster care programs in most inner cities are inadequate and that there is high risk of an insufficient level of protection. Consequently, children are returned to high risk families because there are no alternatives. An ironic paradox is the regular documentation of physical and sexual abuse that occurs within foster homes that were selected to protect children.

One valid concern is that the care of underserved children must be both culturally sensitive and appropriate. It is not adequate to simply provide food and a safe environment for children. In addition to survival considerations, the cultural needs of children must be understood in order that these children will be able to relate to their own families and other members of their neighborhood. It is also critical that value judgments be culturally neutral and focus on the needs of the children as opposed to establishing preconceived expectations of a dominant culture.

In considering failures in caregiving that occur during early childhood, it has been repeatedly noted that the tangible rewards for looking after young children remain very low. Foster parents are often allotted inadequate financial support for taking care of young children, and it is well recognized that the compensation for daycare workers is among the lowest of any service category. The irony of this valuation of childcare is that by being unable to attract committed and competent caregivers, the perpetuation of a class of uncared for young children is guaranteed.

Educational Programs for Parents

There has been a broad attempt to provide parent training to provide young and disadvantaged parents with a better skills to care for their children. Some evidence-based studies have demonstrated that successful programs exist. The best of these programs continue to expand and their results are promising (Webster-Stratton 1990; Webster-Stratton and Hammond 1997; Wolchik et al. 2002). However, many clinicians do not have access to programs that are sufficiently intensive to be able to make a real difference for children who are at high risk for emotional or behavioral problems. In the majority of these more limited parenting programs, there is little effort to make a careful analysis of the underlying problems these young parents are experiencing and which ultimately interfere with their ability to sensitively care for their own children. Furthermore, it is only the very most dysfunctional parents who are regularly referred to parent training programs which may consist of as few as six to eight group sessions. It is hard to imagine that interventions of this intensity can be sufficient to provide troubled parents with the skill sets that are required to care for difficult and disruptive young children.

Research Implications to Improve Caregiving

Despite the recognition that many young families lack interpersonal support, optimism persists that an appropriate investment in young children can make a difference. In that regard, there are a number of promising studies related to prevention of more negative outcomes. An early example was the Perry project, which has some reported positive outcomes even twenty years after the implementation of the intervention. Even more encouraging has been the work of David

Olds (Eckenrode et al. 2000; Olds et al. 1997). He has shown that a carefully designed home visitation intervention can improve parental behavior and the outcomes for young children. This home visitation is currently expected to be widely implemented given that its effectiveness has been demonstrated. Recent work has clarified that the Olds home visitation strategy requires highly trained professionals to provide the intervention. Specifically, skilled nurses have consistently been able to achieve the best long-term outcomes for children and parents. In contrast, lay visitors have not been able to achieve the same degree of improvement. These home visitation programs have been successful in a wide range of geographic communities that have included families with considerable variation in their cultural experiences.

Why Should We Develop Caregiving Programs for Young Children?

In many ways, the answer to this question is self-evident. Young children must be cared for. They simply are unable to take care of themselves. Furthermore, we know that to achieve long-term developmental success, it is critical to establish good interpersonal relationships during the first years of life. When one examines the large number of young children who have been demonstrated to be at risk across the country (CDF 2005), it is disingenuous to deny that a dramatic unmet need exists. Given the importance of emotionally stable children for our future, it is difficult to explain the absence of more aggressive strategies to help young children. The problem is not new and this paradoxical apathy has persisted for many decades (Hersh 1979). The essential question for Americans to face is, "Why does a country, with more resources than any other country in the world, invest so little in the care of their young children when they are in obvious distress?" There is no satisfying answer. One possible hypothesis is that the decision makers still do not appreciate that the "long-term" cost of ignoring this problem is enormous (Mrazek 2001). This cost includes not only billions of dollars spent to control and manage delinquent teenagers and young adults, but also the lost productivity of so many potentially able young adults.

A Public Health Example

A very clear example of one serious health problem that can be best addressed at the stage of early childhood is obesity. Current figures suggest a steady and unremitting increase in the frequency of obese children at all ages (Epstein et al. 1998). However, good data suggests that a particularly critical time for the development of the behaviors associated with ongoing obesity occurs during the early years between two and five years of age. Interestingly, birth weight does not predict later obesity. In contrast, obesity at two years of age strongly predicts obesity at five years. Furthermore, obesity at five years of age is even more highly predictive of teenage obesity. The magnitude of these associations suggests that some biological processes become activated during these early years. Once activated, this new metabolic pattern leads to a lifetime of excessive eating and the maintenance of dangerously excessive weight. Genetic factors place certain children at extremely high risk for obesity, but environmental interventions have been shown to have good outcomes if initiated systematically during the early child years. The irony of the problem is magnified by the fact that minority populations, who are at particularly high risk for the development of obesity, are often less effectively engaged in public health initiatives. While obesity in young children is not seen as problematic in some cultures, the maintenance of traditional values that support overfeeding young children can have severe negative consequences. While a plump three-year-old may have been viewed as a status symbol in a culture where resources were scarce, the same child in the United States will be at much higher risk for diabetes, hypertension, and heart disease as well as suffering from the damaging effects of social rejection by peers.

A Mental Health Example

Depression is the mental illness that is currently responsible for the greatest level of disability throughout the world. If current trends continue, depression may become the number one international public health concern within thirty years (Kleinman 2001). In the face of these alarming predictions, we have now established that depression is a biological illness and that there are strong genetic vulnerabilities that place children at increased risk for problems in maintaining appropriate affect. Professionals have gone beyond simply documenting the frequency of depression in young children and have developed strategies for helping families to deal with this problem which often begins in the first years of life. Dr. William Beardslee, in his recent book, provides a comprehensible plan for how to “come out of the darkness” (Beardslee 2002). While knowledge of genetic vulnerability is increasing dramatically and new interventions are being developed, the problems associated with depression are rapidly growing more pervasive. Evidence of this reality is found in public health statistics that reveal that suicide is now the second most common cause of death among teenagers in America.

What Should Be Done?

Caregiving must become a higher priority during the early childhood years. The consequences of ignoring this imperative need will be both very expensive and morally wrong. Much of the future of a young child is shaped during these years.

Many of the opportunities that are missed during this period can never be regained. Ideally, a national agenda to insure more practical research designed to identify and correct early problems with caregiving during this time period could avert this crisis. With a greater appreciation of the efficiency of appropriate interventions to improve outcomes, policy can be developed to provide desperately needed support for compromised caregivers who are faced with the overwhelming challenges of providing adequate care for their young children.

References

Baumrind, D. (1971). Current patterns of parental authority. *Developmental Psychology Monograph, 4*(1), 1–103.

Beardslee, W. R. (2002). *Out of the darkened room*. Boston: Little, Brown and Company.

Belsky, J. (1984). The determinants of parenting: A process model. *Child Development, 55*, 83–96.

Belsky, J. (2001). Emanuel Miller Lecture: Developmental risks (still) associated with early child care. *Journal of Child Psychology and Psychiatry, 42*(7), 845–859.

Belsky, J. (2002). Quantity counts: Amount of child care and children's socioemotional development. *Developmental and Behavioral Pediatrics, 23*(3), 167–170.

Children's Defense Fund. (2005). *Child abuse and neglect fact sheet.* Retrieved from http://www.childrensdefense.org/site/DocServer/factsheet0805.pdf?docID=397.

Clinton, H. R. (1996). *It takes a village*. New York: Simon & Schuster.

Eckenrode, J., Ganzel, B., Henderson, C. R., Smith, E., Olds, D. L., Powers, J., et al. (2000). Preventing child abuse and neglect with a program of nurse home visitation: The limiting effects of domestic violence. *Journal of the American Medical Association, 284*(11), 1385–1391.

Epstein, L. H., Myers, M. D., Raynor, H. A., & Saelens, B. E. (1998). Treatment of pediatric obesity. *Pediatrics, 101*(3), 554–570.

Hersh, S. P. (1979). Child psychiatry and the national government. In I. N. Berlin & L. A. Stone (Eds.), *Basic handbook of child psychiatry* (pp. 466–472). New York: Basic Books, Inc.

Kleinman, A. (2001). Cross-cultural psychiatry: A psychiatric perspective on global change. *Harvard Review of Psychiatry, 9*(1), 46–47.

Mrazek, D. (2001). A crisis in child psychiatric service delivery: Why hasn't the piper been paid? *Mayo Clinic Procedures, 76*, 1078–1080.

Mrazek, D. A., Mrazek, P., & Klinnert, M. (1995). Clinical assessment of parenting. *Journal of the American Academy of Child and Adolescent Psychiatry, 34*(3), 272–282.

O'Connor, T. G., Rutter, M., & The English and Romanian Adoptees Study Team. (2000). Attachment disorder behavior following early severe deprivation: Extension and longitudinal follow-up. *Journal of the American Academy of Child and Adolescent Psychiatry, 39*(6), 703–712.

Olds, D., Eckenrode, J., Henderson, C., Kitzman, H., Powers, J., Cole, R., et al. (1997). Long-term effects of home visitation on maternal life course and child abuse and neglect: Fifteen-year follow-up of a randomized trial. *Journal of the American Medical Association, 278*(8), 637–643.

Ruppenthal, G. C., Arling, G. L., Harlow, H. F., Sackett, G. P., & Suomi, S. J. (1976). A 10-year perspective of motherless-mother monkey behavior. *Journal of Abnormal Psychology, 85*(4), 341–349.

Rutter, M. L. (1966). *Children of sick parents*. London: Oxford University Press.

Scarr, S. (1992). Developmental theories for the 1900s: Development and individual differences. *Child Development, 63*, 1–19.

Scarr, S. (1993). Biological and cultural diversity: The legacy of Darwin for development. *Child Development, 64*, 1333–1353.

Smyke, A. T., Dumitrescu, A., & Zeanah, C. H. (2002). Attachment disturbances in young children. I The continuum of caretaking casualty. *Journal of the American Academy of Child and Adolescent Psychiatry, 41*(8), 972–982.

Spitz, R. A. (1946). Anaclitic depression: An inquiry into the genesis of psychiatric conditions in early childhood, II. In A. Freud, E. Glover, P. Greenacre, et al. (Eds.), *The psychoanalytic study of the child* (pp. 313–342). New York: International Universities Press.

Webster-Stratton, C. (1990). Enhancing the effectiveness of self-administered videotape parent training for families with conduct-problem children. *Journal of Abnormal Child Psychology, 18*(5), 479–492.

Webster-Stratton, C., & Hammond, M. (1997). Treating children with early-onset conduct problems: a comparison of child and parent training programs. *Journal of Consulting and Clinical Psychology, 65*(1), 93–109.

Winnicott, D. W. (1957). *The child and the family*. New York: Basic Books.

Wolchik, S. A., Sandler, I. N., Millsap, R. E., Plummer, B. A., Greene, S. M., Anderson, E. R., et al. (2002). Six-year follow-up of preventive interventions for children of divorce. *Journal of the American Medical Association, 288*(15), 1874–1881.

Zeanah, C. H., Smyke, A. T., & Dumitrescu, A. (2002). Attachment disturbances in young children. II: Indiscriminate behavior and institutional care. *Journal of the American Academy of Child and Adolescent Psychiatry, 41*(8), 983–989.

Chapter 3
Caregiving in Middle Childhood: Coping with Typical and Atypical Development

Jan Blacher and Kristin Abbott Feinfield

Middle childhood. Few scholars have described what it feels like better than A. A. Milne, in his essay, “In Which Pooh Goes Visiting and Gets Into a Tight Place.” Winnie-the-Pooh ate way, way too much honey and became stuck while climbing through the hole to leave Rabbit’s house.
“Oh, help! said Pooh. “I’d better go back.
“Oh, bother!” said Pooh. “I shall have to go on.”

It’s tough being “caught in the middle….” We focus here on caregiving during middle childhood, the period sandwiched between early childhood and adolescence—roughly ages 7–12 years. Cole and Cole (1993) placed the onset of middle childhood as the point when children begin to lose their baby teeth, and thereafter, adults begin to assign them tasks that require more personal responsibility. Freud, in his psychodynamic framework, termed these years the “latency stage,” in which, essentially, nothing of psychological interest happens. Developmental psychologists, however, have written a great deal about the changes in cognitive development, social relationships, and schooling demands that characterize middle childhood.

There has been relatively little attention, however, to the impact of the middle childhood period on parents—parenting challenges, dilemmas, and caregiving needs. Should parents try to push Winnie-the-Pooh through the hole or let him struggle through himself? Among the voluminous child care books, parents can find much to say about caregiving in early childhood and adolescence, but far less about middle childhood. One of the most cited frameworks of family life cycle stages

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DOI 10.1007/978-1-4614-5553-0_3,

(Carter and McGoldrick 1989) has six basic stages: (1) leaving home; single young adults; (2) marriage, the new couple; (3) families with young children; (4) families with adolescents; (5) launching children and moving on; and (6) families in later life. There is no listed stage of "middle childhood."

Parenting children in middle childhood needs to be more fully considered and, indeed, reconsidered in the early twenty-first century. There are critical emerging abilities, needs, developmental changes, and transitional events that take place in middle childhood and that have profound implications for families. Developmentally speaking, children are experiencing at a younger age what previous generations reserved for adolescence—the challenges for themselves and their parents of sex, drugs, and other issues of moral development.

The purpose of this chapter is to highlight some of the major caregiving needs in middle childhood and to identify core issues as the subject of future research and practice. We first focus on caregiving in middle childhood in the normative case. We then expand the discussion to consider some additional challenges faced by families of children with disabilities, particularly those with severe disabilities. We close with policy recommendations for meeting caregiving challenges in the middle childhood years.

Caregiving: "Typical" Challenges of Middle Childhood

In most developmental textbooks, middle childhood is sandwiched in between early childhood and adolescence, and seems to represent a transition from being a child to being a pre-teen or early adolescent. In order to address caregiving needs during this transitional time, it is important to first understand that both the child and the parents experience individual changes, as well as react to changes in each other.

Because developmental shifts in children's perceptual, cognitive, and social development in turn may alter parental attitudes and behaviors and/or the nature of the adults' own developmentally relevant choices, such as work or career commitment, this clearly argues for the recognition of two developmental trajectories—a child developmental course and an adult developmental sequence (Parke 1995, p. 54).

Child Changes

During middle childhood, children experience developmental changes in a variety of areas, including cognitive, social/emotional, physical, and behavioral. In addition to undergoing maturational changes, children must confront the challenges associated with entry into a more structured school setting that includes increased exposure to peers and non-kin adults. In turn, parents face new demands as they try to both facilitate and respond appropriately to their children's changing abilities and needs. Refer to Table 3.1 for a more detailed description of the expected child changes that take place during this time period.

Table 3.1 Middle childhood (7–12 years) developmental tasks; parental and teacher challenges; discrepancies between normative and atypical development

Description	Parental challenges	Teacher challenges	Discrepancies
Developmental	Steady growth is experienced, with an average gain of 8 pounds in weight and 2–3 inches in height.	Expenditures for clothing and shoes increase. Issues surface concerning "brand-name" clothes, and the appropriateness of clothing.	Be aware of rejected or neglected students who fall outside the norm, either physically or with regard to clothing.
Physical	Nutritional requirements increase from an average 1,600 calories per day (preschool age) to an average 2,400 calories per day.	Food expenses increase, as well as concerns regarding adequate nutrition.	Be aware of the effects of under- and malnutrition upon learning.
	Internal eating control is replaced by external control.	Model and encourage healthy eating habits, appropriate food usage, healthy body image, and adequate exercise.	Teach food basics and healthy eating habits. Encourage positive body image. Incorporate movement into academic lessons.
	Dentition: An average loss of 5 teeth per year, with approximately 24 permanent teeth by age 12.	Continue appropriate dental care. Expenses may increase due to orthodontia.	Be alert to poor hygiene and lack of appropriate dental care. Understand the effects of poor dental health on learning.
	Vision: Approximately 25 % of children 8–12 years old will require glasses for myopia.	Expenses increase for vision correction. Finances may dictate the type of correction.	Recognize vision difficulties. Be willing to make classroom modifications, as necessary.
	Gross motor skills increase through play activity, while fine motor skills are facilitated through activities, such as handwriting. Generally, girls gain fine motor mastery earlier than boys, while boys gain gross motor mastery earlier than girls.	Provide opportunities for girls and boys to practice both types of skills without the pressure of performance expectations. Understand the gender differences in motor skill development, and sincerely praise all efforts at improvement.	Be cognizant of gender differences in motor skill development. Provide opportunities for girls and boys to practice both types of skills without performance expectations. Avoid gender attributions for success or failure.
	Increased physical independence is evidenced by activities, such as biking, skate boarding, roller-skating, etc.	Expenses are engendered for appropriate safety and protective equipment. Model appropriate safety behavior. Do not overestimate the child's judgment abilities.	Teach safety strategies in the classroom, i.e., fire, bicycle, street crossing, etc. Plan lessons to foster growth in estimation, inference, and judgment abilities.
	Participating in organized sports is increased or initiated.	Model and encourage good sportsmanship, and use of safety equipment. Provide opportunities to practice.	Take advantage of increased cognitive development and social cooperation by encouraging student participation in the development of classroom rules and goals.

(continued)

Table 3.1 (continued)

Description	Parental challenges	Teacher challenges	Discrepancies
Cognitive	Use of concrete operational thinking is evident. Mental operations are used to problem solve, though inhibited By rule-oriented thinking. Perspective taking and reversible thinking emerge. There is limited use of abstract reasoning, with occasional use of formal operational thinking.	Recognize the "rule bound" nature of thinking. Stress the importance of logical thinking skills. Encourage use of perspective taking when working out family problems, or in issues of discipline. Scaffold attempts at abstract thought and the use of formal operational thinking.	Be logical and thorough when explaining rules and procedures for both academic work and expected behaviors. Provide opportunities to discuss stories or situations that encourage perspective taking. Systematically include opportunities to engage in abstract thought.
	Memory strategies are increasingly matched to task, though rehearsal remains the primary strategy. Working memory increases.	Provide opportunities though household tasks to learn organization and categorization. Provide opportunities to use increased working memory.	Teach and provide opportunities to apply a variety of memory strategies.
	Increasing self-reflection leads to emergent self-regulation. Ability to be a peripheral participant in adult activities increases.	Provide opportunities for self-regulation, within limits, by allowing participation in family decision-making. Provide opportunities for inclusion in appropriate adult conversations and activities.	Allow more autonomy in decision making within the classroom, i.e., choice of reading material, choices regarding assignments, etc.
	Shows increased understanding of comparatives and temporals, though mathematical skills lack ability to understand abstracts.	Incorporate the use of comparative and temporal questions in everyday conversations about familiar objects and situations.	Structure discussions to include comparative and temporal judgments, i.e., What comes before/after? Which is larger/smaller?
	View of ability/intelligence evolves from an incremental to an entity view.	Encourage effort. Avoid specific ability attributions. Praise effort and ability in combination.	Emphasize mastery, not performance goals. Encourage and reward effort and participation. Praise effort and ability together.
	Gender differences begin to emerge in reading, language skills, math, and mental rotation.	Play games and do chores that allow practice in all ability areas for both genders. Avoid gender attributions for either success or failure.	Avoid gender bias by teaching all skills without expectations of success based upon gender.
	Enjoyment is found in rhymes and word games. Narratives have evolved to have a plot and cause-and-effect. The ability to engage in a sustained, concrete conversation is greatly enhanced.	Read aloud rhyming verse, and encourage participation in rhyming and word games. Encourage storytelling, and ask specific questions to enhance plot and cause-and-effect skills. Provide opportunities to allow inclusion in appropriate adult conversations	In class discussions, explore double meanings, word games, and rhyming poetry. Provide opportunities to write and share short stories with classmates. Provide guided discussions on concrete subjects, such as world events, as appropriate.
	Most pronunciation is correct by 8 years old. Persistent articulation problems become apparent.	Remain aware of persistence speech problems. Decisions must be made regarding consultation with a professional. Concerns could surface about finances, insurance, and prognosis.	Be aware of persistent articulation difficulties. Consult with parents and other appropriate professionals.
	Decoding skills, sight vocabulary, and reading fluency increase. Silent reading emerges. Printed facts are accepted at face value.	Encourage reading skills through family activities, i.e., reading recipes, maps, street signs, etc. Make silent reading a family activity. Encourage critical thinking skills by asking "why" questions.	Teach word "families." Provide regular opportunities for silent reading. Have available quality children's novels. In reading groups, focus on interpretation, drawing inferences, and speculation.
	Greater sociocultural knowledge leads to increased comprehension.	Discuss current events, explore cultural diversity, and value opinions.	Explore a variety of social and cultural environments. Promote and reinforce open discussion.

Social/ Emotional	Ability to regulate emotions increases.	Model appropriate emotional regulation.	Discuss emotions through the feelings of characters in books. Model appropriate emotional behaviors and responses.
	Self-perception is increasingly based upon the perceptions of others.	Provide genuine praise for both effort and ability in numerous areas.	Genuinely praise effort and ability in numerous areas.
	Self-esteem becomes differentiated rather than global, and tends to decline throughout elementary school.	Provide a positive, affectionate home atmosphere with firm rules, but be open to discussion. Be involved in family and school activities. Promote realistic, yet optimistic, views of different types of abilities.	Avoid rewarding only “the best”; find ways to reward participation, effort, and improvement. Be open to discussions about rules. Value opinions. Be flexible.
	Critical life events can undermine well-being and security, and affect school achievement, conduct, and adjustment.	Provide support and comfort. Treat as serious issues. Provide alternate role model, if a parent is absent. Professional counseling may be considered.	Provide opportunities for general class discussions of critical life events. Provide support. Be sensitive to individual situations.
	Peer relationships increase in importance. More time is spent playing with peers without direct adult presence.	Provide safe environment for play with “shadow” supervision.	Provide opportunities for vigorous, safe play. Encourage perspective taking to solve disputes.
	Prosocial actions, empathy for unknown others, cooperation and the ability to compromise increase with age.	Model prosocial and altruistic behavior. Provide opportunities for family-volunteerism. Use cooperation and compromise within the family to work out difficulties.	Use dispositional praise, i.e., praise that links the behavior to the altruistic disposition. Discuss empathy through story characters. Allow negotiation within groups.
	The knowledge of social conventions and appropriate behavior increases. Shame and guilt for misdeeds also increases.	Role-play appropriate behaviors for novel situations. Explain issues surrounding misdeeds in an effort to promote moral development.	Discuss the importance of the class rules, and the consequences for breaking them. Create time for individual discussion regarding misdeeds.
	The ability to delay gratification increases.	Provide opportunities for long-term goal planning. Provide encouragement.	Introduce long-range planning. Have students devise a plan to reach the goal.
	Social comparison becomes more important. Performance goals emerge alongside mastery goals.	Praise individual progress, not comparative progress. Always praise for knowledge gained and progress made rather than grades received.	Focus on individual, not comparative progress. Stress intrinsic value of learning, and downplay the importance of grad.

Adapted from Kail, R. V. (2002). Children. Upper Saddle River, NJ: Prentice Hall. and McDevitt, T. M. & Ormrod, J. E. (2002). Child Development and Education. Upper Saddle River, NJ: Prentice Hall. Additional text by Willayne T. Martinez. University of California, Riverside, 2002.

Caregiver Changes: Evaluation of Identity and Progress Toward Goals

According to Bigner (1994), most parents are in their late 20s or early 30s when their first child enters middle childhood (though with rapidly developing advances in the technology surrounding infertility, this age range is likely to increase). Bigner conceptualizes this period of adulthood as a transitional time in which adults evaluate their level of success in meeting previously established goals. Parents may feel dissatisfied with the choices they've made and begin to re-evaluate their personal identity and life goals. At this time, parents often experience an increasing desire to expand upon or change current work roles, careers, and other areas of personal growth. For example, women may choose to re-enter the work force or if they're already employed, they may increase their work hours. Any change in the family system is generally stressful and will most likely require family adaptations in roles, responsibilities, and/or interaction patterns in order to restore homeostasis (see Dual Income and Single Parents sections in this chapter for a full description of how these changes may impact family well-being).

Caregiving Challenges and Needs

As children and caregivers experience changes, caregivers face new demands and must adopt new strategies and roles. How do caregivers facilitate these changes and how do these changes impact caregivers? This concept of reciprocal interaction recognizes the influence that each individual has over the other. Until recently, socialization was conceptualized from a unidirectional perspective with the parents directly or indirectly teaching their children. The contribution children make to the parents' development has been given minimal attention in the literature (Bigner 1994). Yet parents are both recipients of, and contributors to, their children's developing changes. These changes during middle childhood shape the primary goals and tasks associated with parenting during this time period. At any stage of childhood, it is important for parents to maintain some stability while being flexible enough to accommodate their children's emerging skills, needs, and abilities. This juggling act is particularly complex and difficult to maintain during the middle childhood years (Collins et al. 1995). Parents need help deciding when it is best to push Pooh forward toward independence, pull him back for support, or give him the space to figure it out for himself.

Based on a review of the literature, the major caregiving challenges and needs associated with middle childhood can be broken down into four major categories: involvement with the child, educational services and resources, support for parent and child, and school involvement.

Need for Involvement with Child

During the early childhood years, parent involvement is critical, and often a mandated component of preschool or early education programs. While far less has been written about parent involvement during the middle childhood years, it is necessary to facilitate gradual shifting of parental responsibility to the internalization of child responsibility. In response to children's emerging cognitive skills (e.g., improved planning and problem-solving abilities), parents can provide their children with increasing opportunities for group negotiation, problem-solving, and greater autonomy. For example, parents can involve their children in the selection of age-appropriate chores and/or community volunteer programs that will foster social responsibility within a supportive context.

Supervision/Monitoring. Although monitoring is necessary for responsive caregiving, the intensity and frequency of the monitoring needs to be adapted based on the child's emerging abilities and developmental needs. As children enter the middle childhood stage, they develop a greater capacity for self-regulation, increased knowledge of social norms, a growing sense of social responsibility, and an improved ability to carry out goal-directed plans (Collins et al. 1995; McDevitt and Ormrod 2002). Caregivers are faced with the challenge of finding a balance between too much monitoring (which may inhibit growing autonomy) and too little monitoring (which may lead to externalizing behavior problems) (Barnard and Martell 1995). Caregivers need to continue to monitor the home and school setting, teach safety, and provide social support, while at the same time, both expect and facilitate the development of self-management, independence, and responsibility. Through a process of co-regulation, parents retain some control, while simultaneously providing their children with experiences in self-regulation and social responsibility.

Parents must strengthen in their children the abilities that will allow them to monitor their own behavior, to adopt acceptable standards of good and bad behavior, to avoid undue risks, and to know when they need parental support or guidance. Children must be willing to inform parents of their whereabouts, activities, and problems so that parents can mediate and guide when necessary; parents must keep informed about events occurring outside their presence and must coordinate agendas that link the daily activities of parents and child (Maccoby 1984, pp. 191–192).

Parents need to monitor their children's exposure and facilitate open discussions about their children's self-identity and curiosity about sexuality. Middle schoolers are exposed to sexuality through a variety of sources, ranging from their own physical changes to the media hype surrounding sexy teen idols. Today it is not uncommon for young female singers to emphasize their sex appeal by flaunting belly rings, thongs, and cleavage. Through MTV, magazines, and movies, pre-teens are increasingly exposed to inappropriate and impossible standards regarding their physical appearance (i.e., large breasts, flat stomach, and sexy clothes). Pre-teens are still developing a sense of identity and may turn to sexualized teen idols as role-models; parents may provide their children access to other, more age-appropriate role models.

During these years, many mothers return to the workplace, and it is not uncommon for children to take care of themselves after school. There are contradictory findings concerning the impact of self-care on children's well-being during the middle childhood years. These differences may be due to variations in how self-care is defined, as well as confounding factors (e.g., the quality of the parent–child relationship, work status, and the atmosphere of the home environment) (Colan et al. 1994). Coleman et al. (1990) recommend an evaluation of the child (e.g., maturity level, history of responsible behavior), the home (e.g., materials to help guide the child), and the neighborhood (e.g., safety, closeness of community services) in determining the potential risks and/or benefits of self-care for any given family. Parents should set up consistent contact times and provide children with clear expectations for how their children should inform them of their whereabouts (Collins et al. 1995).

Parents may benefit from community or employee programs aimed at teaching how to individually evaluate their children's readiness for self-care, as well as how to help prepare their children for self-care in the future. Colan et al. (1994) reported studies in which working parents of school-age "latch-key" children were more likely to have decreased productivity and absences relative to their childless coworkers. These authors conducted a needs assessment of two large companies and found that most of the employees used some form of non-parental care and/or self-care (with more than one-third of the subjects using self-care). Additionally, relative to parents who made pro-active arrangements for their self-care situations, somewhat unprepared parents had more concerns about their children's well-being (e.g., safety, substance abuse, inability to do homework, negative peer influences).

Based on this needs assessment and prior studies, Colan et al. (1994) developed a comprehensive family program aimed at helping parents evaluate their children's readiness for self-care and prepare their children for time at home alone. This program consisted of 6 workshops focused on family communication, safety in the home and neighborhood, decision-making, and substance abuse. The information was conveyed through lectures, videotapes, discussion groups, educational fact sheets, and a list of resources. This program was "user-friendly," as it took place after work, involved all members of the family (as either participants or recipients of child care), and provided dinner. Additionally, the program was developmentally sensitive; the curriculum was based on the needs, values, and emerging skills of school-age children (e.g., the authors recognized the importance of peers, children's increased decision-making abilities, and children's potential increased exposure and/or curiosity regarding drugs and alcohol). Preliminary results included high attendance and satisfaction. However, outcomes regarding the experimental versus control group are not yet available. There is a need for further program evaluation studies, as well as research aimed at identifying what constellation of factors make a family more or less ready for self-care.

Relationship. When children begin school, they spend more time interacting with their peers and non-kin adults relative to their parents and family members (Collins et al. 1995). Despite this decrease in the quantity of time spent together, the quality of the parent–child relationship continues to play a significant role in children's development. For example, parental responsiveness relates to children's self-esteem, competence, and social responsibility (Collins et al.). Additionally, the nature and style of these interactions can positively or negatively influence children's subsequent adjustment. Authoritative and child-centered parenting (characterized by warmth, responsiveness, and an appropriate level of control) is positively linked to a range of positive outcomes "that attain salience in middle childhood and that are predictive of successful adaptation in later life. These include peer acceptance, school success, competence in self-care, and competence and responsibility in a broad array of tasks" (Collins et al., pp. 82–83).

In contrast, parenting that is based primarily on parents' needs rather than age-appropriate child needs is correlated with less positive outcomes on these variables, and may put the child at risk for long-term dysfunction. Similar to earlier developmental periods, effective parenting consists of supportive, accepting, child-centered interactions that are responsive to the child's developing needs and abilities. When parents do not provide immediate and appropriate responses to their children's behavior, they may be inhibiting their children's understanding of cause and effect relations, an important cognitive task for the middle-childhood years (Barnard and Martell 1995). Bigner (1994) recommends several major areas that parents should emphasize in their interactions during this period. These include highlighting strengths rather than weaknesses, and supporting children in their development of self-control. Further research is needed to clarify correlates of developmental change during the elementary school years and how these might contribute to a successful transition to adolescence (Feerick et al. 2002).

Discipline. Discipline strategies that were effective with preschoolers may no longer work with 7- to 12-year-old children. Through elementary school and early middle school, children have acquired a more sophisticated set of social and cognitive skills, including: a sense of responsibility; increased knowledge of appropriate behavior; an appreciation for cooperation, compromise, and rules; increased ability for systematic problem-solving; and a capacity for perspective-taking (Collins et al. 1995; Kail 2002; McDevitt and Ormrod 2002). Parents need to be responsive to these developmental changes and choose disciplinary techniques that promote further development of these skills, as well as foster the child's self-esteem and internalization of rules.

When applied appropriately, rules provide children with a sense of security, as well as a framework by which they can learn to internalize their own structure and become more self-directed. However, when parents apply rules in a critical, judgmental, and inflexible fashion without regard to the child's developmental needs, children's self-esteem may be damaged (Bigner 1994; Kail 2002). In order to be effective, discipline should be positive and reasonable, and rules need to be applied within a nurturing framework (Bigner). Clarke and Dawson (1989) report a variety of parenting behaviors that provide both structure and nurturance, including showing approval and positive reinforcement for the child's efforts to acquire new skills, facilitating cause-and-effect reasoning, developing a flexible framework that includes both negotiable and non-negotiable rules, taking responsibility for actions, fostering the child's development of personal interests, and reminding the child that s/he is loved even during disagreements.

Need for Educational Services and Resources

Although the style of parent–child interactions continues to play an important role in children's long-term adjustment, very few educational programs for parents of school-aged children specifically focus on fostering a positive relationship (Barclay and Houts 1995). The parent training programs for this age group that are reported in the research literature are usually quite narrow, typically targeting children with behavior problems and focusing on behavior management skills. This may reflect both the needs that draw parents to such programs and the clinical orientation of the professionals who develop them. It is likely, however, that parents of children who do not have serious behavior problems could benefit from parent programs that provide information on current and future developmental changes, in their children and also in themselves. Based on a family career perspective (Bigner 1994), parent education programs should address developmental changes in family systems resulting from changes in roles (e.g., parent returning to work) and developmental changes in children. Armed with appropriate expectations, parents may be better able to plan ahead and adapt their parenting skills based on the developing needs and abilities within themselves and their children.

Relative to the information available to expecting and/or new mothers, there is a lack of information readily available to help families through the difficult transition to middle childhood (Barclay and Houts 1995). Additionally, the limited information often focuses on child changes rather than a more expansive view that includes caregivers' needs and family well-being. In addition to learning what to expect from children's developmental changes, parents need to be able to recognize the implications of child changes in relation to their own personal identity, mental health, social support, confidence, stress, relationship with their child, and style of discipline. Parents should be supported in learning how to anticipate and overcome potential stressors so that they can enjoy and celebrate the rewards of caregiving.

For example, the distribution of age-paced newsletters is an efficient, convenient, and relatively inexpensive mode of providing information to parents. Cudback et al. (1985) evaluated the effectiveness of distributing different sets of age-paced newsletters to expectant mothers and parents of young children (i.e., up to 4 years of age). The newsletters were generally distributed monthly and provided timely information on child development, gave suggestions for baby care, and highlighted the importance of meeting parents' own needs as individuals and couples. The researchers received 880 evaluation questionnaires back across 10 states in America. These parents, who were primarily middle-class, married, and fairly well educated, reported gains in their child-related knowledge, parenting confidence, relationship with child, and fulfillment of individual needs. It seems reasonable that this focus on developmental changes and parents' needs would be useful to all parents during major transitional periods (e.g., when children start school). These findings raise a number of additional follow-up questions: Would this mode of distributing information be as effective with parents of lower socio-economic status, or with those whose first language is not English (even if translations were provided)? Would these results generalize to a range of families varying in composition (e.g., single parents, dual income earners)? Does this improvement in parent knowledge and confidence translate to objective changes in parents' behaviors and relationships with their children?

Available parent training programs need to take a more generalized, transactional approach. Just as child variables (e.g., temperament, developmental changes) impact parents, adult variables (e.g., spousal conflict, depression, single-parent status) impact children. Researchers have increased the effectiveness of parent training programs by addressing adults' issues in addition to teaching behavior management strategies (Taylor and Biglan 1998). Recognizing parents' other needs and providing them with tools that help them function as healthy adults can enhance their abilities to be effective parents. This understanding that parents experience many roles beyond being a parent (e.g., spouse, employee) needs to be incorporated into treatment development and outcome studies. This is of particular importance when the parents have a child with a developmental disability, because the disability often becomes a defining characteristic for them.

Taylor and Biglan (1998) recommend a variety of procedures for increasing the number of families who ultimately receive help. First, we need to develop better strategies for identifying which families could benefit and then help them to overcome obstacles that may interfere with their participation (e.g., evening programs with child care and light dinners to accommodate a range of family needs and increase the likelihood of consistent attendance). Second, we need to identify a range of "channels" through which we can reach families (e.g., media, health care providers, schools, and religious organizations). Third, therapists, researchers, and policy makers need to work together to develop and refine empirically validated treatments, to identify cost-effective ways to meet family's needs, and to facilitate collaboration amongst individual groups within communities.

Need for Social Support

Support for caregivers. In addition to parent education, caregivers may benefit from support that helps them successfully balance a variety of roles. "New stages of development present new challenges. How does the mother deal with the demands of child care, work, and time for her own physical and emotional well-being?… The role demands the capacity to be emotionally available, alert to needs, and responsive to behavior" (Barnard and Martell 1995, p. 22). Researchers have defined and measured social support in a number of different ways, including emotional comfort (e.g., conveying empathy and encouragement), instrumental help (e.g., providing concrete services that decrease role overload, such as child care or housekeeping), informational support (e.g., sharing knowledge and advice), and social activities (e.g., engaging in leisure activities with another).

Spousal support, too, is important, and has been shown to both mediate and moderate stress and marital adjustment, particularly in families who have children at-risk for behavior disorders. For example, Suarez and Baker (1997) found low levels of stress or negative impact on parenting in the presence of high spousal support, and higher stress in the presence of low spousal support. Similarly, Dennis et al. (2003) found that in Latino families, more general social support mediated the relationship between maternal depression and child internalizing behavior problems. In other words, mothers with higher levels of emotional support had children with lower levels of internalizing problems overall, although it is important to note that depression was associated with increases in child problems even for these supported mothers. On the other hand, mothers with low levels of emotional support had children with higher levels of internalizing problems, regardless of their own reported level of depression.

There are a number of child care services available to parents of school-aged children. Recreational, educational, and skill-building community programs provide parents with instrumental support and give children the opportunity to develop and practice more advanced socialization skills. However, in order for these resources to be effective, families must have the know-how and the opportunity to make use of community settings such as schools, doctor offices, and neighborhood churches (Edgar 1989). Edgar recommends empowering parents by teaching them how to take advantage of services. Researchers need to continue to delineate what specific factors may facilitate or interfere with caregivers seeking and receiving social support, and ask whether or not these factors differ for mothers and fathers. Additionally, we need to identify what specific types of support are most helpful during which periods of developmental changes in families.

Support for children. During the middle childhood period, the peer group becomes an increasingly important socialization agent. Between the ages of 7 and 11, children spend over 40% of their time in peer interactions (Hartup 1983). Unlike adult-child relationships, peer interactions offer equal status relationships that require negotiation and collaborative skills. During middle childhood, the peer group serves a variety of functions, including providing companionship, identifying sex-roles, and creating a context for children to develop social competencies and learn from each other (e.g., following rules, understanding consequences) (Bigner 1994).

Children's acceptance into a peer group has major implications for their current and future well-being. Negative peer status is a powerful predictor of long-term poor adjustment; rejected children are at greater risk for dropping out of school and ultimately engaging in antisocial behaviors (Parker and Asher 1987; Pettit and

Clawson 1996). Additionally, peer rejection plays a role in subsequent externalizing behavior problems, even when controlling for stability in externalizing behavior (Laird et al. 2001).

Fortunately, parents can play many roles in developing their children's social skills and peer relationships. Researchers have identified several ways in which parents *deliberately* influence children's social competency. First, parents can provide opportunities for peer contact, including play dates and after-school group activities. Second, parents can provide concrete advice and guidance about appropriate interaction skills. During middle childhood, parents should encourage the development of emerging social cognitive skills such as empathy, perspective-taking, problem-solving, conflict resolution, and awareness of social cues.

Based on a review of the literature, Pettit and Clawson (1996) identified several *unintentional* ways that stylistic qualities in the parent–child interaction may influence peer competence. Authoritative parenting (i.e., consistent control presented in an affectionate and respectful manner), use of induction and avoidance of harsh and punitive methods, responsive and synchronous parent–child interactions, attachment security, and parental warmth are all linked to social competence. Additionally, they report some evidence that children learn and practice play skills during playful parent–child exchanges.

Engels et al. (2002) found evidence suggesting that parenting factors have both a direct influence on young adolescents' peer relations, as well as an indirect influence via social skills development. Further research is needed in order to clarify the specific ways in which social competence is transmitted across different stages of development.

Need for Involvement with School

The child's entry into a more structured educational system at 5 or 6 years of age is a major transition for families. As children begin the middle childhood period, they engage in an increased number of interactions with both peers and non kin adults. By the time they graduate from high school, children in the United States have accumulated over 15,000 hours of school time (Collins et al. 1995). There is increasing recognition that parents need to have a school presence, and more so in early and middle childhood. In elementary school, parents' involvement with schools and homework is positively associated with children's school performance (e.g., achievement, grades), with low-income minority children showing the most benefit (Collins et al. 1995.; Conroy and Mayer 1994). Further research needs to identify the specific pathways by which parents directly and indirectly impact their children's academic success (Feerick et al. 2002).

Conroy and Mayer (1994) conducted a needs assessment to evaluate parents' interest in school-related parenting programs. Although their response rate was only 36%, most (79%) of responding parents were interested. The vast majority reported that school was the most convenient location for academic support resources. The authors described a parent resource library consisting of books, audio, videotapes, newspapers, magazines, and brochures emphasizing children's issues and services. Also, they discussed the value of distributing parenting materials via newsletters, parent meetings, and individual conferences.

Based on a follow-up needs assessment, Conroy and Mayer (1994) developed a monthly parent education program centered around the highest ranking areas: Helping Your Child Succeed in School, Helping Your Child with Reading, Self-Esteem, Nurturing Your Child's Gifts and Talents, Discipline, and The Strong-Willed Child. Parents seemed to recognize the developmental importance of (a) helping their children develop school-related skills, (b) fostering a positive sense of self, and (c) finding more effective strategies for dealing with problem behaviors. Qualitative data indicated parent satisfaction and involvement. A weekly parent education group was also developed, and the researchers reported that a majority of parents reported improved child and parenting behaviors. Today's computer and internet technology can increase access to all of these resources.

Given the preliminary success of these programs, it seems reasonable to pursue larger-scale, tightly controlled parent involvement studies with control groups and more objective assessments of parent and child behavior change. Also, follow-up studies should include a more expansive outcome evaluation: What is the differential impact of the weekly groups versus the monthly groups? How do school-related parent education programs impact parents' subsequent involvement with their children's schools and study skills? What is the most effective component to these programs (e.g., support from other parents? Parenting advice from "experts"? Increased comfort level and sense of approachability via exposure to the school environment and counselors? Do these programs impact parents' well-being and confidence?) Additionally, a number of questions remain regarding the high rate (64%) of non-responders: What characteristics differentiate responders from non-responders? Does this high percentage accurately reflect a minimal need for these services or are there obstacles that may be interfering with non-responders' receptivity? What role does culture and/or socioeconomic status play in parents' interest and/or ability to participate in these programs?

Cooper et al. (1994) studied the educational goals of low-income Mexican American and European American parents for their school-age children (third through seventh grade). Although both groups expressed high educational aspirations, many expressed vulnerabilities that could hinder the attainment of such goals: Some lacked information regarding college and financial aid applications, as well as the extent of schooling required for certain occupations. Many Mexican-American parents reported fears about drugs, violence, and sex hazards in junior high school, and they expressed concerns about advanced education creating distance between their children and their family/community. Many European American parents were skeptical about the effectiveness of the schools and doubted their own ability to provide the emotional and/or financial resources to help their children achieve these hopes. Although both groups of parents had high educational aspirations for their children, they experienced different types of obstacles, concerns, and fears. Academic outreach and parent education programs need to be developed and assessed within a culturally sensitive framework so that we can build links between school-related goals and a range of resources necessary to achieve them**.**

Caregiving in the Twenty-First Century

In order to fully understand the issues pertaining to caregiver needs and family well-being, researchers have broadened the context. Dual income families and single parents are, in the twenty-first century, two dramatic changes in family roles and structure from the early and mid-twentieth century. How are these likely to impact child development, family relationships, and caregiving capacity during middle childhood?

Dual income. The number of working mothers has dramatically increased since the 1970s (Grolnick and Gurland 2002). It is estimated that 75% of mothers of school-age children are employed (Behrman 1996). Gottfried et al. (1999) summarized a variety of studies and made the following conclusion: "These data suggest that parental occupation is associated with an academic and intellectual achievement orientation in the home, as well as the provision of experiences to foster such achievements" (p. 22). Additionally, children of dual-income families have less rigid stereotypes about women and men (Bigner 1994; Lamb 1999). Gottfried et al. cited numerous studies indicating that women's employment status did not have any direct negative effects on children's development; however, aspects of women's employment impacted proximal variables (i.e., family relationships and the home environment), which in turn, impacted child development. Thus, in evaluating the impact of dual-earner families, it is important to examine family processes, role overload, and the quality of the home environment, rather than a dichotomous analysis of work status (Bigner 1994; Gottfried et al. 1999).

Along with the increase in maternal employment, there has been a corresponding increase in paternal involvement in child rearing. This finding has been replicated in families of varying ethnicities and socioeconomic status (Gottfried et al. 1999). However, fathers continue to be less involved than mothers (Lamb 1999; Silverstein 2002), and mothers continue to take responsibility for household work, despite both parents being employed (Gottfried et al.). Also, even when fathers share equally in routine child care, mothers still tend to perform the executive functions (e.g., scheduling play dates, making doctor appointments, initiating interactions with the school).

Although employment for married women tends to increase their self-esteem and sense of competence (Hoffman 1986), it is not too surprising that they also tend to experience role overload. Bigner (1994) defines this as "the pressures experienced in attempting to perform several competing roles effectively and simultaneously, such as being a provider, a parent, a volunteer, and so on" (p. 309). Trying to balance the demands of work and home can have negative implications for women's health and well-being, as well as for their relationships with other family members. Women experiencing role overload may engage in parent–child relationships that are more rejecting and punishing, which in turn, may lead to increased child behavior problems

(Bigner). Reppetti and Wood (1997) explored the relationship between work-related stress and the quality of parent–child relationships. They reported that on days when mothers experienced high stress at work, they were more behaviorally and emotionally withdrawn from their children. According to a family life career perspective, marriage satisfaction tends to be at its lowest point during the school-age years when parents begin assessing their own happiness and progress toward goals. Bigner reported a number of studies suggesting that role overload, which is commonly experienced during this period, may make a major contribution to parents' marital dissatisfaction. Working mothers of school-aged childhood may benefit from programs focused on how to (a) alleviate stress, (b) find and use support systems, and (c) engage in positive, rewarding interactions with their significant others.

Single parents. Approximately 50% of American children will experience being raised by only one parent (Lamb 1999). These single parents (usually mothers) are more likely to experience social isolation and to lack financial and emotional support. Simons and Johnson (1996) reported that divorced mothers, relative to married mothers, engaged in a range of ineffective parenting strategies (e.g., used high criticism and coercion, inconsistent and harsh discipline, and low monitoring). Given that school-age children are particularly sensitive to negative feedback, caregivers should be encouraged to develop social-cognitive skills via reasoning rather than coercion, and require an appropriate level of supervision. These divorced mothers and their children may be at heightened risk during the middle childhood years.

Caregiving: Intellectual Disability and Further Challenges of Middle Childhood

When a child has a disability, middle childhood brings the aforementioned challenges to the child and family—and then some. We will focus here on children with mental retardation, now more often referred to as intellectual or cognitive disability, and pay special attention to those with severe impairment. Some of the issues raised, however, are applicable to families coping with a wider range of learning, behavioral, and physical disabilities.

Intellectual disability is a far-reaching problem. Approximately 20 million persons, or 7%, of the US general population of 281 million currently experience significant cognitive disabilities. In the year 2000, 1.1 million of these were school children (Braddock 2001). The impact of children with disabilities on their family, and on their parents' ability to provide caregiving during the middle school years, can be profound. Yet the study of caregiving has focused little on children with atypical development.

Curiously, even within the field of mental retardation/developmental disabilities, the study of parents and the family and their role in caregiving has been of relatively recent interest. In a published monograph on families and mental retardation, the authors reviewed the entire literature on families published in the American Association on

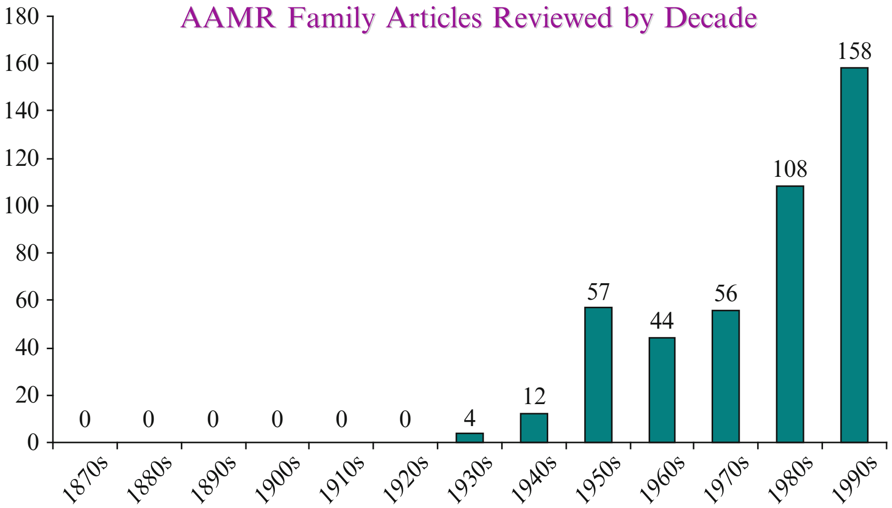

Fig. 3.1 AAMR family articles reviewed by decade

Mental Retardation's journals from 1896 to 2002 (Blacher and Baker 2002). The graph shown in Fig. 3.1 indicates the number of family articles published by decade, and it is obvious that for a long time the family was neglected. In large part, this was because parents were believed to be part of the cause of mental retardation (MR) and therefore absent from discussions of its treatment and caregiving concerns.

We will consider some of the special caregiving issues during middle childhood for such families. In addition to the literature, we will draw from our two decade-long program of family research known as the University of California Riverside (UCR) Families Project. Funded by NICHD (Grant HD 21324) since 1982, the UC Riverside Families Project has studied over 600 families. We've followed 100 of these families from the time their children were preschoolers, through middle childhood, adolescence, and now into young adulthood. We have learned that no single time period dominates over the life-course of the individual child or family (Hetherington and Baltes 1988). Family well-being and caregiving demands evolve over time…what happens at one stage obviously is influenced by earlier stages and, in turn, influences later ones (Seltzer and Ryff 1994). We will consider some of the major caregiving challenges outlined above with reference to families with intellectual disability.

Caregiver changes. We noted above that in the normative case, middle childhood is a transitional time for parents, a time when they reassess their life goals and perhaps set out in new directions. This "stage" notion does not comfortably map onto the special case of disability, however, as parents reassess life goals earlier and yet, in some ways, remain frozen in time. These "exceptional parents" may be forced to think about their child's future as early as grade school, with today's pressures on special educators to plan for what kind of environment in which each given child

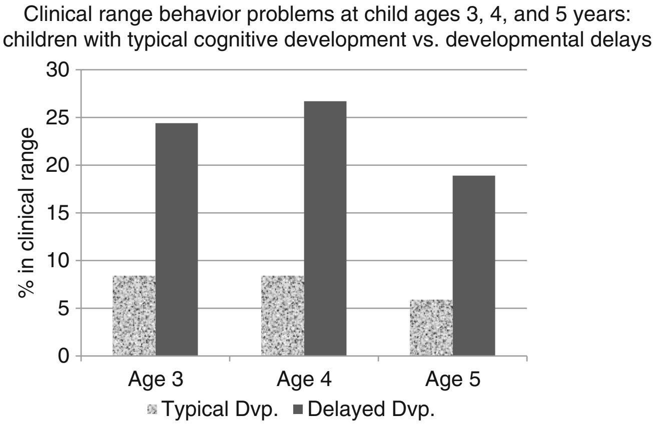

Fig. 3.2 Clinical range behavior problems at age 3 and 4 years: children without and with delays

with an intellectual disability will function, and what kinds of skills he/she needs to survive there. Exceptional parents may never settle comfortably into a real "middle age period" themselves. They may be "out of sync" with their own peers. Those who have very disabled children with severe mental retardation may always be dealing with a preschooler or even an infant, developmentally speaking.

Need for involvement with child and educational intervention. Almost by necessity, parents of children with special needs, especially those with intellectual disability (ID), are highly involved with their child's life, both at home and at school. They often need to learn behavior management and teaching skills to help the child fit in with family routines at home. In addition, a large number of children with ID have concomitant behavior disorders, which requires more vigilance and training on the part of parents.

Indeed, children with ID are at heightened risk for behavior disorders, a situation known as dual diagnosis. We know that even as early as age 3, children with developmental delays present behavioral challenges to their parents above and beyond the challenges expected from the typical counterparts. This is shown clearly in our own data from The Collaborative Family Study, a multi-site (UC Riverside, UCLA, and Penn State) investigation of the onset of behavior disorders and/or psychiatric diagnoses in young children. Figure 3.2 shows the percentage of children whose behavior problems were in the clinical range on the Child Behavior Check list at ages 3, 4 and 5 years. The light bars represent mothers scores for typically developing (TD) children. The dark gray bars represent children with delays. Three to four times as many of them are already scoring in the clinical range for diagnosable behavior problems. This is consistent with findings published in (Baker, Blacher, Crnic & Edelbrock 2002) and (Baker, McIntyre, Blacher et al. 2003).

The continuing "daily hassles" presented to parents as they try to rear such children can also alter the family climate. Furthermore, behavior problems that begin early often continue, with ever increasing intensity. In the absence of intervention, particularly for parents, behavior problems such as aggression, inattention, or even self-injury can dominate the child's interactions during middle childhood and the school years.

Need for involvement with school. Some degree of school involvement is almost unavoidable for parents of children with special needs. Federal legislation mandates annual program planning and efforts on the part of schools to involve parents in the process. Moreover, the need for two-way communication, involvement in planning, and sharing in teaching is ongoing, not waning through middle childhood as with typically developing children. One "school-related" issue that is unique to parents of children with special needs is out-of-home placement. Parents of children who have severe or profound developmental delay realize that the non-normative possibility of out-of-home placement looms as an ever-present reality.

Out of home placement, or "premature launching," involves a transfer of day-to-day caregiving from the biological parents to a paid care provider. While the number of parents that experience premature launching of their child is small, it is a very salient experience. Some have written that the entrance to school (around age 6) is a risk period for placement (Suelzle and Keenan 1981), though today placement more often happens in adolescence or young adulthood, more consistent with the normative launching phase as identified by Carter and McGoldrick (1989).

We have measured parents' views about placing their child on a 6-point scale, where a "1" is "never think about it" and a "6" is already placed (Blacher 1990; Hanneman and Blacher 1998). Across six waves of interviews over about 14 years, we have monitored a progressive decrease in the "1" ratings—each time the percentage of families considering placement or having placed increased.

After placement, though, the old image of "out of sight, out of mind" is no longer accurate. In fact, our studies have shown that even when a child no longer lives in the family home, parents are quite involved, undertaking a variety of caregiving activities, such as: visitations to the residential facility or group home or taking the child home for the weekend; phone calls; or involvement in administrative or overseer roles, by serving on Boards or committees for their child's residence. Indeed, our studies of families following placement have indicated that, on balance, parents report that the new caregiving arrangements are beneficial for the child, the parents, and the family (Blacher and Baker 2002; Blacher et al. 1999).

Parent well-being. We considered the influence of maternal employment and single parenthood on parent well-being, a care responsibility that is only exacerbated by raising a child with disabilities. In 1959, Mrs. Murray (who identified herself on the original article only by her husband's name) pointed out six caregiving concerns for parents of children with ID that are no less salient to today's cohort of parents. Two of those pertain directies to the challenges of caregiving: burden of care imposed by having a child with intellectual disabilities and the lifetime of caregiving responsibility experienced by most parents. While the phrase "burden of care" doesn't recognize the positive contributions that children with retardation can make to their families (Blacher and Hatton 2001), there is no doubt that parents of children with disabilities experience extra caregiving demands required for day-to-day management and control of maladaptive behaviors.

We have been interested in how burden of care and out-of-home placement vary with culture. Our studies of Latino mothers highlight some of the cultural uniqueness. For example, we do not see evidence of any "premature launching" in these families.

Yet while these families keep the child with a disability at home, there appears to be a strong impact of their child with disabilities on mothers' experience of burden of care and of coping. Consider, for example, symptoms of depression. A score of 16 or greater on the Center for Epidemiological Studies Depression Scale (or CES-D) indicates depression (Radloff 1977). Although we found higher depression in Latino mothers of typical children, relative to the normative sample for the CES-D, we found markedly higher depression when Latino mothers had a child with ID (Blacher et al. 1997). That is, the Latina mothers in our study who had children with ID reported stress uniquely due to the child with ID, above and beyond the stress of being poor, recently immigrated, and often without partner. In fact, the reported rate of depressive symptomatology in our sample of 148 Latina mothers was 49%, raising serious mental health concerns for both the mothers and their children (Blacher et al. 1997). Mothers scoring in the risk range on the CES-D also reported more negative feelings about parenting their child with ID. Caregiving challenges for these mothers could likely be reduced if they had access to services to meet their physical and mental health needs, programs to reduce stress directly or indirectly related to the child with mental retardation, and more contact with family and professionals who could supply support.

Future Needs and Directions

There are some generally universal caregiving challenges in middle childhood that confront parents engaging in rearing *typical* or *atypical* children. We mention four here.

Need for Parent Education

Relative to the infancy and adolescent periods, there is a lack of educational resources available to parents of children during middle childhood. This is true for parents of typically developing children without behavior problems, as well as for parents whose children are in special education. Parents of school-aged children are challenged to provide a stable and consistent environment, while being flexible enough to accommodate their children's changing needs, abilities, and, in the case of the atypical child, possible severe behavioral or learning challenges. It is important for caregivers to provide structure and rules within a responsive, child-centered, nurturing context. Parents may benefit from resources that convey: (a) the importance of the parent–child relationship; (b) expected child and parent changes; (c) the impact of the parent on the child and vice versa; (d) how to be responsive to the child's and their own changing needs and abilities; (e) potential stressors, obstacles, and conflicts during middle childhood; and (f) how and where to seek support. Parent education programs should provide parents with effective parenting strategies, in addition to addressing obstacles that may interfere with successful implementation.

Recommendations. Develop and make widely available various modes of delivering information, including written materials, computer access, and group sessions. Therapists, researchers, and policy makers need to work together to develop and evaluate such programs. Caregivers need to have available resources concerning the expected child and caregiver changes during this period, as well as the transactional nature of these changes (i.e., child changes impact the caregiver and caregiver changes impact the child).

Need for More Respite

In "typical" families, the need for babysitting or respite is reduced during the middle childhood period. Children become more independent and can be left alone for longer periods of time. On the other hand, when there is a child with a developmental disability, respite services become more difficult to get and are more needed, for parents to maintain their own relationship, and for some families, to provide quality parenting for their other, typically developing children.

Recommendation. Provide respite or "relief" to parents during this stage, before the stress of caregiving and behavioral crises with the child precipitate premature launching.

Support Services for Parents

Caregivers of school-aged children need emotional, instrumental, informational, and social support for themselves. Additionally, caregivers need to recognize the significance of a positive peer group for their children, and understand the direct and indirect ways in which they can facilitate the development of age-appropriate social skills. Yet studies have indicated that support services for parents drop off to nearly nothing, after the intensity of early childhood. In most states, support shifts from state agencies to the public schools at this age. This transition is often not smooth, and parents get caught in the middle, unable to find the supports they need. Parents who attend support groups are often able, and enabled, to better advocate for their child's needs, whether they are age-appropriate needs or specialized ones pertaining to a developmental disability.

Recommendation. Develop programs and/or groups that connect parents in middle childhood to other parents and to professionals. Schools could take the lead in instituting and supporting such programs.

Need for School Involvement

Parents' involvement in schools is positively associated with children's school success. Parental involvement is mandated by law for children with disabilities.

However, parents of typical children often wonder how or when to best become involved. The majority of school-aged children's mothers are employed; therefore, parents must juggle work demands, teacher conferences, and parent meetings, as well as find time to help their children develop effective study skills.

Recommendations. Schools need to develop and publicize a series of ways that parents can be meaningfully involved in their child's education, with consideration for cultural, socioeconomic, and employment influences on parent availability. How about recommendations for businesses with working parents?

Attention to Social Policy and Research

What becomes apparent as we consider caregiving in both typical and atypical cases is that much about middle childhood caregiving is still not well understood. This period does not draw the attention of research funders (and thus of researchers!) compared to the seemingly more compelling periods of infancy, early childhood, and adolescence. Yet, as we have seen, the middle childhood period is more than a bridge between two compelling developmental stages. It is a time of crucial cognitive, emotional, and behavioral changes.

Recommendations for Policy

Policy makers should support the development of programs in general that help alleviate caregiving stressors and provide support for caregivers trying to balance work and family demands. Two specific recommendations are to support: (1) quality and available after-school child-care programs for working families; and (2) changes in workplace policies, attitudes, and benefits. Businesses should encourage increased involvement of fathers as well as mothers in caregiving of all children, typical or atypical.

Recommendations for Research

Future research should take a broader approach to studying caregiving and middle childhood by going beyond a basic understanding of children's developmental changes. We need to recognize that both parents and children experience changes in needs, roles, abilities, and goals, and that changes in one individual impact the other individual. This transactional approach will lead to a richer understanding of what caregivers need in order to be effective and satisfied when working with their middle age child.

In addition, researchers need to study caregiving within family structures, going beyond the traditional focus on narrowly defined middle-class Anglo married couples consisting of a stay-at-home mother, working father, and biological child. Research should involve more diversity (e.g., single parents, ethnic minorities, parents with disabilities, adopted as well as biological children). Priority areas for study include: (a) Child/parent interactions—What child behaviors are most problematic for parents and what parenting behaviors are most facilitative for children with typical or atypical development? (b) Social supports—Which are most helpful to parents and when are they needed? (c) School involvement—How can meaningful parent participation be facilitated? and (d) Caregiver needs and well-being—How can stress be reduced and mental health promoted?

Conclusions

There is dire need for practitioners, educators, researchers, and policy makers to address issues of middle childhood. As we consider the caregiving needs associated with this stage of the lifespan, we must be mindful of cultural context and concerns. Meeting caregiving needs now will avoid the stresses of caregiving needs in the future. One vital task that has overwhelming support in the literature on research and practice is managing behavioral challenges that may emerge during this time, and the subsequent increases in parental stress that can affect parental mental health. Social and public policy should make caregiving during middle childhood a less daunting task.

References

Baker, B. L., & Brightman, A. J., (with Blacher, J. B., Heifetz, L. J., Hinshaw, S. P., & Murphy, D. M.). (1988). *Steps to independence: A skills training guide for parents and teachers of children with special needs* (2nd ed.). Baltimore: Paul H. Brookes

Baker, B. L., Blacher, J., Crnic, K.A., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year old children with and without developmental delays. *American Journal on Mental Retardation, 107*, 433–444.

Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Preschool children with and without developmental delay: Behavior problems and parenting stress over time. *Journal of Intellectual Disability Research, 47*, 217–230.

Barclay, D. R., & Houts, A. C. (1995). Parenting skills: A review and developmental analysis of training content. In W. O'Donohue & L. Krasner (Eds.), *Handbook of psychological skills training: Clinical techniques and applications* (pp. 195–228). Needham Heights, MA: Allyn & Bacon.

Barnard, K., & Martell, L. K. (1995). Mothering. In M. H. Bornstein (Ed.), *Handbook of parenting: Status and social conditions of parenting* (Vol. 3, pp. 3–25). Hillsdale, NJ: Lawrence Erlbaum.

Behrman, R. E. (Ed.). (1996). Financing child care. *The Future of Children, 6*(2)

Bigner, J. J. (Ed.). (1994). *Parent–child relations: An introduction to parenting* (4th ed.). New York: U.S. Macmillian College.

Blacher, J. (1990). Assessing placement tendency in families with children who have severe handicaps. *Research in Developmental Disabilities, 11*, 341–351.

Blacher, J., & Baker, B. L. (2002). *The best of AAMR: Families and mental retardation: A collection of notable AAMR journal articles across the 20th century*. Washington, DC: American Association on Mental Retardation.

Blacher, J., Baker, B. L., & Feinfeld, K. A. (1999). Leaving or launching? Continuing family involvement with children and adolescents in placement. *American Journal on Mental Retardation, 104*(5), 452–465.

Blacher, J., & Hatton, C. (2001). Current perspectives on family research in mental retardation. *Current Opinion in Psychiatry, 14*, 477–482.

Blacher, J., Lopez, S., Shapiro, J., & Fusco, J. (1997). Contributions to depression in Latina mothers with and without children with retardation: Implications for caregiving. *Family Relations, 46*, 325–335.

Blacher, J., Shapiro, J., Lopez, S., Diaz, L., & Fusco, J. (1997). Depression in Latina mothers of children with mental retardation: A neglected concern. *American Journal on Mental Retardation, 101*, 483–496.

Braddock, D. (2001). *Cognitive disability FAQs.* Retrieved from http://www.cu.edu/colemangift/faq.html.

Carter, B., & McGoldrick, M. (Eds.). (1989). *The changing family life cycle: A framework for family therapy* (2nd ed.). Boston: Allyn and Bacon.

Clarke, J. I., & Dawson, C. (1989). *Growing up again: Parenting ourselves, parenting our children*. Minneapolis, MN: Hazelden.

Colan, N. B., Mague, K. C., Cohen, R. S., & Schneider, R. J. (1994). Family education in the workplace: A prevention program for working parents and school-age children. *Journal of Primary Prevention, 15*(2), 161–172.

Cole, M., & Cole, S. R. (1993). *The development of children* (2nd ed.). New York: Scientific American Books

Collins, W., Harris, M., & Susman, A. (1995). Parenting during middle childhood. In M. H. Bornstein (Ed.), *Handbook of parenting: Children and parenting* (Vol. 1, pp. 65–89). Hillsdale, NJ: Lawrence Erlbaum.

Coleman, M., Robinson, B. E., & Rowland, B. H. (1990). Children in self-care: An examination of research confounds. *Children and Youth Services Review, 12*, 327–339.

Conroy, E., & Mayer, S. (1994). Strategies for consulting with parents. *Elementary School Guidance and Counseling, 29*(1), 60–66.

Cooper, C. R., Azmitia, M., Garcia, E. E., Ittel, A., Lopez, E., Rivera, L., et al. (1994). Aspirations of low-income Mexican American and European American parents for their children and adolescents. In F. A. Villarruel & R. M. Lerner (Eds.), *Promoting community-based programs for socialization and learning* (pp. 65–81). San Francisco, CA: Jossey-Bass.

Cudback, D., Darden, C., Nelson, P., O'Brien, S., Pinsky, D., & Wiggins, E. (1985). Becoming successful parents: Can age-paced newsletters help? Family relations. *Journal of Applied Family and Child Studies, 34*(2), 271–275.

Dennis, J. M., Parke, R. K., Coltrane, S., Blacher, J., & Borthwick-Duffy, S. A. (2003). Economic stress, maternal depression, and child adjustment in Latino families: An exploratory study. *Journal of Family and Economic Issues, 24*(2), 183–292.

Edgar, D. (1989). Strengthening families in the 1990's. *Early Child Development and Care, 52*, 25–31.

Engels, R., Dekovic, M., & Meeus, W. (2002). Parenting practices, social skills, and peer relationships in adolescence. *Social Behavior and Personality, 60*(5), 3–18.

Feerick, M. M., Bristol-Power, M., & Bynum, D. (2002). The National Institute of Child Health and Human Development research on parenting: Past, present, and future directions. In J. G. Borkowski & S. L. Ramey (Eds.), *Parenting and the child's world: Influences on academic, intellectual, and social-emotional development* (pp. 347–364). Mahwah, NJ: Lawrence Erlbaum.

Gottfried, A. E., Gottfried, A. W., Bathurst, K., & Killian, C. (1999). Maternal and dual-earner employment: Family environment, adaptations, and the developmental impingement perspective. In M. E. Lamb (Ed.), *Parenting and child development in "nontraditional" families* (pp. 15–37). Mahwah, NJ: Lawrence Erlbaum.

Grolnick, W. S., & Gurland, S. T. (2002). Mothering: Retrospect and prospect. In J. P. McHale & W. S. Grolnick (Eds.), *Retrospect and prospect in the psychological study of families* (pp. 5–33). Mahwah, NJ: Lawrence Erlbaum.

Hanneman, R., & Blacher, J. (1998). Predicting placement in families who have children with severe handicaps: A longitudinal analysis. *American Journal on Mental Retardation, 102*, 392–408.

Hartup, W. W. (1983). Peer relations. In P. H. Mussen (Ed.), *Handbook of child psychology: Socialization, personality, and social development* (Vol. 4, pp. 103–106). New York: Wiley.

Hetherington, E. M., & Baltes, P. B. (1988). Child psychology and life-span development. In E. M. Hetherington, R. M. Lerner, & M. Perlmulter (Eds.), *Child development in life-span perspective* (pp. 1–19). Hillsdale, NJ: Erlbaum.

Hoffman, L. (1986). Work, family, and the child. In M. Pallak & R. Perloff (Eds.), *Psychology and work: Productivity, change, and employment* (pp. 173–220). Washington, DC: American Psychological Association.

Kail, R. V. (2002). *Children*. Upper Saddle River, NJ: Prentice Hall.

Laird, R. D., Jordan, K. Y., Dodge, K. A., Pettit, G. S., & Bates, J. E. (2001). Peer rejection in childhood, involvement with antisocial peers in early adolescence, and the development of externalizing behavior problems. *Development and Psychopathology, 13*(2), 3–18.

Lamb, M. E. (1999). Parental behavior, family processes, and child development in nontraditional and traditionally understudied families. In M. E. Lamb (Ed.), *Parenting and child development in "nontraditional" families* (pp. 1–14). Mahwah, NJ: Lawrence Erlbaum.

Maccoby, E. E. (1984). Middle childhood in the context of the family. In W. A. Collins (Ed.), *Development during middle childhood: The years from six to twelve* (pp. 184–239). Washington, DC: National Academy of Sciences Press.

McDevitt, T. M., & Ormrod, J. E. (2002). *Child development and education*. Upper Saddle River, NJ: Prentice Hall.

Mrs. Murray. (1959). Needs of parents of mentally retarded children. *American Journal of Mental Deficiency, 63,* 1078–1088

Parke, R. D. (1995). Fathers and families. In M. H. Bornstein (Ed.), *Handbook of parenting: Status and social conditions of parenting* (Vol. 3, pp. 27–31). Hillsdale, NJ: Lawrence Erlbaum.

Parker, J. G., & Asher, S. R. (1987). Peer relations and later personal adjustment: Are low-accepted children "at risk?". *Psychological Bulletin, 102*, 357–389.

Pettit, G. S., & Clawson, M. A. (1996). Pathways to interpersonal competence: Parenting and children's peer relations. In N. Vanzetti & S. Duck (Eds.), *A lifetime of relationships* (pp. 125–154). Pacific Grove, CA: Brooks/Cole.

Radloff, L. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385–401.

Reppetti, R. L., & Wood, J. (1997). Effects of daily stress at work on mothers' interactions with pre-schoolers. *Journal of Family Psychology, 11*, 90–108.

Seltzer, M. M., & Ryff, C. (1994). Parenting across the lifespan: The normative and non normative cases. In D. L. Featherman, R. Lerner, & M. Perlmulter (Eds.), *Life-span development and behavior* (Vol. 12, pp. 1–40). Hillsdale, NJ: Erlbaum.

Silverstein, L. B. (2002). Fathers and families. In J. P. McHale & W. S. Grolnick (Eds.), *Retrospect and prospect in the psychological study of families* (pp. 35–64). Mahwah, NJ: Lawrence Erlbaum.

Simons, R. L., & Johnson, C. (1996). Mother's parenting. In R. L. Simons (Ed.), *Understanding differences between divorced and intact families: Stress, interaction, and child out come,* (Vol. 5, pp. 81–93). *Understanding families.* Thousand Oaks, CA: Sage.

Suarez, L. M., & Baker, B. L. (1997). Child externalizing behavior and parents' stress: The role of social support. *Family Relations, 46*(4), 373–381.

Suelzle, M., & Keenan, V. (1981). Changes in family support networks over the life cycle of mentally retarded persons. *American Journal of Mental Deficiency, 86*, 267–274.

Taylor, T. K., & Biglan, A. (1998). Behavioral family interventions for improving child-rearing: A review of the literature for clinicians and policy makers. *Clinical Child and Family Psychology Review, 1*(1), 41–60.

Chapter 4
Responding to the Challenges of Preadolescence: Roles for Caregivers

Marleen Wong and Erum Nadeem

Responding to the Challenges of Preadolescence: The Role of Caregivers

In the developmental period identified as late childhood or preadolescence, children from the ages of 9 through 12 begin to establish an identity as autonomous social beings outside the family (Grotevant & Cooper, 1998). Spending up to 8 hours a day away from direct parental supervision, they begin to explore their place in the world of school, peers, and adult interactions beyond the family with increasing powers of observation and independent action (Larson & Richards, 1991).

School functions as an agent of socialization with its own set of values and expectations (Wentzel & Juvonen, 1996). Heightened focus on the achievement of academic tasks is one of the major challenges in the lives of children in this developmental stage. Navigating the intellectual and psychosocial tasks of the classroom and playground is also the work of preadolescence. Through interaction and observation, children deduce what is acceptable and valued or undesirable and disagreeable within the context of their peers. Am I liked? Am I smart? Am I popular?

The child's answer to these and many other questions help to formulate the social core of who she or he is and where she or he stands in relation to other children. The ability to observe oneself in relation to others results in the child's increasing self-awareness of his or her physical appearance, gender-related behavior, racial/ethnic identity, attractiveness, and judgments about intellectual and social competence.

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Moreover, some children in preadolescence will experience physical and hormonal changes, and will begin to develop secondary sex characteristics that are noticeable by their peers (Connolly, Paikoff, & Buchanan, 1996). This occurs at a time when social status in preadolescence increasingly depends upon peer judgments; the norms of social groups of the school, neighborhood, and community; and the prevailing standards of youth culture. In this context, the first close friendships are formed, most commonly same sex friendships.

There are risks associated with late childhood from unsupervised exposure to and independent interactions with the environment. Spending longer periods of time with peers in the school and community increases exposure to new learning of both positive and negative information, values, and behaviors (McHale, Crouter, & Tucker, 2001; Steinberg & Morris, 2000). This includes deviant peer behaviors such as aggression, bullying, and risk-taking behavior (Thornberry & Krohn, 1997). Increased freedom to walk home from school or to explore the neighborhood with or without friends increases the risks of exposure to neighborhood violence, illegal or harmful substances, and other trauma-related events, particularly in communities of poverty and high crime.

In addition, children of this age experience unsupervised exposure to a great array of media, such as television, movies, music, and video games (Singer & Singer, 2001). Through media, both positive and negative images, role models, and information can be conveyed. Media can become a de facto caregiver that indiscriminately stimulates and tutors children in behaviors and norms, including some that may be at odds with those of parents.

As the increasing technological sophistication of children at young ages increases their access to the "world wide web," the virtual reality of cyberspace poses more than the threat of exposure to information; it can place children at risk to the predatory criminal behavior of adults. In a speech to the National Center for Missing and Exploited Children, Attorney General Alberto Gonzales reported, "According to one study, one child in every five is solicited online. The television program Dateline estimated that at any given time 50,000 predators are on the Internet prowling for children. It is simply astonishing how many predators there are, and how aggressive they act" (Gonzales, 2006).

The challenges of preadolescence underscore the important role caregivers play not only in building the social and emotional strengths of children, but also in eliminating the risks inherent in this stage of human development.

The Importance of Caregiving in Preadolescence

The importance of caregiving is evident in Dr. Sharon Ramey's listing of some of the developmental tasks of preadolescence and the ways in which caregivers can assist the child. Specifically, children develop (Ramey, 2002; Ramey & Ramey, 2004):

- Knowledge about the world.
- Ability to generate and enact alternative effective solutions to many real world problems.
- Kindness toward others.

- Family and community values.
- Spiritual belief systems.
- Moral and ethical standards.
- Appreciation for diversity and citizenship.

The caregiving adult supports the building of developmental assets by engaging in and modeling the following behaviors:

- Recognizing the individuality of each child.
- Mirroring positive self-regard.
- Acting responsively to individual needs.
- Encouraging identification of feelings and articulation of thoughts and perceptions.
- Conveying emotional support during times of anxiety or fear.
- Providing encouragement for self-reliant behaviors.
- Teaching and explaining desired behavior.
- Assisting with the identification of constructive alternatives to behaviors that are harmful to self or others.
- Protecting children from physical and emotional risks and danger.
- Listening to the child discuss his or her developing inner world (Ramey & Ramey, 2004).

Caregiving in the Home

Changes in caregiving and parenting practices can be noted from generation to generation over the past century. Practices that were common in the era of the Great Depression were considered out of date by the post WWII period when Dr. Benjamin Spock dispensed his advice about raising children (Spock, 1957). These changes were often reflections of the emphasis on the effects of either nature or nurture. As an example, disciplinary actions, such as spanking, fell out of favor when conventional wisdom changed. Corporal punishment, once a commonly accepted practice, became linked with damaging effects on the child's self-esteem (Larzelere, 1996).

Current thinking about caregiving in preadolescence is focused primarily on building resiliency or "developmental assets" in children. The Search Institute, which is based in Minnesota, has conducted research on thousands of young people, exploring the "assets" that support and strengthen children and adolescents as they grow. It is the responsibility of caregiving adults in the home and in the community to build positive relationships with children, guiding them through difficult life experiences, helping them to solve problems constructively and to make positive choices in their daily lives.

Listed below are eight suggestions, based on research conducted by the Search Institute (Benson & Scales, 2004), for ways that adults within the family or from the community can build developmental assets in children:

- Support children with caring and attention.
- Empower them to use their abilities to help others.

- Set reasonable boundaries and have high expectations.
- Help them find activities that make constructive use of their time.
- Spark their commitment to learning.
- Guide them toward a life based on positive values.
- Help them develop social competencies and life skills.
- Celebrate their uniqueness and affirm their positive identity.

In thinking about these strategies, the emphasis on the early bonds of the child's attachment to parents must be modified to meet the developmental needs of this age group. Parents may no longer be the sole source of comfort, guidance, and support to the child in late childhood, but they continue to play a vital role with important modifications. Parents, as caregivers, must continue to provide and closely supervise the child's daily need for physical care and security in a responsible and healthy manner. However, in preadolescence, in order for the child to leave the familiarity of home to interact with peers and adults outside the family, parents must provide encouragement and support in both overt and subtle ways. These include the spontaneous expression of admiration and pleasure in the child's growing competency, enthusiasm for the child's accomplishment and activities, and a sustaining belief in the child's abilities. Parents also play an important role in encouraging the growing child to develop and use his/her verbal ability to express their thoughts and feelings, to find alternative solutions to internal or social conflicts, and to progress from an action orientation to the dominance of speech and thought as precursors to action.

In contrast to parents who have positive expectations of their children during late childhood, negatively charged parental messages can deter healthy development and derail the child's forward progress in negotiating independent relationships and gaining a sense of autonomy in the outside world (Steinberg, 2001). For example, subtle or not so subtle messages can be conveyed that it is better to stay home or to avoid others in the outside world. The world outside of the family can be portrayed as untrustworthy or evil, leaving the child with no avenues to develop his or her own abilities for independent social development and skills for self-regulating behavior and emotion. These messages deny the child the opportunity to form new attachments, explore new social environments, and test his or her capacity for self-awareness and effective autonomous action.

Caregiving Outside the Home

Caregiving outside the home begins to play an increasingly important role in the guidance and support of preadolescents. Caregivers in the school environment come in the form of teachers, principals, education and playground aides, school counselors, school psychologists or social workers, school resource officers, office, cafeteria and custodial workers or church and community activity leaders. Through these caregiving interactions, self-control, compliance, and cooperation with peers and adults can be learned and refined. Management of aggressive and antisocial impulses will be tested. Individually and collectively, the caregiving adults in school are role models who can contribute to or damage the child's self-confidence, sense of accomplishment, and self-regard (for more information on caregiving in education, see Baldwin, and Adelman and Taylor, this series).

Youngsters in preadolescence may begin to take divergent paths from the lessons learned at home. Outside the home, in the school, or in the neighborhood, new social contexts and mores contribute to learned behavior more consistent with peer values than with parents. According to the theory of group socialization (Harris, 1995, 1998), all behavior is learned within a specific group context. Caregiving adults who allow for discussion of rules of conduct in supervised groups help children of this age to benefit from actively exploring ethical dilemmas and differing viewpoints, find alternative solutions to a problem, and attempt compromise or consensus. One such form of caregiving outside the home comes from groups such as the Boy Scouts, Girl Scouts, Brownies, etc., in which caregivers rely heavily on traditional, highly structured meetings and activities that reinforce ideals, values, and mores that are the core of the individual and group identity. Guidebooks for leaders give explicit and detailed directions of how each activity will be conducted and the values represented while youngsters earn merit badges, learn skills, and craft objects individually and in groups (Boys Scouts of America, 1982; Girls Scouts of America, 2001).

Research on resiliency factors and developmental assets have emphasized the importance of the role of caregivers outside of the family (Goldstein & Brooks, 2005). Yet, in times of economic downturns, after school activities and other program providing adult supervision and mentoring are often the first to be cut from school and community service budgets. As activities and caregiver supervision outside the home becomes more important as the child develops, a more stable funding source for a range of special interest clubs, athletics, and service learning activities must be established.

Classroom curricula that promote the teaching and learning of social skills among school age children are available in elementary and middle school classrooms. Teachers, counselors, and educational aides can be taught one or more methods of identifying key concepts in the teaching of pro-social skills. Implementation of these structured lessons in social skills can encourage school age students to be less aggressive, more socially appropriate, and less vulnerable to bullying, drug-taking, and other forms of coercive behaviors.

Second Step, a program developed by the Committee for Children in Seattle, Washington (Grossman et al., 1997), and the *Life Skills Program* from Cornell University (Botvin & Griffin, 2002), are examples of curricula developed for implementation in the classroom by caregivers, such as teachers or counselors. Both programs are endorsed for use in the classroom by the U.S. Department of Education as effective, evidenced-based programs with statistically significant reductions in aggressive behavior and significant increases in pro-social behaviors.

Since 1989, the Search Institute has conducted numerous studies of 6th- to 12th-grade students in public and private schools across the United States using a survey titled *Search Institute Profiles of Student Life: Attitudes and Behaviors*. The developmental asset framework was originally configured as a 30-asset framework.

In 1996, the framework was expanded to 40 developmental assets. The revision was based on the analysis of aggregated data on 254,000 students who took the original 30-asset survey from 1989 to 1994, the additional synthesis of child and adolescent research, and dialogs with researchers and practitioners (Benson, Scales, Leffert, & Roehlkepartain, 1999). The current data on developmental assets on which Search Institute publications are based stem from a diverse sample of 150,000 6th- to 12th-grade youth in 202 communities across the United States who completed the *Search Institute Profiles of Student Life: Attitudes and Behaviors* in calendar year 2003 (Benson & Scales, 2004).

Incorporating the Search Institute's findings, the National Institute of Child Health and Human Development summarized and translated resiliency and asset building research findings into advice for parents and caregivers. Called RPM3, the program stands for the following (U.S. Department of Health and Human Services, 2006):

- Responding to the child in an appropriate manner.
- Preventing risky behavior or problems before they arise.
- Monitoring the child's contact with his or her surroundings.
- Mentoring the child to support and encourage desired behaviors.
- Modeling one's own behavior to provide a consistent, positive example.

We offer RPM3 as research-based guidelines for caregiving behavior. RPM3 advocates that with children, adults must make the effort to be:

- Effective in words and actions that influence the child in a positive fashion.
- Consistent in principles and practices.
- Active in participating the child's life.
- Attentive to what goes on in the child's life (p. 3).

The Roles of Caregivers with High Risk Populations: Children Exposed to Violence or Trauma

Positive caregiving for adolescents plays an important role in relation to environmental stressors. There is growing evidence that preadolescents, particularly those who reside in urban core communities of poverty, are increasingly exposed to violence in their homes, in schools, and in their communities (Wong et al., 2007). In *Poverty in the United States*, the U.S. Census Bureau (2003) estimates that over five million children live in urban centers of poverty and crime. According to a growing number of studies, many of those children are frequently exposed to violence.

Campbell and Schwarz (1996) reported that 88% of preadolescents in an urban middle school had witnessed a robbery, beating, stabbing, shooting, or murder. Taylor, Zuckerman, Harik, and Groves (1994) reported that 10% of children aged

1–5 years who were seen in an inner city health clinic had witnessed a stabbing or shooting. In their 1994 study of urban children's exposure to violence, Richters and Martinez (1993) reported that 47% of children aged 6 and 7 years had witnessed a shooting. Other studies have estimated that between 20 and 50% of children in America are victims of violence within their families, at school, or in their communities (Finkelhor & Dzuiba-Leatherman, 1994).

Hurt, Malmud, Brodsky, and Giannetta (2001) evaluated 119 inner city children, 7 years of age, and 119 biological and foster caregivers; they found that the children were frequently exposed to violence. Of this group, 75% had heard gunshots, 6% had seen drug deals, 18% had seen a dead boy, and 10% had seen a shooting or stabling in their homes. Higher exposure to violence was correlated with higher scores for depression and anxiety, lower self-esteem, lower grade point average, and more days of school absence.

The startling finding of both Hurt et al.'s study (2001) and Richters and Martinez's (1993) work was the poor correlation of the caregiver's assessment of the child's distress with the child's report of his or her level of anxiety. For example, all of the children in the Richters and Martinez study reported that, to some extent, they worried about their safety. Forty-nine percent of the parents in the same study stated that their children never worried about their safety. In the study by Hurt and colleagues, all of the children reported that they worried to some extent about their safety. Fifty-eight percent of the parents in the Hurt study stated that their children never worried about their safety.

In a Los Angeles study by Jaycox et al. (2002), 36% of 1,000 immigrant children aged 8–11 years indicated that they had been exposed to life threatening violence. Thirty-two percent of the children had symptoms of posttraumatic stress disorder. Sixteen percent of the children had clinical symptoms consistent with the diagnosis of depression. Those exposed to life threatening violence had lower grades and higher rates of school absence than children who had not been exposed to life threatening violence. Again, in the majority of cases, teachers and parents were not aware of the incident that caused the children emotional distress. If the parents did identify the incident, such as violence witnessed in the process of immigration, they were unaware of the emotional distress experienced by their children because of the violent incident.

While these studies surveyed violence exposure and its psychological and academic correlates, the common finding germane to the issue of caregiving is the lack of adult recognition of child distress. All three studies suggest that adults close to the child who could offer support or seek professional assistance for the child do not recognize child anxiety or distress.

Hurt et al. (2001) suggest a number of alternative explanations for the lack of caregiver recognition of childhood distress. These include the possibilities that caregivers may be immune to exposure and the effects of exposure through chronic exposure to violence themselves; they may not be aware of the amount of violence to which the child is exposed because the child underreports for fear of curtailment of activities; and they may be preoccupied with social-emotional issues of their own. Whatever the explanation, caregivers need education and training to remedy this critical lack of awareness.

Clearly, environmental factors outside the home, in the school, or in the community, can have a great impact on the child at this period of life, with a close relationship between behavior and stresses in the environment. One of the most dramatic examples of exposure to violence and its effects on the social and emotional health of children is detailed in *Effects of the World Trade Center Attack on New York City Public School Students* (Hoven et al., 2002), which was commissioned by the Board of Education of the City of New York. Conducted 6 months after the terrorist attack on the World Trade Center, the a needs assessment survey was given to a representative sample of 8,266 New York City Public school students in grade 4–12. The key findings of the report was that a broad range of mental health problems was observed among the school children of New York City with as many as 75,000 children having symptoms consistent with posttraumatic stress disorder. It was estimated that 26.5% of the children in grades 4–12 had at least one mental health problem that would require some form of intervention (Hoven et al., 2002).

More recently, in the wake of Hurricane Katrina in New Orleans, an estimated 34% of children had symptoms of post-traumatic stress disorder (PTSD) or depression (Osofsky & Osofsky, 2006). Nearly half of parents reported that at least one child in their household had mental health difficulties related to the hurricane, such as anxiety, depression, or problems sleeping (Abramson & Garfield, 2006; Weisler, Barbee, & Townsend, 2006).

Future Directions in Education: Developing Training for Caregivers

There has been little consensus about the need for formal training for parents and the broad range of caregivers for children in preadolescence as well as children in ages across the developmental spectrum. “Parent education” in schools as well as in health and mental health clinics is offered either for parent caregivers who are identified as “having problems” or conducted with the hope that parents will voluntarily attend. In both situations, only a small percentage of the total parent population in a school or community attends such meetings (Weist, Evans, & Lever, 2003).

Most school-based caregivers have some formal training in children’s developmental needs and the challenges of preadolescents; this training is offered in teacher preparation courses. When teacher shortages occur, many school districts have hired individuals with bachelor’s degrees and no formal teacher preparation. These individuals may not have had the opportunity to take child development courses offered at the undergraduate university level. Educational aides, playground supervisors, bus drivers, and other school support staff who interact meaningfully with children every day may be even less likely to have opportunities for training. For these individuals, preservice training or staff development while in service should include an examination of the social and emotional aspects of the caregiving relationship to students and its place in facilitating the process of learning.

Future Directions in Practice: Increasing Opportunities for After School Activities and Mentoring Programs

Compared to adolescents, preadolescents still rely heavily on their caregivers to provide guidance. The extent to which the child successfully emerges from preadolescence depends on many factors, including the degree to which caregivers in the community help to foster and guide the development of norms in the child's social groups. When available, participation in extracurricular school and weekend activities sponsored by faith-based, neighborhood or community groups add to the child's development of moral and ethical standards, especially when teachers, parents, mentors, tutors, youth clergy, and others play a strong role in supervising and guiding children's activities.

Future Directions in Policy: Normalizing Mental Health Services in Schools

A basic service in every school today is the service provided by the school nurse. A provider of screening, treatment, and public health education, the school nurse is viewed as essential to the well-being of students, parents, and staff. Just as essential as nursing services are mental health services provided in every school; these may be offered by counselors, school psychologists, school social workers, or a school-based community mental health professionals (Dryfoos, 1994; Weist, 1997). Just as the school nurse provides prevention and intervention services, the school counselor, psychologist, or social worker can screen students for conditions that interfere with classroom learning (depression, anxiety, and post-traumatic stress disorder), provide initial intervention and/or treatment, and provide public mental health information that supports healthy development to students, parents, and staff.

In December 1999, the U.S. Surgeon General, Dr. David Satcher, published the first national report on mental health (U.S. Public Health Service, Office of the Surgeon General, 1999). This landmark report provided hundreds of pages of information about child and adult mental health facts and challenges. One of the fundamental assertions was that health and mental health are parts of a whole. They cannot be separated. The second major point was that the stigma of seeking and receiving mental health services must be eliminated. For students and their caregivers, school is often the place that is most accessible for children and adults to receive the information and services that they need, and mental health services should be available in every school.

Future Directions for Research

Scientific inquiry about caregiving in childhood is piecemeal and the challenges are great. According to Leffert et al. (1998), observational studies of children have concentrated primarily on two developmental periods: the early years of life, with extensive studies of "at risk" children under the age of three, and adolescents, usually with families that have already experienced serious difficulty with their children. More research is needed to understand the effects of specific caregiver behaviors and interactions during specific developmental periods and how those interactions increase or decrease positive developmental outcomes for children. There is a lack of data from large scale, population-based longitudinal studies, as well as information from smaller "natural experiments" that examine caregiver/child caregiving and care receiving interactions in the real world settings of the home and school. More research would help to further specify the types and durations of caregiving interactions that are most beneficial to preadolescent children.

Conclusions

The need for caregivers who are actively involved in all aspects of the child's daily life is crucial in preadolescence. This developmental stage is marked by the child's move toward greater separation, independence, and autonomy at a time when she or he have not yet achieved full social competence, moral maturity, or self-control. Preadolescents are increasingly exposed to both positive and negative socialization agents in the form of peers, school, other adults, the media, and the internet. They are also more likely to be faced with stressors that their parents may not be directly aware of, such as being exposed to community violence or being the victim of peer harassment or bullying.

At the same time, preadolescents remain dependent on caregivers and look to them as role models and for guidance to a greater extent than do adolescents. Because preadolescents truly live in multiple contexts, the definition of caregiver must be broadened to include parents and non-parent caregivers, such as teachers, educational aides, counselors, and community youth program leaders, among many others. We have done so in this chapter. It is also important that we provide these various groups of caregivers with the tools they need to foster children's resilience in the form of caregiver training and education, and the implementation of school and community programs that promote mental health for children. Caregivers in and out of the home are role models for preadolescents. Through their guidance and active monitoring of real and virtual environments, they can help children to achieve their potential and to successfully navigate the challenges of this developmental stage.

References

Abramson, D., & Garfield, R. (2006, October 25). *On the edge: Children and families displaced by hurricanes Katrina and Rita face a looming medical and mental health crisis*. New York: Columbia University. Retrieved October 21, 2007 from http://www.ncdp.mailman.columbia.edu/files/On%20the%20Edge%20L-CAFH%20Final%20Report_Columbia%20University.pdf.

Benson, P. L., & Scales, P. C. (2004). Developmental assets. In C. B. Fisher & R. M. Lerner (Eds.), *Encyclopedia of applied developmental science* (Vol. 1, pp. 340–342). Thousand Oaks, CA: Sage Publications.

Benson, P. L., Scales, P. C., Leffert, N., & Roehlkepartain, E. C. (1999). *A fragile foundation: The state of developmental assets among American youth*. Minneapolis, MN: Search Institute.

Botvin, G., & Griffin, K. (2002). Life skills training as a primary prevention approach for adolescent drug abuse and other problem behaviors. *International Journal of Emergency Mental Health, 4*(1), 41–47.

Boys Scouts of America. (1982). *Cub Scout leader book*. Charlotte, NC: Boys Scouts of America.

Campbell, C., & Schwarz, D. F. (1996). Prevalence and impact of exposure to interpersonal violence among suburban and urban middle school students. *Pediatrics, 98*(3, Pt. 1), 396–402.

Connolly, S. D., Paikoff, R. L., & Buchanan, C. M. (1996). Puberty: The interplay of biological and psychosocial processes in adolescence. In E. Gerald, R. Adams, & E. Raymond Montemayor (Eds.), *Psychosocial development during adolescence*. Thousand Oaks, CA: Sage Publications, Inc. pp. ix, 322.

Dryfoos, J. (1994). *Full-service schools: A revolution in health and social services for children, youth and families*. San Francisco: Jossey-Bass.

Finkelhor, D., & Dzuiba-Leatherman, J. (1994). Victimization of children. *The American Psychologist, 49*(3), 173–183.

Girls Scouts of America. (2001). *Brownie Girl Scout handbook*. New York: Girls Scouts of America.

Goldstein, S., & Brooks, R. B. (2005). *Handbook of resilience in children*. New York: Springer.

Gonzales, A. (2006, April 20). *Transcript of attorney general Alberto R. Gonzales' address to the employees at the National Center for Missing and Exploited Children*. Washington, DC: U.S. Department of Justice. Retrieved October 22, 2007 from http://www.usdoj.gov/ag/speeches/2006/ag_speech_0604202.html.

Grossman, D. C., Neckerman, H. J., Koepsell, T. D., Liu, P. Y., Asher, K. N., Beland, K., et al. (1997). Effectiveness of a violence prevention curriculum among children in elementary school. A randomized controlled trial. *Journal of the American Medical Association, 277*(20), 1605–1611.

Grotevant, H. D., & Cooper, C. R. (1998). Individuality and connectedness in adolescent development: Review and prospects for research on identity, relationships, and context. In E. E. A. Skoe & A. L. von der Lippe (Eds.), *Personality development in adolescence: A cross national and life span perspective* (pp. 3–37). New York: Taylor & Francis/Routledge.

Harris, J. R. (1995). Where is the child's environment? A group socialization theory of development. *Psychological Review, 102*(3), 458–489.

Harris, J. R. (1998). *The nurture assumption: Why children turn out the way they do*. New York: Free Press.

Hoven, C. W., Duarte, C. S., Lucas, C. P., Mandell, D. J., Cohen, M., Rosen, C., et al. (2002). *Effects of the World Trade Center attack on NYC public school students—Initial report to the New York City board of education*. New York: Columbia University Mailman School of Public Health, New York State Psychiatric Institute, and Applied Research and Consulting. Retrieved October 21, 2007 from http://eric.ed.gov/ERICDocs/data/ericdocs2/content_storage_01/0000000b/80/27/ce/00.pdf.

Hurt, H., Malmud, E., Brodsky, N. L., & Giannetta, J. (2001). Exposure to violence: Psychological and academic correlates in child witnesses. *Archives of Pediatric and Adolescent Medicine, 155*(12), 1351–1356.

Jaycox, L. H., Stein, B. D., Kataoka, S. H., Wong, M., Fink, A., Escudero, P., et al. (2002). Violence exposure, posttraumatic stress disorder, and depressive symptoms among recent immigrant schoolchildren. *Journal of the American Academy of Child and Adolescent Psychiatry, 41*(9), 1104–1110.

Larson, R., & Richards, M. (1991). Daily companionship in late childhood and early adolescence: Changing developmental contexts. *Child Development, 62*, 284–300.

Larzelere, R. E. (1996). A review of the outcomes of parental use of nonabusive or customary physical punishment. *Pediatrics, 98*(4), 824–828.

Leffert, N., Benson, P. L., Scales, P. C., Sharma, A., Drake, D., & Blyth, D. A. (1998). Developmental assets: Measurement and prediction of risk behaviors among adolescents. *Applied Developmental Science, 2*(4), 209–230.

McHale, S. M., Crouter, A. C., & Tucker, C. J. (2001). Free-time activities in middle childhood: links with adjustment in early adolescence. *Child Development, 72*(6), 1764–1778.

Osofsky, J., & Osofsky, H. (2006). *In the eye of the storm: Resilience in Katrina's wake*. New Orleans, LA: Paper presented at the meeting of the American Psychological Association.

Ramey, S. L. (2002). The science and art of parenting. In J. G. Borkowski, S. L. Ramey, & M. Bristol-Power (Eds.), *Parenting and the child's world: Influences on academic, intellectual, and social-emotional development* (pp. 47–71). Mahwah, NJ: Lawrence Erlbaum Associates.

Ramey, C. T., & Ramey, S. L. (2004). How children learn and how parents can help. *Plain Talk: The Newsletter for the Center for Development and Learning, 9*(2), 1–12.

Richters, J. E., & Martinez, P. (1993). The NIMH community violence project: I. Children as victims of and witnesses to violence. *Psychiatry: Interpersonal & Biological Processes, 56*(1), 7–21.

Singer, D. J., & Singer, J. L. (2001). *Handbook of children and media*. Thousand Oaks, CA: Sage Publications.

Spock, B. (1957). *The common sense book of baby and child care*. New York: Duell, Sloan and Pearce.

Steinberg, L. (2001). We know some things: Parent-adolescent relationships in retrospect and prospect. *Journal of Research on Adolescence, 11*(1), 1–19.

Steinberg, L., & Morris, A. S. (2000). Adolescent development. *Annual Review of Psychology, 52*, 83–110.

Taylor, L., Zuckerman, B., Harik, V., & Groves, B. M. (1994). Witnessing violence by young children and their mothers. *Journal of Development and Behavioral Pediatrics, 15*(2), 120–123.

Thornberry, T. P., & Krohn, M. D. (1997). Peers, drug use, and delinquency. In D. M. Stoff, J. Breiling, & J. D. Maser (Eds.), *Handbook of antisocial behavior* (pp. 218–233). New York: John Wiley & Sons.

U.S. Census Bureau. (2003). *Poverty in the United States: 2002*. Washington, DC: U.S. Government Printing Office.

U.S. Department of Health and Human Services. (2006). *Adventures in parenting: How responding, preventing, monitoring, mentoring, and modeling can help you be a successful parent*. Bethesda, MD: National Institute of Child and Human Development, National Institutes of Health.

U.S. Public Health Service Office of the Surgeon General, National Institute of Mental Health. (1999). *Mental health: A report of the Surgeon General*. Rockville, MD: Department of Health and Human Services, U.S. Public Health Service.

Weisler, R. H., Barbee, J. G. T., & Townsend, M. H. (2006). Mental health and recovery in the Gulf Coast after Hurricanes Katrina and Rita. *Journal of the American Medical Association, 296*(5), 585–588.

Weist, M. D. (1997). Expanded school mental health services: A national movement in progress. *Advances in Clinical Child Psychology, 19*, 319–352.

Weist, M. D., Evans, S. W., & Lever, N. A. (2003). *Handbook of school mental health: Advancing practice and research: Issues in clinical child psychology*. New York: Kluwer Academic/Plenum Publishers.

Wentzel, K. R., & Juvonen, J. (1996). *Social motivation: Understanding children's school adjustment*. Cambridge: Cambridge University Press.

Wong, M., Rosemond, M., Stein, B. D., Langley, A. K., Kataoka, S., & Nadeem, E. (2007). School-based intervention for adolescents exposed to violence. *Prevention Researcher, 14*(1), 17–20.

Chapter 5

Caregiving Across the Lifespan: Adolescence

Deryl F. Bailey and Mary Bradbury-Bailey

Adolescence marks a time period in the life span characterized by a myriad of physical, cognitive, and emotional changes (Cobb, 2001; Duesk, 1996; Erikson, 1968; Jaffe, 1998; Kaplan, 2000; Vernon, 2004; Vernon & Al-Mabuk, 1995). Oftentimes, caregivers of adolescents can find these changes difficult to understand and challenging to deal with on a daily basis. Unfortunately, a lack of understanding of how to effectively "allow" adolescents to deal with and work through the challenges unique to this portion of the lifespan can often result in negative behaviors and a general decline in mental health. An examination of the education and training of adolescent caregivers, its impact on actual practice, research findings on adolescent caregivers, and the development of policy that affects adolescent caregivers could help reverse this trend and promote positive mental health for adolescents.

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Education and Training and Its Impact on Caregivers of Adolescents

As in any other time across the lifespan, effective caregiving during adolescence can provide the emotional, social, and physical support necessary for healthy development. Essential to the caregiver of any time in the lifespan is an understanding of what makes that time period unique, challenges that might arise, causes of those potential challenges, and strategies that can be employed to prevent or counter those challenges. Armed with this knowledge, decisions made by caregivers during this time period in the lifespan could help the adolescent transition to young adulthood prepared to meet the next set of challenges life brings. Naturally, this knowledge depends on the caregivers' education and training as it specifically relates to adolescents.

Currently, a basic understanding of adolescent development remains a part of the curriculum for caregivers that might include educators, counselors, social workers, and mental health workers. Most courses on adolescent development review the stages of adolescence and the corresponding developmental tasks that need to be accomplished during that stage in order for the adolescent to make a successful transition to adulthood. To better understand the marked changes that occur during each period, researchers (Cobb, 2001; Duesk, 1996; Jaffe, 1998; Vernon, 2004) typically divide adolescence into an early adolescence ages 10–14 and mid-adolescence ages 14–18 and have assigned certain developmental tasks for each stage.

Developmental tasks refer to a set of physical, cognitive, self, social, and emotional benchmarks through which the individual should progress as a part of normal development. These benchmarks help describe normal adolescent behavior; because of the unique changes that occur during this time period, it is important to understand them so that adult reactions to adolescent behavior or misbehavior are appropriate (Bailey & Paisley, 2004). Vernon (2004) explains that "in assessment, age-specific developmental characteristics can serve as a barometer to indicate how a child is progressing relative to normal developmental guidelines. Without such a barometer, parents, and professionals can easily misconstrue or misdiagnose problems; with it, they have a general sense of what is 'normal'" (p. 31). Understanding the changes or developmental tasks that occur during this time period is critical for caregivers working with this population. These changes involve many different aspects of the individual thus setting the stage for a complex interaction of variables that could have an impact on an adolescent's mental health.

A search of the required courses for several highly ranked colleges of education shows that only one course in adolescent development or educational psychology is required for a bachelor's degree, one for a masters' degree, and one more for a doctoral degree in the teaching field. Many school systems offer further professional development for teachers related to adolescent mental health that are required for new teachers or teachers transferring into their system. Within each school, teachers are typically given guidelines to follow for making recommendations each year to the school's counselors, social worker, or system psychologist. These guidelines usually include a list of symptoms for particular mental health disorders; based on these lists, teachers are asked to make the appropriate referrals if they observe certain behaviors. If a student has already been referred and is receiving services through the school's special needs department, then teachers are expected to follow that student's Individualized Education Plan (IEP) to provide an appropriate learning environment. Students with severe mental health issues usually receive their education in a specialized school setting separated from the regular school population.

Overall, teachers receive little formal training as it relates to adolescent mental health; given their responsibility for the education of adolescents, their course work focuses on content and delivery. Due to the increase in mental health illnesses for adolescents and the amount of time teachers spend with adolescents, teachers could act as a first line of defense through the referral process given additional training. Through a combination of their course of studies and intentional training provided by school districts, teachers could become more effective at recognizing early warning signs based on student behavior in their classroom. What might work against most teachers in recognizing early warning signs for one or two particular adolescents is the fact that they have to work with anywhere from 90 to 120 students each day and manage a classroom of 20–30 adolescents while delivering instruction. Thus, additional training would probably need to be reoccurring and include application scenarios with small group discussion instead of short lectures accompanied by handouts that are usually only one segment of long meetings at the beginning of each year. Many teachers already feel overwhelmed with additional non-teaching responsibilities, but well-thought out training that stresses the referral process and allows them to discuss their observations may be more effective in helping teachers recognize early warning signs.

Counseling training programs, whether school or community, require several courses related to adolescent mental health. Accredited counseling programs adhere to the following standards as it relates to adolescent development and adolescent mental health:

Human Growth and Development—studies that provide an understanding of the nature and needs of individuals at all developmental levels, including the following:

(a) Theories of individual and family development and transitions across the life-span.
(b) Theories of learning and personality development.
(c) A general framework for understanding exceptional abilities and strategies for differentiated interventions.
(d) Human behavior including an understanding of developmental crises, disability, exceptional behavior, psychopathology, and situational and environmental factors that affect both normal and abnormal behavior.
(e) Theories and etiology of addictions and addictive behaviors including strategies for prevention, intervention and treatment.
(f) Strategies for facilitating optimum development and wellness over the life-span (http://www.cacrep.org/StandardsRevisionText.html, 2005).

Some programs, such as community counseling programs, typically require more specific courses, such as "Foundations of Mental Health and Community Counseling, Psycho-Diagnosis, and Alcohol and Drug Therapy" (http://www.coe.

uga.edu/chds/communitycounseling/curriculum.html, 2006), than do school counseling programs due to the nature of their clientele. Community counselors usually operate from an intervention perspective while school counselors, along with educators, would be more preventive or part of that first line of defense for adolescents. Researchers (House & Hayes, 2002; House & Sears, 2002; Martin, 2002) advocate for school counselors to serve as "brokers of services" in the referral process. In this role, school counselors would need to be thoroughly acquainted with local agencies and the services they provide for children and adolescents with mental health issues.

Many programs mandate their students to complete a school profile as well as a research project that requires students to investigate mental health services available to them from their prospective internship sites. In addition, school and community counseling students often work together to create preventive and intervention measures for a variety of age groups; students not only experience the development of their own measure, but also have access to copies of other group interventions. Practical application projects such as these help foster valuable connections between school counseling and community counseling students that could continue after graduation. Furthermore, counseling students see the value and the necessity of collaboration. Working as teams in both schools and communities, each in their prospective areas, allows for more effective use of resources and more creative solutions in helping adolescents navigate their way to adulthood. Equipped with this knowledge, counselors could act as both preventive and intervention agents for adolescents with potential mental health issues.

School social workers represent another set of agents who could advocate for the mental health of adolescents. Traditionally, school social workers have represented a liaison between the students, school, home, and community (Constable, Flynn, & McDonald, 1991; Whitfield, 1999). A review of the standards for social workers as established by the Council for Social Work Education reveals two standards that address mental health issues or variables that could potentially impact adolescent mental health: "4.2 Populations At-Risk and Social and Economic Justice and 4.3 Human Behavior and Social Environment" (http://www.cswe.org, 2001). Within standard 4.2, accredited social work programs are expected to educate students as to how group membership could influence access to resources, risk factors for certain populations, and strategies to address these problems. Standard 4.3 addresses more developmental issues and how systems could impact the well-being of the individual. Course work for bachelor degrees and masters' degrees generally include courses that provide an overview of mental health issues across the lifespan as well as strategies to address them to fulfill these accreditation standards. Depending on the age group in which the social worker specializes, more on-the-job-training would be essential for social workers to effectively help adolescents with mental health issues. The quality of on-the job-training and continual professional development for social workers depends on the agency and its leadership.

To help bridge the gap between formal education and the real world application, the California Social Work Education Center (CalSWEC) has established a mental health initiative representing "the nation's largest state coalition of social work educators and practitioners. It is a consortium of the state's 18 accredited social work graduate schools, the 58 county departments of social services and mental health, the California Department of Social Services, and the California Chapter of the National Association of Social Workers" (http://calswec.berkeley.edu/MHInitiative_Competencies.html, 2006). The Education Center is located at the University of California, Berkeley. As a result of this collaboration, "the CalSWEC Board of Directors adopted the Mental Health Curriculum Competencies in May 2005. Currently, regional meetings with representatives of schools, county mental health agencies, and non-profit mental health contract agencies are under way across the state to develop strategies for implementing the curriculum and continuing the collaborative work." (http://calswec.berkeley.edu/MHInitiative_Competencies.html, 2006). This type of collaborative work between students and practitioners could greatly increase the effectiveness of mental health delivery systems working with adolescents.

Unlike the carefully mapped out curriculum for accredited programs, no manual automatically comes to parents or grandparents who represent adolescent caregivers to assist them with parenting techniques that would help their adolescents navigate adolescence. Ironically, "parenting" represents a critical component of successful adolescent development and yet it never shows up as a "required" course in our educational system. Traditionally, parents receive very little "formal" training as it relates to adolescence unless their chosen profession deals with this part of the lifespan, and thus, have relied on their own personal experiences as a guide for how to raise their children whether those experiences were negative or positive. As parents of adolescents attempt to navigate their way through this phase of the parenting process, trial and error would best describe the method most frequently employed for a variety of reasons. Hectic lifestyles of parents trying to juggle careers, community, and parenting responsibilities as well as the misapprehension of "appearing" as if they "don't know it all" often prevent parents from seeking outside support.

Parents of adolescents as well as other caregivers have a wealth of information literally at their fingertips if they can gain access to the internet, invest the time to "google" parenting, and then review their research results. Typing in "parenting education" yielded 21 million different sites dedicated to this topic. Given that some may not be reliable or professionally grounded, it is safe to assume that parents have a tremendous resource with little expense that also offers the anonymity many parents might appreciate as they begin to search for information concerning adolescent mental health issues. Parents would also be able to participate in chat rooms or discussion groups with other parents trying to deal with the same mental health issues; given the limited financial situation for most families as well as demanding schedules, on-line support groups could be an effective approach to helping parents work through their adolescent's mental health issue.

Research: Challenges Facing Adolescents

In the human experience, adolescence could represent one of the most precarious times. Because this time period involves a series of physical, cognitive, personal, social, and emotional changes, caregivers need to understand that from the adolescent's perspective, life seems like a series of challenges and trials. Healthy identity development results in a healthy adult, but too often this "crossing over" into adulthood leaves a trail of painful statistics. An astounding 50% of adolescents experiment with one or more risky behaviors including substance abuse, early unprotected sex, violence, and school dropout (Weissberg, 1998). Some researchers (Ingersoll & Orr, 1989; Orr, Beiter, & Ingersoll, 1991) view this risk-taking as a "rites of passage" into adulthood with results that can be damaging. National data sources report that for adolescents between 14 and 17, 30% binge drink, 31% smoke, 25% engage in unprotected sex, 8% have carried a gun, and 9% have attempted suicide (Dryfoos, 1997; Sickmund, Snyder, & Poe-Yamagata, 1997). A more recent study examined the behaviors of 1,600 seventh, eighth, and ninth graders relative to risky behaviors; 53% reported having drunk alcohol at least once, 36% two or three times, and 26% had drunk recently. Thirty-nine percent have smoked cigarettes while 21% have smoked marijuana. Thirty-four percent of the adolescents surveyed have been involved in a fight and 10% acknowledged carrying a weapon to school (Smith, 2001).

These risky behaviors have been associated with the mental health of many adolescents. More specifically, mental health experts believe that 10–15% of adolescents may experience depression resulting in the aforementioned behaviors (Guida, 2001; Seligman, 1998; Swartz, 2001). Depression represents a mental illness that involves much more than feelings of sadness. According to Seligman, the mean age for the first sign of depression 50 years ago was 29.5 years of age; the mean age now is an astounding 14.5 years of age. Moreover, the effects of depression spread to other areas of the adolescent's life including school and result in decreased productivity, achievement, and increased absenteeism. Seligman believes three factors have contributed to this "epidemic" of depression among adolescents. He writes:

> The first is that the "I-We" balance has changed. We now have a larger "I" than ever before, and a smaller "we." The spiritual furniture that buffered our parents and grandparents when they failed in life—relationship to God, relationship to nation, patriotism, community, extended family—all of that spiritual furniture has become shopworn. The second thing that has changed is the development of a movement that praises unwarranted self-esteem. We value feeling good as opposed to doing well in the world. Finally, we have adopted a victimology. Our young people believe that when things go wrong, it is someone else's fault. This is a formula for passivity and depression. (1998, p. 38)

According to the *Surgeon General's Call to Action to Prevent Suicide* (1999), suicide is the third leading cause of death for adolescents. "Between 1952 and 1996, the reported rates of suicide among adolescents and young adults nearly tripled. From 1980 to 1996, the rate of suicide among persons aged 15–19 years increased 14% and among persons aged 10–14 years by 100%" (U.S. Public Health Service, 1999, p. 3). For adolescents of color, the suicidal rates are even more alarming. Native Americans and Alaskan Natives suicide rates have long been over the national average. "Between 1980 and 1996, the rate of suicide among African American males 15–19 years of age increased 105% and almost 100% of the increase in this group is attributable to the use of firearms" (U.S. Public Health Service, 1999, p. 3). Because of the stigma attached with suicide for this particular population, researchers believe that many cases listed as homicides may actually have been suicides pushing the percentage even higher (Poussaint & Alexander, 2000).

In addition to an increase in depression and suicide rates, 20% of adolescents can be diagnosed with some type of disorder ranging from anxiety or mood disorders to more disruptive disorders (Poussaint & Alexander, 2000). While treatable, the more disruptive disorders can be especially draining for the caregivers emotionally as well as financially. For those families already strained financially, receiving the necessary treatment may prove problematic thus creating even more stress for the caregivers. Some of the disorders on the rise are more prevalent among certain populations; for example, eating disorders for adolescent females have increased dramatically over the past few decades presenting their own unique set of challenges (U.S. Public Health Service, 2002). As with any disorder, the resulting behavior proves disruptive for both the adolescent and the caregivers.

Because adolescent caregivers often work through the family, then it is important to understand how those experiences have changed since family dynamics have changed in the past 40–50 years. Recent statistics indicate a change in the dynamics of "who" represents the caregivers of adolescents today. One apparent change is the number of adolescents raised in single-parent families as opposed to two parent households; since the 1960s, the rate has tripled from 9% of adolescents living in single-parent households to 23% (http://youthviolence.edschool.virginia.edu, 2006; http://www.census.gov, 2006). "In 1980, 77% of all children under age 18 lived with two parents, falling to 73% in 1990 and only 68% by 1998, according to the Current Population Survey (CPS)" (http://youthviolence.edschool.virginia.edu, 2001). Parenting can be difficult with a two-parent household, but having to represent both parents can add additional emotional, physical, and financial stress.

Additional Challenges Facing Special Populations

It is important for caregivers working with adolescents from special populations to understand that differences do exist and attempting to work with any of these groups could prove problematic if these differences are ignored. Caregivers working with adolescents from special populations need to be aware of additional challenges that might impact this group including, but not limited to, failure to successfully negotiate additional developmental tasks, financial stress, level and quality of service, and negative environmental stressors.

For students of color, the challenges of adolescent development are multiplied because of certain historical and social factors arising from institutional racism. The interaction of these factors during this time period can result in additional developmental tasks for students of color (Crawley & Freeman, 1993). These tasks are most directly influenced by race, ethnicity, and culture. Additional developmental tasks are presented in Table 5.1.

For students of color, these additional developmental tasks compound the problems already associated with navigating adolescence and should be considered as

Table 5.1 Developmental task challenges for students of color

Early school age	Incorporation of racial labels into evolving self-concept Recognize, identify, and label social inconsistencies
Middle school age	Recognize and develop skills for negotiating multiracial environments and bicultural experiences, each containing mixed and contradictory messages Enhances and deepen skills for handling social inconsistencies, e.g., racism, discrimination, prejudice Forge an appropriate and healthy identity in the fact of racism, discrimination, prejudice
Puberty	Fine-tune sensing and judging skills to screen out or transform negative racial/color images and messages Refine healthy identity which transforms and/or transcends societal messages of inferiority, pathology, and deviance based on color, race, and/or culture Strengthen skills for negotiating bicultural and multiracial environments

From Crawley, B., & Freeman, E. (1993). Themes in the life views of older and younger African American males. *Journal of African American Men Studies, 1*(1), 15–29.

risk factors when considering mental health issues. The additional stress resulting from these tasks or the inability to successfully complete them may explain the negative self-concepts too many students of color exhibit through poor academic and social performance.

Many minority adolescents come from families with limited financial resources. Poverty has a direct impact on minority women and their children. This is important to understand because a lower socioeconomic status has long been associated with mental health issues. Although the exact nature of the relationship is not understood, researchers believe increased stress levels and having to deal with more frequent uncontrollable life events may be part of the problem (U.S. Public Health Service, 2002). For example, research indicates that the rate of mental disorders for African Americans is higher than their White counterparts until socioeconomic differences are factored out and then the rates are similar (Regier et al., 1993; Vontress & Epp, 1997). The burden of trying to pay bills and handle the unexpected financial responsibilities can cause such stress and worry that it can have an impact on every aspect of one's life, especially our mental state. Although adolescents in this environment have no direct financial stake in their predicament, they still feel the effects experienced by the adults surrounding them.

Compounding the problems associated with development for minority adolescents is the fact that people of color are typically underserved by mental health services (Parham, White, & Ajamu, 1999; Poussaint & Alexander, 2000; U.S. Public Health Service, 2002). Cost, mistrust, and stigma are a few of the reasons cited by researchers for the lack of appropriate services (U.S. Public Health Service). Due to jobs associated with poor to nonexistent health benefits, cost represents the most obvious barrier to adolescents of color receiving care or participating in preventative measures. Mistrust of mental health professionals by minority patients may stem from their experience with racism. If institutional racism exists in other agencies, then the possibility that it exists in mental health agencies can be assumed. Clinician bias has already been cited as a possible explanation for the over diagnosis of schizophrenia and under diagnosis of depression for African Americans (Lawson, Hepler, Holladay, & Cuffel, 1994; Primm, Lima, & Rowe, 1996). Like most groups, the stigma associated with mental health illnesses acts as another barrier for prevention and treatment. Too often, minority populations try to deny the existence of any problems associated with mental health and instead depend on their own self-reliance as a possible cure (Snowden, 1998).

In addition, it is not uncommon to find environmental forces converging to impact negatively on the psychosocial development for adolescents of color (Lee, 1996; Madhubuti, 1990; Majors & Billson, 1992). Adolescents from these special populations are often confronted with extreme environmental stressors during the crucial early years of life. These environmental stressors are connected to racism and prejudice that can result in poorer housing opportunities, job opportunities, and medical services as well as second hand treatment in day to day interactions (Lee & Bailey, 1997; Myers & King, 1980). This stress may manifest itself in home, community, or school experiences and have a direct impact on the mental health for this particular population. For example, it is not unusual for African American males to reach adolescence with a basic mistrust of their environment, doubts about their abilities, and confusion about their place in the social structure. This makes developing an identity during the crucial boyhood-to-manhood transition of the adolescent years extremely problematic.

Compounding this problem is the social reality that many African American male youth may have to engage in the process of identity formation with minimal or no positive adult male role modeling. Significantly, identity formation during adolescence is a process in which youth develop aspects of their personal and social identities by selecting and identifying with various role models. Given the historical, social, and economic limitations placed on Black manhood in America, the range of adult African American role models available to adolescent males are often severely restricted. The developmental passage to adulthood becomes a confusing experience for many African American male youth because the evolution of gender appropriate roles and behaviors for African American males has often been stifled by historical and social powerlessness. By the age of 18, the sum total of these impediments towards healthy psychosocial development during adolescence oftentimes manifest themselves in negative attitudes, self-destructive attitudes, risky behaviors, and maladaptive values among young African American males. The impact of such factors has resulted in negative consequences related to educational underachievement, unemployment, delinquency, substance abuse, homicide, and incarceration (Cordes, 1985; Gibbs, 1988).

It is important to mention what is happening for adolescents now relative to mental health issues because the rapidly changing dynamics cannot be addressed by what was popular or seemed to be working 20 years ago. Furthermore, caregivers, usually predominantly white, middle class females, need to be aware of the issues facing adolescents of color and how these issues may impact mental health. Their own personal life experiences cannot provide any reasonable experience from which they can draw understanding so it is imperative that they obtain awareness and knowledge of these differences so as to apply the appropriate skills as adolescent caregivers.

In addition to the increase in the number of adolescents diagnosed with some type of mental disorder, recent statistics concerning delivery systems for these adolescents show a lack of effective treatment. According to the U.S. Office of Technology Assessment, approximately six to eight million children in need of mental health interventions do not even receive care while another 50% of those receiving some type of care do not receive appropriate treatment. Lack of resources represents one part of the problem while an incomplete knowledge of causes for adolescent mental health disorders as well as a thorough understanding of how to establish and maintain effective delivery systems the other. The *National Plan for Research on Child and Adolescent Disorders* suggests that "by examining and evaluating the structure and process of existing service delivery systems, by testing innovative changes in these systems, and by developing and testing new service models" (Judd, 1990, p. 27), the necessary knowledge based could be established.

Since this report, several universities received grants to establish mental health research centers most of which represent collaborative efforts between university staff and practitioners. Initial studies and reports from these centers have yielded valuable information relative to causes of adolescent mental disorders as well as their delivery systems. With respect to causes, the field of research seems to have split into two directions—one physiological and the other environmental. Physiological research led to an increase in the development of medications with an understanding that a cause and effect relationship exists for mental health disorders. As a result, a generation of adolescents has been medicated in an attempt to alleviate the effects of their mental health disorder.

Relative to environmental causes two distinct factors have emerged that play an opposite role in whether or not a particular mental illness could take hold in a person's life; these factors include risk and protective factors. Risk factors represent those variables that seem to predispose an individual to the onset of a mental health disorder (Carbonell, Reinherz, & Giaconia, 2001; U.S. Public Health Service, 1999). Risk factors may include negative life-changing events, family and social environments, and individual characteristics. Negative life-changing events may include something as traumatic as the death of a parent, sibling, and close friend, school violence (i.e., Columbine shootings), or something as transitional as a moving to a new school or the birth of a sibling. Family environmental risk factors range from abusive relationships, alcoholism, to separation and divorce. Individual characteristics that serve as risk factors include insecurities associated with physical appearance and the dramatic body changes that occur during adolescence (Carbonell et al., 2001; McKinney & Gierla, 2001).

Protective factors, opposite of risk factors, encourage resilience and help foster a more positive adaptive outcome for the individual. Carbonell et al. (2001) describe resilience as “the capacity to be unaffected by, to recover from, or even gain strength or grow from difficult life experiences or adversity” (p. 8). Protective factors counteract the effects of risk factors and may reside within the individual or be a part of their family or community (Institute of Medicine [IOM], 1994; Rutter, 1979). In addition to countering the onset of mental illness, these factors can result in a more positive self-esteem for the adolescent translating into fewer behavioral problems, better academic performances, and positive interpersonal relationships (Carbonell et al., 2001). The Search Institute has compiled a list of 40 developmental assets, both internal and external, that can help communities or organizations assess available protective factors for their adolescents. According to Benson (1998), “as the number of assets rises, major reductions occur in alcohol use, tobacco use, illicit drug use, early sexual activity, violence, anti-social behavior, and gambling. A rise in the developmental assets is linked to increases in school success, the affirmation of diversity, and other thriving indicators” (p. 46). Any intervention or prevention action needs to carefully consider how their action plan will encourage and stimulate protective factors.

Research on delivery systems seemed to indicate a need for a more collaborative effort in treatment that definitely included the family, community, and schools. For example, more severe emotional disorders (SED) ranging from depression, attention-deficit hyperactivity disorder to obsessive-compulsive disorder have been more effectively treated with “a service model that focuses on the child and family, includes different types of services from many different agencies, and includes providers from different fields who work together to address the needs of each child individually. Services provided in this manner (sometimes called *wraparound services*) are effective in attaining desired outcomes, such as reducing the number of out-of-home placements and psychiatric hospitalizations experienced by the child” (http://www.psych.uic.edu/mhsrp/children_youth.htm, 2006, p. 1). Furthermore, research designed to specifically examine the effects of attempting to provide care for adolescents with SED shows considerable strain for the caregivers such as family members that can translate into depression and fatigue. The research recommended that “family members should have available to them services they need to combat depression, fatigue and frustration with service systems which often are uncoordinated. Therefore, these caregivers also benefit from a wraparound or collaborative service model” (http://www.psych.uic.edu/mhsrp/children_youth.htm, 2006, p. 1).

This comprehensive model sought to treat the adolescent from a more holistic approach; families and community members or organizations needed to be involved because of their daily interaction with the adolescent as intervention measure while schools were included as a more preventative measure. In addition to school counselors, many schools now staff a mental health counselor often provided by a community organization to accept referrals from both teachers and counselors. This preventative measure hoped to be a first line of defense against the lack of response to adolescents with mental health disorders. Furthermore, early diagnosis and treatment of certain mental health disorders could reduce the incidence of alcohol and drug addiction often shown by adolescents who never received treatment.

Policy/Advocacy and Adolescent Caregivers

A report completed by the National Advisory Mental Health Council's Workgroup suggests that the *National Plan for Research on Child and Adolescent Mental Disorders* did help expand and shape the research knowledge base as it relates to causes of and treatment for adolescent mental health disorders. However, according to this same report, the research still has several gaps. The following is a summary of their findings:

- Scientifically proven treatments, services, and other interventions do exist for some conditions but are often not completely effective.
- Most of the treatments and services that children and adolescents typically receive have not been evaluated to determine their efficacy across developmental periods.
- Even when clinical trials have included children and adolescents, the treatments have rarely been studied for their effectiveness in the diverse populations and treatment settings that exist in this country.
- Those interventions that have been adequately tested have not been disseminated to the children and their families who need them, or to the providers who can deliver them.
- Services for children are often fragmented, and many of the traditional service models do not meet the needs of today's children and families.
- In sum, there is a shortage of evidence-based treatment, and much of the evidence that does exist is not being used. As a result, the burden of mental illness among children and adolescents is not decreasing. (National Institute of Mental Health [NIMH], 2001, p. 2).

As with other social sciences, action-based research has taken a more prominent role in the selection of effective prevention and intervention models. Too often treatment models were selected based on cost effectiveness, convenience, and its compatibility to those having to implement it rather than its suitability for the adolescents that it needed to serve. Action-based research requires the caregivers, counselors or mental health workers, to collect data concerning the population they serve, review successful models that are serving a similar population, if applicable, conduct a site visit of the model for a more thorough understanding of how it works, and then collect data on the program after it has been implemented to verify its effectiveness. Although action-based research has increased, understaffing and time constraints too often prevent caregivers from using this model to make more effective decisions concerning treatment options. To combat this, education and training of caregivers should include not only an overview of this model, but its application across the curriculum; for those practitioners already in the field, the use of action-based research to make treatment decisions will depend on the leadership of the organization or the facility. Many professional organizations including the American Counseling Association and the National Association of Social Workers offer workshops at their annual conferences on this topic; in addition, many of the research presentations accepted employ this model so attendees may see its application as a part of the daily sessions.

Delivery systems for treating adolescents with mental health disorders like any other institution usually resist change in spite of overwhelming evidence of failure. According to the National Institute of Mental Health (2001) report mentioned earlier, "Research has also identified treatments that are potentially ineffective or, worse yet, harmful. Some forms of institutional care do not lead to lasting improvements after the child is returned to the community. Some services provided to delinquent juveniles are also ineffective (e.g., boot camps and residential programs); peer-group based interventions have been found to actually increase behavior problems among high-risk adolescents" (NIMH, p. 4). Funding agencies and charitable organizations need to be aware of such findings before they review proposals or even establish the criteria for treatment options that will be accepted for review; in this way, funding can help mold the direction of treatment for mental health disorders to more effective options. If treatment options cannot show a reasonable measure of success qualitatively or quantitatively over a period of time, then funding should be discontinued.

High levels of bureaucracy as well as a disproportionate amount of management positions within a delivery system explain why many ineffective delivery systems for treating adolescents with mental health disorders remain open; too often the bureaucracy and top-heavy management positions are so busy protecting their "turf" that the needs of the adolescents they need to serve are overlooked or secondary. Funding accountability along with the implementation of action-based research can help a delivery system change its focus to a more daily accountability that seeks to serve its clientele. Delivery systems that can involve their entire staff and invoke the writing and implementation of a 3–5 year improvement plan grounded in action-based research with clearly defined and measurable goals for each year can promote change in the direction that benefits the adolescents they serve.

While delivery systems usually represent a more intervention approach to working with adolescents with mental health disorders, educational and community organizations that have daily contact with adolescents could serve as prevention models if properly educated. Leaders within public and private schools, youth organizations (i.e., Boy Scouts, Girl Scouts, Boys, and Girls Clubs, etc.), civic organizations, and church representatives from each community need to be encouraged to attend seminars that present the mental health crisis concerning youth. In addition, these seminars should address the problems associated with adolescent mental health issues, investigate their role in helping to educate both adolescents and the professionals working with them, and develop possible interagency action plans focusing on intervention and prevention.

The U.S. Public Health Service (1999) in the *Surgeon General's Call to Action* against suicide has already developed a possible blueprint for these seminars. This action plan, referred to as AIM, includes three main components: awareness, intervention, and methodology. Awareness involves getting the information about mental health to people on both sides of the spectrum, those who may need treatment or intervention and those involved in the treatment/intervention process. As a part of awareness, the stigma associated with mental illness needs to be effectively dealt with, thus removing a potential barrier to treatment. In addition, mental health providers should be forever diligent in challenging their biases and inappropriate attitudes towards clients from diverse backgrounds. They should constantly re-evaluate how their biases and attitudes may contribute to the stigma associated to the under-utilization of mental health services by people of color. The intervention component calls for collaboration among agencies, the development of training programs for mental health professionals, educational professionals, high-risk families, and adolescents, and the elimination of barriers that dissuade treatment and participation in prevention programs. With methodology, further research on risk and protective factors as well as scientific strategies for better evaluation and prescription of treatment could help develop more effective action plans (U.S. Public Health Service, 1999).

As identified by the NIMH (2001) report, those involved in mental health research need to improve the procedure for identifying mental illnesses and support more research on diverse populations. These findings then need to be communicated to those in direct contact with this particular population. Those involved in administration need to help remove barriers to quality services for all adolescents, fight for a budget plan that would reduce the counselor-client ratio, and increase the number of counselors from diverse backgrounds. Each professional group working with this population needs to be involved in quality professional development that will enhance their training in the area of mental illnesses. Furthermore, professionals from institutions and mental health agencies that operate from the deficit model might conclude that these are problems created by the individual's inability or willingness to achieve their potential. The more multicultural competent mental health professional would recognize the impact of negative environmental stressors and see these as mental health issues requiring treatment or preventive measures rather than "problems." Moreover, the caregiver needs to recognize that these behaviors directly correlate to mental health issues that require resolution and healing.

Finally, effective collaboration among agencies working with adolescents needs to become a working reality. Unfortunately, federal and state budget cuts usually translate into the loss of special support programs and mental health positions geared towards the well-being (emotional, academic, and social) of adolescents. One need only pay attention to the statistics regarding adolescents, especially adolescents of color, to realize that adolescents are experiencing challenges in all domains (emotional, social, and academic). Mental health professionals, educators, community-based organizations, and family support networks associated with this population need a well-funded, coordinated plan to counter these challenges. The National Institute of Mental Health's report, *A Blueprint for Change: Research on Child and Adolescent Mental Health*, outlines a 10 year plan that has assessed the strengths and weaknesses of adolescent caregivers and made recommendations for more effective research, use of resources, and potential treatment options (NIMH, 2001). Education, sharing of ideas, and establishing common goals could provide a more unified effort by caregivers to counter the challenges concerning the mental well-being of all adolescents.

References

Bailey, D. F., & Paisley, P. O. (2004). Developing and nurturing excellence in adolescent African American males. *Journal of Counseling and Development, 82*(1), 10–17.

Benson, P. (1998). Uniting communities to promote child and adolescent development. In *Promoting positive and healthy behaviors in children: The 14th annual Rosalynn Carter Symposium on Mental Health Policy* (pp. 41–47). Atlanta: The Carter Center Mental Health Program. Retrieved October 23, 2008, from http://www.cartercenter.org/documents/1228.pdf.

CACREP 2008 standards revision. (2005). Retrieved October 23, 2008, from http://www.cacrep.org/StandardsRevisionText.html.

Carbonell, D. M., Reinherz, H. Z., & Giaconia, R. M. (2001). Risk for depression and resilience in late adolescence. *The Prevention Researcher, 8*(4), 7–9.

Cobb, N. J. (2001). *Adolescence: Continuity, change, and diversity* (4th ed.). Mountain View, CA: Mayfield Publishing.

Community counseling curriculum. (2006). Retrieved October 23, 2008, from http://www.coe.uga.edu/chds/communitycounseling/curriculum.html.

Constable, R., Flynn, J. P., & McDonald, S. (Eds.). (1991). *School social work*. Chicago: Lyceum Books, Inc.

Cordes, C. (1985). At risk in America: Black males face high odds in a hostile society. *American Psychological Association Monitor, 16*(1), 9–11, 27.

Council on Social Work Education. (2001). *Education policy and accreditation standards.* Retrieved October 23, 2008, from http://www.cswe.org/accreditation/EPAS.

Crawley, B., & Freeman, E. (1993). Themes in the life views of older and younger African American males. *Journal of African American Men Studies, 1*(1), 15–29.

Dryfoos, J. G. (1997). The prevalence of problem behaviors: Implications for programs. In R. P. Weissberg, T. P. Gullotta, R. L. Hampton, B. A. Ryan, & G. R. Adams (Eds.), *Healthy children 2010: Enhancing children's wellness* (pp. 17–46). Thousand Oaks, CA: Sage.

Duesk, J. (1996). *Adolescent development and behavior*. Englewood Cliffs, NJ: Prentice-Hall.

Erikson, E. (1968). *Identity: Youth and crisis*. New York: Norton.

Gibbs, J. T. (Ed.). (1988). *Young, black, and male in America: An endangered species*. New York: Auburn House.

Guida, A. (2001). Depression…or just the blues? *ASCA School Counselor, 39*(2), 10–13.

House, R. M., & Hayes, R. L. (2002). School counselors: Becoming key players in school reform. *Professional School Counseling, 5*, 249–256.

House, R. M., & Sears, S. J. (2002). Preparing school counselors to be leaders and advocates: A critical need in the new millennium. *Theory into Practice, 41*, 154–162.

Ingersoll, G. M., & Orr, D. P. (1989). Behavioral and emotional risk in early adolescents. *Journal of Early Adolescence, 9*(4), 396–407.

Institute of Medicine. (1994). *Reducing risks for mental disorders: Frontiers for preventive intervention research*. Washington, DC: National Academy Press.

Jaffe, M. L. (1998). *Adolescence*. Danvers, MA: Wiley.

Judd, L. L. (Ed.). (1990). *National plan for research on child and adolescent mental disorders*. Darby, PA: U.S. Department of Health and Human Services, DIANE Publishing Co.

Kaplan, P. S. (2000). *A child's odyssey* (3rd ed.). Belmont, CA: Wadsworth.

Lawson, W. B., Hepler, N., Holladay, J., & Cuffel, B. (1994). Race as a factor in inpatient and outpatient admissions and diagnosis. *Hospital and Community Psychiatry, 45*, 72–74.

Lee, C. C. (1996). *Saving the native son: Empowerment strategies for Black males*. Greensboro, NC: ERIC/CASS Publications.

Lee, C. C., & Bailey, D. F. (1997). Counseling African American male youth and men. In C. C. Lee (Ed.), *Multicultural issues in counseling: New approaches to diversity* (2nd ed., pp. 123–154). Alexandria, VA: American Counseling Association.

Madhubuti, H. (1990). *Black men: Obsolete, single, dangerous? Afrikan American families in transition: Essays in discovery, solution, and hope*. Chicago: Third World Press.

Majors, R., & Billson, J. M. (1992). *Cool pose*. New York: Touchstone Publishers.

Martin, P. J. (2002). Transforming school counseling: A national perspective. *Theory into Practice, 41*, 148–153.

McKinney, S., & Gierla, J. (2001). Struggling in silence. *ASCA School Counselor, 39*(2), 12.

Mental Health Curriculum Competencies adopted by the CalSWEC Board of Directors. (2006). Retrieved October 23, 2008, from http://calswec.berkeley.edu/MHInitiative_Competencies.html.

Mental health services research program: Children/youth. (2006). University of Illinois at Chicago. Retrieved October 23, 2008, from http://www.Psych.uic.edu/mhsrp/children_youth.htm.

Myers, H. F., & King, L. M. (1980). Youth of the Black underclass: Urban stress and mental health. *Fanon Center Journal, 1*, 1–27.

National Institute of Mental Health. (2001). *Blueprint for change: Research on child and adolescent mental health.* A Report of the National Advisory Mental Health Council's Workgroup on Child and Adolescent Mental Health. Retrieved October 23, 2008, from http://www.nimh.nih.gov/publicat/nimhblueprint.pdf.

Orr, D., Beiter, M., & Ingersoll, G. (1991). Premature sexual activity as an indicator of psychosocial risk. *Pediatrics, 87*(2), 141–147.

Parham, T. A., White, J. L., & Ajamu, A. (1999). *The psychology of Blacks: An African centered perspective*. Upper Saddle River, NJ: Prentice Hall.

Population Profile of the United States. (2006). *Chapter 6: From birth to seventeen: The living arrangements of children, 1998.* Retrieved October 23, 2008, from http://www.census.gov/population/pop-profile/1999/chap06.pdf.

Poussaint, A. F., & Alexander, A. (2000). *Lay my burden down*. Boston: Beacon.

Primm, A. B., Lima, B. R., & Rowe, C. L. (1996). *Integrated mental health services: Modern community psychiatry*. New York: Oxford University Press.

Regier, D. A., Farmer, M. E., Rae, D. S., Myers, J. K., Kramer, M., Robins, L. N., et al. (1993). One month prevalence of mental disorders in the United States and sociodemographic characteristics: The Epidemiologic Catchment Area Study. *Acta Psychiatrica Scandinavica, 88*, 35–47.

Rutter, M. (1979). Protective factors in children's responses to stress and disadvantage. *Annals of the Academy of Medicine, Singapore, 8*(3), 324–338.

Seligman, M. (1998). The epidemic of depression among American youth. In *Promoting positive and healthy behaviors in children: The 14th annual Rosalynn Carter Symposium on Mental Health Policy* (pp. 37–40). Atlanta: The Carter Center Mental Health Program. Retrieved October 23, 2008, from http://www.cartercenter.org/documents/1228.pdf.

Sickmund, M., Snyder, H. N., & Poe-Yamagata, E. (1997). *Juvenile offenders and victims: 1997 update on violence*. Washington, DC: U.S. Department of Justice, Office of Justice Programs, Office of Juvenile Justice and Delinquency Prevention.

Smith, K. (2001, Fall). Owens lecturer posits holistic theory of adolescent development. *The independent variable: Institute for Behavior Research of the University of Georgia*, pp. 2–3.

Snowden, L. R. (1998). Barriers to effective mental health services for African Americans. *Mental Health Services Research, 3*(4), 181–187.

Swartz, K. L. (2001). Recognizing teenage depression. *The Prevention Researcher, 8*(4), 1, 3.

U.S. Public Health Service. (1999). *The Surgeon General's call to action to prevent suicide 1999.* Washington, DC: Author. Retrieved October 23, 2008, from http://www.surgeongeneral.gov/library/calltoaction/calltoaction.htm.

U.S. Public Health Service. (2002). Fundamentals of mental health and mental illnesses. In *Mental health: A report of the Surgeon General* (Chapter 2). Retrieved October 23, 2008, from http://www.surgeongeneral.gov/library/mentalhealth/chapter2/sec1.html.

Vernon, A. (2004). *Counseling children and adolescents* (3rd ed.). Denver, CO: Love Publishing Company.

Vernon, A., & Al-Mabuk, R. (1995). *What growing up is all about: A parents' guide to child and adolescent development*. Champaign, IL: Research Press.

Vontress, C. E., & Epp, L. (1997). Historical hostility in the African American client: Implications for counseling. *Journal of Multicultural Counseling and Development, 25*, 170–184.

Weissberg, R. (1998). Healthy children 2010: Next steps? In *Promoting positive and healthy behaviors in children: The 14th annual Rosalynn Carter Symposium on Mental Health Policy* (pp. 30–36). Atlanta: Carter Center Mental Health Program. Retrieved October 23, 2008, from http://www.cartercenter.org/documents/1228.pdf.

Whitfield, G. W. (1999). Validating school social work: An evaluation of a cognitive-behavioral approach to reduce school violence. *Research on Social Work Practice, 9*, 344–426.

Youth Violence Project: Parent Statistics. (2006). *Trends in family composition.* Retrieved October 23, 2008, from http://www.youthviolence.edschool.virginia.edu/prevention/parent-statistics.html.

Part II
Issues for Caregivers of Adults

In Part I, the authors clearly described the unique experiences and challenges of caregiving that parents and other caregivers encounter as children develop and mature from infancy through late childhood. The chapters included in Part II extend our knowledge of family caregiving as they focus on the experiences of caregivers who attend to the need of adults in early, middle, and old age, including those who are at the end of life.

In Chap. 6, Givens and his colleagues focus on early adult caregivers. They underscore the prevalence of women as caregivers and highlight the challenges that caregivers face as their relationship to the care recipient is transformed from one of adult to child or spouse to a caregiver. In particular, they note the isolation, the role conflicts, added role responsibilities, and the common need to use a “trial and error” approach to acquiring necessary care skills. The authors provide important insights into the changing nature of the caregiving experience which is associated with fluctuations and change in the patient status. They describe a process that is linked to changes in the types and intensity of support that caregivers need as the patient’s disease and problems progress.

In Chap. 7, Gonyea reiterates these common themes as she describes caregiving experienced by middle-aged adults, most of whom care for aging parents. After providing an overview of the demographic trends that have transformed family structures and functioning, she discusses the role conflicts that often emerge for caregivers in this stage of life. In particular, she explores the demands of caregiving in the context of work obligations and other familial obligations, which can include responsibilities for grandchildren. She gives special attention to the significant differences that are associated with gender, race, and income. Finally, Gonyea turns her attention to both public and organizational policies that could potentially reduce role conflicts and address the gender bias that is now inherent in public policies.

In Chap. 8, Montgomery and Kosloski offer a theoretical framework that has implications for research, practice, and policy. Building upon the vast research about caregiving and interventions, they have drawn on both social and psychological literature to create a vision of the caregiving process. The model highlights the dyadic nature of the caregiving role and describes caregiving as a dynamic process wherein the caregiver oscillates between periods of identity change and identity maintenance. The model provides insights into the sources of caregiver stress and mechanisms for identifying interventions to effectively alleviate stress. After describing five phases of caregiving, Montgomery and Kosloski illustrate the way that the model can be used by providers to effectively target services to support family caregivers.

Finally, in Chap. 9, Haley provides a disturbing description of the experience of dying in America and addresses the special situation of caregivers who are attending to the needs of persons at the end of life. A significant emphasis of this chapter is on the grief and emotional work that takes place as the dyadic relationship is transformed from a familial relationship to a caregiver relationship. While emphasizing the fact that family members are often forced to do the work alone, the chapter also provides a glimmer of hope as Haley describes the many benefits of hospice. As a model for developing support services, hospice may be the beginning of an effective policy to support families.

Combined with the chapters in Part I of the book, these chapters complete a portrait of caregiving across the lifespan. In Chapter 10, the editors summarize the common themes that emerge this portrait, which underscore both the continuity of the caregiving experience and the changing nature of the role as it prevails across the life span.

Chapter 6
Early Adult Caregivers: Characteristics, Challenges, and Intervention Approaches

Charles W. Given, Barbara A. Given, Paula Sherwood, and Danielle DeVoss

I am 36 years old, married, with a 7-year-old girl. We live on a farm with my mother, who is 81. She has chronic leukemia, congestive heart failure, high blood pressure, etc. She is currently recovering from pneumonia, which has left her very weak and in need of bladder catherization several times a day. My husband and daughter are very supportive, but my older brother and his family think that all they need to contribute is her supper a few nights a week. . . Now, I worry that if she should become beyond my ability to care for, she might end up in a rest home (Patricia, posted to http://www.caps4caregivers.org/).

My mother is 60 years old. . . As the years went by, the problems got worse, but she was still able to somewhat care for herself, although she could not drive and handle some household chores. . . It has been almost two years now that I have been

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caring for her. My husband is wonderful; he helps me as much as he can and I have a sitter that comes in 5 hours a day, Monday-Friday, which is a huge help. But since she needs round-the-clock care, it get rough; add a new baby girl to the picture (born in April) and three boys, 8–12, and it gets downright tiring. . . If anyone has any suggestions or knows of any agencies that can help, please e-mail me (Julie, posted to http://www.caps4caregivers.org/).

When chronic illness is extreme enough to warrant patient assistance in the home, numerous dimensions of family life are affected, including the social, employment, and family roles of both the patient and the family members providing care. Daily household activities, family income, patterns of communication, family member independence, social support, and family cohesion are affected by patient home care (Lewis, Woods, Hough, & Bensley, 1989; Lewis, Zahlis, & Issel, 1989; Weitzner, Moody, & McMillan, 1997). Family members who care for a loved one have to not only negotiate patient health, but also have to monitor their own physical health and overall well-being, which are often influenced by illness-related stressors or even sacrificed to provide for patient care demands (Beach, Schulz, Yee, & Jackson, 2000; Given et al., 1993).

The effects of home care provision on family caregivers are influenced by a myriad of variables, including the type of disease and its treatment, patient and caregiver age, and access to resources and support, among others. Here we focus specifically on the care experiences of early adult caregivers and the effects that accompany providing care to this demographic cohort. Early adult caregivers merit concentrated attention because younger family members appear to have more difficulty adjusting to the caregiver role. Younger caregivers often have other competing role demands—such as obligations to their spouses and children, and responsibilities related to their employment situation (Given et al., 1993; Schumacher, Dodd, & Paul, 1993). Because of their age—individuals between the ages of 20 and 40 are typically regarded as early adults—it is much more likely for an early adult caregiver to be employed than it is for an elderly caregiver to be employed. Also, for many families with two adults in the household, both must work, whereas historically one family member—typically the wife—remained in the home and coordinated and conducted child care and was also available to provide health care for an ill family member.

Early adult caregivers also merit attention because of changing population dynamics in the United States: The number of elderly persons is increasing at the same time that the number of young people able to provide care is decreasing. A 1996 report indicated that in 1990, 11 caregivers existed for every one individual requiring care for a chronic illness; by 2050, the ratio will have decreased to 4 to 1 (*Chronic Care in America,* 1996). The reasons for the shrinking caregiver pool are diverse and complex. One reason why the pool continues to shrink is because families in the United States are shrinking—couples are having fewer children, and thus have fewer family resources to draw upon as they age. Further, more and more individuals are choosing to enter marriage and childrearing later in life, at a time where traditionally their children may have already been out of the home or near independence. Thus, their time and energy are dedicated toward raising young children rather than providing care for an aging family member, for example, an elderly parent. Moreover, if they themselves become ill, their children may be unable to provide care for them—for example, the children of a couple who waited until their early 40s to have children may be only in their teens when a parent becomes ill, and these children may be emotionally, physically, and financially unable to provide care.

At the same time that social and family dynamics continue to shift, cuts in state and national health care budgets continue to constrict access to and provision of services. Hospital stays are now often quite short. Individuals with a chronic illness typically face regular treatments, procedures, and/or surgeries, and may be returned home—or, in the case of early adult caregivers, to their child's home—while still requiring health care and assistance with follow-up care. The relationship of employment and who owns the health insurance, as a part of employment, can become a major financial issue in many care situations. A tentative financial status, in turn, can significantly increase the emotional distress associated with providing care (Clipp & George, 1990; Given et al., 2004), particularly as resources become depleted. Further, if a caregiver holds the family's health care insurance policy, he or she may be unable to take a leave from work to provide care for an ill family member. Caregivers are thus forced to juggle the demands of a changing formal health care system and the demands of health care provision for their own families.

There are numerous unique challenges facing early adult caregivers that add to the need for sustained attention to their specific caregiving experiences. Often, family roles conflict and compete with, and are disrupted by, care demands (Aneshensel, Pearlin, Mullan, Zarit, & Whitlach, 1995; Hileman, Lackey, & Hassanein, 1992; Kristjanson & Ashcroft, 1994). For example, an adult daughter may be forced to juggle the demands of parent care, child care, and work. Regardless of specific situation, however, role tension is especially acute for early adult caregivers, who often have young children and are may be early in their careers (Stephens & Franks, 1999; Stephens, Franks, & Atienza, 1997). Being caught within multiple and often competing roles as caregiver to an older parent, as parent to children, and as paid worker—who may be responsible for the bulk of the family's income and may hold the family's health insurance policy—is rarely a normative experience for middle-aged adults (see Marks, 1996), but such multiple role commitments are in fact the rule rather than the exception among those adult children involved in parent care. The provision of care may be "off time" and/or unexpected. Resources necessary to provide care—ranging from physical space in the home to money for supplies—may not exist. Lost opportunities at work and in careers, missed social activities, and economic costs such as loss of patient and family income and related to costs of out-of-pocket expenses reflect additional burdens (Collins, Stommel, King, & Given, 1991; Nijboer, Triemstra, Tempelaar, Sanderman, & van der Bos, 1999; Stephens, Townsend, Martire, & Druley, 2001). Because they are relatively young and often assumed to be capable of doing so, early adult caregivers may also take on the roles vacated by the patient (Buehler & Lee, 1992). Balancing multiple roles, including those roles that are new or unfamiliar, is a difficult task, and a task that many early adult caregivers face with limited or inaccessible resources. Making all of these variables even more complex is the fact that caregivers are often left alone to apply "trial and error" techniques to acquire the skills needed to implement caregiving tasks.

Although younger caregivers are more likely to be in better health than their older counterparts—who are more likely to have chronic disease —the health status of early adult caregivers is understudied and provides further justification for a research focus on this caregiver demographic. The physical effects on the caregiver of providing care in the home, such as increased mortality and poor immune functioning (Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991; Schulz & Beach, 1999; Schulz et al., 2001), have been reported in the literature. However, research on the specific health problems of early adult caregivers is largely absent from the literature. While elderly caregivers may suffer from health effects such as forgetting to take routine medications and exacerbations of pre-existing comorbidities, early adult caregivers may face a different set of health effects such as increased health risk behaviors (i.e., smoking) related to stress, altered nutrition, and a decrease in health-promotion activities such as not having routine physicals and screening tests (Beach et al., 2000).

In this chapter, we focus on specific areas of concern related to early adult family caregivers as they become involved in care for a family member, typically a spouse or a parent. We first describe caregiver distress and burden, then identify caregiver characteristics that have been found in relationship to the experience of burden. We then move on to recommendations for education, intervention, practice, and research.

Caregiver Responses to Care: Distress and Burden

Understanding Distress and Burden

Caregiver distress or *caregiver burden* are terms often used interchangeably to describe the physical, psychological, social, financial, and emotional problems experienced by family members providing care (Stetz, 1989). Descriptive studies have provided evidence of caregiver distress and have indicated that this distress continues and worsens over time as care responsibilities increase and/or change (McCorkle et al., 1989; Northouse & Peters-Golden, 1993; Northouse, Mood, Templin, Mellon, & George, 2000; Raveis, Karus, & Siegel, 1998). Restricted work and social roles, lack of privacy, lack of personal and recreational time, decreased overall life satisfaction, frustration, anger, anxiety, and depression may result from caregiving. Depression and anxiety have been most often examined as indicators/symptoms of caregiver distress; descriptive studies have documented that caregivers also experience a sense of helplessness and fear (Nijboer, Tempelaar, Triemstra, van den Bos, & Sanderman, 2001; Northouse, Dorris, & Charron-Moore, 1995; Weitzner et al., 1997).

Distress and burden accumulate to become a persistent hardship—magnified by the reactions of family members and by reactions of the family as a unit (Given, Stommel, & Given, 1989; Given et al., 2005; McCorkle et al., 1989). Caregiver distress is triggered by the strain of care tasks, such as performing complex medical procedures, and by the stress of restrictions in daily life, such as foregoing normal activities (Bisno & Richardson, 1987; Northouse, 1989; Northouse & Swain, 1987). Distress is often linked to confinement imposed by the need to provide monitoring, supervision and care and to perceived abandonment by family members who are not sharing in the provision of care.

Distress is further associated with discrepancies in caregiving role expectations. Early adults who have not experienced the intensity of care provision may be unprepared for the caregiving role. They may have expectations that do not necessarily mesh with their actual experiences providing care. For example, they may not be aware of the physical and emotional toll of bathing an ill family member, or assisting a parent with toileting. They may anticipate rewards that are nonexistent or few and far between, for example, they may expect thanks and gratitude, or recognition for their work by other family members or their community, but that thanks may not actually manifest. In addition, there may be expectations about assuming the caregiving role stemming from family dynamics and sociodemographic characteristics. Differences in expectations by age and ethnicity, for example, may place additive pressure on early adult caregivers to assume the caregiving role (Price, 1994). Family members who assume the caregiving role under social or normative pressure because of their ethnic background or age group may be at increased risk for a negative reaction to providing care (Kurtz, Given, Kurtz, & Given, 1994; Nijboer et al., 2000).

A key dimension contributing to distress and burden for early adult caregivers is overload in role obligations (Northouse, 1989; Northouse et al., 1995, 2000; Oberst & Scott, 1988). Whereas a retired spouse providing care for an ill and also elderly husband may be able to dedicate more time to care, a young adult caregiver may have to juggle employment and care, along with parenting and care, along with multiple other roles. Conflict between the multiple dimensions of a caregiver's life may occur when experiences in one or more roles are especially stressful or in conflict with one another. Further, distress experienced in the caregiver role can proliferate—or spill over—into other life domains and social roles (Aneshensel et al., 1995; Pearlin, Leonard, Mullan, Semple, & Skaff, 1990).

Care Demands That Lead to Distress and Burden

Distress and burden are obviously influenced and often accelerated by the multiple care and role demands that caregivers face. Specific care requirements include performance of or assistance with activities of daily living (e.g., bathing, toileting, dressing) and instrumental activities of daily living (e.g., cooking, cleaning, preparing and/or taking medications, managing household finances). Care tasks range from providing direct care to performing complex health monitoring, assisting with decision-making, and providing emotional support and comfort. Each form of involvement draws upon the mental, emotional, and physical abilities of caregivers, and each type of care task demands different skills and organizational capacities (Schumacher et al., 1993; Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000; Stommel, Given, & Given, 1990). These complex care tasks and associated caregiver requirements can be a source of caregiver distress—although they can often be a source of positive response, as we will discuss later.

Symptom management and control become a major focus for the patient and family as they struggle to manage the disease and its treatment (McCorkle et al., 1989). The severity, number, and frequency of symptoms may dictate the level and type of involvement or care required from the family caregiver. Family care activities may vary from dealing with anger and depression in the patient to the management of acute and severe pain, shortness of breath, nausea, vomiting, or the care of tracheotomies and infusa ports. Symptom distress influences social and physical function, curtails caregiver/patient interaction, and may limit role interactions with others (Clipp & George, 1990; Ferrell, Taylor, Grant, Fowler, & Corbisiero, 1993; Given et al., 1993). Patient symptom distress may lead to such emotional responses as anger, frustration, or depression and fatigue; these symptoms are frustrating and difficult to manage by the caregiver.

Providing emotional support can be equally or more burdensome than providing direct care (Carey, Oberst, McCubbin, & Hughes, 1991). Restrictions of role activities and strain in marital relationships (Weitzner et al., 1997) add to the emotional distress of both patients and caregivers. Changes or restrictions in work roles and career opportunities coupled with financial costs and demands reflect additional burdens (Raveis et al., 1998; Siegel, Raveis, Mor, & Houts, 1991; Stommel, Given, Given, & Collins, 1995).

Duration of Care, Distress, and Burden

A relationship between distress and actual care demands has been assumed to exist, but has not been systematically documented. The amount of time devoted to care, the inability to control timing of care, the intimacy of care required, and the amount of physical care provided have not been systematically examined across diseases. For example, in the Alzheimer's caregiving literature, studies have examined the differential effects of patient related variables (such as functional and cognitive status) on caregiver outcomes (Kaufer et al., 1998; Vitaliano, Russo, Young, Teri, & Maiuro, 1991). Authors have also identified which variables are particularly troublesome for caregivers (for example, dealing with cognitive issues is typically more problematic than assisting with activities of daily living) (Pinquart & Sörensen, 2003). Stage of disease, length of illness, phase in treatment trajectory, symptom experience, impact of the disease and treatment on functional status, psychological impact, and mobility status influence patient needs, and thus also influence the care demand (Given et al., 1993). Most families can respond to needs for assistance of short duration (e.g., 4–6 weeks). However, once care provision extends beyond this time, and as exacerbations and remissions begin to occur, then distress is likely to occur. Unfortunately, this is a time in which little support is available to the caregiver. For example, caregivers typically receive some level of information and support to assist them in providing care during the patient's active treatment. Yet, care demands do not end when active treatment is over (either due to patient's remission of disease or due to the choice of palliative care) (National Cancer Institute, 2003). Caregivers report having to make changes in their personal and social lives to be available to the care recipient well after the patient's diagnosis and initial treatment (Given et al., 1993; Northouse et al., 2000; Northouse & Peters-Golden, 1993). In addition, providing care is typically considered to be a balance—caregivers try to balance care demands with available resources (Folkman, 1997; Lazarus, 1996). If a care situation becomes long-term, available resources may be depleted, which can increase the caregiver's negative stress response (Given, Given, Stommel, & Azzouz, 1999).

Care Across the Illness Trajectory, Distress, and Burden

Making the care situation more complex and sometimes adding to caregiver distress is the fact that caregivers—along with other family members and care providers—must interact and negotiate with the multiple components and representatives of the health care system to obtain information, access services, and acquire equipment. Caregivers must also coordinate with family and friends to enlist and mobilize support for assistance with care. As care demands and requirements change over the course of the disease or illness, caregivers are forced to adapt the amount and intensity of their assistance.

Each fluctuation and change in patient status is associated with differing care demands. The early phase of illness is often accompanied by the need for emotional support and information about the disease and treatment, as well as periods of coping with the disease and treatment. Later stages of illness are accompanied by tasks of care that include numerous medical treatments and care activities centered around personal and dependent care. As the disease and problems progress, the care demands continue but become more complex as the threat of death and caregiver emotions become intertwined with the care. In the terminal stages, caregivers may be overwhelmed with the demands of not only the illness, but also the poor prognosis and threat of approaching death (Cassileth et al., 1985).

Patient reaction to illness across the disease trajectory appears to influence early adult family member reactions, and, at times, caregiver distress equals or exceeds that of the patient (Carey et al., 1991; Given & Given, 1990). Research has indicated that it is not necessarily the number of tasks performed or the caregiving load, but rather changes in care demands that result in caregiver distress (Given et al., 1993). Changes in patient condition due to remissions and exacerbations necessitate changes in caregiver responsibilities; change contributes to stress, and constant adaptations require more work, continued negotiation of roles, and additional adjustment.

It is crucial to consider early adult caregivers in the context of their life situations—not just their care situations—and to assess their multiple role demands, especially when those demands may influence their experiences of illness and burden. Another tool for assessing the situation of early adult caregivers specifically is an understanding of the general characteristics of caregivers that influence their relationship to the care role, and their potential experiences of distress and burden.

Caregiver Characteristics

The characteristics an early adult family caregiver brings to the care situation are crucial in understanding how they might respond to the demands of care. Identifying factors that help define which early adult caregivers might be at risk for negative outcomes is important, and requires attention to age, sex, physical health, living arrangements, costs of care, employment status, role relationships, and family relationships and family functioning.

Age

As discussed in the introduction of this chapter, age is a crucial variable—often providing the larger context of care. Although there are certainly multiple instances that deviate from the norm, family dynamics are generally related to age. Early adult caregivers are at a particular age and often stage in life where they become "sandwiched" between providing care for their spouses and/or children and providing care for a family member. Early adult caregivers are also at a particular age and stage in life where crucial life decisions are made, especially those related to childrearing and career options.

Sex

Sex has been shown to be differentially related to caregiver distress. Female caregivers (wives and daughters) may be more adversely affected by the caregiving role than male caregivers (husbands or sons), a pattern that holds among caregivers of physically impaired, stroke, heart disease, dementia, and cancer patients (Miller & Cafasso, 1992; Robinson, 1990; Sales, Schulz, & Beigel, 1992; Schulz & Williamson, 1991; Schulz, Visintainer, & Williamson, 1990; Siegel et al., 1991). Adverse effects often result from women assuming higher levels of involvement in care. Also following larger social trends, women are often seen as the default caregiver—because women are stereotypically assumed to be more nurturing, they often are assumed to be the family member who will adopt the caregiving role.

Physical Health

Little research has been conducted on physical health outcomes of family caregivers (Schulz & Beach, 1999; Weitzner et al., 1997). Research that has been conducted indicates that family caregivers experience significant negative physical health consequences as patient illness progresses (Given et al., 1992, 1993;

Kurtz et al., 1994). Beach et al. (2000) and Schulz and Beach (1999) found that caregiver strain was generally associated with poor caregiver health status, increased health risk behaviors, higher use of prescription drugs, and increased anxiety and depression. In addition to eating disorders and sleep disturbances (Kiecolt-Glaser et al., 1991), other research has reported lower caregiver immune functioning, altered response to influenza vaccinations (Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, & Sheridan, 1996), slower wound healing (Kiecolt-Glaser et al., 1995), increased blood pressure, and altered lipid profiles (Vitaliano, Russo, & Niaura, 1995) in persons who provide care. Being a high-level caregiver—for example, taking on the bulk of care and performing the majority of care tasks—increases the odds of caregivers getting inadequate rest, having limited time to exercise, and forgetting to take prescription drugs (Burton, Newsom, Schulz, Hirsch, & German, 1997).

Living Arrangements

Caregiver stress may be related to living arrangements, but this relationship has seldom been examined. A patient may move into the caregiver's home to facilitate care provision, or family members may move into the home of the patient to provide care. These sorts of rearrangements may be particularly problematic to early adult caregivers with families of their own; there may not be room in the home, children's rooms may need to be rearranged, or rooms in the home may have to be reconfigured if not rebuilt to accommodate equipment needed for care. In one of the few studies assessing the relationship between living arrangements and caregiver distress, caregivers who lived with a person with cancer were more depressed than those who lived in separate households (Stommel & Kingry, 1991); separate households may provide some respite to the ongoing care activities.

Costs of Care

The informal costs of continuing care can include substantial out-of-pocket costs, loss of income, and family labor costs (Given, Given, & Stommel, 1994). Out-of-pocket expenses for transportation, clothing, special foods, and long-distance telephone charges may cause substantial burden and distress for families. Care is most burdensome for early adult caregivers with low incomes if there are substantial out-of-pocket costs, because of limited financial resources and reserves (Nijboer et al., 1999). Income and overall financial concerns cause distress for caregivers during long periods of caregiving (Clipp & George, 1990) as resources are depleted.

Families with higher incomes may not be as affected by financial hardships, because they are able to purchase or seek additional resources that allow them to better meet care demands (Davis-Ali, Chesler, & Chesney, 1993). Caregivers with fewer economic resources are less likely to hire outside help and are thus more likely to provide more extensive care, which may interfere with the enactment of work and social roles (Aneshensel et al., 1995; Given, Given, Stommel, & Linn, 1994).

Employment Status

Among early adult caregivers, often the care of a family member is done in combination with the potentially conflicting demands of employment (Marks, 1996; Seccombe, 1992). The caregiving role may exacerbate work/family conflict; employee expectations and caregiver expectations are often at conflict. For some caregivers, however, employment provides respite from ongoing care activities and serves as a buffer to distress (Raveis et al., 1998).

Regardless of whether or not work provides a buffer zone for early adult caregivers, most contemporary work environments are not organized to facilitate employee fulfillment of family responsibilities (Glass & Estes, 1997). Caregivers are often forced to adapt employment obligations to manage and meet caregiving obligations (Anastas, Gibeau, & Larson, 1990; Franklin, Ames, & King, 1994; Neal, Chapman, Ingersoll-Dayton, & Emlen, 1993). Caregivers who are employed report withdrawal from work, work absences, or reductions in work productivity (Scharlach, 1994). Perry and Roades de Meneses (1989) found that half of caregivers had difficulty maintaining work roles while assisting family members with cancer. As family members take leaves of absence, miss days of work, or leave work early to provide care, they may be sacrificing economic rewards and benefits, a diversion from caring, enhanced self-esteem, and other personal rewards (Given, Given, Stommel, et al., 1994b). Caregivers who are employed in minimum wage positions or work at small companies may not qualify for paid time off or may not be in situations where the Family Medical Leave Act can be enacted (Bradley, Given, Given, & Kozachik, 2000). In addition, these caregivers may not be financially secure enough to switch to a part-time position, search actively for another job, or retire.

Research has shown that rather than divide time among care tasks and employment responsibilities, employed caregivers do not provide less care to their patients than those caregivers who are not employed (Barnes, Given, & Given, 1992). Sacrifices that caregivers engage in as they maintain high levels of care and fulfill work roles include less personal time for themselves, less social activities, and less privacy. Whereas employed early adult caregivers may face role conflict, unemployed caregivers may experience distress because they may have fewer resources, less financial reserves, and diminished capacity to respond to distress (Mor, Guadagnoli, & Wool, 1988).

Role Relationships

Depending on established family role relationships, caregiving may be a stressful normative expectation, with feelings of obligation and attachment; families may assume caregiving responsibilities as part of expectations that support the commitment to family (Cicirelli, 1993; Vess, Moreland, & Schwebel, 1985a, 1985b). Although care may be initiated with commitment to the family and an overall dedication to care, caregivers often experience conflicts arising from their attempts to balance the demands of the caregiver role with the multiple demands of their other social and family roles (Aneshensel et al., 1995; Stephens & Franks, 1999).

Individuals who have limited personal resources and who are faced with caregiver role demands are more vulnerable to compromised relationships, and role obligations in all life spheres will be perceived as overly demanding, making interrole conflict the norm.

Early adult caregivers who provide parental care, for example, may be caught between their work life and professional careers, and their own family roles as spouse and/or parent. Care responsibilities may at times take precedence over responsibilities to a spouse, to children, to co-workers, and to employers because the care is seen as the more pressing and immediate need (Barnes et al., 1992).

Spousal caregivers appear to be at particular risk for role-related distress, because—meeting the obligations of “in sickness or in health”—they typically provide the most extensive and comprehensive care, maintain the care role longer, and continue to maintain care as patients become more physically challenged (Siegel et al., 1991). Early adults who contribute to or carry the burden of entire responsibility of spouse care also experience more lifestyle adjustment, as they may not only provide care, but also take on roles vacated by their spouse, such as primary breadwinner for the family (Buehler & Lee, 1992). All of these factors can place spousal caregivers at a higher risk for negative reactions to providing care (Given et al., 2004). Compared with spousal care situations, secondary caregivers are more involved in parental care. When a patient is widowed, single, or divorced, more caregivers are typically involved (Given, Given, Stommel et al., 1994b; Tennstedt, McKinlay, & Sullivan, 1989).

Caregiver Characteristics: Family Relationships and Family Functioning

Family caregiving must be placed within a historical context, because the bonds of affection and reciprocity that sustain caregiving take root in past relationships. Both recipient and provider of care bring a history of interactions that may enhance or complicate the caregiving process. Therefore, it is important to consider not only the influence of relationship type (e.g., spouse, parent) but also the quality of the relationship between patient and caregiver. Quality of relationship is incredibly complex; a poor-quality relationship may result in increased caregiver burden, because the caregiver may not feel emotionally committed to the patient and/or may resent care tasks and care provision. A high-quality relationship, however, may also result in increased caregiver burden, because the caregiver may be more emotionally committed to and influenced by care provision (Lawrence, Tennstedt, & Assmann, 1998). Tensions created by not dedicating time to other family members—such as children or, in the care of the provision of care for a parent, a spouse—may contribute to distress within and across family relationships and thus add to the overall distress of the early adult caregiver (Stommel et al., 1990).

Positive Reactions to Care

Although the complex and taxing roles and tasks described above—compounded by a focus on characteristics that may place caregivers at risk—may indicate that caregivers find no relief, no joy, and no escape from distress in the caregiving role, reactions to caregiving may be both negative *and* positive (although the majority of research has focused on the negative aspects of providing care). Positive aspects of caregiving—although not as well documented—are an important but less well documented aspect of care provision. Caregivers, in fact, have described a sense of competency resulting from the accomplishment of organizing and performing caregiving tasks, an improved relationship with the patient, and other positive consequences of providing care (Archbold et al., 1995; Picot, 1995; Picot, Youngblut, & Zeller, 1997). This sense of competency may emerge from the mutuality and reciprocity in the relationship with the care recipient (Given & Given, 1990).

Being a caregiver may be distressing, but, at the same time, caregiving may offer an opportunity to experience increased purpose in life, accelerated personal growth, an amplified sense of accomplishment, and an overall sense of strength. Caregiving may be associated with a sense of gratification, self-satisfaction, and well-being—and the knowledge that one is successfully fulfilling a valued responsibility and tackling a personal challenge (Collins & Given, 1988; Kramer, 1997). Furthermore, levels of caregiver self-esteem and mastery may mediate the relationship between care-related stress and poor psychological well-being (Franks & Stephens, 1992; Moen, Robison, & Dempster-McClain, 1995; Moen, Robison, & Fields, 1994). Especially important for early adult caregivers, rewards and satisfaction experienced through the caregiving role may provide a buffer to help prevent interrole conflict (Raveis et al., 1998).

Few researchers have examined how to create the conditions for positive experiences, yet many investigators have monitored the importance of positive reactions to caregiving. Picot, for example, developed and described the use of a caregiver rewards scale (Picot, 1995; Picot et al., 1997), and Archbold and colleagues (1995) first described the mutuality between the patient and caregiver. It is important to recognize that stressful *and* positive reactions can occur simultaneously (Given et al., 1992; Lawton, Rajagopal, Brody, & Kleban, 1992). Thus it is imperative that both the challenges and the rewards of caregiving be considered when tailoring assistance and that we not focus solely on the negative view, especially for the early adult caregiver. Positive responses need to be fostered to strengthen the patient/caregiver relationship and create a buffer zone for caregivers (Archbold et al., 1995; Stommel et al., 1990).

Strategies to Assist Early Adult Family Caregivers

The needs of early adult family caregivers are based on level and types of care demands; the situations and multiplicity of role demands caregivers face; those caregiver characteristics that influence responses to care; and whether caregiver responses to care provision are negative, positive, or a complex interplay among both negative and positive reactions. Within this complex dynamic are strategies that health care professionals can employ to assess—and also to help avoid—caregiver distress and burden for early adult caregivers. Here we describe a set of these strategies, including understanding the relationships among distress, burden, and caregiver characteristics; fostering communication with caregivers; assessing caregiver preparedness; supporting caregiver ability to cope with and adapt to changing care demands; supporting caregiver self-care; and recognizing existing caregiver resources.

Understanding Distress, Burden, and Caregiver Characteristics

Caregiver distress and burden are biopsychosocial reactions resulting from the interplay of demands relative to resources available, the multiple competing roles early adult caregivers face, and the specific characteristics that may place an early adult caregiver at risk of burden. Caregiver reactions to the patient, to the tasks of care, and to the impositions of the disease and treatment on their lives need to be determined in order to plan for assistance that will enable caregivers to avoid or mediate burden and to continue providing care (Given & Given, 1990; Lewis, Ellison, & Woods, 1985; McCorkle et al., 1989; Northouse, 1988, 1989; Schulz, Fello, & Love, 1989; Stetz, 1989; Stommel et al., 1990).

Overall role relationships and previous relationships between the patient and caregiver need to be considered as variables affecting the dynamics of care and the caregiver's response to providing care (Hong & Seltzer, 1995; Moen, Dempster-McClain, & Williams, 1989). Integration of care roles with usual family roles may prevent caregiver distress (Zarit, Todd, & Zarit, 1986) during care provision; thus, caregiver roles must be assessed beyond caregiving tasks. Health care providers should pay attention to the larger family, social, and employment roles typically held by the caregiver. Integration of roles, when possible, can serve to facilitate better communication among family members, protect against role disruption, and mediate role strain. It is also essential to understand how caregivers view the caregiving role and how that role contributes to their overall sense of well-being as well as to their distress (Stephens et al., 1997).

The age of the primary caregiver, family stage, and relationship to the care recipient can all affect how the care situation will be implemented. Health care professionals should anticipate the demands of the other social and work roles of caregivers and how these can be accomplished while meeting the care needs of the family member. Early adult caregivers need assistance to examine and attempt to balance all their family and household roles along with the care roles they must assume. Such examination allows caregivers to identify where conflicts are likely to arise, pinpoint sources of conflict, identify who can help to alleviate them, and focus on what can be done to deal with role overload or role conflict. Caregivers need assistance to forgo non-essential roles as well as to delegate roles, where possible, when care demands are heavy. Resources need to be matched to the needs of the caregiver. Young caregivers, who may be more independent, may further need support to recognize when they need help and to accept available assistance.

Reducing work/family conflict for employed caregivers might considerably lower caregiver distress. More flexible time schedules, higher availability of quality part-time work, access to sick leave and family leave for family care, access to more information pertinent to caregiving, and additional day programs could reduce distress and, perhaps, increase work performance among young adult caregivers (Glass & Estes, 1997; Neal et al., 1993; Seccombe, 1992). Society in general needs to better address the work/care dynamic more carefully as the United States faces the care of an aging population.

Because caregiving demands—and thus responses to care provision—shift as patient needs change over time, it is important to determine what gives rise to both positive and negative reactions, and how reactions accumulate, wax, and wane in response to the challenging needs of patients. Caregivers need to be assisted by health care professionals to adjust to changing demands—both improvements and deterioration.

Fostering Communication with Caregivers

Caregivers as well as patients must be considered integral collaborative members of the health care team and should be involved in all components of care management and care-related decisions. It is critical that health professionals begin from that premise and integrate family members into plans of care. Caregivers need accurate and dependable information about diagnosis, prognosis, treatment, and expected care trajectory so that they can predict needed care and thus anticipate the demands they are likely to face.

Receiving information concerning the disease and treatment and knowing what symptoms and side effects to expect will reduce uncertainty and hopefully mediate unexpected occurrences. Care guidelines can assist caregivers to understand what is happening to the patient and may promote communication among family members and between family members and health care professionals. Early adult caregivers typically want to be informed and want access to information; information gives them a sense of control over their caregiving responsibilities. Caregivers need assistance from professionals to gain knowledge and skills, to feel competent, and to feel as if their contribution to care are valuable and valued.

Assessing Caregiver Preparedness

Open patterns of communication with caregivers will help formal health care providers to determine if caregivers are prepared to assume the caregiving roles unique to their patient. A family member may be suitably prepared to undertake care given their patient's current needs. Ongoing assessment of and assistance with preparedness are necessary, however, if caregivers are to assume and master new and or additional physical, social, and psychological demands of home care as their patient moves through the disease course. Anticipation of cares requirements, information, guidance, and support for family caregivers should be part of providers ongoing plan of care. Caregivers may not know which tasks are most important, which tasks they will face and when, and which resources they can draw upon across the disease trajectory. Assessing caregiver preparedness on a task-by-task or role-by-role basis and intervening where necessary is a crucial step in assessing caregiver preparedness and developing preparedness across the care trajectory.

Caregiver capacity and capability of performing skills necessary to care successfully for their patient at home need to be assessed and reassessed at regular intervals. Skills might be broken down and approached as follows. First is the ability to monitor, which includes the ability to make accurate and specific observations and notice subtle changes and patterns. The ability to interpret is needed next, which involves a capacity to recognize deviations from the normal course of the illness, judge the seriousness of the problem, seek an explanation of the problem, ask detailed questions, and make correct attributions for the problem. Another caregiver skill that may require assessment is the ability to make decisions and take action—that is, the ability to prioritize patient problems and think ahead about the possible consequences of decisions (Schumacher et al., 2000).

Supporting Caregiver Ability to Cope with and Adapt to Changing Care Demands

The ability to cope with and to negotiate care demands as patient conditions change help caregivers to adapt effectively to the demands of caregiving roles. Although longitudinal data suggest that families do adapt to the multiple changes that occur across the course of illness—related to, for example, changes in patient dependency, depression, and negative reactions to being cared for—each family situation is unique, and each caregiver presents characteristics that must be recognized and assessed (Lewis, Woods, et al., 1989; Vinokur, Threatt, Caplan, & Zimmerman, 1989).

Care of a family member creates demands not previously experienced by most family members. Further, the pattern of care demands varies in magnitude and type and changes numerous times depending on the illness and treatment. Family members move through multiple transitions characterized by periods of uncertainty, role change, and emotional change. This is especially difficult for young adult caregivers who may have many competing family, work, and social role demands. Families need assistance to reframe their perception of the care experience so that they focus on the strengths and resources they bring to the care situation and health professionals need to be attentive to this.

Supporting Caregiver Self-Care

The physical and emotional health of the caregiver should be considered. Caregivers tend to sacrifice their own health care demands, particularly preventive health behaviors, in exchange for meeting patient medical demands (Given & Given, 1996). Caregivers are less likely to make and keep annual physical checkup appointments, have routine screening evaluations such as yearly mammograms, and maintain current immunizations. In addition, caregivers tend to display more risky health behaviors and have poorer perceptions of their health status (Beach et al., 2000).

Recognizing Caregiver Resources

Caregiver personal resources—such as disposition and ability to recognize and try to mediate experiences of stress—may contribute to the experience of burden or distress (Pearlin et al., 1990). Personality traits such as optimism or personal hardiness may have an important role in determining how the caregiver is likely to react to the imposition of caring for a family member. Social and psychological resources required by caregivers need to be considered as caregivers take on the process of care (Nijboer et al., 2001). Caregiver optimism can mediate caregiver reactions to care and overall burden, but optimism must be fostered and supported, especially for caregivers who do not have personality reserves to drawn upon (Given et al., 1989; Kurtz, Kurtz, Given, & Given, 1993).

Informal support may lead to respite or assistance in care tasks. Most studies have documented that perceived quality and perceived adequacy of family and friend support is more important than actual quality of support received (Clipp & George, 1990). The amount of social support provided by secondary caregivers to support family members may be influenced by severity and length of illness, and literature suggests that over time, secondary caregivers leave the care situation (Given et al., 1992).

Conclusions

We can never know all of the characteristics that affect experiences of care or caregiver role adoption and negotiation, but we can be better equipped to support family caregivers, especially early adult caregivers. A complete assessment of the care situation, including the evaluation of caregiver knowledge, skills, health, family roles, and available resources is vital before any interventions to support caregiver health and well-being are instituted. Once interventions have been put in place, the practitioner should reassess the situation at regular intervals throughout the course of illness, anticipating that caregiver roles, skills, and needs will change throughout the patient's trajectory of illness. In particular, it is critical to reevaluate the care situation during family life cycle transitions such as births, deaths, and retirement. Reassessment will provide the opportunity to continue monitoring caregiver health, provide support for the caregiver with troubleshooting and problem solving, and identify potentially burdensome problems before they escalate into caregiver distress. Such deep assessment and work with family caregivers begins with early preparedness of health care professionals and with continued research focused on caregiving, especially on the experiences of early adult caregivers.

Preparing Health Care Professionals

There is a tremendous need to better prepare health care professionals to be attentive to the needs of caregivers and to carefully evaluate the strengths and shortcomings of the family unit within the dynamics of care for chronic conditions. Professionals need to be educated during as well as after their formal training about the value of the family care role. With training, health care professionals are more likely to appreciate the value of family care to their ongoing practice settings. Professionals need to understand how to assess the roles and trends within a family to understand when challenges and conflicts might occur. A systematic assessment of family roles and relationships and how those relationships influence family patterns of care should be a part of every medical/nursing health professional school. Family members are valuable partners in patient care and recovery, and should be recognized as part of the health care team; this recognition is rarely visible in health care curriculum. Returns on this investment could well be expressed in terms of fewer unnecessary visits and hospital admissions, as well as fewer medical crises for patients whose family members are able to monitor effectively and to detect early on signs and symptoms that require action.

Professionals need to be taught how to assess caregiver capacity to care in light of patient needs. Although general caregiving programs are available, effective home care will occur only when health professionals assess the needs of patients, the capacity of caregivers to provide care and to educate caregivers as to what are key signs and symptoms or other aspects of care to achieve the desired outcomes. In this chapter, we have reviewed the situational and personal features that may affect caregiver success.

Fostering Further Research on Early Adult Caregivers

Future research should examine further the impact of multiple role commitments on early adult caregivers well-being and, in particular, should include representative samples of caregivers, assess the impact of multiple roles on both male and female caregivers, and differentiate primary from secondary caregivers. Future research should also focus on the complexities of the relationships involved in care situations, elaborating what it is about various combinations of roles that enhances or reduces caregiver stress and well-being, as well as examining when and for whom multiple roles enhance or reduce caregiver stress and well-being. Future research also needs to focus on younger families; we know little about the special needs of family caregivers in early adulthood. Most of the existing literature is focused on the caregivers of patients having bone marrow transplants, and even that literature is limited (Boyle et al., 2000; McDonald, Stetz, & Compton, 1996).

Important research questions to address include:

- Which early adult caregiver variables most influence caregiver distress and burden?
- Which processes of care in the home interact with caregiver variables in early adulthood to explain differing levels of distress and burden?
- What are the unreported or understudied early adult caregiver variables that most require research attention?
- What approaches and interventions best seem to prevent and/or moderate the experiences of distress and burden among early adult caregivers?
- What further research can be conducted to explore both the similarities and differences in experiences among early adult and elderly caregivers?
- Do responses of early adult caregivers vary based on relationship to patient; if so, in what ways does the variance become manifest?
- Do the care responses of early adult caregivers vary based on ethnic and/or racial diversity?
- What roles can health professional play in providing information and support to make caregiving more effective and does this reduce distress and burden for the caregiver and or improve the quality of life of the patient?

These questions are a short list of possible future research directions necessary for us to begin to address so that we can better understand the care experiences of early adult caregivers. We are—as health care providers and as a larger society—in dire need of more complex and robust knowledge of the experiences of early adult caregivers as we face the population trends predicted in the coming years. More and more underequipped and unprepared early adults will face the multiple and complex tasks necessary to provide home care for a loved one. More and more underequipped and unprepared early adults will face multiple and competing role tasks as they add the care role onto their already substantial list of life roles. Without understanding the trajectory of distress and burden, the complex characteristics that may place early adult caregivers at risk, the breadth of responses and reactions to the care situation, and ways that we can perhaps mediate negative caregiver reactions and caregiver experiences of distress and burden, we are unequipped to face the inevitable future.

I am 25 years old, youngest of three daughters of. . . a 58-year-old who sufferers with Alzheimer's disease. I am also her caregiver for now, it is sad to say. But it is a struggle because I am pregnant and already have a 7-year-old son and because of my mother's condition I can only work about three days per week. I currently have my mom in adult day care, which is very helpful but also expensive. For now this is my story (Doreen, posted to http://www.caps4caregivers.org/).

I just found this site. I am nearly out of my mind. My mother is becoming confused at 76 and her husband of 27 years has severe dementia. He is going to be going home with my mother from a nursing home this Saturday. I don't know how to deal. They have no money. I am a single mother of two and have dedicated my life to my children. Now this. Do I stop living? My mother is not a very pleasant person and to live with her or her with us, first of all, is impossible right now; but if it works out, it would drive my children away. . . Any suggestions would be appreciated. I work all day, oftentimes 14 to 16 hours, then come home to my children. I feel so useless in all of this (Darlene, posted to http://www.caps4caregivers.org/).

References

Anastas, J. W., Gibeau, J. L., & Larson, P. J. (1990). Working families and eldercare: A national perspective in an aging America. *Social Work, 35*(5), 405–411.

Aneshensel, C. S., Pearlin, L., Mullan, J. T., Zarit, S. H., & Whitlach, C. J. (1995). *Profiles in caregiving: The unexpected career*. San Diego, CA: Academic Press.

Archbold, P. G., Stewart, B. J., Miller, L. L., Harvath, T. A., Greenlick, M. R., Van Buren, L., et al. (1995). The PREP system of nursing interventions: A pilot test with families caring for older members. Preparedness (PR), enrichment (E), and predictability (P). *Research in Nursing Health, 18*(1), 3–16.

Barnes, C. L., Given, B. A., & Given, C. W. (1992). Caregivers of elderly relatives: Spouses and adult children. *Health and Social Work, 17*(4), 282–289.

Beach, S., Schulz, R., Yee, J., & Jackson, S. (2000). Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the Caregiver Health Effects Study. *Psychology and Aging, 15*(2), 259–271.

Bisno, B., & Richardson, J. L. (1987). The relationship between depression and reinforcing events in cancer patients. *Journal of Psychosocial Oncology, 5*, 63–71.

Boyle, D., Blodgett, L., Gnesdiloff, S., White, J., Bamford, A. M., Sheridan, M., et al. (2000). Caregiver quality of life after autologous bone marrow transplantation. *Cancer Nursing, 23*(3), 193–203.

Bradley, C., Given, B., Given, C., & Kozachik, S. (2000). Physical, economic, and social issues confronting patients and families. In C. Yearbo, M. Frogge, M. Goodman, & S. Groenwald (Eds.), *Cancer nursing: Principles and practice* (5th ed., pp. 1550–1564). Boston: Jones & Bartlett.

Buehler, J. A., & Lee, H. J. (1992). Exploration of home care resources for rural families with cancer. *Cancer Nursing, 15*(4), 299–308.

Burton, L. C., Newsom, J. T., Schulz, R., Hirsch, C. H., & German, P. S. (1997). Preventive health behaviors among spousal caregivers. *Preventative Medicine, 26*(2), 162–169.

Carey, P., Oberst, M., McCubbin, M., & Hughes, S. (1991). Appraisal and caregiving burden in family members caring for patients receiving chemotherapy. *Oncology Nursing Forum, 18*(8), 1341–1348.

Cassileth, B. R., Lusk, E. J., Strouse, T. B., Miller, D. S., Brown, L. L., & Cross, P. A. (1985). A psychological analysis of cancer patients and their next-of-kin. *Cancer, 55*(1), 72–76.

Cicirelli, V. G. (1993). *Family caregiving: Autonomous and paternalistic decision making*. Newbury Park, CA: Sage.

Chronic care in America: A 21st century challenge. (1996, August). Princeton, NJ: RWJ Foundation.

Clipp, E. C., & George, L. K. (1990). Caregiver needs and patterns of social support. *Journal of Gerontology, 45*, S102–S111.

Collins, C., & Given, C. W. (1988, November). *Use of community services among family caregivers of Alzheimer's patients*. Presented for the Department of Mental Health, Alzheimer's Demonstration Projects, Lansing, MI.

Collins, C., Stommel, M., King, S., & Given, C. (1991). Assessment of the attitudes of family caregivers toward community services. *Gerontologist, 31*(6), 756–761.

Davis-Ali, S. H., Chesler, M. A., & Chesney, B. K. (1993). Recognizing cancer as a family disease: Worries and support reported by patients and spouses. *Social Work in Health Care, 19*(2), 45–65.

Ferrell, B. R., Taylor, E. J., Grant, M., Fowler, M., & Corbisiero, R. (1993). Pain management at home: Struggle, comfort, and mission. *Cancer Nursing, 16*(3), 169–178.

Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science and Medicine, 45*, 1207–1221.

Franks, M. M., & Stephens, M. (1992). Multiple roles and middle-generation caregivers: Contextual effects and psychological mechanisms. *Journals of Gerontology, Psychological Sciences and Social Sciences, 47*, S123–S129.

Franklin, S. T., Ames, B. D., & King, S. (1994). Acquiring the family elder care role: Influence on female employment adaptation. *Research on Aging, 16*(1), 27–42.

Given, B., & Given, C. W. (1990, May). *Cancer patients' symptoms: Relationship to family reactions and involvement in care.* Presented at the 15th Annual Congress of the Oncology Nursing Society, Washington, DC.

Given, B. A., Given, C. W., & Stommel, M. (1994a). Family and out-of-pocket costs for women with breast cancer. *Cancer Practice, 2*, 187–193.

Given, B., Given, C. W., Stommel, M., & Linn, C. S. (1994b). Predictors of use of secondary careers used by the elderly following hospital discharge. *Journal of Aging and Health, 6*, 353–376.

Given, C., Given, B., Stommel, M., & Azzouz, F. (1999). The impact of new demands for assistance on caregiver depression: Testing an inception cohort. *Gerontologist, 39*(1), 76–85.

Given, C. W., Given, B., Stommel, M., Collins, C., King, S., & Franklin, S. (1992). The caregiver reaction assessment (CRA) for persons with chronic physical and mental impairments. *Research in Nursing and Health, 15*, 271–283.

Given, B., Given, C., Wyatt, G., DeVoss, D., Rahbar, M., & Gift, A. (2005). Burden and depression among caregivers of patients with cancer at the end-of-life. *Oncology Nursing Forum, 31*(6), 1105–1117.

Given, B., Stommel, M., & Given, C. W. (1989). *The role of patients' symptoms, functional status, and psychological health on families' reactions to caregiving*. Atlanta, Georgia: Presented at the First National Conference on Cancer Nursing Research sponsored by the American Cancer Society.

Given, C. W., Stommel, M., Given, B., Osuch, J., Kurtz, M., & Kurtz, J. C. (1993). The influence of cancer patients' symptoms and functional states on patients' depression and family caregivers' reaction and depression. *Health Psychology, 12*, 277–285.

Given, B., Wyatt, G., Given, C.W., Sherwood, P., Gift, A., DeVoss, D., et al. (2004). Burden and depression among caregivers of patients with cancer at the end of life. *Oncology Nursing Forum, 31*(6), 1105–1117.

Glass, J. L., & Estes, S. B. (1997). The family responsive workplace. *Annual Review of Sociology, 23*, 289–313.

Hileman, J. W., Lackey, N. R., & Hassanein, R. S. (1992). Identifying the needs of home caregivers of patients with cancer. *Oncology Nursing Forum, 19*(5), 771–777.

Hong, J., & Seltzer, M. M. (1995). The psychological consequences of multiple roles: The non-normative case. *Journal of Health and Social Behaviour, 36*, 386–398.

Kaufer, D., Cummings, J., Christine, D., Bray, T., Castellon, S., Masterman, D., et al. (1998). Assessing the impact of neuropsychiatric symptoms in Alzheimer's disease: The Neuropsychiatric Inventory Caregiver Distress Scale. *Journal of the American Geriatrics Society, 46*(2), 210–215.

Kiecolt-Glaser, J. K., Dura, J. R., Speicher, C. E., Trask, O. J., & Glaser, R. (1991). Spousal caregivers of dementia victims: Longitudinal changes in immunity and health. *Psychosomatic Medicine, 53*(4), 523–535.

Kiecolt-Glaser, J. K., Glaser, R., Gravenstein, S., Malarkey, W. B., & Sheridan, J. (1996). Chronic stress alters the immune response to influenza vaccine in older adults. *Proceedings of the National Academy of Sciences of the United States of America, 93*(2), 3043–3047.

Kiecolt-Glaser, J. K., Marucha, P. T., Gravenstein, S., Malarkey, W. B., Mercado, A. M., & Glaser, R. (1995). Slowing of wound healing by psychological distress. *Lancet, 346*(8984), 1194–1196.

Kramer, B. J. (1997). Gain in the caregiving experience: Where are we? What next? *Gerontologist, 37*, 218–232.

Kristjanson, L. J., & Ashcroft, T. (1994). The family's cancer journey: A literature review. *Cancer Nursing, 17*, 1–17.

Kurtz, M., Given, B., Kurtz, J., & Given, C. (1994). The interaction of age, symptoms, and survival status on physical and mental health of patients with cancer and their families. *Cancer, 74*(7 Suppl.), 2071–2078.

Kurtz, M. E., Kurtz, J. C., Given, C. W., & Given, B. (1993). Loss of physical functioning among patients with cancer: A longitudinal view. *Cancer Practice, 1*(4), 275–281.

Lawrence, R. H., Tennstedt, S. L., & Assmann, S. F. (1998). Quality of the caregiver-care recipient relationship: Does it offset negative consequences of caregiving for family caregivers? *Psychology and Aging, 13*, 150–158.

Lawton, M., Rajagopal, D., Brody, E., & Kleban, M. (1992). The dynamics of caregiving for a demented elder among Black and White families. *Journals of Gerontology: Series B, Psychological Sciences & Social Sciences, 47*(Suppl), 156–164.

Lazarus, R. (1996). *Psychological stress and the coping process*. New York: McGraw-Hill.

Lewis, F., Ellison, E., & Woods, N. (1985). The impact of breast cancer on the family. *Seminars in Oncology Nursing, 1*(3), 206–213.

Lewis, F. M., Woods, N. F., Hough, E. E., & Bensley, L. S. (1989). The family's functioning with chronic illness in the mother: The spouse's perspective. *Social Science Medicine, 29*, 1261–1269.

Lewis, F. M., Zahlis, E. H., & Issel, L. M. (1989, May). *The couple's experience with early stage breast cancer: A qualitative analysis*. San Francisco, CA: Presented at the Annual Congress of the Oncology Nursing Society.

Marks, N. F. (1996). Caregiving across the lifespan: National prevalence and predictors. *Family Relations, 45*, 27–36.

McCorkle, R., Benoliel, J. Q., Donaldson, G., Georgiadou, F., Moinpour, C., & Goodell, B. (1989). A randomized clinical trial of home nursing care for lung cancer patients. *Cancer, 64*, 1375–1382.

McDonald, J. C., Stetz, K. M., & Compton, K. (1996). Educational interventions for family caregivers during marrow transplantation. *Oncology Nursing Forum, 23*(9), 1432–1439.

Miller, B. H., & Cafasso, L. (1992). Gender differences in caregiving: Fact or artifact? *Gerontologist, 32*, 598–607.

Moen, P., Dempster-McClain, D., & Williams, R. M., Jr. (1989). Social integration and longevity: An event history analysis of women's roles and resilience. *American Sociological Review, 54*, 635–647.

Moen, P., Robison, J., & Dempster-McClain, D. (1995). Caregiving and women's well-being. *A life course approach. Journal of Health and Social Behaviour, 36*, 259–273.

Moen, P., Robison, J., & Fields, V. (1994). Women's work and caregiving roles: A life course approach. *Journal of Gerontology, 49*(4), S176–S186.

Mor, V., Guadagnoli, E., & Wool, M. (1988). The role of concrete services in cancer care. *Advances in Psychosomatic Medicine, 18*, 102–118.

National Cancer Institute. (2003). *After cancer treatment ends—The impact on caregivers and families. Report of focus groups with caregivers and oncology social workers*. Bethesda, Maryland: Author.

Neal, M. B., Chapman, N. J., Ingersoll-Dayton, B., & Emlen, A. C. (1993). *Balancing work and caregiving for children, adults, and elders*. Newbury Park, CA: Sage.

Nijboer, C., Triemstra, M., Tempelaar, R., Mulder, M., Sanderman, R., & van den Bos, G. (2000). Patterns of caregiver experiences among partners of cancer patients. *Gerontologist, 40*(6), 738–746.

Nijboer, C., Tempelaar, R., Triemstra, M., van den Bos, G., & Sanderman, R. (2001). The role of social and psychological resources in caregivers of cancer patients. *Cancer, 89*(5), 1029–1039.

Nijboer, C., Triemstra, M., Tempelaar, R., Sanderman, R., & van der Bos, G. (1999). Determinants of caregiving experiences and mental health of partners of cancer patients. *Cancer, 86*(4), 577–588.

Northouse, L. (1988). Social support in patients' and husbands' adjustment to breast cancer. *Nursing Research, 37*, 91–95.

Northouse, L. (1989). A longitudinal study of the adjustment of patients and husbands to breast cancer. *Oncology Nursing Forum, 16*, 511–516.

Northouse, L., Dorris, G., & Charron-Moore, C. (1995). Factors affecting couples' adjustment to recurrent breast cancer. *Social Science and Medicine, 41*(1), 69–76.

Northouse, L., Mood, D., Templin, T., Mellon, S., & George, T. (2000). Couples' patterns of adjustment to colon cancer. *Social Science and Medicine, 50*, 271–284.

Northouse, L., & Peters-Golden, H. (1993). Cancer and the family: Strategies to assist spouses. *Seminars in Oncology Nursing, 9*, 74–82.

Northouse, L., & Swain, M. A. (1987). Adjustment of patients and husbands to the initial impact of breast cancer. *Nursing Research, 36*, 221–225.

Oberst, M. T., & Scott, D. W. (1988). Post discharge distress to surgically treatment cancer patients and their spouses. *Research in Nursing, 11*, 223–233.

Pearlin, L., Leonard, I., Mullan, J. T., Semple, S., & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist, 30*(5), 583–594.

Perry, G., & Roades de Meneses, M. (1989). Cancer patients at home: Needs and coping styles of primary caregivers. *Home Healthcare Nurse, 7*(6), 27–30.

Picot, S. (1995). Rewards, costs, and coping of African American caregivers. *Nursing Research, 44*(3), 147–152.

Picot, S., Youngblut, J., & Zeller, R. (1997). Development and testing of a measure of perceived caregiver or adults. *Journal of Nursing Measurement, 5*(1), 33–52.

Pinquart, M., & Sörensen, S. (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depressed mood: A meta-analysis. *Journal of Gerontology: Psychological Sciences, 58B*(2), 112–128.

Price, M. (1994). African American daughters' attitudes about caregiving to frail, elderly parents. *The Journal of the Association of Black Nursing Faculty in Higher Education, 5*(4), 112–116.

Raveis, V., Karus, D., & Siegel, K. (1998). Correlates of depressive symptomatology among adult daughter caregiver of a patient with cancer. *Cancer, 83*(8), 1652–1663.

Robinson, K. M. (1990). Predictors of burden among wife caregivers. *Scholarly Inquiry for Nursing Practice, 4*(3), 189–203.

Sales, E., Schulz, R., & Beigel, D. (1992). Predictors of strain in families of cancer patients: A review of the literature. *Journal of Psychosocial Oncology, 10*, 1–26.

Scharlach, A. (1994). Caregiving and employment: Competing or complementary roles? *Gerontologist, 34*, 378–385.

Seccombe, K. (1992). Employment, the family, and employer-based policies. In J. W. Dwyer & R. T. Coward (Eds.), *Gender, families, and elder care* (pp. 165–180). Newbury Park, CA: Sage.

Schumacher, K., Dodd, M., & Paul, S. (1993). The stress process in family caregivers of persons receiving chemotherapy. *Research in Nursing and Health, 16*, 395–404.

Schumacher, K., Stewart, B., Archbold, P., Dodd, M., & Dibble, S. (2000). Family caregiving skill: Development of the concept. *Research in Nursing and Health, 23*(3), 191–203.

Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *Journal of the American Medical Association, 282*(23), 2215–2219.

Schulz, R., Beach, S., Lind, B., Martire, L., Zdaniuk, B., Hirsch, C., et al. (2001). Involvement in caregiving and adjustment to death of a spouse: Findings from the Caregiver Health Effects Study. *Journal of the American Medical Association, 285*(24), 3123–3129.

Schulz, R., Fello, M., & Love, J. (1989). Grant entitled "Living with Homecare Cancer Patients and Caregivers." Funded by the National Institutes of Health.

Schulz, R., Visintainer, P., & Williamson, G. (1990). Psychiatric and physical morbidity effects of caregiving. *Journal of Gerontology: Psychological Sciences, 45*, P181–P191.

Schulz, R., & Williamson, G. (1991). A 2-year longitudinal study of depression among Alzheimer's caregivers. *Psychology and Aging, 6*, 569–578.

Siegel, K., Raveis, V., Mor, V., & Houts, P. (1991). The relationship of spousal caregiver burden to patient disease and treatment-related conditions. *Annals of Oncology, 2*(7), 511–516.

Stephens, M. A. P., & Franks, M. M. (1999). Parent care in the context of women's multiple roles. *Current Directions in Psychological Science, 8*, 149–152.

Stephens, M. A. P., Franks, M. M., & Atienza, A. A. (1997). Where two roles intersect: Spillover between parent care and employment. *Psychology and Aging, 12*, 30–37.

Stephens, M., Townsend, A., Martire, L., & Druley, J. (2001). Balancing parent care with other roles: Interrole conflict of adult daughter caregivers. *Journal of Gerontology, Series B, Psychological Sciences and Social Sciences, 56*(1), 24–34.

Stetz, K. (1989). The relationship among background, characteristics, purpose in life, and caregiving demands on perceived health of spouse caregivers. *Scholarly Inquiry for Nursing Practice: An International Journal, 3*, 133–151.

Stommel, M., Given, B., Given, C. W., & Collins, C. (1995). The impact of the frequency of care activities on the division of labor between primary caregivers and other care-providers. *Research on Aging, 17*(4), 412–433.

Stommel, M., Given, C. W., & Given, B. (1990). Depression as an overriding variable explaining caregiver burdens. *Journal of Aging and Health, 2*, 81–102.

Stommel, M., & Kingry, M. (1991). Support patterns for spouse-caregivers of cancer patients: The effect of the presence of minor children. *Cancer Nursing, 14*(4), 200–205.

Tennstedt, S., McKinlay, J., & Sullivan, L. (1989). Informal care for frail elders: The role of secondary caregivers. *Gerontologist, 29*(5), 677–683.

Vess, J., Moreland, J., & Schwebel, A. (1985a). An empirical assessment of the effects of cancer on family role functioning. *Journal of Psychosocial Oncology, 3*, 1–6.

Vess, J., Moreland, J., & Schwebel, A. (1985b). A follow-up study of role functioning and the psychosocial environment of families of cancer patients. *Journal of Psychosocial Oncology, 3*, 1–4.

Vinokur, A., Threatt, B., Caplan, R., & Zimmerman, B. L. (1989). Physical and psychosocial functioning and adjustment to breast cancer: Long-term follow-up of a screening population. *Cancer, 63*, 394–405.

Vitaliano, P., Russo, J., & Niaura, R. (1995). Plasma lipids and their relationships with psychosocial factors in older adults. *Journals of Gerontology, Series B, Psychological Sciences and Social Sciences, 50*(1), 18–24.

Vitaliano, P., Russo, J., Young, H., Teri, L., & Maiuro, R. (1991). Predictors of burden in spouse caregivers of individuals with Alzheimer's disease. *Psychology and Aging, 6*(3), 392–402.

Weitzner, M., Moody, L., & McMillan, S. (1997). Symptom management issues in hospice care. *American Journal of Hospice and Palliative Care, 14*(4), 190–195.

Zarit, S., Todd, P., & Zarit, J. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. *Gerontologist, 26*, 260–266.

Chapter 7
Midlife, Multigenerational Bonds, and Caregiving

Judith G. Gonyea

The dramatic increases in life expectancy that have occurred throughout the twentieth century have had a profound impact on both individuals and families. In 1900, the average life expectancy was 47 years and people over 65 years of age accounted for approximately only 4% of the U.S. population—or less than one in 25 persons. Today, life expectancy at birth has risen to 72.5 years for men and 79.3 years for women and people over the age of 65 represent 12.8% of the total U.S. population (U.S. Census Bureau, 2000). The democratization of the aging experience or the longevity revolution has led to a life course revolution (Skolnick, 1991). The changes in mortality have greatly influenced the concepts of young, middle, and older adulthood. Moreover, as a result of longer life expectancy, many of today's families are multigenerational. Indeed, the modal family structure for American adults aged 50–54 is a three-generation family of adults who have one or more parents or parents-in-law and one or more children.

In this chapter, we explore the impacts of families experiencing more years of "shared living between generations" on middle-aged adults. Our focus is on the role of the middle generation as the "kinkeepers" with a special emphasis on the adult child and aging parent caregiving relationship. As part of our analysis we explore how gender, race, ethnicity, and culture may influence appraisal of the parent care role. We also examine the effectiveness of caregiver interventions in enhancing family members' well-being. For most individuals, the midlife experience revolves around family and work. Thus, we examine how structural transformations in these two domains affect how men and women negotiate their caregiving responsibilities as well as the responsiveness of public and private sector policies to the changing realities confronting families.

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Middle Adulthood

The middle years of adulthood have been referred to as the "last uncharted territory in human development" (Brim, 1992, p. 171). Concern about the welfare of children and the elderly contributed to the scientific study of these two vulnerable populations. In contrast, few resources were directed towards the study of middle adulthood because, from a public policy perspective, adults were not viewed as a vulnerable population requiring protection of "their best interests" by the state. The aging of the baby boomer generation and the sheer number of this cohort entering midlife, however, has generated new interest in this life stage. In 2000, over 80 million members of the baby boomer generation were between the ages of 35 and 54 (U.S. Census Bureau, 2000). This interest spurred, for example, the MacArthur Foundation Research Network on Successful Midlife Development (MIDMAC), one of the most significant interdisciplinary research endeavors devoted to the study of midlife. Indeed, a primary objective of MIDMAC is to support the development of national representative databases that allow the identification of "major biological, psychological well-being, and social responsibility during their adult years" (http://midmac.med.harvard.edu).

It has been noted that the period called middle age lacks well-defined boundaries. Farrell and Rosenberg (1981, p.16) suggest "like defining a period of history, no one quite agrees when middle age begins or ends." Not surprisingly, the subjective boundaries of middle age vary positively with age (Lachman, Lewkowicz, Marcus, & Peng, 1994). The older an individual is, the more likely s/he will identify later entry and exit years as demarcating middle age. Although the ages of 40–60 are typically considered to be middle-aged, for some individuals middle age starts as young as 30 and for others middle age is not perceived as ending until age 75. As life expectancy increases, the boundaries of middle age may continue to be extended upwards. In fact, one-third of Americans who are currently in their 1970s describe themselves as being middle-aged (National Council on Aging Survey, 2000).

The research of the past decade has dispelled many of the myths and negative stereotypes of middle age. Although they express concerns about weight gain, future declining health and mortality, most middle-aged adults enjoy good physical health (American Board of Family Practice, 1990). Only 7% of adults in their early 40s, 16% of adults in their early 50s, and 30% of adults in their early 60s have a disabling health condition. Despite the persistent societal view of menopause as a stressful life experience, research has consistently documented that most women pass through menopause with little difficulty (Avis & McKinley, 1991; Dillaway, 2005; Gonyea, 1996).

While childhood and adolescent transitions are often marked by rites of formal passage, the transition from young adult to middle aged adult is marked neither by special rites of passage nor by predictable chronological events. Rather the transition from young adulthood to middle adulthood is often a gradual one and social cues, especially changes in family and work domains, may be better indicators of developmental change than chronological age. Increases in life expectancy have led to middle age becoming the normative life stage in which adult children typically confront parental declining health and death. About 40% of Americans enter midlife with both parents alive, while 77% leave middle adulthood with no living parents.

Demographic Trends Impacting the Family

A number of demographic changes that occurred over the twentieth century have profoundly affected American families. Increased life expectancy accompanied by decreased fertility means that contemporary American families have more generations alive, but fewer members in each generation. The U.S. birthrate has declined from 4.1 in 1900 to 2.0 in 2000 (Fields & Casper, 2001). This shift from "high mortality-high fertility" to "low mortality-low fertility" means that for most families the age structure has changed from a "pyramid" to a "beanpole" (Bengston, Rosenthal, & Burton, 1990). Exploring the effects of the past century's mortality changes on the supply of kin to provide support to family members, Uhlenberg (1996) found that for those born in 1900, only 21%—about one in five—had any grandparent living by the time they reached age 30. In contrast, he noted that for those individuals born in 2000, by age 30, 76% will have at least one grandparent alive. Bengston (2001, p.5) comments that "what might be lost in a review of macrosocial demographic trends are the consequences for individual family members and their chances of receiving family support." He proceeds to identify both potentially positive and negative consequences of more years of shared living across generations. For example, greater years of "cosurvivorship between generations" may offer a multigenerational kinship network to provide family continuity and stability across time as well as instrumental or emotional support in times of need. Yet, longer years of shared living may also mean extended years of caregiving for frail or disabled elders or family conflict (Bengston, 2001). Parents and children now share five decades of life, siblings may share eight decades of life, and the grandparent–grandchild bond may last three or four decades.

In addition to the verticalization of the family, other demographic and social changes of the latter half of the twentieth century have affected American family life, including increased educational and labor force opportunities for women, technological advances in reproductive choice, and greater public acceptance of diverse lifestyle and family choices. Contemporary adults—both men and women—face unprecedented choices about whether and when to marry, whether to remain married, divorce, or remarry, and whether and when to have children. Phenomena that were once clear markers of young adulthood, such as marriage and parenthood, are less predictable and there is greater diversity in the structure of families. Between 1970 and 2000, the median age at first marriage for women increased by 4.3 years to 25.1 years of age; for men, the increase was 3.6 years to 26.8 years of age. One in five women in the U.S. now has her first child after age 35. There has also been a dramatic change in the numbers of American women who have entered the paid labor force. In 1950, about one in three women participated in the labor force whereas today nearly three out of every five women of working age are actively engaged in the labor force. This increase reflects the dramatic rise in working mothers; the labor force participation rate for American working mothers has grown from slightly less than half (47.5%) in 1974 to 70.7% in 2004 (U.S. Bureau of Labor Statistics, 2005).

It is important to note that not only has America's population grown older, it has also become more ethnically diverse. Persons of color are the fastest growing segment of the U.S. older population. Whereas elders of color currently comprise only 16% of the aging population, they will account for 25%, or one in every four elders, by 2030. Immigration has played an increasingly important role in reshaping the makeup of the aged population. The March 2000 Current Population Survey revealed that the number of foreign-born residents and children of immigrants in the United States has reached the highest level in history. In 2000, 56 million Americans, or 20% of the population, had either been born in a foreign country or had at least one parent who was foreign born, with the largest immigrant group being Mexican. Although the immigrant population is comprised disproportionately of working-age adults, these individuals will "age in place" and bring their parents as "invited elders" to this country. It is increasingly important to understand the possible consequences of these demographic shifts on the ability of current and future cohorts of adult children to provide care for their aging parents.

The Adult Child-Aging Parent Caregiving Experience

Prior to the 1970s and 1980s, family caregiving for older dependent members was largely invisible and often assumed to be nonexistent. The field of caregiver research owes much to early pioneers such as Ethel Shanas whose groundbreaking research refuted the prevailing social myth of families' abandonment of their elders and Elaine Brody who introduced the notion of parent care as a normative family stress (Brody, 1985; Shanas, 1979). In fact, during the past three decades, caregiver research has burgeoned. Today, the central role that families play in the lives of older frail and/or disabled members is widely recognized and the term "family caregiver" has entered American lexicon. According to the 1989 National Long-Term Care Survey, among community-dwelling elders with disabilities, over 90% of this population receives care informally from family, friends, and neighbors, approximately 25% use a combination of informal and paid care, and only 9% rely exclusively on formal care.

Much of the early research on elder care sought to describe who were these family members engaged in caring, the type of supports provided as well as the intensity and duration of this caring, and the consequences of taking on the caregiving role. Estimates of the numbers of families actively engaged in elder care vary widely based on the definition of "caregiving" used. The 2005 National Alliance for Caregiving (NAC)/AARP report, for example, estimated that 16% (or 33.9 million) of American adults are involved in caregiving for an elder. In the survey, the estimate included those caring for any friend or relative age 50 or older, including those free of a chronic disability, in the prior 12 months. In contrast, the 1994

National Long Term Care Survey (NLTCS) defined an informal caregiver as someone providing help with one or more activities of daily living (ADLs) or instrumental activities of daily living (IADLs) because of the elder's health or disability for at least 3 months. Based on this more restrictive definition, slightly less than 2% of the U.S. population aged 15 and older were viewed as actively engaged in elder care and an additional 7% were labeled potential family caregivers (Spillman & Pezzin, 2000).

The importance of the parent–child bond across the life span is underscored by the fact that adult children represent the largest group of active carers for disabled elders. Two-thirds of the active informal caregivers, according to the 1994 NLTCS, were spouses or children of the older care recipient. However, given both high rates of widowhood among the older population and the sharing of caregiving responsibilities by multiple siblings, children greatly outnumbered spouses as active carers (Spillman & Pezzin, 2000). Among adult children there is a significant gender difference as to who takes on the primary caregiver role. Although the participation of sons as primary caregivers rose by 50% between 1984 and 1994, they still accounted for only 15% of the primary caregivers in 1994. Daughters remain twice as likely to become the primary caregiver than are sons (Spillman & Pezzin, 2000).

In fact, one of the most consistent findings in family research is that the vast majority of carers for relatives with chronic disabilities are women. Although male and female roles within the American families have changed over the past few decades, women are still the primary nurturers, kinkeepers, and carers of family members. Moreover, it is women in the middle generation who are most centrally involved in maintaining family communication and cohesion across generations. Of all family caregivers to the elderly, 23% are wives, 29% are daughters and daughters-in-law, and 20% are more distant female relatives (Older Women's League, 1989). The crucial role of gender in the hierarchy of obligation to elderly family members is reflected in the fact that after spouses and daughters, it is daughters-in-law and not sons who are the next lines of resort (Qureshi & Walker, 1989). It has been argued that social scientists' continued use of gender-neutral terms such as parent, spouse, sibling, and family caregiver has obscured differences in men's and women's roles and led to gender insensitivity in the development of social policies and programs (Traustadottir, 1991). Family caregiver has become a euphemism for one primary caregiver, typically female (Hooyman & Gonyea, 1995).

Even when men provide care to elders, there appears to be a gender difference in the type of support rendered. Men are more likely to help with IADLs such as yard care, financial management, and transportation rather than perform ADLs such as bathing, dressing, and feeding. Females are more likely than males to perform tasks that are physically draining, involve daily interruptions, and entail intimate or bodily contact (Delgado & Tennstedt, 1997; Matthew, Mattocks, & Slatt, 1990). Increasingly, researchers have explored not only how men and women differ in their enactment of the caregiving role, but also the way gender influences the meaning of caring, the social context of providing care, and the consequences of performing the carer role. Women, for example, generally have more extensive social networks than do men. Yet, as Antonucci (1990) notes, while women's more extensive family networks and involvements may be useful resources in adaptation to life's stresses, the networks themselves may also be sources of stress. Russel's (2001) qualitative study of male caregivers revealed that men employ a more managerial approach that potentially offers them a "greater perceived control, the sense of being in charge, feelings of self-efficacy, as well as the ability to choose to act or not to act" (p. 355).

In addition to gender, variations in the caregiving experience also exist due to factors such as race, ethnicity, sexual orientation and marital history as well as the structural availability of family, contact between family members, the type of support exchanged, norms of filial obligation and the quality of these relationships. Personal experiences, social location and membership in social groups, birth cohort and social context influence the nature of the adult child-aging parent bond. In fact, diversity and complexity characterize families' patterns of support. For example, distance—both geographic and emotional in nature—often inhibits family members' provision of care. In the 1994 NLTCS, 97% of primary caregivers and 93% of secondary caregivers lived within an hour's distance of the elder (Spillman & Pezzin, 2000). Divorce has also been shown to have a negative effect on interaction with children—especially for men. Cooney and Uhlenberg (1990), for instance, found that divorced fathers were less likely to consider their adult child as a potential source of support in times of need.

Hierarchies of privilege—race, ethnicity, social class, gender, and sexual orientation—reveal how accumulated advantages and disadvantages across the life course differentially equip families with a set of skills, liabilities, and resources that affect how they are able to care for older dependent members. The question of who will care for frail and disabled older parents is a particularly salient question among ethnic minority communities. Due to greater exposure to risk factors such as inadequate housing, poverty, poor nutrition, smoking, manual jobs that are potentially physically debilitating, and lack of adequate health care, elders of color have higher rates of morbidity and mortality than do White elders. The higher rates of health problems do not, however, translate into higher rates of institutional care; a smaller percentage of elders of color (3%) than White elders (5.8%) live in nursing homes. Yet, as research in the emerging field of ethnogerontology reveals, even among ethnic groups who have strong norms of filial piety and familism, economic and social forces are increasingly impacting their abilities to care for aging family members (Angel & Angel, 1997; Olson, 2001).

The Phenomenon of the Sandwich Generation

One phenomenon of the changing age structure of families that has received growing attention is the *sandwich generation*. As Ward and Spitze (1998) note there are two meanings to this term:

> Structurally, it refers to middle-generation cohorts sandwiched between older and younger cohorts in the population. Individually, it refers to persons in middle adulthood who simultaneously have relations with their adult children, as they enter and

> adjust to adulthood, and their parents, as they deal with issues of later life. Members of this sandwich generation are presumed to face potential stresses from the combined and perhaps competing demands of their intergenerational roles as parents and children. (p. 647)

Recent research has raised questions, however, about the size of this phenomenon. Spillman and Pezzin (2000) analysis of the 1994 NLTC data set reveals that among women with children under the age of 15 only 9.1% were the primary caregiver and 25.5% were the secondary caregiver for either a disabled elderly spouse or parent. Among men with children less than age 15 only 5.6% were primary caregivers and 21.1% were secondary caregivers for a disabled elder. Similarly, a study of 12 European Union countries found that only 4% of men and 10% of women aged 45–54 had overlapping responsibilities for children and older adults who required care (Hagestad, 2000). A much larger proportion of American and European midlife men and women faced the competing demands of caregiving responsibilities and paid employment than the dual responsibilities of child and elder care.

Although it appears that there are fewer members of the sandwich generation who are simultaneously engaged in caring for children and aging parents, there may be substantial burdens for those who are in fact providing intergenerational assistance. Moreover, others stress that rather than using a narrow definition of caregiving we should look more broadly at the effects of dual occupancy of the parent and adult child roles. For example, in industrialized societies young adults from their late teenage years through their twenties are increasingly allowed a prolonged period of independent role exploration which has correspondingly led to a prolonged parenting phase for many midlife parents. Arnett (2000) suggests that this period of "emerging adulthood" should be viewed as a new life stage. He argues that emerging adulthood is the only period of life in which nothing is normative demographically. Almost all American adolescents from 12 to 17 years of age live at home, are enrolled in school, and are unmarried and childless. In contrast, emerging adults' lives are characterized by diversity. About one-third of young persons in the United States go off to college, another 40% move out of their parental home for independent living and work, and about 10% of men and 30% of women remain at home until marriage (Arnett, 2000). It is estimated that about 40% of recent cohorts of young adults have returned to their parents' home after moving away (Goldschieder & Goldscheider, 1994). A significant proportion of midlife parents are actively engaged in helping their children (i.e., advising, guiding, worrying) as they explore choices in love and work and transition to young adulthood. In an era of rising costs, particularly for younger families attempting to buy a first home and/or as new parents coping with child care costs, there may be growing expectations for assistance from the middle generation (Goldschieder, Thornton, & Yang, 2001).

Grandparenting as a Midlife Role

Although the popular image of grandparents is as frail older adults, most people become grandparents for the first time between the ages of 49 and 53. The transition to the role of grandparent as well as the experience of grandparenting itself varies by life circumstances. For example, factors that have been identified as significant predictors of grandparent contact with grandchild include: geographic distance, quality of relationship between grandparent and parent, number of grandchild sets, gender of grandparent, lineage of the grandchild set, and marital status of the grandparent (Uhlenberg & Hammill, 1998).

Utilizing a family life course perspective, Silverstein and Marenco (2001) found that younger grandparents tended to live closer to and have greater contact with grandchildren, often babysitting and sharing recreational activities. In contrast, older grandparents tended to provide greater financial assistance, assume a more formal relationship with grandchildren, and more strongly identify with the grandparent role. Many of the age difference effects in grandparent roles may also be related to the grandchildren's age and the type of interaction that the youth are seeking. By the time grandparents approach their late 60s or early 70s, most of their grandchildren have entered adolescence or young adulthood.

Parents are a bridge between the two generations. They often set the tone for grandparent and grandchild relations by how they function as gatekeepers between the two generations. Generally, greater closeness and contact between parents and grandparents results in greater closeness and contact between grandchildren and grandparents. Most studies suggest that adults derive considerable pleasure from the grandparent role. The two exceptions are when an individual takes this role on at a relatively early age due to a teenage birth or when a grandparent becomes the primary caregiver due to events in the parent generation such as divorce, drug addiction, incarceration, illness, and death. In recent decades, the crack cocaine and HIV/AIDs epidemics have contributed to a dramatic rise in the number of grandparents who are surrogate parents for their grandchildren (Casper & Bryson, 1998).

The Consequences of Elder Care

Recognition of the family as the primary source of long-term care for the elderly has led to the proliferation of research studies exploring the consequences of assuming the caregiving role. Before discussing the findings, however, it is important to point out several limitations in the existing literature. First, our understanding of caregiver is primarily derived from information gathered from one member of the family, typically a woman. The concept of caregiving as a "woman's role" has led to the respondents to surveys and interviews being overwhelmingly women. Second, while supporting a family member can be a rich and rewarding experience, the literature has often focused on the negative effects of taking on the caring role. Although recognizing that this emphasis on the costs of caregiving is an attempt "to argue that families cannot absorb additional obligations and that government must devote adequate resources to support them." Abel (1991, p. 8) criticizes the current caregiving research agenda "which has focused almost exclusively on the issue of stress." Third, most studies of caregiving are based on nonprobability samples and, at times, lack a comparison group of noncaregivers. Fourth, the findings on the nature of caregiving experience are, at times, inconsistent. These inconsistencies may partly reflect variations in the populations studied, such as type of impairment as well as the caregiver's gender, race and ethnicity, and the nature of the relationship to the care recipient, whether the bond is as a spouse, an adult child or a sibling. Finally, longitudinal studies remain relatively sparse. Most of the conclusions regarding the long-term effects of providing care are based on cross-sectional studies and must be viewed as tentative.

The Concept of Caregiver Burden

Although it is often assumed that the burdens of caregiving are fairly obvious, developing a concise definition of "caregiver burden has proven difficult because it is a multidimensional concept that encompasses a wide range of stressors, including "physical, psychological or emotional, social and financial problems" (George & Gwyther, 1986, p. 253). In her review of the caregiving literature, Braithwaite (1992) identifies two major theoretical efforts to define the burden concept more precisely. The first effort was the theoretical distinction drawn between objective and subjective burden. This differentiation was first noted by Hoenig and Hamilton (1966) in their research on the effects of an adult with schizophrenia on the household and was subsequently adopted by the mental health, gerontology, and developmental disabilities fields (Marsh, 1992a, 1992b; Montgomery, Gonyea, & Hooyman, 1985; Thompson & Doll, 1982).

Objective burden refers to the real demands that confront the family member who assumes the carer role. The dimensions of objective burden can include symptomatic behaviors of the impaired relative, disruptions of family life in areas such as domestic routines, leisure activities, and opportunity to socialize, problems with health and legal systems, and alterations in family roles (Bulger, Wandersman, & Goldman, 1993; Marsh, 1992a, 1992b). Whereas objective burden focuses on behavioral phenomena associated with performing the caring role, subjective burden refers to the feelings and emotions aroused in family members as they fulfill their caregiving functions (Braithwaite, 1992). These emotional reactions may include anger, guilt, worry, tension, loneliness, sadness, depression, difficulty sleeping, withdrawal, and empathic suffering (Bulger et al., 1993; Marsh, 1992a, 1992b). The second major theoretical effort noted by Braithwaite (1992) was the recognition that burden is a subjective experience—that is, what is difficult for one caregiver need not be difficult for another. This phenomenon, first identified by Poulshock and Deimling (1984), helped to explain the confusion as to why family members did not experience the same or similar caregiving experiences as "burdensome." For example, when two adult daughters are providing the same levels of personal care assistance, such as dressing, feeding, and bathing, one might report feeling "very burdened" while the other might identify "very little stress." Variation in the experience of caregiver burden may also reflect differences in midlife expectations and priorities. As parenting demands diminish, some begin to anticipate a greater sense of freedom relative to their own time and the ability to pursue new or postponed opportunities. The onset of parent care responsibilities may therefore be viewed by some as a burden. The frailties of aging parents also may underscore one's own mortality and the finite nature of the lifespan. For those in midlife, decisions about parent care are thus increasingly made within a framework of having a limited amount of time available to achieve one's life goals, creating for some a stronger sense of urgency.

In fact, much of the caregiving literature has attempted to understand the nature, prevalence, and predictors of carer burden. And, the research to date does suggest that taking on the caregiver role is not without risks. A number of studies have found that family members who provide care to disabled family members experience increased health problems, including physical exhaustion, poorer immune responses, and deterioration of their own health status (Biegel, Sales, & Schulz, 1991; Kiecolt-Glaser et al., 1987; Marks, 1996). Moreover, poorer physical health or lower physical stamina has been found to be associated with emotional distress and psychiatric disturbances (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Hooker et al., 2002; Schulz & Martire, 2004; Schulz, O'Brien, Bookwalla, & Flesissner, 1995).

Gender and Caregiver Outcomes

A growing number of researchers are investigating how gender, race, ethnicity, and culture may shape the caregiving experience (Dilworth-Anderson, Williams, & Gibson, 2002; Harrington Meyer, 2000; Hooyman & Gonyea, 1995; Campbell & Martin-Matthews, 2003). Miller and Cafasso (1992) meta-analysis of 14 studies of gender differences in caregiving conducted from 1980 to 1990 revealed that female and male carers did not differ either in terms of the severity of the elder's functional impairment or the level of total care involvement, but a significant difference was found in terms of the type of task involvement and the level of caregiver burden. While the size of the gender effect was small, female caregivers were more likely to perform personal care and household tasks and were more likely to report greater burden than male caregivers do. Based on their findings, Miller and Cafasso (1992, p.152) suggest that "what is needed may be less documentation of specific gender differences in isolated components of caregiving and more attention to the role that gender-role expectations play in assigning meaning to the caregiving experience."

Updating and further expanding upon Miller and Cafasso meta-analysis, Yee and Schulz (2000) synthesis of 30 research reports examining gender differences in psychiatric morbidity among caregivers published between 1985 and 1998 revealed that women caregivers reported higher levels of depression, anxiety, psychiatric symptomatology, and lower life satisfaction than did men caregivers. Yee and Schulz note that several studies found that male caregivers were more likely to obtain informal assistance, to relinquish the caregiver role, and to engage in preventative health behaviors than female caregivers.

Raschick and Ingersoll-Dayton (2004) found that gender, rather than relationship status, was a predictor of caregiving costs; women, whether wives or daughters, reported experiencing greater caregiving costs than did men (husbands or sons). The authors attribute this difference to not only gender differences in caregiving styles but also dissimilar internalized norms about nurturing responsibilities. Women may be more likely to view caregiving as the expected mode of behavior or a moral responsibility while men may be more prone to feel abandoned or alone when cast into the caregiving role (Harris, 2002).

The role that gender may play is also reflected in Strawbridge and Wallhagen (1991) study of family conflict in caring for frail elders. Their data not only underscored that one family member's disability reshapes each family member's life, but that there may also be significant gender differences in caregiving expectations. Over 40% of 100 adult children caring for a frail parent or parent-in-law in their sample reported a serious conflict with another family member, usually a sibling who was unwilling to provide the amount of assistance the caregiver expected. Moreover, a greater proportion of female caregivers experienced conflict than did their male counterparts. Although this gender difference may reflect that fewer male caregivers had a living sibling available, it may also reflect gender-based assumptions regarding the appropriate roles of men and women in family care. A married working daughter with young children may resent the fact that her brother with fewer responsibilities (simply as a function of gender) is not asked to do more, or volunteers to do so little.

Parks and Pilisuk (1991) study of the psychological costs and coping strategies used by adult children caring for a parent with Alzheimer's disease suggests that men and women approach the caregiving role from different perspectives and that it takes on very different meanings for the two groups. The researchers discovered that while daughters and sons did not differ in terms of depression or anxiety, daughters did have a higher rate of self-reported stress than did the sons. They also found that daughters predominantly used fantasy to cope, whereas withdrawal was the most common technique employed by sons. Perhaps what is most intriguing was the differential effectiveness of these coping strategies for men and women assuming the caring role. Significant predictors of anxiety for daughters were an external sense of control and the use of fantasy as coping mechanisms. For sons, anxiety was associated with lack of social support coupled with the use of either fantasy or withdrawal as a dominant coping style.

Race, Ethnicity, Culture, and Caregiver Outcomes

As Dilworth-Anderson and her colleagues' analysis of 20 years (1980–2000) of caregiving research exploring issues of race, ethnicity, and class reveals, it is difficult to draw definitive conclusions as methodological issues such as nonprobability samples and noncomparable measures limit our understanding of caregiving among diverse populations. Although outcomes over a range of constructs (i.e., depression, burden, role strain) do vary across racial and ethnic groups, the findings are inconsistent (Dilworth-Anderson et al., 2002). For example, while several studies suggest a lack of significant difference in depression among African American and White caregivers (Cox, 1999; Knight & McCallum, 1998; White, Townsend, & Stephens, 2000), other research has found that African American caregivers report significantly lower levels of depressive symptomology (Farran, Miller, Kaufman, & Davis, 1997; Haley et al., 1995). Janevic and Connell (2001), in their review of 21 articles published between 1996 and 2000 comparing two or more racial, national, or cultural groups on the dementia caregiving experience, also found inconsistencies in the findings. They note a general trend toward White caregivers reporting caregiving as more stressful and experiencing greater depression than do African American caregivers; however, findings were mixed regarding differences in coping and social support.

Both sets of authors—Dilworth-Anderson and her colleagues and Janevic and Connell—identify a number of the same methodological limitations in the current body of research including the appropriateness of using the "grouping variable"—race, ethnicity, culture, or national origin—to attribute differences between groups of caregivers. Janevic and Connell comment:

> When grouping caregivers by any of these categories, researchers should have a clear idea about the hypothesized mechanism by which membership in this category can affect the caregiving experience. In general, effects of the grouping may be due to cultural factors (the symbolic and normative aspects of social life, such as language, values, beliefs or norms); or minority status, with the latter implying the effects of inequality and discrimination, factors that continue to play a major role in the lives of minority group members in the United States and affect the psychological outcomes in these groups. (2001, p. 344)

Montgomery and Kosloski (1994) similarly caution that despite social scientists' fondness of measuring sociodemographic variables (i.e., gender, race, marital status), these variables are not the causes of caregiver outcomes; rather, sociodemographic variables vary with the underlying causes. Through their articulation of a sociocultural stress and coping model, Knight, Silverstein, McCallum, and Fox (2000) make an important contribution to the caregiving field. In this model, ethnicity is viewed as a cultural variable that influences how individuals are socialized to view caregiving. They suggest that African American families' religious beliefs, traditions, and social support bolster the value of family caregiving and caregiver rewards.

Indeed, there is a growing call for the conduct of more qualitative or ethnographic studies to understand the meaning of the findings of significant cultural differences in caregiver outcomes emerging from the quantitative studies. For example, through open-ended ethnographic interviews with African American, Chinese American, Irish American and Latino family caregivers for elders with dementia, Levkoff and her colleagues explored cultural differences in symptom appraisal (biomedical model versus folk model of attribution), family management of the disease, and help-seeking behaviors (Fox, Hinton, & Levkoff, 1999;

Hinton & Levkoff, 1999; Levkoff, Levey, & Weitzman, 1999). Such research offers greater insights into how caregivers from different cultural groups perceive the nature and cause of their family member's illness as well as normative expectations about the caregiver role. The growing body of ethnographic studies suggest that to gain a better understanding of the diversity in the caregiving experience, we must also increase our understanding of cultural variations in the meaning and significance of dependency, autonomy, family, community, health, illness, medicine, and death and dying.

Positive Aspects of Caregiving

The dominance of caregiver stress or burden research in the caregiving literature has often overshadowed other aspects of the caregiving experience. The literature increasingly suggests that family members caring for relatives with a cognitive, physical, or psychological impairment can experience both burden and satisfaction from their caregiving roles. Similarly, feelings of conflict and intimacy can coexist for the carer. There is growing evidence that feelings of caregiver satisfaction or gratification may be linked to the subjective meanings attributed to the caregiver role. In their study of role engulfment or loss of self in the caregiving role, Skaff and Pearlin (1992) report that one of their more intriguing findings is the lack of relationship between loss of self and self-gain:

> The independence of these two indicators of the impact of caregiving on the individual suggests that loss and gain are not opposite points on the same continuum… Some caregivers may feel that they have grown as a result of their experiences, but whatever personal enrichment they might experience does not protect them from suffering a loss of identity. (p. 659)

Kramer (1997) argues for research focused on the positive aspects of caregiving experience emphasizing that: it is an area which caregivers want to talk about, understanding the positive gains may enable professionals to work more effectively with families; and it may enhance theories of caregiver adaptation and well-being. Based on her analysis of 29 studies focused on positive gains published through 1996, Kramer suggests the adoption of a conceptual framework in which the appraisal of positive role gains and role strains are viewed as intervening processes in understanding caregiver well-being outcomes.

Recent research has, in fact, sought to elaborate on our understanding of the "meaning of caregiving" in individuals' lives as well as how positive appraisals may mediate the negative effects of the caregiver role. Based on a qualitative study of 48 caregivers, for example, Noonan, Tennstedt, and Rebelsky (1996) found the predominant themes of "caregiving meaning" to include: gratification and satisfaction; family responsibility and reciprocity, and friendship and company. Several researchers have sought to develop a quantitative measure tapping the positive aspects of caring. Picot, Youngblut, and Zeller (1997), for instance, constructed and tested the "perceived caregiver rewards scale" while Farran and her colleagues, using an existential framework, developed the “finding meaning checklist scale” (Farran, Miller, Kaufman, Donner, & Fogg, 1999). Recent research also suggests the potential importance of caregiving meaning to the stress process. Noonan and Tennstedt (1997) found that meaning in caregiving explained a significant portion of the variation in depression and self-esteem even after controlling for demographic and stressor variables. Similarly, Cohen, Colantonio, and Vernich (2002) study of 289 Canadian caregivers revealed that almost three-quarters of the individuals could identify at least one positive aspect of caregiving; and that positive feelings of caregiving were associated with lower levels of depression and burden and better self-assessed health.

There is also a growing exploration of how culture or ethnicity influences caregiving appraisal. Picot and her colleagues (1997), for example, found that race had both direct and indirect effects on perceived caregiver rewards. Black caregivers in general, and Black caregivers who received comfort from religion and prayer, reported greater rewards in the caregiving role than did White caregivers. Picot suggests that for many African American caregivers faith and prayer may act as a buffer to caregiving stresses and may be associated with perceptions of rewards, such as being blessed by God for their efforts. They note that many African American families have an expectation of caring for an aging relative and that there is often a sense of pride in being able to fulfill this role. Similarly, White et al. (2000) found that African American adult daughters reported less stress and more rewards in the parent care role than White adult daughters did. They suggest that these racial differences may reflect a normative expectation among African American families of impairment as a part of the aging process as well as more positive and respectful views of elders. More recently, Roff and her colleagues, in a study of 275 African American and 343 Caucasian caregivers of individuals with Alzheimer’s disease, also found that African Americans appraised their caregiver role more positively than Caucasians (Roff et al., 2004). Consistent with the Picot et al. (1997) study, they found higher religiosity among the African Americans; and, this higher religiosity partially mediated the relationship between race and positive appraisal. Their data also revealed that for African Americans, higher positive appraisals were associated with lower anxiety, lower bother by care recipient’s behavior, and lower socioeconomic status. Together, these studies underscore the importance of understanding how sociocultural variables influence both caregiver appraisals and outcomes.

Caregiving as a Process: Conceptual Frameworks

Although social scientists recognize that caregiving is a dynamic process that unfolds over time there are still relatively few longitudinal studies of caregiving outcomes. Moreover, given that these studies are characterized by a variety of measures and variability in samples, the results are inconsistent and difficult to compare. Yet, despite the continued reliance on cross-sectional or panel studies, researchers have increasingly adopted process models as an analytic tool to understand the caregiving experience. One of the most frequently used conceptual frameworks is the stress and coping process model (Lazarus & Folkman, 1984; Pearlin, Mullan, Semple, & Skaff, 1990; Pearlin & Schooler, 1978). This model differentiates between the occurrence of stressful events and how individuals react to and appraise them. In fact, recent research suggests that subjective appraisals of caregiver stressors may be better predictors of caregiver outcomes than objective stressors (Gonyea, O'Connor, Carruth, & Boyle, 2005; Pot, Deeg, van Dyck, & Jonker, 1998). Schulz, Gallagher-Thompson, Haley, and Czaja (2000), therefore, propose ways in which this theoretical model may be used by professionals to guide the development, implementation and evaluation of caregiver interventions whether throughout targeting the actual stressors, strengthening social supports and/or altering caregivers' appraisals of behaviors and events.

Research on the caregiving experience has often focused almost exclusively on the help given to vulnerable family members and ignored the contributions of the care recipients. The use of social exchange theory, which emphasizes the interdependence in dyadic relationships, offers us a greater understanding of bidirectional or mutual exchanges between older parents and their adult children (Dwyer, Lee, & Jankowski, 1994; Walker, Martin, & Jones, 1992). In fact, there is a growing body of research focused on caregiving as a dyadic process, which incorporates the perspectives of both the caregiver and receiver (Lyons, Zarit, Sayer, & Whitlatch, 2002). Much of this literature focuses on the attachment bonds between adult daughters and older mothers and the ways in which they negotiate care (Carpenter, 2001; Hollis-Sawyer, 2003; McGraw & Walker, 2004).

A number of social scientists have used role strain theory—felt difficulty in fulfilling role obligations—to explore the dynamics of elder care. Role strain theory argues that individuals have a limited amount of time and energy and that social organizations demand most of that energy (Marks, 1977). Barnett and Baruch (1985) identified two types of role strain that impact women who are simultaneously occupying various roles such as spouse, parent, employee, and/or elder caregiver: role demand overload and role conflict. Role demand overload is having so many demands related to one's roles that satisfactory performance is improbable. Role conflict emerges when the demands from multiple roles are such that adequate performance of one role jeopardizes adequate performance in another role. Role strain theory has been employed as a conceptual framework in the burgeoning field of work-family research. Recognizing that the worlds of family and work are not separate or parallel domains, researchers are increasingly exploring the specific intersections, transactions, and spillovers between family and work (Marks, 1998).

Emphasizing the concept of "caregiving as a career," an increasing number of researchers are employing a life course-role identity perspective to understand the caregiving role and its consequences. Drawing on the principles of the life course perspective (Elders, 1992), Moen and her colleagues propose that to understand the consequences of caregiving role on well-being, one must consider the developmental timing of transitions to the caregiver role, the intersection of other roles in relation to the carer role, and the historical context of performing the caregiver role (Moen, Robison, & Fields, 1994). Whereas most researchers study the work-family interface in terms of individuals at one point in time, Han and Moen (1999, p. 98) propose "a coupled-careers model directly addressing the multiple interfaces between work and family and between men and women as they unfold overtime." Central to Moen's work is the concept of "linked lives"—that is, "individuals' life paths are played in tandem with the life courses of parents, spouses, children, friends, and co-workers" as well as a recognition that there are clear gendered cohort differences in normative expectations for later life (Moen, 2001, p. 181). Thus, Moen stresses "that men and women frequently experience different transitions and trajectories in later adult years, but even the *same* trajectories can be vastly different by gender" (Moen, 2001, p. 184). Based on her work, Moen concludes that we must create more flexible and open arrangements to support both men and women in balancing work and family at all stages of their life course.

Caregiver Interventions

During the past two decades interventions or services to support caregivers—psychoeducational interventions, support or mutual help groups, and respite and adult day care—have proliferated. Whereas the primary objective of psychoeducational interventions and support groups is typically to enhance caregiver competence, coping, and/or well-being, the primary aim of respite care and adult day care is to reduce the amount of care provided by the family member. Both types of interventions, however, are typically motivated by an overarching goal of prolonging the family's ability to provide care, reducing institutionalization, and thereby saving public monies (Hooyman & Gonyea, 1995). Early studies on the effects of caregiver interventions, which relied primarily upon the clinical impressions of the group leaders or professionals or satisfaction surveys of small, select samples of caregiver consumers, often reported strong positive effects (Toseland & Rossiter, 1989). However, more recent studies that use standardized measures of caregiver distress and more rigorous research designs have found, on average, only small to moderate effect size on caregiver outcomes (Knight, Lutzky, & Macofsky-Urban, 1993). Based on their review of 29 studies of respite care, for example, McNally, Ben-Shlomo, and Newman (1999) conclude that respite care produced neither consistent nor enduring positive effects on the carer.

Arguing that the geropsychotherapy field is still in need of better process and outcome measures, Arean and her colleagues offer guidelines for the optimal conduct of intervention research that include the selection of age-appropriate therapies and control conditions as well as treatment outcomes, the use of consumer-based methods for recruitment, and adjusting the research design to accommodate age-specific life events (Arean et al., 2003). There is also growing emphasis on the importance of culturally-sensitive or appropriate interventions and the need to assess possible differential effects of interventions by race and ethnicity (Burgio, Stevens, Guy, Roth, & Haley, 2003; Gallagher-Thompson et al., 2003).

Based on their analysis of the body of dementia caregiver research published between 1996 and 2001, Schulz and colleagues report that "although many studies have reported small to moderate statistically significant effects on a broad range of outcomes, only a small proportion of these studies achieved clinically meaningful outcomes" (Schulz et al., 2002, p. 589). Noting that the caregiver intervention research is now more than a decade old, they urge researchers to focus on demonstrating clinical significance—that is, "the practical value of the effects of an intervention, or the extent to which it makes a 'real' difference in the everyday life of the individual" (Schulz et al., p. 590).

Sorensen, Pinquart, and Duberstein (2002) meta-analysis of 78 intervention studies offer important insights into the effectiveness of six types of programs—psychoeducational interventions, supportive interventions, respite and adult day care, psychotherapy, care receiver competence interventions, and multicomponent or combination intervention—on the outcomes of caregiver burden, depression, coping, sense of well-being and knowledge as well as care recipients' symptoms. Moreover, the researchers investigated the moderating influence the sets of variables—intervention characteristics, caregiver characteristics, and care recipient characteristics—on the targeted outcomes. Based on their analysis, Sorensen and her colleagues conclude that: (a) psychoeducational and psychotherapeutic interventions produce the most consistent short-term effects; (b) while group interventions were less effective at improving caregiver burden and well-being than individual or combined individual and group interventions, group interventions were more effective with regard to improving caregiver knowledge and ability and care recipient symptoms; (c) length of treatment was important in terms of alleviating caregiver depression and care receiver symptoms; (d) adult children appeared to benefit more from interventions than spousal caregivers; and (e) dementia caregivers experienced fewer benefits from interventions than did carers for elders with other disabling types of conditions.

Together, these meta-analyses identify the existing challenges and opportunities in conducting caregiver intervention research and offer creative strategies for producing scientifically rigorous and clinically meaningful evaluations of practice interventions for older adults and their families. They also suggest that professionals' choice of intervention strategies should be guided by the primary treatment goals as well as the characteristics of the caregiver and receiver (i.e., gender, age, ethnicity, functional status); and, professionals should maintain realistic expectations with regards to the targeted caregiver and receiver outcomes.

Supports for Family Caregivers

Surveys consistently reveal that Americans are experiencing stress in balancing their work and family responsibilities and wish that both government and businesses would take a more active role in seeking solutions to resolve this tension. For example, the 1998 National Partnership for Women and Family Survey found that two-thirds of Americans say that time pressures on working families are getting worse, not better, and that most want employers (90%) and government (72%) to do more to help working families. The United States' lack of an explicit and coherent national family policy, however, has led to the creation of ambiguous and sometimes conflicting policies for specific programs to address the long-term care needs of chronically ill or disabled older adults. While few disagree with the abstract statement that the state should facilitate families' ability to care for dependent members, translating that philosophy into specific public policies and programs has proven challenging.

America's domestic policies are based on an ideology of familism—that is, the assumption of the primacy of families in meeting the care needs of their members. Predicated on the notion of "families first," formal alternative arrangements are perceived as necessary only when families are unavailable or unable to perform their responsibilities. Clark (1993) notes that both the United States and Canada embrace an ideology of familism; however, Canada tempers familism through an emphasis on collectiveness or sense of community whereas the U.S. stress on individualism heightens familism:

> [The United States] particularizes and compartmentalizes social policies along the lines of individual or static group-based need, rather than seeing public programs as responding to changing life course needs across the entire society. (p. 34)

These values of familism and individualism have formed the basis for residual approach to public policy in the United States. Residualism—meaning that the state becomes involved only after the family has assumed as much responsibility as possible—serves the federal government's goal of cost containment of public funds. Research by Binney, Estes, and Humphers (1993) and Glazer (1990) found that efforts to contain Medicare costs, through such mechanisms as the 1983 Medicare Prospective Payment system, have transferred work (and costs) from the formal to the informal care system. Because of the shifting of highly technical work to unpaid family members, Glazer estimates that the medical industry has saved $10 billion annually in costs. More recent limits on Medicare home health visits resulting from the 1997 Balanced Budget Act have placed even greater demands on family caregivers. Focusing on Medicaid (the primary method through which the United States distributes long-term care), Harrington Meyer and Storbakken (2000, p. 217) demonstrate how recent Medicaid cost-containment efforts are reshaping frail and disabled elders' access to long-term care and "shifting the burden back to families."

One of the primary barriers to the expansion of formal (paid) home care services for chronically ill or disabled elders is the fear that policymakers have that it will cause families to reduce or curtail their caregiving efforts (Binney et al., 1993; Hooyman & Gonyea, 1995). This concern or fear continues to exist despite almost two decades of research revealing that formal in-home care services do not appear to substitute for informal care provided by family, friends, and neighbors. Penning (2002) study, for example, provides convincing evidence refuting the "substitution hypothesis." She found that the extent of self-care and informal care received was most strongly related to the level of health care need (i.e., chronic conditions, functional impairment; cognitive impairment) and, in the case of informal care, the availability of informal resources. Summarizing her findings, Penning notes that contrary to expectations, there was no evidence that as older adults' health declines, "self-care gradually gives way first to informal care and ultimately to formal care. Rather they seem to suggest that as health declines, all forms of care (self, informal, and formal) may increase" (Penning, 2002, p. 14).

While policymakers continue to remain concerned with the willingness of families to provide care, two recent significant—albeit modest—federal policy initiatives have been directed toward supporting families' ability to perform caregiving activities: The Family and Medical Leave Act of 1993 (FMLA) and the National Family Caregiver Support Program of 2000 (NFCSP). Having been debated in the U.S. Congress since the mid 1980s, the Family and Medical Leave Act (Public Law 103–3) was signed into law by President Clinton on February 5, 1993. The private sector generally opposed the passage of the FMLA perceiving it as costly and not beneficial to businesses; whereas many women's organizations stressed the necessity for a federally-mandated leave policy noting the difficulties that American workers were confronting in their efforts to balance their work and family lives. Women's organizations further buttressed their argument by underscoring that the United States was among the last industrialized countries to offer a leave policy.

Under the FMLA, businesses with 50 or more employees are required to grant up to 12 weeks of unpaid leave annually when a child is born or adopted, when an immediate family member with a serious health condition needs care, or when the employee is unable to work because of a serious health condition. The FMLA defines a serious health condition as an illness, injury, impairment or physical or mental condition that requires inpatient care in a hospital, hospice, or residential medical facility or continuing treatment by a health care worker. The worker has the right to take the leave intermittently or on a reduced schedule basis. The employer is required to maintain any preexisting health coverage during the leave period, and once the leave was completed, reinstate the employee to the same or equivalent job. For retirement and pension plans, FMLA leave is counted as continuous service for purposes of eligibility and vesting.

As the FMLA only applies to employers with 50 or more employees, it is estimated that slightly more than 10% of private sector worksites are covered under the Act. This relatively small percentage of U.S. businesses, however, employs almost 60% of American workers. Yet, not all workers of covered employers are eligible for FMLA benefits. The Act only provides benefits to employees who have worked for an employer for at least 12 months and who, during that 12-month period, worked for at least 1,250 h (an average of 25 h per week). Based on these criteria it is estimated that less than half (46.5%) of private sector employees are eligible for leave under FMLA (Commission on Family and Medical Leave, 1996).

As mandated by federal law in 2000, the U.S. Department of Labor (DOL) commissioned a survey of usage of FMLA. The DOL survey revealed that since its enactment, usage has been fairly limited; approximately 35 million American workers have taken leave under the FMLA with the median length of leave being 10 days. Among leave takers, approximately half (52%) did so because of their own health; about 39% was taken by relatively young parents to care for children at birth, adoption, or during a serious illness; and about 19% was taken by somewhat older employees to care for ill parents or spouses. Although latent demand for leave may be high, the fact that it is unpaid is a major barrier to utilization. Approximately three-quarters of workers who desired to take a leave stated that they could not do so because of financial reasons.

Proposals to reform FMLA continue to be debated in U.S. Congress. On the right, legislators continue to question the basic premise of the law. Republican members of Congress, in an effort to limit the FMLA, are pressing for clarifying amendments to restore the definition of “serious medical condition” and “intermittent leave” to the original intent of the Act. In contrast, Democratic proposals build upon the ideology that government has a legitimate role in addressing employment-related tensions between employer and employee. Their most fundamental proposal focuses on the importance of wage replacement and the need for paid leave. Democrats have also proposed to extend coverage to: (a) employers with at least 25 employees; (b) beyond “immediate family members” to include a parent-in-law, adult children, sibling, grandchild, grandparent, and domestic partner; and (c) allow workers to take up to 4 h in any 30-day period to accompany children to school or extracurricular activities or accompany ill relatives to medical appointments. In the Republican and Democratic proposals, we saw different visions about personal, private, and public responsibilities for care of dependent members (Hudson & Gonyea, 2000).

The National Family Caregiver Support Program (NFCSP) was established through enactment of the Older Americans Act Amendments of 2000 (Public Law 106–501) and reauthorized in 2006. The federal share of the funding is 75% with the remaining 25% provided by the state and local sources. The NFCSP gives a higher priority to services to older caregivers having the greatest social and economic needs (emphasizing lower-income older individuals), and to older caregivers of persons with mental retardation and developmental disabilities. Recognizing the growing phenomenon of grandparents who are the sole caregivers for grandchildren, the Act also allows each state to use some funds to support grandparents who are aged 55 or older and relative caregivers of children who are not more than 18 years of age or handicapped children of any age. The principal component of the NFCSP calls for all states to work in partnership with the local Area Agencies on Aging (AAAs) and other service providers to establish a network of services. The five service areas outlined under the NFCSP are: (1) information for caregivers about available services; (2) assistance to caregivers in gaining access to services; (3) individual counseling, organizing of support groups, and caregiver training; (4) respite care; and (5) supplemental services, on a limited basis, to complement the care provided by caregivers. A number of current NFCSP activities implemented at the state level should greatly expand the development and testing of evidence-based approaches to support, complement, and sustain the efforts of families to care for dependent relatives.

Conclusion

The demographic changes of the aging population mean more years of “shared living” between generations. Family relationships are of unprecedented duration as parents and children now share five decades of life, siblings may share eight decades of life, and the grandparent–grandchild bond may last two or even three decades. We might therefore anticipate that multigenerational bonds will be of greater importance in the upcoming decades. Although there is great heterogeneity in the time and sequencing of adult life transitions, increases in life expectancy have resulted in middle age becoming the normative life stage in which adult children confront parental declining health and death. Despite the popular rhetoric that the American family is in decline, research has consistently demonstrated the strength and resilience of family members' bonds across the generations. The vast majority of long-term care to older frail and disabled relatives is provided by families—typically spouses, daughters, and daughters-in-law. While male and female roles within American families have changed over the past few decades, women remain the primary nurturers, kinkeepers, and caregivers.

The caregiving experience is diverse, complex, and dynamic. Appraisal of the parent care role is shaped by our family experience, history, and values. A growing number of researchers are exploring gender, race, and cultural differences in symptom appraisal, family management of the disease and illness, caregiver stress and burden, coping strategies, and help-seeking behaviors. Although much of the caregiving literature has focused on caregiver stressors and role strain, attention is now also being directed toward positive gains in assuming the caregiving role. Conceptualizing caregiving as a dynamic process has led to a growing number of researchers adopting a life course perspective to understand the nature of the work-family interface as it unfolds over time.

Although most women, men, and children now live in households that bear little resemblance to the male breadwinner and female homemaker families that symbolized the 1950s, both public and private sector policies have not kept pace with the changing realities of work and family. The challenge is to understand the impact of our social policies on the quality of life for both the caregiver and recipient. Madonna Harrington Meyer (2000, p. 2) emphasizes that as we search for policy reforms we must assess: "What are the complexities, strengths, and weaknesses of emphasizing families, market-based solutions, or welfare state programs?" and "How might we create a mixture of options that balance the burden across all three spheres?" Policies such as the Family and Medical Leave Act of 1993 and the National Family Caregiver Support Program of 2000 represent efforts to address this question of what is society's shared responsibility for care of dependent members.

References

Abel, E. K. (1991). *Who cares for the elderly?: Public policy and the experiences of adult daughters*. Philadelphia: Temple University Press.

American Board of Family Practice. (1990). *Perspectives on middle age: The vintage years*. Princeton, NJ: New World Decisions.

Angel, R. J., & Angel, J. L. (1997). *Who will care for us? Aging and long-term care in a multicultural America*. New York: New York University Press.

Antonucci, T. (1990). Social supports and social relationships. In R. Binstock & L. George (Eds.), *Handbook of aging and the social sciences* (3rd ed.). San Diego, CA: Academic.

Arean, P. A., Cook, B. L., Gallagher-Thompson, D., Hegel, M. T., Schulberg, H. C., & Schulz, R. (2003). Guidelines for conducting geropsychotherapy research. *The American Journal of Geriatric Psychiatry, 11*, 9–16.

Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist, 55*, 469–480.

Avis, N. E., & McKinley, S. M. (1991). A longitudinal analysis of women's attitudes toward the menopause. *Maturitas, 13*, 65–79.

Barnett, R. C., & Baruch, G. (1985). Women's involvement in multiple roles and psychological distress. *Journal of Personality and Social Psychology, 49*, 139–145.

Bengston, V. L. (2001). Beyond the nuclear family: The increasing importance of multigenerational bonds. *Journal of Marriage and Family, 63*, 1–16.

Bengston, V., Rosenthal, C., & Burton, L. (1990). Families and aging: Diversity and heterogenity. In R. Binstock & L. George (Eds.), *Handbook of aging and the social sciences* (3rd ed.). San Diego, CA: Academic.

Biegel, D., Sales, E., & Schulz, R. (1991). *Family caregiving in chronic illnesses: Alzheimer's disease, heart disease, mental illness and stroke*. Newbury Park, CA: Sage.

Binney, E. A., Estes, C. L., & Humphers, S. E. (1993). Informalization and community care. In C. L. Estes & J. H. Swan (Eds.), *Long-term care crisis: Elders trapped in the no-care zone* (pp. 155–170). Newbury Park, CA: Sage.

Braithwaite, V. (1992). Caregiver burden: Making the concept scientifically useful and policy relevant. *Research on Aging, 14*, 3–27.

Brim, O. G. (1992). Theories of male mid-life crisis. *The Counseling Psychologist, 6*, 2–9.

Brody, E. M. (1985). Parent care as a normative family stress. *The Gerontologist, 25*, 19–30.

Bulger, M.W, Wandersman, A., Goldman, C.R. (1993). Burdens and gratifications of caregiving: Appraisal of parental care of adults with schizophrenia. *American Journal of Orthopsychiatry, 63*, 255–265.

Burgio, L., Stevens, A., Guy, D., Roth, D. L., & Haley, W. E. (2003). Impact of two psychosocial interventions on White and African American family caregivers of individuals with dementia. *The Gerontologist, 43*, 568–579.

Campbell, L. D., & Martin-Matthews, A. (2003). The gendered nature of men's filial care. *Journal of Gerontology Series B: Psychological Sciences and Social Sciences, 58B*, S350–S358.

Carpenter, B. D. (2001). Attachment bonds between adult daughters and their older mothers: Associations with contemporary caregiving. *Journal of Gerontology Series B: Psychological Sciences and Social Sciences, 56B*, 57–266.

Casper, L. M., & Bryson, K. R. (1998). *Co-resident grandparents and their grandchildren: Grandparent maintained families (Working Paper No. 26)*. Washington, DC: U.S. Census Bureau.

Clark, P. (1993). Public policy in the United States and Canada: Individualism, familial obligation and collective responsibility in the care of the elderly. In J. Hendricks & C. Rosenthal (Eds.), *The remainder of their days: Domestic policy and older families in the United States and Canada* (pp. 13–48). New York: Garland.

Clyburn, L., Stones, M., Hadjistavropoulos, T., & Tuokko, H. (2000). Predicting caregiver burden and depression in Alzheimer's disease. *Journal of Gerontology Series B: Psychological Sciences and Social Sciences, 55B*, S2–S13.

Cohen, C. A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: Rounding out the caregiving experience. *International Journal of Geriatric Psychiatry, 17*, 184–187.

Cooney, T. M., & Uhlenberg, P. R. (1990). The role of divorce in men's relations with their adult children after mid-life. *Journal of Marriage and Family, 52*, 619–625.

Cox, C. (1999). Race and caregiving: Patterns of service use by African American and White caregivers of persons with Alzheimer's disease. *Journal of Gerontological Social Work, 32*, 5–19.

Delgado, M., & Tennstedt, S. (1997). Making the case for culturally appropriate community services: Puerto Rican elders and their caregivers. *Health and Social Work, 22*, 246–255.

Dillaway, H. E. (2005). Menopause is the "good old"—Women's thoughts about reproductive aging. *Gender and Society, 19*, 398–417.

Dilworth-Anderson, P., Williams, I. C., & Gibson, B. E. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980–2000). *The Gerontologist, 42*, 237–272.

Dwyer, J. W., Lee, G. R., & Jankowski, T. B. (1994). Reciprocity, elder satisfaction, and caregiver stress and burden: The exchange of aid in the family caregiving relationship (in between generations). *Journal of Marriage and Family, 56*, 35–43.

Elder, G. (1992). The life course. In E. Borgatta & M. Borgatta (Eds.), *Encyclopedia of sociology* (3rd ed., pp. 1120–1130). New York: Macmillan.

Farran, C. J., Miller, B., Kaufman, J. E., & Davis, L. (1997). Race, finding meaning, and caregiver distress. *Journal of Aging and Health, 9*, 316–333.

Farran, C. J., Miller, B., Kaufman, J. E., Donner, E., & Fogg, L. (1999). Finding meaning through caregiving: Development of an instrument for family caregivers of persons with Alzheimer's disease. *Journal of Clinical Psychology, 55*, 1107–1125.

Farrell, M. P., & Rosenberg, S. D. (1981). *Men at midlife*. Boston: Auburn House.

Fields, J., & Casper, L. M. (2001). America's families and living arrangements. *Current Population Reports.* Washington, DC: U.S. Census Bureau.

Fox, K., Hinton, W. L., & Levkoff, S. (1999). Take up the caregiver's burden story: Stories of care for urban African American elders with dementia. *Culture, Medicine and Psychiatry, 23*, 501–529.

Gallagher-Thompson, D., Coon, D. W., Solano, N., Ambler, C., Rabinowitz, Y., & Thompson, L. W. (2003). Chances in indices of distress among Latino and Anglo female caregivers of elderly relatives with dementia: Site specific results from the REACH national collaborative study. *The Gerontologist, 43*, 580–591.

George, L. K., & Gwyther, L. P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *Gerontology, 26*, 253–259.

Glazer, N. (1990). The home as a workshop: Women as amateur nurses and medical care providers. *Gender and Society, 4*, 479–499.

Goldschieder, F. K., & Goldscheider, C. (1994). Leaving and returning home in 20th-century America. *Population Bulletin, 48*, 2–33.

Goldschieder, F. K., Thornton, A., & Yang, L.-S. (2001). Helping out the kids: Expectations about parental support in young adulthood. *Journal of Marriage and Family, 63*, 727–740.

Gonyea, J. G. (1996). Finished at fifty: The politics of the menopause and hormone replacement therapy. *American Journal of Preventive Medicine, 12*, 415–419.

Gonyea, J. G., O'Connor, M., Carruth, A., & Boyle, P. (2005). Subjective appraisal of Alzheimer's disease caregiving: The role of self-efficacy and depressive symptoms in the experience of burden. *American Journal of Alzheimer's Disease and Other Dementias, 20*(5), 273–280.

Hagestad, G. O. (2000). *Intergenerational relations*. Paper prepared for the United Nations Economic Commission for Europe Conference on Generations and Gender, Geneva, Switzerland.

Haley, W. E., West, C. A., Wadley, V. G., Ford, G. R., White, F. A., Barrett, J. J., et al. (1995). Psychological, social and health impact of caregiving: A comparison of Black and White dementia caregivers and noncaregivers. *Psychology and Aging, 10*, 540–552.

Han, S.-K., & Moen, P. (1999). Work and family over time: A life course approach. *The Annals of the American Academy of Political and Social Science, 562*, 98–110.

Harrington Meyer, M., & Storbakken, M. K. (2000). Shifting the burden back to families? In M. Harrington Myer (Ed.), *Carework: Gender, labor and the welfare state*. New York: Routledge.

Harrington Meyer, M. (2000). *Carework: Gender, labor and the welfare state*. New York: Routledge.

Harris, P. B. (2002). The voices of husbands and sons caring for a family member with dementia. In B. J. Kramer & E. H. Thompson (Eds.), *Men as caregivers—Theory, research and service implications* (pp. 213–233). New York: Springer.

Hinton, W. L., & Levkoff, S. (1999). Constructing Alzheimer's: Narratives of lost identities, confusion, and loneliness in old age. *Culture, Medicine and Psychiatry, 23*, 453–475.

Hoenig, J., & Hamilton, M. W. (1966). The schizophrenic patient in the community and his effect on the household. *The International Journal of Social Psychiatry, 12*, 165–176.

Hollis-Sawyer, L. A. (2003). Mother–daughter eldercare and changing relationships: A path-analytic investigation of factors underlying positive-adaptive relationships. *Journal of Adult Development, 10*, 41–52.

Hooker, K., Bowman, S., Coehlo, D., Lim, S., Kaye, J., Guariglia, R., et al. (2002). Behavioral change in persons with dementia: Relationships with mental and physical health of caregivers. *Journal of Gerontology Series B: Psychological Sciences and Social Sciences, 57B*, 453–460.

Hooyman, N. R., & Gonyea, J. G. (1995). *Feminist perspectives on family care: Policies for gender justice*. Thousand Oaks, CA: Sage.

Hudson, R. B., & Gonyea, J. G. (2000). Time not yet money: The promise and politics of the Family and Medical Leave Act. *Journal of Social Policy and Aging, 11*, 189–200.

Janevic, M. R., & Connell, C. M. (2001). Racial, ethnic, and cultural differences in the dementia caregiving experience: Recent findings. *The Gerontologist, 41*, 334–337.

Kiecolt-Glaser, J. K., Glaser, R., Shuttleworth, E. E., Dyer, C. S., Ogrocki, P., & Speicher, C. E. (1987). Chronic stress and immunity in family caregivers of Alzheimer's disease patients. *Psychosomatic Medicine, 49*, 523–535.

Knight, B. G., Lutzky, S.M. & Macofsky-Urban, F. (1993). A meta-analytic review of interventions for careqiver distress: Recommendations for Future Research. *Gerontologist, 33*, 43–51.

Knight, B. G., & McCallum, T. J. (1998). Heart rate reactivity and depression in African American and White dementia caregivers: Reporting bias or positive coping? *Aging and Mental Health, 2*, 212–221.

Knight, B. G., Silverstein, M., McCallum, T. J., & Fox, L. S. (2000). A sociocultural stress and coping model for mental health outcomes among African American caregivers in southern California. *Journal of Gerontology Series B: Psychological Sciences and Social Sciences, 46*, P181–P189.

Kramer, B. J. (1997). Gain in the caregiving experience: Where are we? What next? *The Gerontologist, 37*, 218–232.

Lachman, M. E., Lewkowicz, C., Marcus, A., & Peng, Y. (1994). Images of midlife development among young, middle-aged, and older adults. *Journal of Adult Development, 1*, 201–211.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.

Levkoff, S. E., Levey, B. R., & Weitzman, P. E. (1999). The role of religion and ethnicity in the help seeking of family caregivers of elders with Alzheimer's disease and related disorders. *Journal of Cross-Cultural Gerontology, 14*, 335–356.

Lyons, K. S., Zarit, S. H., Sayer, A. G., & Whitlatch, C. J. (2002). Caregiving as a dyadic process: Perspectives from caregiver and receiver. *Journal of Gerontology Series B: Psychological Sciences and Social Sciences, 57B*, P195–P204.

Marks, S. R. (1977). Multiple roles and role strain: Some notes on human energy, time and commitment. *American Sociological Review, 41*, 921–936.

Marks, N. F. (1996). Caregiving across the lifespan: National prevalence and predictors. *Family Relations, 45*, 27–36.

Marks, N. F. (1998). Does it hurt to care: Caregiving, work-family conflict, and midlife well-being. *Journal of Marriage and Family, 60*, 951–956.

Marsh, P. (1992a). *Families and mental illness: New directions in professional practice*. New York: Praeger.

Marsh, P. (1992b). *Families and mental retardation: New directions in professional practice*. New York: Praeger.

Matthew, L. J., Mattocks, H., & Slatt, L. M. (1990). Exploring the roles of men in caring for demented relatives. *Journal of Gerontological Nursing, 16*, 20–25.

McGraw, L. A., & Walker, A. J. (2004). Negotiating care: Ties between aging mothers and their caregiving daughters. *Journal of Gerontology Series B: Psychological Sciences and Social Sciences, 59B*, S324–S332.

McNally, S., Ben-Shlomo, Y., & Newman, S. (1999). The effect of respite care on informal cares' well-being: *A systematic review, Disability and Rehabilitation, 21*, 1–14.

Miller, B., & Cafasso, L. (1992). Gender differences in caregiving: Fact or artifact? *The Gerontologist, 32*, 498–507.

Moen, P. (2001). The gendered life course. In R. H. Binstock & L. K. George (Eds.), *Handbook of aging and the social sciences* (5th ed., pp. 179–196). New York: Academic.

Moen, P., Robison, J., & Fields, V. (1994). Women's work and caregiving roles: A life course approach. *Journal of Gerontology Series B: Psychological Sciences and Social Sciences, 49*, S176–S186.

Montgomery, R., Gonyea, J. G., & Hooyman, N. R. (1985). Caregiving and the experience of objective and subjective burden. *Family Relations, 34*, 19–26.

Montgomery, R., & Kosloski, K. (1994). Outcomes of family caregiving: Lessons from the past and challenges for the future. In M. Cantor (Ed.), *Family caregiving: An agenda for the future*. San Francisco, CA: American Society on Aging.

National Alliance for Caregiving & AARP. (2005). *Caregiving in the U.S*. Bethesda, MD: National Alliance for Caregiving & AARP.

National Council on Aging. (2000). *Myths and realities 2000 survey results*. Washington, DC: National Council on Aging.

Noonan, A. E., & Tennstedt, S. L. (1997). Meaning in caregiving and its contribution to caregiver well-being. *The Gerontologist, 37*, 785–794.

Noonan, A. E., Tennstedt, S. L., & Rebelsky, F. G. (1996). Making the best of it: Themes of meaning among informal caregivers to the elderly. *Journal of Aging Studies, 10*, 313–327.

Older Women's League. (1989). *Failing America's caregivers: A status report on women who care*. Washington, DC: Older Women's League.

Olson, L. K. (2001). *Age through ethnic lenses: Caring for elderly in a multicultural society*. Lanham, MD: Rowman & Littlefield.

Parks, H., & Pilisuk, M. (1991). Caregiver burden: Gender and the psychological costs of caregiving. *The American Journal of Orthopsychiatry, 6*, 501–509.

Pearlin, L., Mullan, J., Semple, S., & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*, 583–594.

Pearlin, L. I., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior, 19*, 2–21.

Penning, M. J. (2002). Hydra revisited: Substituting formal for self- and informal in-home care among older adults with disabilities. *The Gerontologist, 42*, 4–16.

Picot, S. J. F., Youngblut, J., & Zeller, R. (1997). Development and testing of a measure of perceived caregiver rewards in adults. *Journal of Nursing Measurement, 5*, 32–52.

Pot, A.M., Deeg, D.J., vanDyck, R., & Jonker, C. (1998). Psychological distress of caregivers: The mediator effect of caregiving appraisel. *Patient Education and Counseling, 34*, 43–51.

Poulshock, SW., & Deimling, G.T. (1984). Families caring for elders in residence: Issues in the measurement of burden. *Journal of Gerontology, 39*, 230–239.

Qureshi, H., & Walker, A. (1989). *The caring relationship: Elderly people and their families*. Philadelphia, PA: Temple University Press.

Raschick, M., & Ingersoll-Dayton, B. (2004). The costs and rewards of caregiving among aging spouses and adult children. *Family Relations, 53*, 317–325.

Roff, L. L., Burgio, L. D., Gitlin, L., Nichols, L., Chaplin, W., & Hardin, J. M. (2004). Positive aspects of Alzheimer's caregiving: The role of race. *Journal of Gerontology Series B: Psychological Sciences and Social Sciences, 59B*, P185–P190.

Russell, R. (2001). A qualitative study of elderly men who care for wives with dementia. *Journal of Aging Studies, 15*, 351.367.

Schulz, R., Gallagher-Thompson, D., Haley, W. E., & Czaja, S. (2000). Understanding the interventions process: A theoretical conception framework for intervention approaches to caregiving. In R. Schulz (Ed.), *Handbook on dementia caregiving: Evidence-based interventions for family caregivers* (pp. 33–60). New York: Springer.

Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry, 12*, 240–249.

Schulz, R., O'Brien, A. T., Bookwalla, J., & Flesissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates and causes. *The Gerontologist, 35*, 771–791.

Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martire, L. M., et al. (2002). Dementia caregiver intervention research: In search of clinical significance. *The Gerontologist, 42*, 589–602.

Shanas, E. (1979). The family as a support system in old age. *The Gerontologist, 19*, 169–174.

Silverstein, M., & Marenco, A. (2001). How Americans enact the grandparent role across the family life course. *Journal of Family Issues, 22*, 493–522.

Skaff, M. M., & Pearlin, L. I. (1992). Caregiving: Role engulfment and loss of self. *The Gerontologist, 32*, 656–664.

Skolnick, A. (1991). *Embattled paradise*. New York: Basic Books.

Sorensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist, 42*, 356–372.

Spillman, B. C., & Pezzin, L. E. (2000). Potential and active family caregivers: Changing networks and the "sandwich generation". *The Millbank Quarterly, 78*, 347–374.

Strawbridge, W. J., & Wallhagen, M. I. (1991). Impact of family conflict on adult child caregivers. *The Gerontologist, 31*, 770–771.

Thompson, E. H., & Doll, W. (1982). The burden of families coping with the mentally ill: An invisible crisis. *Family Relations, 31*, 379–388.

Toseland, R. W., & Rossiter, C. M. (1989). Group interventions to support family caregivers: A review and analysis. *The Gerontologist, 29*, 465–471.

Traustadottir, R. (1991). Mothers who care: Gender, disability, and family life. *Journal of Family Issues, 12*, 211–218.

U.S. Bureau of Labor Statistics. (2005). *Women in the labor force: A databook* (Report 985). Retrieved February 2006 from www.bls.gov/cps/wlf-table7-2005.pdf

U.S. Census Bureau. (2000). *Population projections of the United States by age, sex, race, hispanic origin, and nativity: 1999 to 2000*. Retrieved January 2001 from www.census.gov/projections/natproj.html.

U.S. Commission on Family and Medical Leave. (1996). A working balance: Report to congress on family and medical leave policy. Retrieved January 1997 from http://digitalcommons,ilr.cornell.edu/cgi/viewcontent.cgi?ortical=1002&context=Key_workplace.

Uhlenberg, P. (1996). Mutual attraction: Demography and life-course analysis. *The Gerontologist, 36*, 226–229.

Uhlenberg, P., & Cooney, T. M. (1990). Family size and mother–child relationships in later life. *The Gerontologist, 30*, 618–625.

Uhlenberg, P., & Hammill, B. G. (1998). Frequency of grandparent contact with grandchild sets: Six factors that make a difference. *The Gerontologist, 38*, 276–285.

Walker, A. J., Martin, S. K., & Jones, L. L. (1992). The benefits and costs of caregiving and care receiving for daughters and mothers. *Journal of Gerontology Series B: Psychological Sciences and Social Sciences, 47B*, S130–S139.

Ward, R. A., & Spitze, G. (1998). Sandwiched marriages: The implications of child and parent relations for marital quality in midlife. *Social Forces, 77*, 647–666.

White, T. M., Townsend, A. L., & Stephens, M. A. (2000). Comparisons of African American and White women in the parent care role. *The Gerontologist, 40*, 718–728.

Yee, J. L., & Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: A review and analysis. *The Gerontologist, 40*, 147–164.

Chapter 8

Pathways to a Caregiver Identity and Implications for Support Services

Rhonda J.V. Montgomery and Karl D. Kosloski

Caregiving at the end of the life cycle is now widely recognized as a normal role in later life for most women and many men. The caregiving role, however, is not uniformly embraced by all potential caregivers, nor is it experienced in the same manner by those who assume the role. Indeed, a large number of studies conducted over the two past decades have documented differential impacts of caregiving on caregivers' lives (Anhensel, Pearlin, Mulan, Zarit, & Whitlach, 1995; Farran, Miller, Kaufman, & Davis, 1997). Despite early questions about the utility of research on caregiving and its corresponding costs (Zarit, 1989), the experience of caregiving has been designated by The National Institute on Aging as one of the top priorities for social and behavioral research. Caregiving has also moved on to center stage in the policy arena. Where in the past, the presence of a family caregiver was often the basis for denial of public services, the introduction of the National Family Caregiver Support Program (NFCSP) as Title III-E of the Older American's Act in 2000 legitimized family caregivers as a group with needs deserving of assistance. Since the initial implementation of the NFCSP in 2000, there has been an explosion of newly developed family support programs at both the state and local levels.

This proliferation of family support services makes careful examination of our current knowledge of caregiving for older adults a timely endeavor. In particular, it

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is useful to explore ways in which information gained from research can be used to guide practice and policy.

The purpose of this chapter is to introduce the caregiver identity theory as a conceptual framework that is grounded in the findings of previous research and has the potential to be a useful tool for guiding the delivery of support services to caregivers. This caregiver identity theory identifies common elements of the caregiver role while acknowledging that for each individual the caregiver role is uniquely defined by cultural and familial experiences. The theory is grounded in the fundamental observation that there is no single generic caregiver role (Montgomery & Kosloski, 2000). It also takes into account great diversity among caregivers as to the type and quantity of tasks they undertake and the duration of time over which they serve in this role. The theory is advanced as a framework to help service providers understand the sources of caregiver distress, effectively target support services to family caregivers, and help policy makers to design support systems that are both effective and efficient.

This model of the caregiving process also provides a framework for interpreting previous research findings about caregiver outcomes and patterns of service use and non-use. Just as there is wide variation in the tasks that caregivers undertake, there is also wide variation among caregivers in the costs they incur and the benefits they perceive as a consequence of their caregiving role. An extensive body of work now exists that documents both positive and negative outcomes of caregiving. The majority of studies has documented negative impacts and has identified a host of factors as predictors of stress or burden. Negative outcomes can include infringement on a caregiver's time and life style role conflict (Anhensel et al., 1995; Chappell, 2002; Stephens, Townsend, Martire, & Druley, 2001), isolation (Shaw, O'Bryant, & Meddaugh, 1991), emotional stress which can be experienced as anxiety and/or depression (Bourgeois, Schulz, & Burgio, 1996; Haley et al., 1995), disruption or deterioration of the dyadic relationship between the caregiver and the care recipient (Cox & Monk, 1993; Mui, 1992; Stephens et al., 2001), role strain (Mui, 1992; Stephens et al., 2001), and decline in the caregiver's physical health (Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1995; Schulz, O'Brien, Bookwalla, & Flesissner, 1995).

Although widespread agreement exists that caregiving has negative consequences for many caregivers, positive outcomes have also been observed including a sense of mastery, positive affect, and an improvement in quality of the dyadic relationship between the caregiver and the care recipient (Beach, Schulz, Yee, & Jackson, 2000; Farran et al., 1997; Sherrell, Buckwalter, & Morhardt, 2001). Studies directed toward understanding variation in the consequences of caregiving have also focused on a large number of factors that could include the relationship of the caregiver to the care recipient (e.g., Miller, 1989; Miller & Cafasso, 1992; Miller, McFall, & Montgomery, 1991; Stephens et al., 2001), race and culture (Dilworth-Anderson, Williams, & Gibson, 2002; Farran et al., 1997; Janevic & Connell, 2001; Knight & McCallum, 1998; Lawton, Rajagopal, Brody, & Kleban, 1992), health characteristics of the care recipient (Gallagher-Thompson et al., 1997; Pearlin, Mullan, Semple, & Skaff, 1990) and of the caregiver (e.g., Beach et al., 2000; Kramer & Kipnis, 1995; Stuckey & Smyth, 1997), the level and type of care provided (Beach et al., 2000), the length of caregiving (Donaldson & Burns, 1999; Van den Heuvel, De Witte, Schure, Sanderman,

& Meyboom-de Jong, 2001), and the availability and use of informal and formal sources of support (Bass & Noelker, 1996; Chappell, 2002).

Despite extensive research, little consistency has emerged in the literature concerning factors linked to the experience of burden or stress. The two factors most consistently reported to be associated with higher levels of stress are gender and living arrangement. Generally, women and those who reside with the care recipient experience higher levels of stress (Merrill, 1997; Winslow & Carter, 1999; Yee & Schulz, 2000). Even these patterns, however, have not been uniformly supported by past research (Parks & Pilisuk, 1991). Consequently, the critical question of differential impacts remains unanswered. For some family members, caregiving is a difficult experience that has serious negative consequences. Yet, other caregivers who have similar responsibilities are able to cope well and report little impact or even positive outcomes (Call, Finch, Huck, & Kane, 1999; Lévesque, Cossette, & Laurin, 1995; Merrill, 1997; Montgomery & Datwyler, 1990; Pyke & Bengtson, 1996). To some degree, inconsistent findings reflect variations among studies in the definition and measurement of caregiving and of caregiver stress or burden (Gaugler, Kane, & Kane, 2002; Montgomery & Kosloski, 2000; Walker, Pratt, & Eddy, 1995). However a major methodological and conceptual limitation of research stems from ignoring the longitudinal and dynamic nature of caregiving. Over time, care contexts and needs of care recipients change in ways that require corresponding changes in caregiving behaviors. Consequently, caregivers may engage in very different care behaviors over the course of their careers and experience their roles differently at different points in their careers (Beach et al., 2000). This understanding of caregiving as a dynamic, rather than a static, process is not only essential for clarifying the links between caregiving and caregiver outcomes, but is also essential for identifying effective strategies and resources for supporting caregivers.

Over the past two decades an array of community-based service programs to support family caregivers has been developed and funded through federal, state, and local agencies. Some of these services are designed to supplement caregiving efforts by providing assistance with direct care tasks and skilled nursing care (e.g., home health care) that may exceed the abilities or capacities of informal providers. Other services are intended, primarily, to relieve informal caregivers of their responsibilities for short periods of time, to enable them to provide higher quality of care, or to provide moral support to relieve the psychological distress of caregiving. These latter efforts have generally involved some combination of respite, education, counseling, and support-group programming. Despite considerable consensus about the value of such programs for assisting caregivers, provider organizations and care managers continue to wrestle with two important issues as they attempt to deliver services effectively. First, there is little information available to guide care managers or service providers as they make decisions about the effective allocation and delivery of services (Knight & Lutzky, 1993; Pillemer, Suitor, & Wethington, 2003). Second, consistent research findings and anecdotal evidence from formal service providers indicate that such programs frequently go under utilized by caregivers who are ostensibly good candidates for these services. One of the most important and persisting practical questions, then, is why do caregivers underutilize services?

Attributions have been made to (1) lack of perceived need by the caregiver (Caserta, 1987), (2) inappropriate targeting of services to caregivers' needs (Horowitz, 1985; Montgomery & Kosloski, 2000), and (3) barriers created by providers in the manner in which services are delivered (Caserta, 1987; Gwyther & Ballard, 1990; Montgomery, Marquis, Schaefer, & Kosloski, 2002; Montoro-Rodriguez, Kosloski, & Montgomery, 2003).

One important goal of our theory is to provide an understanding of the reasons for non-use of services and to articulate the circumstances under which services will be maximally useful for caregivers. We will argue that perceived need for respite or another service on the part of caregivers accrues when there is: (1) a substantial discrepancy between the way in which the caregiver views herself relative to her caregiving activities; (2) a change in the way in which she views her relationship with the care receiver; and/or (3) a fundamental change in the caregiving situation. Each of these factors has different implications for the need and, ultimately, the efficacy of a given support service. These differing causal factors are also likely to be reflected by different subjective measures of caregiving outcomes (e.g., objective vs. subjective burden). Our approach stands in stark contrast to previous approaches that have treated caregivers as a homogeneous population characterized by uniform need for services.

The Caregiver Identity Theory

The caregiver identity theory is built around three key premises that are consistent with findings that have emerged out of the extensive body of research that has been conducted on the caregiving experience. First, the caregiving role is acquired in a systematic way. Second, it is a dynamic process that changes over time. Third, as caregivers experience change in their role, they also experience a change in their own identity. It is on these fundamental premises that it is possible to develop a theory of caregiving.

Acquisition of the Caregiver Role

To understand the outcomes associated with caregiving and the differential experiences of these outcomes among caregivers, it is first necessary to understand how individuals acquire the caregiver role and the demands that the role places on occupants. Like many other social behaviors, caregiving is governed by norms or social rules. The prominence of adult daughters and daughters-in-law in the caregiving role suggests systematic cultural rules operate to dictate responsibility for care. Cantor (1979) has attempted to explicate these shared cultural understandings of filial responsibility in what she has called the "hierarchical compensatory theory of social supports." That is, there is an order as to who will assume the caregiver role. The caregiving role is assumed first by a spouse, if one is available. Children are next in line, followed by more distant family members, friends and neighbors, and then formal caregiving organizations, in a well-ordered hierarchy of caregiver selection.

Even with the existence of these shared expectations, there is a great deal of variability among caregivers in the extent to which general social norms influence attitudes and behavior (Franks, Pierce, & Dwyer, 2003). There are several sources of this variability. First, specific ethnic and cultural backgrounds influence expectations and norms about caregiving (Connell & Gibson, 1997; Haley et al., 1995; Youn, Knight, Jeong, & Benton, 1999). Second as Rossi and Rossi (1990) point out, there may be a high degree of consensus on the general norm (e.g., honor thy father and mother), but the application of the norm always occurs in highly specific circumstances. There is less unanimity in the specific application (Franks et al., 2003). Third, each family appears to develop a unique family ethos (Brubaker & Brubaker, 1989; Pyke & Bengtson, 1996; Riley, 1983). This ethos actually determines which members in the family are responsible for caregiving, the types of care that are appropriate, and the specific conditions under which it is appropriate to seek assistance from outside the family (e.g., from public or private agencies). Thus, the effects of broad social expectations are filtered through the unique circumstances of the individual family with the result that the normative demands and constraints on a caregiver in one family are unlikely to be the same in another family (Franks et al., 2003). Fourth, each culture has its own rules concerning the conditions that provide exceptions to the prevailing social norms (Cox & Monk, 1993; Franks et al., 2003; Pyke & Bengtson, 1996). For example, there are rules that govern the avoidance of family responsibility based on (a) temporary conditions (e.g., illness or unemployment), (b) status (e.g., being too young or old, or chronic mental or physical illness), (c) special occasions (e.g., recent marriage or death of someone close), or (d) settings (e.g., extreme physical distances). As a result, normative pressure on caregiving behavior is tempered by the circumstances under which it occurs. The end result is that the acquisition of the caregiving role is always an idiosyncratic process and, once assumed, there is no single, generic caregiver role. On the one hand, as Gonyea (Chap. 7) has observed, there are consistencies observed in the caregiving process because caregiving is a rule-governed process that emerges out of an existing role relationship.

On the other hand, there is variability in the normative pressure experienced by caregivers to assume the caregiving role. These differing pressures reflect the unique histories and circumstances surrounding the role relationships (Bookwala & Schulz, 2000; Pyke & Bengtson, 1996). As a result, there are considerable differences among caregivers in their perceived duty to provide care in the first place, in their expectations regarding appropriate care tasks, and ultimately, in their level of commitment to the caregiving role (Corcoran, 1992; Montgomery & Williams, 2001; Pruchno, Burant, & Peters, 1997).

Caregiving as a Dynamic Process

The notion that caregiving is a process or career has been articulated by a number of writers in the past (Anhensel et al., 1995). Yet the importance of studying caregiving as a process of change has only recently been emphasized by scholars who have noted the serious implications of this change process for conducting adequate studies and identifying effective interventions (Gaugler et al., 2002; Langa et al., 2001; Montgomery & Kosloski, 2000; Seltzer & Li, 2000; Soerensen, Pinquart, & Duberstein, 2002).

Once a caregiver assumes the role, caregiving becomes a dynamic process that unfolds over time. At its most fundamental level, the caregiving experience is jointly characterized by two factors: (1) the activities in which the caregiver is engaging, and (2) the meaning that the caregiver attaches to these behaviors (Skaff & Pearlin, 1992). This seemingly obvious observation has profound implications for the study of caregiving. First, it means that caregiving is not a unitary process and the process will be different for each disease trajectory. For example, in the case of Alzheimer's disease, caregiving activities change dramatically across each stage of the disease, ranging from simple reminders, to custodial care, to high levels of personal care and, in the end stages, to medical care. Second, it means that the same caregiving activities can be perceived differently, depending upon a host of factors that serve to define the caregiving circumstance. These factors include the normative pressures to assume the caregiving role, as well as the innumerable idiosyncratic circumstances that determine the caregiver's commitment to the role.

From a purely research perspective, it may seem hopeless to specify accurately and completely all of the factors that determine the caregiving experience. Indeed, many of these factors belong to the unique personal histories of the actors and may be unknowable even to them. Nonetheless, it is the totality of these factors that serve to define each caregiving experience and uniquely identify caregivers one from another. Put another way, the caregiving role affects the identity of each person that assumes the role. Indeed, the caregiving role is a role identity that becomes merged with all the other role identities that make each individual unique and serves to define the manner in which people experience their world.

Identity Change

As noted earlier, the caregiving role emerges out of an existing role relationship, usually a familial role such as daughter, wife, or husband. As the needs of the care recipient increase in quantity and intensity over time, a change takes place in the dyadic relationship between the caregiver and the care recipient. The initial familial relationship gives way to a relationship characterized by caregiving. As caregivers move through their caregiving career, they not only change their behaviors, but they also change their role identity in relation to the care recipient. This identity change occurs because the care tasks that are required to maintain the health of the care recipient become inconsistent with the expectations associated with the caregiver's initial role in relation to the recipient. To a large degree this shift in identity is necessitated by significant changes in the care context, which most often involves an increase in the level of dependency of the care recipient. Other significant changes in the care context, however, might include an increase or decrease in the availability of informal or formal supports or a change in living arrangement.

For most caregivers of persons with chronic conditions or dementia, the change in the role identity that a caregiver experiences in relation to the care recipient is a slow, insidious process that proceeds in stops and starts, ultimately resulting in a significant shift from one's initial role relationship (e.g., spouse, daughter, or friend) to that of caregiver. Initially, the care needs of the elder may be relatively small, and the corresponding care tasks represent minimal extensions of the familial role relationship. For example, a daughter may quite easily assist her mother who has some difficulty with paying bills, shopping, or transportation to appointments without experiencing stress. As the disease progresses, the needs of the mother, and resultant demands placed on the daughter, increase. As this process unfolds, the daughter's activities gradually increase in intensity and become discrepant with the norms that a daughter has internalized with respect to her role as a daughter. Thus, over time, the caregiving activities transform the initial mother–daughter relationship into a caregiving relationship. The daughter may now find herself engaging in activities with respect to her parent that she never engaged in previously. Simply put, her activities are now discrepant with her previous role identity.

Furthermore, these activities make time demands that limit her other role performances (e.g., time for being a spouse, for being a mother, for friendship roles, etc.). The end result is incongruence between what the daughter is now doing as a caregiver and the way that she views herself (i.e., her role identity) as a daughter. To the extent that the daughter's behavior is discrepant with her self-view, the daughter experiences distress (e.g., burden) and a pressure accrues to reconcile this discrepancy. It is the incongruence between the caregiving tasks and the meaning attached to these tasks that causes caregivers distress, and prompts actions to restore congruence, in whatever way possible, to relieve this distress. We argue here that such relief may ultimately require an identity change. This identity change, however, is usually not a smooth, continuous process. Rather the assumption of a caregiver identity is an iterative process of change, which alternates between periods of relative stability wherein a role identity is maintained through small adjustments in behavior or perceptions, and periods when there are significant shifts in the caregiver's identity that are associated with the acceptance of new norms for behavior.

Avenues of Identity Change

A central tenet of caregiver identity theory is that a caregiver experiences distress or burden as a result of a disruption in an identity maintenance process. The pressure toward identity change can be understood within the Piagetian notions of assimilation and accommodation (Piaget, 1971). (See also Whitbourne (1986) who has used such an approach to explain personality change.) Assimilation refers to the integration of one's activities into an existing role structure. For example, early in the disease process, a wife may incorporate a few caregiving activities into her existing view of the spousal relationship with no distress whatsoever. So, for example, she may assume responsibilities for paying bills that were once her husband's, or she may remind him to attend to grooming tasks or lay out his clothes. Assimilation is the stretching of an existing identity to incorporate some care tasks that may not be fully consistent with the internalized standards for behavior that exist for one's identity. This stretching or assimilation allows the continuation of the caregiving process without a significant change of the caregiver's identity and generally takes place when there are only minor changes in the caregiving context.

Accommodation, in contrast, refers to a fundamental and noticeable shift in the dyadic role relationship and, ultimately, in one's role identity. This would occur, for example, when a wife realizes that she must now assume complete responsibility for her husband's grooming needs and constantly monitor his behavior. Prior to this point in time, the wife had been performing caregiving activities, but had been able to assimilate these activities into her role as a wife without completely undermining her spousal identity. As the caregiving demands increased and formalized, however, they now far exceed the activities that typically define the wife role as she perceives it. This creates a discrepancy between behavior and identity. To reduce the discrepancy, the wife must change either her role identity in relation to her husband to account for these activities or reject the caregiver role altogether. In other words, she must change her identity to accommodate the caregiving activities that are no longer merely an extension of the wife role or she must remove the caregiving tasks from her repertoire of role behaviors so that she can retain the wife role as her dominant identity in relation to her husband. The essential point is that the caregiving role, which emerged merely as an extension of the spousal role, has the potential to transform the spousal role dramatically for the husband–wife dyad. Specifically, in an effort to accommodate the demands of caregiving, the spousal role identity must change and give way to a new identity component—that of caregiver.

Thus caregiving is characterized by periods of identity stability and identity change, reflecting the underlying processes of assimilation and accommodation. When caregiving activities can be easily assimilated into one's existing identity structure, minimal distress is experienced, and no identity change is required. As the discrepancy increases between a caregiver's activities, on the one hand, and her self-identity, on the other, psychological distress increases as well. This distress may be manifested as a sense of time compression (i.e., objective burden), distress in the interpersonal relationship (i.e., relationship burden), or anxiety/depression (i.e., stress burden). However manifested, the caregiver is motivated to reduce this distress *by restoring congruence between her identity and her behavior (i.e., care activities)*. Knowledge of the iterative process of change wherein caregivers alternate between periods of maintaining an existing identity and periods of restoring congruence through identity change is essential for understanding both the source of caregiver distress and for identifying strategies that will be effective for relieving this distress.

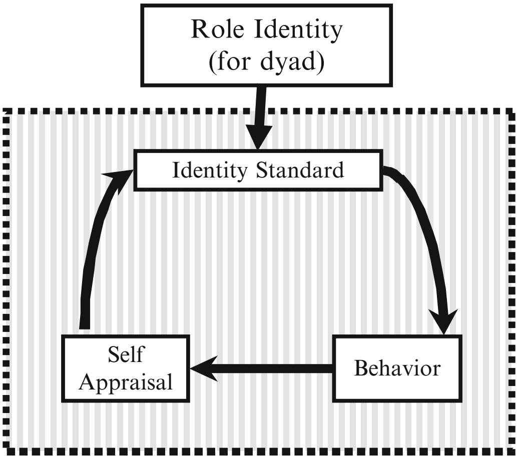


Fig. 8.1 Identity maintenance process. *Arrows* represent temporal process

The Identity Maintenance Process for Caregivers

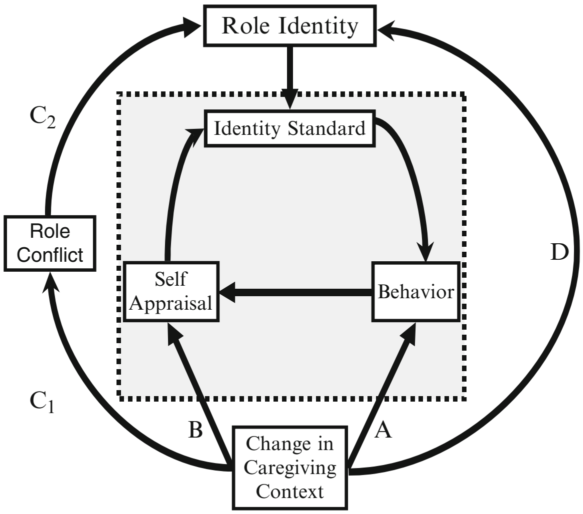
The *caregiver identity maintenance process*, described here and illustrated in Fig. 8.1, is grounded in identity theory as articulated by Stryker and his colleagues (Stryker, 1968, 1994; Stryker & Burke, 2000; Stryker & Serpe, 1982) and draws on the work of Burke and his associates (Burke, 1991; Burke & Reitzes, 1991) who view identity maintenance as a homeostatic control system. A characteristic feature of this homeostatic system is a pressure toward the maintenance of identity stability. From this perspective, an identity is a set of meanings applied to the self in a social role or situation that define an individual's conception of self. This set of meanings serves as a set of personal norms or a standard that a person uses as a reference point to guide his or her behavior in relation to that social role or situation. According to Burke (Burke & Tully, 1977) when an individual assumes a role identity, a control process is initiated that consists of a feedback loop that regulates behavior to maintain that identity. This identity maintenance process takes place within an environment that consists of a social interaction system that includes resources and behaviors of others (Burke, 1980, 1991). For caregivers, this environment is the *caregiving context* defined by the care needs of the care recipient, the living arrangement, and the array of informal and formal resources available to support the caregiver. The shaded area in Fig. 8.1 represents this caregiving context.

The identity maintenance process is initiated with the establishment of an *identity standard* or set of individualized norms that is linked to the actor's unique role identity. The identity standard consists of the set of meanings that an individual internalizes as rules that define which behaviors or actions are appropriate for acting in the selected role. This identity standard is linked to a specific role identity that an actor holds in relation to a role partner. For example, a son has an identity standard that is linked to his role as son in relation to his parent. Thus, the internalized norms that define the identity standard are largely influenced by the general social expectations and specific cultural norms and familial relationship that make each role identity idiosyncratic. As a result, for most caregivers, their initial identity standard is closely linked to their familial role as wife, husband, son, daughter, etc. Thus, the caregiver acts in a manner, and performs tasks, that he or she deems consistent with being a "good" husband, wife, son, daughter, etc. In addition, this identity standard includes norms and beliefs about the conditions under which it is appropriate to seek out and accept help and support from other formal and informal sources. For example, in their study of male caregivers, Coe and Neufeld (1999) found that caregivers' beliefs about family responsibility are primary factors influencing the use or non-use of formal support services.

As a caregiver engages in care activities and interacts with the care recipient, the caregiver also engages in a self-appraisal process wherein a judgment is made about the extent of congruence that exists between the individual's behavior and his or her identity standard. This judgment is based upon feedback received from the care-recipient and other actors in a caregiver's social environment (i.e., caregiving context). This notion of feedback is a central tenet of symbolic interaction theory, which asserts that *self-appraisal* is a reflection of appraisals of actors in a person's social world (Coe & Neufeld, 1999). If this self-appraisal process leads to the conclusion the caregiver's actions are consistent with the caregiver's internalized norms or identity standards, then there is homeostasis and the identity is maintained. If, however, the self-appraisal leads to the conclusion that an individual's behavior is incongruent with the identity standard, the caregiver will experience some level of distress due to the discrepancy.

To alleviate the distress that stems from a discrepancy between a caregiver's behavior and her personal identity standard, a caregiver might make small, incremental changes in her *behavior* to restore congruency between her behavior and her identity standard. For example, a wife who in the past had participated in a weekly bridge club might limit her attendance to once a month in response to her husband's increased need for care. This small change in behavior is a concession that will allow her maintain her identity as an independent wife while still meeting his needs. The identity maintenance process then is a continuous, self-adjusting feedback loop that operates as a control system to maintain homeostasis within an established caregiving context much like a thermostat works to maintain even temperature in a room (Burke, 1980; Stryker, 1968). In some situations, however, a behavioral change may be too big of a stretch for a caregiver, relative to her identity standard, and cause her to experience significant distress. In the previous example, this might occur if playing bridge is a central component of the woman's identity and her husband insists that she give up the bridge club altogether. Large discrepancies between an actor's self-appraisal of behaviors and an identity standard create significant stress, which, in turn, creates pressure toward identity change.

Fig. 8.2 Identity change process



Change in the Care Context as Pressure Toward Identity Change

Large discrepancies between an actor's behavior and an identity standard are most apt to be caused by external forces such as changes in the caregiving context. A substantial change in the physical or cognitive abilities of the care recipient, in the living arrangement, or support resources for the caregiver, is likely to create a large discrepancy between a caregiver's self-appraisal and his or her identity standard. This influence of the caregiving context on the identity maintenance process is depicted in Fig. 8.2 by the two arrows (A and B) drawn from the caregiving context to behavior and self-appraisal. When there is a change in the caregiving context, such as a significant decline in a care recipient's condition, the change can require a caregiver to engage in behaviors that are not congruent with his or her identity standard. For example, if a daughter is confronted with her mother's need for assistance with bathing or dressing, that daughter may be faced with a conundrum that is not resolvable within the context of her existing role identity. If the daughter engages in hands on care as dictated by the change in the caregiving context (arrow A) her behavior will be inconsistent with her internalized conception of the daughter role. If she rejects such tasks, her mother's needs may go unmet, and cause her to appraise her behavior (arrow B) as inconsistent with her identity as a "good" daughter. Hence there is a pressure for the daughter to accommodate the situation by changing her role identity to expand into a caregiver identity.

Another way that changes in the care context can prompt identity change is through the creation of role conflicts as shown by the arrows (C1 and C2) on the left side of the diagram in Fig. 8.2. Role conflict is essentially a negative connection between two identities such that an increase in the congruence of an actor's self-appraisal with one identity standard decreases the congruence of the actor's self-appraisal with a second identity standard. Up to this point, we have restricted our discussion of role identity to the single identity that is directly tied to the dyadic relationship between the caregiver and the care recipient. However, this dyadic relationship is only one of many identities that a caregiver may assume. In reality, individuals have a whole set of roles which, together, create an individual's sense of self (Burke, 1991; Stryker, 1968). For example a caregiver who is a daughter may also have role identities in relation to other actors such as a wife, mother, and employee. Usually, actors do not equally value all of their roles, but instead view one or more of their role identities as more salient than the others. The salience of each role, however, may change over time. At some point, actors may choose to give up an identity or change the role that is viewed as the most salient role for guiding their behavior. That is to say, pressures placed on any given role identity within an actor's constellation of roles may lead to changes in a second identity. For example, role conflict can occur when there is a significant change in the care needs of a parent. When the care needs of a parent are relatively low, a daughter can perform care tasks in a manner that is consistent with her role identity as daughter. As her parent's care needs increase, however, the demands associated with the daughter–caregiver identity may interfere with her ability to engage in behavior that she deems appropriate for her role as mother or wife. Such role conflict often creates significant stress or burden that will place pressure on the daughter to change her role identity in relation to her parent. One possible change is to opt out of the caregiving role altogether and only retain the role of daughter. Such a change will reduce the number of roles that a daughter is juggling and, thereby, reduce the stress that she is experiencing as a consequence of role conflict. This raises the possibility that when a person assumes a stronger identity as a caregiver, other role identities of that individual will be affected. As a result, distress is likely to accrue as the caregiver assumes more of a caregiver identity (Skaff & Pearlin, 1992).

Whether it is possible to "stretch" one's identity by assimilating new caregiving behaviors within the existing identity standard, or it is possible to accommodate these behaviors into a new caregiving identity will depend, in part, on the norms of the broader culture. For example, the context of a caregiving situation, in which a child is caring for his or her mother, will change dramatically when the mother begins to require personal care. For daughters, the change may be too great for easy assimilation of the behaviors into a daughter identity but the accommodation of the behaviors through an identity change remains a viable alternative. In contrast, for sons, the taboo against non-spouse males engaging in personal care may be too strong to allow for either assimilation or accommodation of such activities into an existing role identity. In the latter case, sons will typically turn the new caregiving tasks over to other informal, or formal, providers.

Phases of the Caregiving Career and Identity Change

To understand caregiving as an identity change process more fully, it is useful to examine the caregiving career as it is linked to changes in the care recipient's need for assistance. The disease process of the care recipient and the initial familial or

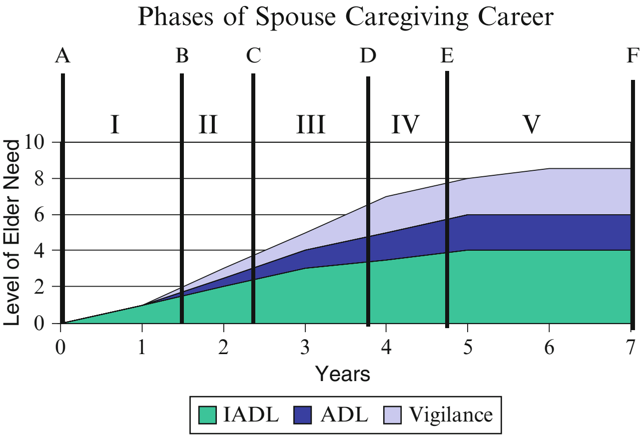


Fig. 8.3 Five phases of a spouse caregiving career. The letters demarking the five phases identify six markers of the caregiving career: *A* = initial onset of care tasks, *B* = self-identification as caregiver, *C* = performance of personal care tasks, *D* = first consideration of nursing home placement, *E* = placement in institutional setting, *F* = end of career

friendship relationship of the caregiver to the care recipient establish the context for the caregiving career. As shown in Fig. 8.3, over a hypothetical 7 year period of caring for an Alzheimer's patient, the care recipient's need for assistance with instrumental activities of daily living and activities of daily living increases as does the need for vigilance on the part of the caregiver. Over this period a spouse can move through an identity change process that entails five possible phases of accommodation.

Phase I of the career is the period of role onset. This period begins at the point that a caregiver assists the care recipient in a manner that is not usually a part of the familial role that connects the caregiver to the care recipient (e.g., daughter or spouse) in the first place. For example, a wife might take on financial tasks that have traditionally been the responsibility of her husband. In this first phase of the caregiving career, the caregiver's identity with respect to the care recipient is dominated by his or her familial role, such as spouse or daughter, which has salience over the caregiving role. In fact, in this first phase of the care process, caregivers are rarely aware of their caregiving role identity. This salience of the familial identity is illustrated in the upper left quadrant of Fig. 8.4. Here the spousal identity is shown as the dominant identity for the caregiver in relation to the care recipient.

Phase II of the caregiving career begins when the caregiver acknowledges that his or her care activities are beyond the normal scope of the initial familial role. This is the point of self-identification as a caregiver (Burke, 1991; Stryker, 1968). During this phase of the career, a caregiver is still maintaining his or her primary familial identity in relation to the care recipient, but acknowledges the presence of the caregiver role. The diagram in the upper right quadrant of Fig. 8.4 illustrates this shift in identity.

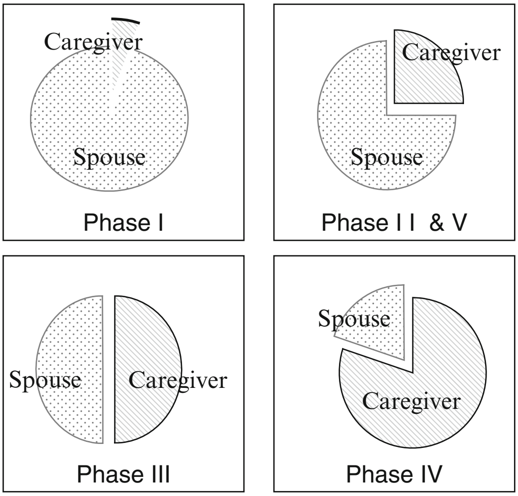


Fig. 8.4 Caregiver identity mapped to phases of the caregiving career

Phase III of the caregiving career begins when the care needs of the care recipient increase in quantity and intensity to a level that requires assistance that is beyond the normal boundaries of the initial familial relationship. Most often this involves assistance with personal grooming. For children, this may be as minimal as helping a parent to dress. For spouses, it usually entails assistance with bathing or toileting that entail more body contact. At this point in the caregiving career, the caregiver wrestles with maintaining his or her initial familial identity (e.g., daughter, wife, son etc.) versus assuming the role of caregiver as a primary identity. This fifty–fifty situation is illustrated by diagram in the lower left quadrant of Fig. 8.4.

Caregivers who opt to continue with their caregiving tasks through Phase III usually increase the intensity of care they provide over time to such an extent that the caregiver identity comes to dominate the dyadic relationship. This shift in identity, which is illustrated by the fourth diagram in Fig. 8.4, is usually accompanied by the initial consideration of an alternative living arrangement for the care recipient (Montgomery & Kosloski, 2000). For many spouses, Phase IV can continue for an extended time period in which the caregiver continues to revisit the option of nursing home placement.

The final phase of the caregiving career, Phase V, begins when the care recipient is moved to a setting that relieves the caregiver of primary responsibility for care. Most often this phase entails placement in an assisted living or nursing home facility, but it could entail movement to the home of another family member. During this final phase, the caregiver is often able to shift his or her primary identity back to the initial familial role and significantly reduce the salience of the caregiver role (Montgomery & Kosloski, 2000). Although early studies of caregiving often conceptualize nursing home placement as the endpoint of the caregiving career, more recent examination of the issues has affirmed that the caregiving role does not stop, but is simply altered by placement (Gaugler et al., 2002). The relative salience of the caregiver role relative to the familial role would be very similar to that experienced in Phase II and is illustrated by the diagram in the upper right quadrant of Fig. 8.4.

Although the five phases delineated here provide a useful heuristic description of the caregiving career, it is important to note that movement between phases is not a steady continuous process, nor is it necessarily unidirectional. Tremendous variation exists in the trajectory of caregiving careers. In fact, many caregivers, especially adult children, exit from the caregiving role during Phase II or Phase III, and move directly into Phase V. The type and level of impairment that the care recipient exhibits, the relative stability of the care recipients functioning level, the physical and social environment in which care is provided, and the initial familial relationship between the caregiver and the care recipient all influence the caregiving trajectory. What is uniform about caregiving careers is that the threshold period just prior to movement *between phases* is linked to the experience of *significant* stress, which can only be alleviated by a significant change in identity. In contrast, distress that is experienced by caregivers *within a phase* of the caregiving process results from small discrepancies between behaviors and an identity standard that can be alleviated by small changes in behavior or by stretching the identity standard to allow the discrepant behaviors to assimilated into and an existing role identity. As a result, distress is not a linear function of time in the caregiving role. Instead, it is sporadic throughout the caregiving career, arising from discrepancies between identity and behavior, and relieved through the joint processes of assimilation and accommodation.

Practice Implications

Perhaps the most useful aspect of the caregiver identity theory is the direction it provides for effectively supporting caregivers. When caregiving stress is understood to be caused by a discrepancy between *what a caregiver is doing* and *what he or she expects* to be doing, it becomes possible to target support services to alleviate the source of this distress more effectively. Equally important, this theory makes clear the fact that specific care tasks or responsibilities are not inherently stressful. Rather, it is the performance of care tasks that are inconsistent with one’s identity that is stressful to a caregiver.

One implication of this understanding of caregiver stress is that it places a demand on providers to know more about their clients’ personal circumstances in order to support them effectively. No single intervention will be uniformly effective, because no single care activity or responsibility is more or less stressful to the full range of caregivers. In short, the theory both explains and underscores the fact that shotgun approaches tend to be very inefficient strategies for supporting caregivers (Burgio, Solano, Fisher, Stevens, & Gallagher-Thompson, 2003; Coon, Gallagher-Thompson, & Thompson, 2003). At the same time, the theory provides important guidance for effectively targeting services.

Pathways to Stress Reduction

This caregiver identity theory suggests that the primary goal of support services should be the reduction of distress that stems from a caregiver's appraisal that her behaviors are incongruent with her current identity standards. While such a goal may sound abstract or academic, in reality there are only three avenues for achieving this goal. We can help caregivers to avoid or alleviate stress by helping them to: (1) change their behaviors to bring them in line with their identity standard; (2) change their self-appraisal; or (3) change their identity standard. When specific support services such as respite care, education programs, counseling, and support groups, or case management are understood to be mechanisms for achieving one or more of these three outcomes, providers will be better able to target services to effectively help caregivers.

Change of Behaviors

Perhaps the easiest means to create congruence between a caregiver's behavior and his or her identity standard is to change the caregiver's behaviors to make them consistent with an established identity standard. For most caregivers, this means avoiding care tasks that infringe upon an initial familial role (e.g., daughter role), which usually lead to obtaining outside assistance. The introduction of in-home chore services, respite care, and meal programs can all serve this purpose depending upon the needs of the care recipient and the relationship of the caregiver to the care receiver. A daughter who cares for her mother may maintain congruence with her internalized norms for performing as a daughter by using respite services for her mother. In this way, the daughter may restrain the time demands placed upon her as a result of caregiving responsibility to a level that will allow her sufficient time for other roles in her life such as being a spouse, a mother, or an employee. That is, the daughter is able to maintain her initial role identity as daughter by shifting care tasks that are not consistent with this identity to other formal or informal helpers. Changing behaviors, however, is not always an appropriate or viable avenue for relieving stress, because the new behavior also may be inconsistent with an established identity standard. Consider, for example, the situation where a care attendant was hired to provide personal care for a dependent husband. While this service may relieved the wife from duty of bathing her husband, it may also created stress as it is undermined her ability to comply with her personal identity standard that deemed caring for her husband a proper wifely duty.

An extreme form of behavior change involves placing the care recipient in a nursing home and allowing paid workers to provide the necessary care. Caregiving, of course, doesn't end at this point, but the dramatic change in the caregiving context allows the caregiver to attempt to restore a form of identity that is associated with a new set of behaviors. For example, the daughter may now engage in behaviors that are more consistent with the daughter role, such as joining her mother for lunch, or taking her shopping and essentially re-structuring her identity back to an earlier form.

Enhance Self-Appraisal

A second avenue for relieving caregiver distress caused by incongruence between a caregiver's self-appraisal and an identity standard is to alter the caregiver's self-appraisal in some way. This can be accomplished by helping the caregiver to cognitively reframe her situation and thereby counter any negative self-evaluation. For example, a support group or individual counseling can be used to help caregivers redefine their behaviors as appropriate, given their specific caregiving context. Sometimes this may entail countering negative messages caregivers may receive from the care recipient or other family members (e.g., the long distance sibling). The reframing strategies introduced as part group intervention process now being studied by Lévesque and her colleagues (2002) are an excellent example of a program that is being used to help families enhance their self appraisal. As part of a two-pronged group intervention, caregivers participate in three meetings where they are introduced to the four re-framing strategies. Three of these strategies assist the caregiver to re-interpret the action of the care recipient or the caregiver in a manner that would support a positive self-appraisal. Noting that dementia affects the core of a person's identity, Lévesque and her colleagues (2002) purposefully created an intervention process that goes beyond information and task-oriented aspects of care to address fundamental stressful demands at the core of the caregiving experience.

Change of Identity Standard

A third means to reduce distress caused by incongruence between identity standards and behavior is to help the caregiver alter his or her rules. Changes in identity standards may lead to either assimilation or accommodation. When discrepancies are small, providers can help the caregiver to "stretch" an identity standard to fit the behavior and thereby allow a positive self-appraisal (assimilation). For example, a daughter operating primarily in the role of daughter may expand or "stretch" her identity standard to include such tasks as daily telephone check up calls, weekly shopping, or even weekly housekeeping for her parent. This extension of her personal norms allows the daughter to appraise her care activities as consistent with the "daughter role." That is, she can judge herself to be acting as a "good" daughter within the constraints of her current identity standard. This strategy is consistent with the work of Sherrell and her colleagues (2001) who recommend that counselors emphasize psychological processes of change when working with adult children that help them "endow the experience of caregiving with new meaning."

When distress is high due to significant incongruence between behaviors and identity standards, caregivers may be better helped by encouraging them to adopt a new identity that is accompanied by a new set of rules or identity standard (i.e., accommodation). Through education, counseling, or care management, caregivers can be taught about the changing needs of the care recipient and encouraged to embrace an identity in relation to the care recipient that places greater emphasis on the caregiver role than on the initial familial role. In the case of the daughter caring for her mother, the daughter may come to define herself primarily as a caregiver. With this shift in identity, the daughter may more comfortably discontinue activities associated with other roles that are less salient or less central to her overall (e.g., employee, friend or club member) (Coe & Neufeld, 1999). Again the intervention used by Lévesque and her colleagues (2002) serves as an example of a strategy that leads to an identity change. The fourth reframing strategy that they introduce as part of their group process is an emotion-focused strategy of acceptance useful for helping caregivers when they confront an inevitable decline in the demented relative. By helping caregivers to focus on the present reality, that is, on their loved one as he/she is now, caregivers are helped to begin the process of accepting daily losses and a new identity.

Multiple Support Services as Vehicles to Change

It is important to note that the three outcomes that serve as pathways for reducing stress (i.e., change in behavior change in self-appraisal, and change in identity standard) can be reached by using a variety of support services. For example, a wife who is initially reluctant to bathe or groom her husband because she views this type of care task as inconsistent with her identity may be encouraged to assume this responsibility if she is taught to perform the task in a more efficient manner. This type of information could be conveyed to the wife as part of a caregiver education program that focuses on direct care skills. An alternate source of instruction might be an adult day care program that includes consultation with families. Yet another avenue for helping the caregiver maintain congruence between her behavior and her identity is to encourage the use of a respite program that offers personal care services. This type of service would obviate the need for the caregiver to assimilate caregiving activities into her existing identity.

Similarly, a variety of support services can be used as vehicles to influence a caregiver's self-appraisal to help bring it into congruence with an established identity standard. Support groups can provide a caregiver with a knowledgeable friend to give positive feedback on care behaviors when a care recipient is unable to provide such feedback. Care managers can also provide positive feedback and education programs can teach caregivers to discount inappropriate feedback from other, uninformed family members. In short, multiple support services could be used to help caregivers maintain congruence between an existing identity standard and the caregivers' behaviors because they all target the fundamental cause of distress—the discrepancy between identity and behavior.

Multiple Benefits of a Single Support Service

Just as it is possible to use a variety of support services to achieve a desired change in one of the components of the caregiver's identity maintenance process (e.g., behavior, self-appraisal, or identity standard), it is also possible to use a single support service to reduce stress through multiple pathways. For example, an education program can reduce stress by teaching a caregiver more efficient or effective methods for performing care tasks and in this way directly change the caregiver's behavior. An education program can also be used to help define a realistic role model for caregivers by exposing a caregiver to a new philosophy of the care and the realities of day-to-day caregiving. In other words, an education program can help establish an appropriate identity standard by which caregivers can assess their own performance. Such education programs help caregivers to make a realistic self-appraisal of their performance. Similarly, a support group can help a caregiver to adjust behavior to fit an existing identity or it can serve as a source of positive feedback to reinforce a positive self-appraisal. Targeting single services to accomplish multiple goals may require greater flexibility, but this flexibility is critically important when many communities are restricted in the variety of services that are available.

Implications for Research

In addition to providing guidance for caregiver interventions, the caregiver identity theory is useful for understanding and integrating empirical findings concerning caregiver distress and interventions, which in the past have appeared to be quite inconsistent with dominant theories of the stress process. The theory suggests that the relationships between stress and disability and between stress and level and type of care tasks should not be simple linear relationships. From the perspective of the caregiver identity theory, stress arises because caregiving activities are appraised to be incongruent with behaviors necessary to maintain one's identity standard. For this reason distress is not inherent in caregiving activities and the very same task can be oppressive in one circumstance and not another. Consider a similar situation in the workplace. If a required task is not perceived as being part of one's job description, a worker may see the task as burdensome and complain: "It is not my job." Expanding one's job description to assimilate the task, re-writing one's job description to accommodate the task, or off-loading the task to someone else, all serve the same function of relieving the distress of performing the activities in question. These may not be equally viable options, however, in any given circumstance. If the offensive activities represent a minor discrepancy (e.g., a corporate vice-president who makes his own travel arrangements), they may be easily assimilated into one's identity. If they are major (e.g., a vice-president who is also responsible for janitorial services), a change in identity is required.

So too, stress arises in caregiving. The caregiver identity theory suggests that stress should not have a linear relationship to length of time in the caregiving role or to the level of care provided. Rather, the theory suggests that the experience of stress will be cyclical with high levels of stress occurring immediately before significant changes in the caregiver's identity and moderate to low levels of stress occurring between these peak periods when the caregiving context is stable and caregiving activities can be assimilated into one's current identity. This process may well account for the seemingly inconsistent findings that have been reported which support both a mastery model of caregiving and a "wear and tear" model. According to the mastery model of caregiving, caregivers' stress will decrease with time as caregivers master their caregiving tasks (Buckwalter et al., 1999; Schulz & Williamson, 1991). In contrast, the wear and tear model of caregiving suggests that there is an accumulation of stress over time associated with growing care needs. The caregiver identity theory suggests that both the mastery model and the wear and tear model are applicable as has been suggested by recent research findings (Gaugler, Kane, Kane, Clay, & Newcomer, 2005). The mastery model of caregiver stress is consistent with patterns observed within a single phase of the caregiver's career, while the wear and tear model of stress is more consistent with stress observed at periods of identity change (Miller, Campbell, Farran, Kaufman, & Davis, 1995).

Previous results of intervention studies intended to identify effective support services for caregivers have often been disappointing, as they have generally failed to provide clear guidance to practitioners (Pillemer et al., 2003). This lack of guidance is a result of several factors. First, there has been considerable inconsistency in findings regarding this relationship between support services and caregiver stress. The large majority of intervention studies have failed to support a statistically significant link between specific caregiver support services and relief of caregiver stress (Acton & Kang, 2001; Bourgeois et al., 1996; Pillemer et al., 2003; Soerensen et al., 2002; Toseland & Rossiter, 1989; Yin, Zhou, & Bashford, 2002) or have identified effects sizes that are not clinically significant (Knight & Lutzky, 1993; Schulz et al. 2002; Soerensen et al., 2002). Even when a relationship between support services and caregiver stress has been documented, there has not been strong evidence of a link between caregiver stress and caregivers' choices to continue or abdicate the role of primary caregiver (i.e., nursing home placement). It is also the case that the most promising findings regarding the positive impact of support services have emerged from intervention studies that have included multiple and a relatively comprehensive set of support services (Acton & Kang, 2001; Beach et al., 2000; Bourgeois et al., 1996; Burgio et al., 2003; Mittelman, 2000; Mittelman et al., 1993). While this latter finding is informative and important, it does not provide critical information for targeting specific services in a service package (Bourgeois et al., 1996; Burgio et al., 2003; Pillemer et al., 2003). The need to understand more about which services are most expedient for serving different types of caregivers at different points in their caregiving careers remains a challenge for researchers and service providers (Knight & Lutzky, 1993; Soerensen et al., 2002; Thompson, Gallagher-Thompson, & Haley, 1993).

The caregiver identity theory provides useful insights that can be used to understand these inconsistencies in the literature and to help practitioners utilize findings from previous intervention studies to guide their work. The theory highlights the inappropriate assumption on which most intervention strategies have been based (i.e., caregiving is inherently stressful). When the caregiving process is understood from the perspective of caregiver identity maintenance and identity change, it becomes very clear that not all caregivers are distressed. The theory is also consistent with findings from recent studies that highlight the importance of understanding individual caregiving trajectories of role entry and exit in the context of the relationship between the caregiver and the care recipient and the experience of stress (Caron & Bowers, 2003; Gaugler et al., 2005). The theory suggests that the level of stress is simultaneously influenced by the caregiver's functional level and the caregiver's identity standards, which are largely influenced by cultural norms and established familial roles. Therefore it is not surprising that stress and burden are not linearly related to the type or quantity of care provided; nor is it surprising that support services are not uniformly effective strategies for relieving caregiver stress.

The utility of the caregiver identity theory for interpreting mixed findings with respect to caregiver interventions can be demonstrated by focusing on inconsistent findings related to respite programs (see Gallagher-Thompson, 1994, for a review). Respite programs are generally targeted to all caregivers and a common explanation for their small impact is that they reach caregivers in a manner that is "too little, too late." The low use rate of such programs, however, suggests a different explanation. Respite programs are most attractive to caregivers who are experiencing incongruence between their caregiving activities and their self-identity (i.e., for the proportion of caregivers who are not doing what they think they should be doing). Moreover, to the extent that the respite programs do not affect the source of incongruity for caregivers, the programs will not be perceived as useful and the caregivers will be "brief users" (Bookwala et al., 2000; Montgomery et al., 2002).

Summary and Conclusion

After more than two decades of extensive research on caregiving and caregiver stress, and the development of a plethora of caregiver intervention programs, policy makers and practitioners are still faced with the challenge of effectively serving a growing population of informal caregivers. It is this challenge that has prompted us to advance the caregiver identity theory as a tool to be used to explain the mechanisms by which stress arises in a caregiving relationship and, by implication, the mechanisms by which it can be relieved. An additional benefit is an improved understanding of why caregiver interventions are helpful, unhelpful, or simply irrelevant in any given circumstance. Essentially the theory allows us to identify five ways that support services can be used to relieve stress. Each of these strategies is directly linked to one of the five elements of the identity change process depicted in Fig. 8.2. Support services can be used to: (1) *alter the caregiver's behavior* to make it more consistent with an existing identity standard, (2) provide feedback to the caregiver to *support a self appraisal* that the caregiver's behavior is congruent with an existing identity standard, (3) encourage the caregiver *to "stretch" his or her identity standard* to assimilate new and necessary care behaviors, (4) encourage the caregiver to change his or her role identity to more fully embrace the caregiver role or to simply leave the caregiver role or (5) *alter the caregiving context* to reduce the need for incongruent behavior or to enhance the back to assure a positive self-appraisal. Each of these strategies is intended to increase congruence between a caregiver's identity standard and his or her self-appraisal, and thereby reduce or prevent distress.

Armed with an understanding of the source of caregiver distress and the intended purpose of support services, i.e., increased congruence between self-appraisals and identity, providers will have a greater opportunity to effectively support caregivers. Providers will also be better able to select a strategy for change that is most appropriate for a caregiver at any given point in the caregiving career. Most importantly, the caregiver identity model reinforces the notion that there is a need for multiple support services to serve the diversity of needs that exists across caregivers and across the caregiving career.

References

Acton, G. J., & Kang, J. (2001). Interventions to reduce the burden of caregiving for an adult with dementia: A meta-analysis. *Research in Nursing and Health, 24*(5), 349–360.

Anhensel, C., Pearlin, L., Mulan, J., Zarit, S., & Whitlach, C. (1995). *Profiles in caregiving: The unexpected career*. San Diego, CA: Academic.

Bass, D. M., & Noelker, L. S. (1996). The moderating influence of service use on negative caregiving consequences. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 51B*, S121.

Beach, S. R., Schulz, R., Yee, J. L., & Jackson, S. (2000). Negative and positive health effects of casing for a disabled spouse: Longitudinal findings from the caregiver health effects study. *Psychology and Aging, 15*(2), 259–271.

Bookwala, J., & Schulz, R. (2000). A comparison of primary stressors, secondary stressors, and depressive symptoms between elderly caregiving husbands and wives: The caregiver health effects study. *Psychology and Aging, 15*(4), 607–616.

Bookwala, J., Yee, J. L., Schulz, R., Williamson, G. M., Shaffer, D. R., & Parmelee, P. A. (2000). Caregiving and detrimental mental and physical health outcomes. In G. M. Williamson, D. R. Shaffer, & P. A. Parmelee (Eds.), *Physical illness and depression in older adults: A handbook of theory, research, and practice* (pp. 93–131). New York: Kluwer Academic Publishers.

Bourgeois, M. S., Schulz, R., & Burgio, L. (1996). Interventions for caregivers of patients with Alzheimer's disease: A review and analysis of content, process, and outcomes. *International Journal of Aging and Human Development, 43*, 35–92.

Brubaker, T., & Brubaker, E. (1989). Toward a theory of family caregiving: Dependencies, responsibility, and use of services. In J. Mancini (Ed.), *Aging parents and adult-children* (pp. 245–257). Lexington, MA: D. C. Heath.

Buckwalter, K. C., Gerdner, L., Kohout, F., Hall, G. R., Kelly, A., Richards, V., et al. (1999). A nursing intervention to decrease depression in family caregivers of persons with dementia. *Archives of Psychiatric Nursing, 13*(2), 80–88.

Burgio, L. D., Solano, N., Fisher, S. E., Stevens, A., & Gallagher-Thompson, D. (2003). Skill-building: Psychoeducational strategies. In D. W. Coon, D. Gallagher-Thompson, & L. W. Thompson (Eds.), *Innovative interventions to reduce dementia caregiver distress: A clinical guide* (pp. 119–138). New York: Springer.

Burke, P. (1980). The self: Measurement implications from a symbolic interactionist perspective. *Social Psychology Quarterly, 43*, 18–29.

Burke, P. (1991). Identity processes and social stress. *American Sociological Review, 56*, 836–849.

Burke, P., & Reitzes, D. C. (1991). The link between identity and role performance. *Social Psychology Quarterly, 44*, 83–92.

Burke, P. J., & Tully, J. (1977). The measurement of role identity. *Social Forces, 55*, 880–897.

Call, C. T., Finch, M. A., Huck, S. M., & Kane, R. A. (1999). Caregiver burden from a social exchange perspective: Caring for older people after hospital discharge. *Journal of Marriage and Family, 61*, 688–699.

Cantor, M. (1979). Neighbors and friends: An overlooked resource in the informal support system. *Research on Aging, 1*, 434–463.

Caron, C., & Bowers, B. (2003). Deciding whether to continue, share, or relinquish caregiving: Caregiver views "check this out". *Qualitative Health Research, 13*(9), 1252–1271.

Caserta, M. S. (1987). Caregivers to dementia patients: The utilization of community services. *The Gerontologist, 27*(2), 209–214.

Chappell, N. R. (2002). Burden and well-being among caregivers: Examining the distinction. *The Gerontologist, 42*(6), 772–780.

Coe, M., & Neufeld, A. (1999). Male caregivers' use of formal support. *Western Journal of Nursing Research, 21*(4), 568–588.

Connell, C. M., & Gibson, G. (1997). Racial, ethnic, and cultural differences in dementia caregiving: Review and analysis. *The Gerontologist, 37*(3), 355–364.

Coon, D. W., Gallagher-Thompson, D., & Thompson, L. W. (2003). *Innovative interventions to reduce dementia caregiver distress*. New York: Springer.

Corcoran, M. A. (1992). Gender differences in dementia management plans of spousal caregivers: Implications for occupational therapy. *American Journal of Occupational Therapy, 46*(11), 1006–1012.

Cox, C., & Monk, A. (1993). Hispanic culture and family care of Alzheimer's patients. *Health and Social Work, 18*(2), 92–100.

Dilworth-Anderson, P., Williams, I. C., & Gibson, B. E. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980–2000). *The Gerontologist, 42*(2), 237–272.

Donaldson, C., & Burns, A. (1999). Burden of Alzheimer's disease: Helping the patient and caregiver. *Journal of Geriatric Psychiatry and Neurology, 12*(1), 21–28.

Farran, C. J., Miller, B. H., Kaufman, J. E., & Davis, L. (1997). Race, finding meaning, and caregiver distress. *Journal of Aging and Health, 9*(3), 316–333.

Franks, M. M., Pierce, L. S., & Dwyer, J. W. (2003). Expected parent-care involvement of adult children. *Journal of Applied Gerontology, 22*(1), 104–117.

Gallagher-Thompson, D. (1994). Direct services and interventions for caregivers: A review of extant programs and a look to the future. In M. H. Cantor (Ed.), *Family caregiving: Agenda for the future* (pp. 102–122). San Francisco: American Society on Aging.

Gallagher-Thompson, D., Leary, M. C., Ossinalde, C., Romero, J. J., Wald, M. J., & Fernadndex-Gammarra, E. (1997). Hispanic caregivers of older adults with dementia: Cultural issues in outreach. *Group: Journal of the Eastern Group Psychotherapy Association, 21*(2), 211–232.

Gaugler, J. E., Kane, R. L., & Kane, R. A. (2002). Family care for older adults with disabilities: Toward more targeted and interpretable research. *International Journal of Aging and Human Development, 54*(3), 205–231.

Gaugler, J. E., Kane, R. L., Kane, R. A., Clay, T., & Newcomer, R. C. (2005). The effects of duration of caregiving on institutionalization. *The Gerontologist, 45*, 78–89.

Gwyther, L. P., & Ballard, E. L. (1990). *Overcoming barriers to appropriate service use: Effective individualized strategies for Alzheimer's care*. Durham, NC: Duke University Center for Study of Aging.

Haley, W. E., West, C. A., Wadley, V. G., Ford, G. R., White, F. A., Barrett, J. J., et al. (1995). Psychological, social, and health impact of caregiving: A comparison of black and white dementia family caregivers and noncaregivers. *Psychology and Aging, 10*(4), 540–552.

Horowitz, A. (1985). Family caregiving to the frail elderly. In L. A. Maddox (Ed.), *Annual review of gerontology and geriatrics*. New York: Springer.

Janevic, M. R., & Connell, C. M. (2001). Racial, ethnic, and cultural differences in the dementia caregiving experience: Recent findings. *The Gerontologist, 41*(3), 334–347.

Kiecolt-Glaser, J., Marucha, P., Malarkey, W., Mercado, A., & Glaser, R. (1995). Slowing of wound healing by psychological stress. *Lancet, 346*(8984), 1194–1197.

Knight, B., & Lutzky, S. (1993). A meta-analytic review of interventions for caregiver distress: Recommendations for future research. *The Gerontologist, 33*, 240.

Knight, B., & McCallum, T. J. (1998). Heart rate reactivity and depression in African-American and White dementia caregivers: Reporting bias or positive coping? *Aging and Mental Health, 2*(3), 212–221.

Kramer, B. J., & Kipnis, S. (1995). Eldercare and work-role conflict: Toward an understanding of gender differences in caregiver burden. *The Gerontologist, 35*(3), 340–349.

Langa, K. M., Chernew, M. E., Kabeto, M. U., Herzog, A. R., Ofstedahl, M. B., Willis, R. J., et al. (2001). National estimates of the quantity and cost of informal caregiving for the elderly with dementia. *Journal of General Internal Medicine, 16*(11), 770–778.

Lawton, M. P., Rajagopal, D., Brody, E., & Kleban, M. H. (1992). The dynamics of caregiving for a demented elder among Black and White families. *Journal of Gerontology: Series B, Psychological Sciences and Social Sciences, 47*, S156–S164.

Lévesque, L., Cossette, S., & Laurin, L. (1995). A multidimensional examination of the psychological and social well-being of caregivers of a demented relative. *Research on Aging, 17*(3), 332–361.

Lévesque, L., Gendron, C., Vézina, J., Hébert, R., Ducharme, F., Lavoie, J.-P., et al. (2002). The process of a group intervention for caregivers of demented persons living at home: Conceptual framework, components, and characteristics. *Aging and Mental Health, 6*(3), 239–247.

Merrill, D. (1997). *Caring for elderly parents: Juggling work, family, and caregiving in middle and working class families*. Westport, CT: Auburn House.

Miller, B. (1989). Adult children's perceptions of caregiver stress and satisfaction. *Journal of Applied Gerontology, 8*(3), 275–293.

Miller, B., & Cafasso, L. (1992). Gender differences in caregiving: Fact or artifact. *The Gerontologist, 32*, 498–507.

Miller, B., Campbell, R. T., Farran, C. J., Kaufman, J. E., & Davis, L. (1995). Race, control, master, and caregiver distress. *Journal of Gerontology: Series B, Psychological Sciences and Social Sciences, 50B*, S374–S382.

Miller, B., McFall, S., & Montgomery, A. (1991). The impact of elder health, caregiver involvement, and global stress on two dimensions of caregiver burden. *Journal of Gerontology, 46*(1), S9–S19.

Mittelman, M. S. (2000). Effect of support and counseling on caregivers of patients with Alzheimer's disease. *International Psychogeriatrics, 12*(1), 341–346.

Mittelman, M. S., Ferris, S. H., Steinberg, G., Shulman, E., Mackell, J. A., Ambinder, A., et al. (1993). An intervention that delays institutionalization of Alzheimer's disease patients: Treatment of spouse-caregivers. *The Gerontologist, 33*(6), 730–740.

Montgomery, R., & Datwyler, M. M. (1990). Women and men in the caregiving role. *Generations, 14*(3), 34–38.

Montgomery, R., & Kosloski, K. (2000). Family caregiving: Change, continuity and diversity. In R. L. Rubenstein (Ed.), *Alzheimer's disease and related dementias: Strategies in care and research*. New York: Springer.

Montgomery, R. J. V., Marquis, J., Schaefer, J., & Kosloski, K. D. (2002). Profiles of respite use. In R. J. V. Montgomery (Ed.), *A new look at community-based respite programs* (pp. 33–64). New York: Haworth Press.

Montgomery, R. J. V., & Williams, K. (2001). Implications of differential impacts of caregiving for the future research on Alzheimer care. *Aging and Mental Health, 5*(Suppl. 1), S23–S34.

Montoro-Rodriguez, J., Kosloski, K., & Montgomery, R. J. V. (2003). Evaluating a practice-oriented service model to increase the use of respite services among minorities and rural caregivers. *The Gerontologist, 43*(6), 916–924.

Mui, A. C. (1992). Caregiver strain among Black and White daughter caregivers: A role theory perspective. *The Gerontologist, 32*, 203–212.

Parks, S. H., & Pilisuk, M. (1991). Caregiver burden: Gender and the psychological costs of caregiving. *The American Journal of Orthopsychiatry, 61*(4), 501–509.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583–595.

Piaget, J. (1971). *Biology and knowledge*. Chicago: University of Chicago Press.

Pillemer, K., Suitor, J., & Wethington, E. (2003). Integrating theory, basic research, and intervention: Two case studies from caregiving research. *The Gerontologist, 43*(Special Issue 1), 19–28.

Pruchno, R. A., Burant, C. J., & Peters, N. D. (1997). Typologies of caregiving familes: Family congruence and individual well-being. *The Gerontologist, 37*, 157–167.

Pyke, K. D., & Bengtson, V. L. (1996). Caring more or less: Individualistic and collectivist system of family eldercare. *Journal of Marriage and Family, 58*(2), 379–393.

Riley, M. (1983). The family in an aging society: A matrix of latent relationships. *Journal of Family Issues, 4*, 429–454.

Rossi, A., & Rossi, P. (1990). *Of human bonding: Parent-child relations across the life course*. New York: Aldine de Gruyter.

Schulz, R., O'Brien, A., Bookwalla, J., & Flesissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates and causes. *The Gerontologist, 35*, 771–791.

Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martire, L. M., et al. (2002). Dementia caregiver intervention research: In search of clinical significance. *The Gerontologist, 42*, 589–602.

Schulz, R., & Williamson, G. (1991). A 2-year longitudinal study of depression among Alzheimer's caregivers. *Psychology and Aging, 6*, 569–578.

Seltzer, M. M., & Li, L. W. (2000). The dynamics of caregiving: Transitions during a three-year prospective study. *The Gerontologist, 40*, 165–178.

Shaw, L. B., O'Bryant, S. L., & Meddaugh, D. L. (1991). Support system participation in spousal caregivng: Alzheimer's disease versus other illness. *Journal of Applied Gerontology, 10*, 359–371.

Sherrell, K., Buckwalter, K. C., & Morhardt, D. (2001). Negotiating family relationships: Dementia care as a midlife developmental task. *Families in Society: The Journal of Contemporary Human Services, 82*, 383–392.

Skaff, M. M., & Pearlin, L. I. (1992). Caregiving: Role engulfment and the loss of self. *The Gerontologist, 32*(5), 656A–664A.

Soerensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist, 42*(3), 356–372.

Stephens, M. A. P., Townsend, A. L., Martire, L. M., & Druley, J. A. (2001). Balancing parent care with other roles: Inter-role conflict of adult daughter caregivers. *Journals of Gerontology: Series B, Psychological Sciences and Social Sciences, 56*(1), P24–P34.

Stryker, S. (1968). Identity salience and role performance. *Journal of Marriage and Family, 4*, 558–564.

Stryker, S. (1994). Identity theory: Its development, research base, and prospects. *Studies in Symbolic Interaction, 16*, 9–20.

Stryker, S., & Burke, P. J. (2000). The past, present, and future of an identity theory. *Social Psychology Quarterly, 63*(4), 284–297.

Stryker, S., & Serpe, R. T. (1982). Commitment, identity salience, and role behavior: A theory and research example. In W. Ickes & E. S. Knowles (Eds.), *Personality, roles, and social behavior* (pp. 199–218). New York: Springer.

Stuckey, J. C., & Smyth, K. A. (1997). The impact of social resources on the Alzheimer's disease caregiving experience. *Research on Aging, 19*(4), 423–441.

Thompson, L. W., Gallagher-Thompson, D., & Haley, W. (1993). Future directions in dementia caregiving intervention research and practice. In D. W. Coon, D. Gallagher-Thompson, & L. W. Thompson (Eds.), *Innovative interventions to reduce dementia caregiver distress* (pp. 299–311). New York: Springer.

Toseland, R., & Rossiter, C. (1989). Group interventions support family caregivers: A review and analysis. *The Gerontologist, 29*(4), 438–448.

Van den Heuvel, E. T. P., De Witte, L. P., Schure, L. M., Sanderman, R., & Meyboom-de Jong, B. (2001). Risk factors for burn-out in caregivers of stroke patients, and possibilities for intervention. *Clinical Rehabilitation, 15*(6), 669–677.

Walker, A. J., Pratt, C. C., & Eddy, L. (1995). Informal caregiving to aging family members: A critical review. *Family Relations, 44*, 402–411.

Whitbourne, S. (1986). The psychological construction of the life span. In J. B. W. Schaie (Ed.), *Handbook of the psychology of aging* (pp. 594–618). New York: Van Nostrand.

Winslow, B., & Carter, P. (1999). Patterns of burden in wives who care for husbands with dementia. *Nursing Clinics of North America, 34*, 275–287.

Yee, J. L., & Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: A review and analysis. *The Gerontologist, 40*, 147–164.

Yin, T., Zhou, Q., & Bashford, C. (2002). Burden on family members: Caring for frail elderly: A meta-analysis of interventions. *Nursing Research, 51*(3), 199–208.

Youn, G., Knight, B. G., Jeong, H. S., & Benton, D. (1999). Differences in familism values and caregiving outcomes among Korean, Korean American, and White American dementia caregivers. *Psychology and Aging, 14*(3), 355–364.

Zarit, S. (1989). Do we need another "stress and caregiving" study? *The Gerontologist, 29*, 147–148.

Chapter 9
Family Caregiving at the End-of-Life: Current Status and Future Directions

William E. Haley

Family caregiving has been widely studied throughout the life course, but there has been relatively little attention paid in the caregiving literature to the special problems of caregivers at the end-of-life. Families providing care at the end-of-life face unique challenges and rewards. The care that they provide can be a precious gift for a loved one facing death, and can be among the most rewarding experiences of life. End-of-life care can also be extremely stressful and associated with great difficulties not only while providing care, but also during the ensuing bereavement.

While all caregiving can be stressful, end-of-life caregiving presents a number of particular challenges, which will be described in detail below. These include the necessity of making life and death decisions about matters such as whether to utilize life sustaining treatments, hospice care, and other options at the end of life. The actual care demands at the end-of-life can also be particularly intense, and families may witness pain and suffering in their loved one that makes death seem both a loss and a relief. All of these experiences have the potential to affect the course of bereavement, and subsequent reengagement of the caregiver into a new life without caregiving responsibilities.

This chapter will review the literature on family caregivers' roles in end-of-life care, and what is known about the burdens and benefits experienced by these caregivers. The chapter will also review the current status of care for the dying in the United States, emphasizing issues that affect family caregivers. Recommendations for future improvements in research, clinical practice, education and training, and policy will be discussed.

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Dying in America: Basic Facts

Recent figures on mortality in the United States (Minino & Smith, 2001) show that just over 2,400,000 Americans died in the year 2000. Age-adjusted death rates for the year 2000 were the lowest in US history, and are part of a continuing historical trend for increasing life expectancy. Life expectancy for males was 74.1, and for females 79.5, a sharp contrast to the average life expectancy of 47 years in 1900.

Death has largely become the province of late life. Less than 3% of deaths occurred in people under age 25, and 75% of deaths were in persons over age 65, with those over 85 accounting for 27% of deaths (Minino & Smith, 2001). The leading causes of death in the United States—heart disease, cancer, stroke, and chronic obstructive pulmonary disease—are chronic diseases, and account for about 2/3 of all deaths in the United States (Emanuel & Emanuel, 1998).

Lunney, Lynn, and Hogan (2002) examined Medicare data and found that there were four common trajectories at the end of life that accounted for nearly all deaths: sudden death (7%), terminal illness (22%), organ failure (16%), and frailty (47%), with only 8% of deaths not fitting these categories. In considering these trajectories in the light of family caregiving issues, all have different implications. The most common pattern, frailty, suggests a sustained period of caregiving in which death occurs after years of severe impairment due to dementia, stroke, and multiple comorbid illnesses. The organ failure category similarly implies serious long-term disability and caregiving, with relatively intense periods of exacerbation. Deaths after congestive heart failure or chronic obstructive pulmonary disease are typical of this pattern. In both of these patterns, family caregivers can experience long periods of caregiving responsibilities. Patients categorized as having terminal illness in this article experience a relatively brief but intense period of deterioration leading to death, with a prototype being death after lung cancer. With this pattern, family members may face a relatively short period of caregiving, but experience very intense caregiving demands that require extensive effort over this period of time. Only in the sudden death category is family caregiving not an important problem (although bereavement issues still affect the family).

While the United States has been successful in increasing life expectancy and in delaying death, we have been much less successful in providing high quality care for dying persons and their families. Most deaths in the United States occur in institutional settings, including hospitals (44%) and nursing homes (25%) (Hogan, Lunney, Babel, & Lynn, 2001). This growth in institutionalized death has distanced many Americans from the experience of death and this lack of experience with death may make confronting end-of-life issues particularly difficult when crisis situations arise.

Although most persons preferred to die at home and without excessive technological intervention, preferences concerning life-sustaining treatments are usually not adequately discussed, documented, or adhered to by healthcare providers (Larson & Tobin, 2000). It is estimated that 20% to 70% of dying patients experience inadequate pain relief, that over 1/3 of dying patients are depressed, and 35% have unmet emotional needs (Bradley, Fried, Kasl, & Idler, 2000). Little specialized attention is generally given to the dying experience for patients and families in these hospital and nursing home settings.

A series of studies and reviews (Field & Cassel, 1997; Larson & Tobin, 2000; The SUPPORT Investigators, 1995) provide chilling evidence of the shortcomings of our current system of care for dying persons in hospitals. Americans too often die after prolonged hospitalization or intensive care, with inadequate pain management and with excessive high-technology intervention in hospitals. There have also been serious concerns raised about the quality of end of life care in nursing homes. Nursing home residents who do not receive hospice care commonly receive poor pain and symptom management (Zearson, Sterns, & Hanson, 2000), and factors such as inadequate numbers of staff, lack of privacy, and insufficient supervision and training of staff exacerbate these problems (Kayser-Jones et al., 2003). In addition, few bereavement services are generally offered to families after death in nursing homes (Murphy, Hanrahan, & Luchins, 1997) unless hospice is involved in care.

The end of life is also very expensive. Using the four categories of death described above, Lunney et al. (2002) showed that Medicare expenditures during the final year of life varied from $625 per person for individuals in the sudden death category, to $36,834 for the organ failure group. The terminal group ($31,052) and frail ($24,849) groups also had high expenses. Yang, Norton, and Stearns (2002) have demonstrated that a great deal of the association between age and health care costs is actually related in large part to costs during the final few months of life. It has also been found that the 5% of Medicare beneficiaries who die in a given year account for over 25% of Medicare expenses (Lunney et al., 2002), highlighting the importance of end of life care from a policy perspective.

There are some causes for optimism, however. There is a growing movement toward increased hospice and palliative care programs in the United States, and a number of innovations in end-of-life care, including palliative care centers of excellence, hospice consultation teams (Dunlop & Hockley, 1998), pre-hospice and care management programs (Connor, 1999), advance directives efforts (Cugliari et al., 1999; Emanuel, 1995), and advanced illness coordinated care programs (Larson & Tobin, 2000). Hospice care, which will be described in detail below, is also reaching increasing numbers of patients and families.

Family Caregiver Roles in End-of-Life Care

Family roles in end-of-life care can include not only direct caregiving, but also involvement in decision making related to end-of-life care. Families may be involved in discussions and decision making about end-of-life care well before the onset of a terminal illness. Families are often very much involved in decisions about when to seek medical care, in the medical encounters during which treatment decisions are made, and in the subsequent decisions concerning choices such as hospice care (Haley et al., 2002). A recent study found that family members were central to discussions and decisions about hospice care, and hospice patients reported that family members made the decision to utilize hospice in over 40% of cases (Chen, Haley, Robinson, & Schonwetter, 2003)—rating family as more important than themselves or physicians in making this decision.

Physicians rarely discuss end-of-life options with their patients; instead, they tend to consult with family members—even in the presence of written advance directives of their patient (Cole & Holstein, 1996). The extent to which families trust their care to their relatives is revealed by a study that found that a majority (54%) of terminally ill patients would select their surrogate's treatment decision rather than the treatment outlined in their own advance directive (Terry et al., 1999). This decision-making about end-of-life care can be very stressful. Family members may be placed in the position of making very difficult decisions about, for example, whether to begin tube feeding, institute antibiotic therapy for infections, or to decline medical procedures that might extend duration of life when the quality of life is poor. Presence of written advance directives, or even a history of verbal discussions of end of life issues, helps the family to cope with these issues. Tilden, Tolle, Nelson, and Fields (2001) found that family stress associated with the decision to withdraw treatment was high immediately following the death of the decedent and, while it decreased over time, remained high half a year later. Several factors affected stress; most notably, family stress was highest in the absence of advance directives, was lower when verbal advance directives guided the family, and was lowest when written advance directives guided the family.

Public attention was focused on end-of-life family decision making, and the potential for family conflict, in the Schiavo case (Roscoe, Osman, & Haley, 2006). Roscoe et al. note that intense conflict within families is generally less common than conflict with professional staff for such decisions, that in most cases family conflict can be successfully addressed, and that the Schiavo case was atypical in terms of the extreme divisions within the family. The Schiavo case appears to have led to greater public attention to the importance of advance directives. However, Hampson and Emanuel (2005) note that only 20% of Americans have written living wills, and the increased public recognition and discussion about these matters may not dramatically increase the percentage with legal documentation of their wishes at the end-of-life.

Cultural diversity issues can become particularly prominent at the end-of-life, and affect decision-making. There are considerable racial/ethnic differences in use of advance directives, the extent to which families believe that patients should be informed about prognosis, preferences for family versus individual decision-making, and in patients' wishes about withholding life-sustaining treatments (Kwak & Haley, 2005). For example, African-American older adults are less likely than others to agree to withhold life-sustaining treatment even when quality of life is poor, and cultural values among many Asian groups discourage direct disclosure to dying patients and encourage decision making by family members (Kwak & Haley, 2005).

In terms of providing care, families provide the majority of care for individuals with chronic illness. They provide care for multiple reasons, including their sense of attachment, cultural expectations, and preferences for avoiding institutional care (Schulz, Gallagher-Thompson, Haley, & Czaja, 2000). Caregiving can be a long and extended "career" (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995) that often begins with minimal levels of assistance, such as assisting a parent or spouse with occasional tasks. Over time, in the context of disabling chronic illness, caregiving can become an all-encompassing activity that dominates one's life. Wives providing end-of-life care for patients with lung cancer in hospice reported an average of over 125 hours per week of caregiving activities (Haley, LaMonde, Han, Narramore, & Schonwetter, 2001). Family members are involved in many aspects of care, including providing emotional support, administration of medications, help with activities of daily living, and often assist with very personal activities such as toileting. They are also often asked to make reports of patients' symptoms, such as pain (Allen, Haley, Small, & McMillan, 2002), serving as a surrogate when the patient is either incapacitated or being sheltered by family and/or staff.

Risks and Benefits of Caregiving at the End of Life

Despite the large number of studies on caregiving and its associated stresses, very little of the research literature to date has focused specifically on caregiving near the end-of-life. Valuable insights about end-of-life caregiving comes from clinical reports of the dying process (Nuland, 1994), ethnographic studies (Sankar, 1999), and observations of experienced clinicians who work with families through hospice and palliative care or bereavement programs (Doka, 1997; Lynn & Harrold, 1999). These authors dramatically portray the extremely difficult circumstances experienced by caregivers near the end of life, who not only have to deal with ongoing caregiving responsibilities but also with anticipatory grief related to their loved one's impending death, along with the frustrations of dealing with an often unresponsive health care system.

Emanuel et al. (1999) and Emanuel, Fairclough, Slutsman, and Emanuel (2000) conducted a national study that documents the high levels of assistance provided by family caregivers of terminally ill patients, and the burdens experienced by families in the context of terminal illness. They showed that burden and depression are higher in family caregivers of patients with substantial care needs regardless of the specific terminal illness. Consistent with this finding, Haley et al. (2001) found that hospice caregivers for terminally ill patients with either lung cancer or dementia showed high rates of depression, lower life satisfaction, and poorer self-rated health than noncaregiving controls, with no significant differences in caregiver well-being across disease type. Haley et al. (2001) also found that many families also report experiencing benefits from caregiving. Most caregivers do not provide care just because they feel obligated to do so and trapped in the role. Some of the gains that are reported by caregivers include giving back to someone who has cared for them, satisfaction of knowing that their relative is getting excellent care, sense of personal growth, and gaining meaning and purpose in one's life. Some caregivers also feel that they are passing on a tradition of care and that by modeling caregiving their children will be more likely care for them if this is necessary. This sense of satisfaction and well-being can have important benefits for caregivers well after caregiving has ended (Carter, 1994).

Stress process models of caregiving have also been successfully applied to the end-of-life caregiving context. Haley, LaMonde, Han, Narramore, and Schonwetter (2003) found that, in a sample of hospice family caregivers, the magnitude of objective caregiving stressors faced (e.g., type of patient illness, hours per week caregiving, patient impairments) was less important than psychosocial resource factors in predicting caregiver depression and life satisfaction. In particular, caregivers who had more positive appraisals (e.g., finding benefits in caregiving), and better social support, had lower levels of depression and higher life satisfaction than caregivers without these resources. These findings suggest that stress process models could be used to develop interventions for caregivers at the end-of-life, an issue discussed in greater detail below.

When Caregiving Ends: The Effects of Bereavement

Since death in the United States increasingly comes after a sustained period of chronic illness and family caregiving, caregiving experiences can have important effects on bereavement. At the time of the death of the care recipient, family members often react with a mixture of relief and grief: death provides relief from the relentless strain of caregiving, and relieves the suffering of the care recipient, but also represents a significant loss to the family and to the primary caregiver.

In the broader literature, bereavement has been widely studied as a common and important stressful life event, and clearly is a stressor that has the potential to produce serious negative effects on both mental and physical health (Osterweis, Solomon, & Green, 1984). However, recent research has shown that, even among bereaved spouses, most show trajectories of grief and depression that can be characterized as showing resilience, e.g., an absence of significant depression either before the death, in the immediate aftermath of the death, or at longer-term follow-up (Bonanno et al., 2002). Longitudinal research on bereavement shows that most individuals cope effectively with loss. By 2 years after the death of a spouse, only about 15% of bereaved individuals experience patterns such as chronic grief or chronic depression (Bonano & Kaltman 2001). These individuals are often described in the clinical literature as experiencing pathological bereavement, chronic grief, traumatic grief, complicated grief, chronic depression, or other descriptors indicating that the extent and course of the grief response do not fit the more common pattern of acute distress with a return to relatively good subsequent adjustment (Hays, Kasl, & Jacobs, 1994; Prigerson et al., 1995; Worden, 2001). Within experts on psychiatric diagnosis and bereavement, there is currently considerable controversy about whether complicated grief should be considered a distinct diagnostic syndrome, versus a problem that can be considered under conventional diagnostic categories including major depression and post-traumatic stress disorders (Bonano & Kaltman 2001; Jacobs, Mazure, & Prigerson, 2000).

Recent research has also called some traditional ideas about grief into question. For example, the idea that "grief work" is necessary, and that those who do not experience intense grief are at risk for subsequent delayed grief, has not been supported (Bonano & Kaltman, 2001). In fact, bereaved persons who use high levels of rumination do more poorly during bereavement (Nolen-Hoeksema, McBride, & Larson, 1997). Increasingly, theory about grief and other circumstances requiring coping with negative events emphasizes the importance of finding meaning in negative events (Folkman, 1997; Neimeyer, 2001).

The relationship of caregiving to bereavement has received relatively little attention but is increasingly recognized as an important topic. Schulz, Newsom, Fleisner, DeCamp, and Nieboer (1997), in a thoughtful review of the literature on caregiving and bereavement, describe several theoretical frameworks that can be brought to bear on understanding end stage period of caregiving. Stress and coping theories have been widely used to study caregiving (e.g., Haley, Levine, Brown, & Bartolucci, 1987; Pearlin, Mullin, Semple, & Skaff, 1990), and are also relevant to the study of end of life care and bereavement. Schulz et al. (1997) note that stress and coping theories make two important suggestions concerning the effects of caregiving on bereavement. First, stressors may decrease for the caregiver after the death of the care recipient, and lead to relief, even in the face of loss. Second, extensive caregiving may lead to a depletion of psychosocial resources, such as loss of roles or social supports, which might make caregivers vulnerable to the effects of bereavement. In addition to stress process theories, Schulz et al. review other theories emphasizing grief processes, and anticipatory grief, which may be usefully applied to end-of-life caregiving and bereavement (e.g., Rando, 2000). These theories emphasize issues of attachment and loss, and note that in the context of chronic illness and caregiving, the family member may grieve losses before the actual time of death, which can be adaptive.

Burton, Haley, and Small (2006) found that, while caregiving can be a highly stressful prelude to bereavement, spouses who experienced the unexpected death of a spouse showed much greater increases in depression after the death than was found among spouses who had been caregivers, even under highly stressful circumstances. Thus caregiving, even highly stressful caregiving, may provide opportunities for caregivers to deal with some aspects of their loss before the death when loss is expected, consistent with Rando's (2000) writing.

Consistent with the observations noted in the review by Schulz et al. (1997), research findings have demonstrated that highly stressed caregivers may show not only distress after the death of a care recipient, but also feelings of relief. Schulz et al. (2003) found that, in a sample of family caregivers for persons with Alzheimer's disease who were assessed after the death of their care recipient, 72% reported that the death of their care recipient was somewhat or very much a relief to themselves. Over 90% of these caregivers also reported that they viewed the death as somewhat or very much a relief for the person with dementia. This study also found that death of the person with dementia led to significant declines in caregivers' depressive symptoms, due to the relief the caregiver experienced both in daily caregiving stress, and witnessing the suffering of their loved one. These findings do not suggest a coldness or lack of caring on the part of these highly strained caregivers—but instead, reflect an honest awareness of the fact that the end stages of dementia cause considerable suffering.

There has been relatively little attention to cultural diversity issues and bereavement after caregiving at the end of life. Owen, Goode, and Haley (2001) found that White and African-American caregivers differed in their reactions to the death of a relative with Alzheimer's disease. White caregivers were more likely than African-Americans to report a sense of relief, while African-American caregivers were more likely than White families to view this as a loss experience. African-American caregivers were also less likely to report anticipatory grieving. Since cultural factors are known to be very important in grief, studies of caregiving and bereavement need to pay increasing attention to diversity issues.

Bereaved family members have also been studied as informants about ways in which end-of-life care might be improved. Hanson, Danis, and Garrett (1997) found that in reviewing their experiences in end-of-life care, families report the greatest concerns about problems in communication, and inadequate pain control of their relatives, rather than decision-making per se. Families who received hospice care were most satisfied with their experiences, but families who had not participated in hospice were more critical of care in hospitals and nursing homes, and of the lack of time received from physicians.

Differences across settings are also evident in availability of bereavement services. Although hospice programs offer families considerable bereavement services after the death of a loved one (Foliart, Clausen, & Siljestrom, 2001), few bereavement services are generally offered to families after death in nursing homes and hospitals (Billings & Kolton, 1999; Murphy et al., 1997) unless hospice is involved in care.

While clinicians have written extensively about bereavement, and thoughtful clinicians have provided guidelines for caring for grieving families (e.g., Worden, 2001), there is a large gap in research evaluating the effectiveness of bereavement interventions. Evidence to date is disappointing about the effectiveness of commonly used bereavement interventions, with effect sizes much smaller than what is found in psychotherapy studies (Neimeyer, 2000). In addition, a report from the Center for the Advancement of Health (2004) suggests that grief therapies have the potential to cause harm among individuals who would be likely to cope successfully with bereavement without therapeutic intervention. This report calls for further research that identifies subgroups of bereaved individuals at highest need of grief therapy, and more research to identify effective evidence-based interventions for people having difficulty with bereavement.

In Aneshensel et al.'s (1995) discussion of the caregiving career, the authors note that when caregiving ends, the family member must adapt to a new life after caregiving, including taking on new roles that may have been abandoned due to the time demands of caregiving. While in most cases former caregivers appear to adapt successfully, Schulz et al. (2003) found that 30% of caregivers showed clinically significant elevations in depression at one year after the death of the care recipient. Some caregivers may need special help in dealing with grief, and in addressing social isolation that often occurs with highly stressful caregiving (Burton et al., 2008).

Systems of Care to Support Dying Patients and Their Families

In conventional healthcare, delaying death is often conceived of as the primary goal. The idea of creating a "good death," or a death relatively free of pain and discomfort, becomes the primary goal in the context of terminal illness. Emanuel and Emanuel (1998) have presented a conceptual framework for "a good death" that suggests six major modifiable dimensions of the patient's experience. These include physical symptoms, such as pain and fatigue; psychological and cognitive symptoms, such as depression, anxiety, and confusion; social relationships and support; economic demands and caregiving needs; hopes and expectations; and spiritual and existential beliefs. Interviews with patients with life-threatening illnesses suggest similar priorities, with an additional value placed on achieving a sense of control (Singer, Martin, & Kelner, 1999). Caregivers can be a key part of helping the patient to achieve a good death, and attention to caregiver needs is consistent with the goals of providing good care for dying patients. Ideally, systems of care should support the needs of patients and families from diagnosis through treatment, living with life-threatening illness, disease progression, and end of life. Achieving the best quality of life for patients and their families is the goal of palliative care, and the best way to achieve this goal is to integrate medical and psychological symptom management, psychosocial support, and advance care planning (Weinstein, 2001).

As noted above, families tend to receive little organized support and services when death occurs in hospitals or nursing homes without hospice care. However, hospice programs make the family the unit of care, and emphasize caregiver issues both while the patient is alive and during bereavement. Hospice programs in the United States began in the 1970s, and the introduction of the Medicare hospice benefit in 1982 led to a dramatic growth of hospice care (Miller, Mor, Gage, & Coppola, 2000). Nearly 360,000 Medicare patients used hospice services in 1998, about 20% of all Medicare beneficiaries who died in that year (General Accounting Office, 2000), with recent figures showing that 950,000 patients were served by hospice in 2003 (NHPCO, 2005). Patients are eligible for the Medicare hospice benefit if they are certified by a physician as having less than 6 months of life expectancy. Contrary to common misconceptions, there are no regulations requiring hospices to cease care or refund payments received if patients survive more than 6 months; in fact, only about 7% of patients remain in hospice care beyond 6 months, a figure that has remained fairly stable over time (GAO, 2000; NHPCO, 2005). As long as the hospice provides appropriate documentation of patients' prognosis, they can be re-certified for longer stays in hospice.

While hospice programs initially focused on cancer patients and their families, there is an increasing trend for noncancer patients and their families to receive hospice care. The percentage of noncancer patients in hospice rose from 24.4% in 1992 to 42.6% in 1998 (GAO, 2000), and increased further to 51% in 2003 (NHPCO, 2005). Hospice in the United States was designed to deliver care in the home and to allow patients to die in their homes. Residential hospices account for very few beds, but hospice is increasingly serving patients in nursing homes. It is estimated that

24% of Medicare hospice beneficiaries receive these services in nursing homes (Miller, Gozalo, & Mor, 2000). Hospice care in nursing homes has considerable promise to improve end-of-life care in these settings. Miller, Gozalo, and Mor (2001) found evidence that Medicare hospice patients residing in nursing homes had lower rates of hospitalization than nursing home residents not receiving hospice care. Interestingly, there was also evidence that the presence of hospice care in nursing homes leads to lower rates of hospitalization even for non-hospice patients. It appears that the presence of hospice leads to beneficial spillover effects that affect patients not even enrolled in hospice, perhaps due to the increased knowledge gained by nursing home staff due to the presence of hospice personnel. Hospice provision in nursing homes not only reduces hospitalization, but also improves pain control and reduces tube feeding (Zearson et al., 2000).

Hospice under Medicare covers prescription drugs, oxygen, aides, volunteer and respite companions, spiritual counseling, advance planning, and support and bereavement resources for family. While it represents a significant advance, hospice faces some serious problems. A very important problem faced by hospices is that of extremely short stays. In 2003, 36.9% of patients admitted to hospice died within 7 days of admission (NHPCO, 2005), an increase from the 1998 figure of 28% of patients dying within a week of hospice admission (GAO, 2000). Median length of stay in hospice has declined from 29 days in 1995 to 22 days in 2003 (NHPCO, 2005). Multiple factors likely contribute to these decreasing lengths of stay. Among these are patient, family, and physician efforts to continue aggressive medical treatment until illness is quite advanced; conceptions that hospice involves “giving up”; and unrealistic fears about financial consequences of referring patients who survive longer than 6 months. Physicians, who have a critical role in referring patients to hospice, greatly overestimate life expectancy in terminally ill patients (Glare et al., 2003), an issue discussed in greater detail below. The decreasing lengths of stay in hospice create a number of problems. Patients and families receive relatively short periods of service. Hospices have high “front-end” expenses, and it is very costly to admit large number of patients seen for brief periods of time, since reimbursement is on a per diem basis. Hospices are expected to provide a year of bereavement care for families even when the number of paid days of service is small.

Studies examining the impact of hospice care (which includes attention to family caregivers) on caregivers suggest that hospice is consistently related to higher caregiver satisfaction with end-of-life care. Some studies also suggest lower anxiety while caregiving and lower depression during bereavement when families receive hospice care (Miller et al., 2000).

Psychosocial Interventions and Training for End-of-Life Caregivers

While there is a large research literature on caregiver interventions, which generally shows that psychosocial interventions for caregivers can be effective in reducing depression and burden (Sorensen, Pinquart, & Duberstein, 2002), few studies have focused on interventions for caregivers facing the end of life. In one recent project, McMillan et al. (2006) conducted a randomized study with family caregivers providing in-home assistance for a relative who was terminally ill with cancer and receiving hospice care. Caregivers were randomly assigned to receive either usual hospice care alone; hospice care plus a three-session emotional support intervention; or hospice care plus a three-session coping skills training intervention. Results showed that, compared with the other two interventions, the coping skills training intervention had unique benefits in improving caregiver quality of life, and reducing caregivers' perceived burden (McMillan et al., 2006). While this area deserves greater attention, this project demonstrates that even caregivers facing very serious problems at the end-of-life can benefit from carefully developed interventions that provide them with skills that they can use to cope with the demands of end-of-life care.

There is also increasing recognition of the need to train family caregivers in end-of-life care skills, and some innovative projects have been conducted with this goal. The Hospice Institute of the Florida Suncoast recently conducted a national family caregiver needs assessment, and a subsequent "train the trainer" program in which, with support from the Administration on Aging, they developed a structured curriculum training caregivers not only in the hands-on aspects of care at the end-of-life, but also in issues such as how caregivers can derive meaning and satisfaction from their experience of care. This program also provides caregivers with information relevant to coping with loss. Findings from the needs assessment are described in a recent article (Salmon, Kwak, Acquiviva, Brandt, & Egan, 2005), and information on the training program is available for those interested in participating or using training materials (Kwak et al. 2007).

In summary, while interventions for end-of-life caregivers have received relatively little attention, work to date suggests that such programs can be helpful. Model programs are also available that could be more broadly disseminated.

Professional Training for End-of-Life Care

Although there is little data available on this topic, it is apparent that education for diverse healthcare professions—physicians, nurses, social workers, psychologists, and others—rarely includes training in end-of-life care. However, there are outstanding models for such care. For example, the EPEC program for physicians (http://www.epec.net/) provides physicians with training in such areas as comprehensive assessment, communication of bad news, goals of care, treatment priorities, and advance care planning; symptom management, including patient depression, pain, and confusion; and bereavement support. This training also includes a special module on care given during the final hours of the patient's life, including care for the caregiver.

A number of professions have recognized the need to improve end-of-life training. For example, the American Psychological Association (APA) has appointed several groups to advise the organization on steps that it should take to be better prepared to prepare psychologists to contribute more to end of life clinical care. As part of this effort, Haley, Larson, Kasl-Godley, Neimeyer, and Kwilosz (2003) reviewed professional issues for psychologists related to end-of-life care, and proposed the development of skill-building programs for psychologists interested in end-of-life. The APA has produced a continuing education program for psychologists and other healthcare professionals on end-of-life care (http://www.apa.org/ed/ce/resources/eol.aspx) and family caregiving is one of the ten modules included in this program.

Public Policy and End-of-Life: Where Do We Need to Go?

One part of improving end-of-life care for caregivers is to improve end-of-life care in general. If patients can be helped to attain a "good death," and patients and families can receive appropriate end-of-life care, this may have the effect of easing the burdens on family caregivers. In fact, Christakis and Iwashyna (2003) found evidence that family caregivers of patients cared for in hospice had lower mortality rates during bereavement than matched control spouses who had been widowed without the benefit of hospice care.

Lynn (2000) notes that our current healthcare system was developed largely to respond to acute illness, and is not well equipped to respond to chronic, debilitating, terminal illness. She presents a number of proposals to improve care for the dying, including clinicians improving their own skills, healthcare organizations monitoring pain and other symptoms and engaging in quality improvement efforts, and improved communication between agencies and care providers. Government agencies can provide funds and incentives, including research funds to study end-of-life care.

One recent book (Foley & Hendin, 2002) argues that there should be a societal shift toward considering quality end-of-life care as a fundamental right. These authors and contributors to their edited volume note that physician assisted suicide has become such a prominent topic largely because of failure to make highly effective palliative care more widely available, and failure to educate the public and health care providers about the benefits of comprehensive end-of-life care. Policy options to promote the goals of compassionate care, and protection of vulnerable populations, are presented in this highly recommended book.

Medicare reform, in particular a closer look at hospice eligibility criteria that allow access to hospice only with 6 months or less of survival, is also necessary. Hospice began as a program primarily targeting patients with cancer, for whom 6-month prognosis is relatively easy to predict, but as reviewed above, most Americans die after lengthy experiences of frailty that may not fit this pattern. Medicare has adopted criteria for determining 6-month prognosis for noncancer diagnoses, such as dementia and congestive heart failure, but evidence to date is that it is impossible to accurately foretell 6-month survival in such disorders and many patients should have more than 6 months of palliative care (Fox et al., 1999; Schonwetter et al., 2003). Broader availability of Medicare-funded hospice and/or palliative care will be vital in serving the large population of dying patients and families who do not easily fit into the 6-month window of the current Medicare hospice system.

While hospice care does provide increased services for family members, the financial costs of hospice are of increasing concern. While early research on hospice care demonstrated that hospice reduced end-of-life costs, more recent research paints a complex picture of cost issues and hospice. One recent article (Campbell, Lynn, Louis, & Shugarman, 2004) showed that hospice care is associated with lower costs for younger patients, and those with cancer, but is associated with increased costs for older patients, particularly those with non-cancer diagnoses. For example, compared with individuals who did not use hospice, hospice care was associated with 17% less in Medicare costs for individuals aged 68–79 with lung cancer, but was associated with 44% more Medicare costs in individuals over age 85 with dementia. The authors note that these analyses do not address possible improved quality of care with hospice, or non-Medicare costs, but these results show that policy efforts to expand the Medicare hospice benefit to non-cancer groups may not yield the cost savings that characterize hospice care in cancer that were found during early years of the Medicare hospice benefit.

Beyond efforts to more generally improve end-of-life care for dying patients, caregivers have some special needs that deserve attention. Over 1/3 of family members of terminally ill patients experienced significant financial strain, due to loss of income, having to move to provide care, and direct costs of care (Lynn, 2001). We need to look at reforms that might provide financial support and compensation for family caregivers, systems that are widely used in other wealthy countries.

Greater public education about hospice care and earlier referral to hospice by health care providers could also do much to help patients and families access services earlier, when they could benefit most from them. The timing of communications about hospice can have a potent impact on the decision process (Gochman & Bonham, 1990). Families who had heard of hospice prior to the terminal illness of the patient but who received no additional communication during the illness were about seven times less likely to report considering use of hospice than families who received information both before and during the illness, or who received information *only* during the illness. The issue of delay in referral is also related to the difficulty of making accurate prognostic judgments about survival time. Glare et al. (2003) showed that, across eight carefully designed studies, physicians tend to greatly overestimate survival time in terminally ill cancer patients, overestimating survival by more than 4 weeks in 27% of cases. The authors note that physicians' estimates of survival were highly correlated with actual length of survival, but that the estimates typically overestimate survival time by about 30%. Thus, it is possible that future research could find ways to integrate subjective prognosis from physicians with objective predictors to gain greater accuracy.

Recommendations for improvement of end-of-life care have primarily focused on the needs of dying patients. This is appropriate, but the needs of family caregivers and bereaved survivors are important as well. It must be a priority to provide better supportive services for caregivers, and to improve aftercare for bereaved persons.

Research Priorities for Understanding Family Caregiving and End-of-Life Issues

A number of topics merit greater attention in future research. One important area has to do with end of life decision making, and the role of patients and families. Many patients, rather than focusing only on autonomy, prefer to make end-of-life and other critical life decisions within a family context (Allen & Shuster, 2002; King, Kim, & Conwell, 2000; Puchalski et al., 2000), but this family context has been understudied. Cultural issues and how decisions are made within ethnically diverse families, and explication of the role of religious beliefs and practices (with particular emphasis on specific beliefs about death and the after-life), are of particular salience to this discussion and vary widely among ethnic and racial groups (Chatters, Taylor, & Lincoln, 2001; Kwak & Haley, 2005; Mouton, Espino, Esparza, & Miles, 2000).

In broader studies of family caregivers (mostly focused on caregivers of patients with dementia), evidence suggests that psychosocial interventions can yield potent benefits for caregivers, decreasing depression, and even delaying nursing home placement (Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; Sorensen et al., 2002). However, there has been little work documenting the impact of psychological intervention on family members providing end of life care. Much greater attention also should be paid to studying the effectiveness of bereavement services, and ways to prevent caregivers from developing long-term problems in coping after providing care. While some literature has begun to demonstrate that grief therapy can make a positive contribution (Jacobs et al., 2000), critical review of this literature (Center for the Advancement of Health, 2004; Neimeyer, 2000) suggests that randomized studies of grief therapy yield mixed results. More research is needed about how and whether various forms of therapy are effective in assist grieving persons in decreasing psychological distress and moving forward toward a more hopeful future.

Concluding Comments

Caring for a family member who is terminally ill is among the most difficult tasks one can experience. The commitment and resilience shown by most family members is remarkable, but many families face unnecessary strain due to the inefficiency of our systems of end-of-life care. In too many cases, patients have not provided adequate advance directives; the acknowledgement that patients are terminally ill and that hospice care would be beneficial comes too late; and specialized palliative and hospice care is provided either not at all or for briefer than optimal periods of time. While there is much that can be improved in end-of-life care, there are encouraging signs that family caregivers can benefit from available hospice care programs, and from special caregiver interventions that have been developed.

Caregiving at the end-of-life is full of both risks and rewards. People can at the same time gain a lot from being a caregiver, but experience negative stress-related problems that come from caregiving. In designing policy and interventions, we need to keep in mind that caregivers may need both help with their problems, but also acknowledgement that caregiving can be satisfying and enriching.

Finally, all of us should give our thanks to those who are caregivers during this trying period of the end-of-life. Caregivers make enormous financial, emotional, and sometimes health sacrifices to provide this care. Caregivers are the hidden heroes of our society today and we should do everything possible to give them the support they need for this important role.

References

Allen, R., Haley, W. E., Small, B. J., & McMillan, S. C. (2002). Pain reports by older hospice cancer patients and family caregivers: The role of cognitive functioning. *The Gerontologist, 42*, 507–514.

Allen, R. S., & Shuster, J. L. (2002). The role of proxies in treatment decisions: Evaluating capacity to consent to end-of-life treatments. *Behavioral Sciences & the Law, 20*, 235–252.

Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C. J. (1995). *Profiles in caregiving: The unexpected career*. San Diego, CA: Academic.

Billings, J. A., & Kolton, E. (1999). Family satisfaction and bereavement care following death in the hospital. *Journal of Palliative Medicine, 2*, 33–49.

Bonanno, G. A., Wortman, C. B., Lehman, D. R., Tweed, R. G., Haring, M., Sonnega, J., et al. (2002). Resilience to loss and chronic grief: A prospective study from pre-loss to 18 months post-loss. *Journal of Personality and Social Psychology, 83*, 1150–1164.

Bonano, G. A., & Kaltman, S. (2001). The varieties of grief experience. *Clinical Psychology Review, 21*, 705–734.

Bradley, E. H., Fried, T. R., Kasl, S. V., & Idler, E. (2000). Quality-of-life trajectories of elders in the end of life. *Annual Review of Gerontology and Geriatrics, 20*, 64–96.

Burton, A. M., Haley, W. E., & Small, B. J. (2006). Bereavement after caregiving or unexpected death: Effects on elderly spouses. *Aging & Mental Health, 10*(3), 319–326.

Burton, A. M., Haley, W. E., Small, B. J., Finley, P., Dillinger-Vasille, M., & Schonwetter, R. (2008). Predictors of well-being in bereaved former hospice caregivers: The role of caregiving stressors, appraisals, and social resources. *Palliative and Supportive Care, 6*, 149–158.

Campbell, D. E., Lynn, J., Louis, T. A., & Shugarman, L. R. (2004). Medicare program expenditures associated with hospice use. *Annals of Internal Medicine, 140*, 269–277.

Carter, R. (1994). *Helping yourself help others: A book for caregivers*. New York: Times Books.

Center for the Advancement of Health. (2004). Report on bereavement and grief research. *Death Studies, 28*(6), 491–575.

Chatters, L. M., Taylor, R. J., & Lincoln, K. D. (2001). Advances in the measurement of religiosity among older African Americans: Implications for health and mental health researchers. *Journal of Mental Health and Aging, 7*, 181–200.

Chen, H., Haley, W. E., Robinson, B., & Schonwetter, R. S. (2003). Decisions for hospice care in patients with advanced cancer. *Journal of the American Geriatrics Society, 51*, 789–797.

Christakis, N. A., & Iwashyna, T. J. (2003). The health impact of health care on families: A matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. *Social Science & Medicine, 57*, 465–475.

Cole, T. R., & Holstein, M. (1996). Ethics and aging. In R. H. Binstock & L. K. George (Eds.), *Handbook of aging and the social sciences* (4th ed., pp. 480–497). New York: Academic.

Connor, S. R. (1999). New initiatives transforming hospice care. *The Hospice Journal, 14*, 193–203.

Cugliari, A. M., Sobal, J., & Miller, T. (1999). Use of a videotape for educating patients about advance directives. *American Journal of Health Behavior, 23*, 105–114.

Doka, K. J. (Ed.). (1997). *Living with grief when illness is prolonged*. Bristol, PA: Taylor & Francis.

Dunlop, R. J., & Hockley, J. M. (Eds.). (1998). *Hospital-based palliative care teams*. New York: Oxford University Press.

Emanuel, L. L. (1995). *Structured deliberation to improve decisionmaking for the seriously ill*. Briarcliff Manor, NY: Hastings Center. Special Suppl.

Emanuel, E. J., & Emanuel, L. L. (1998). The promise of a good death. *The Lancet, 351*(Suppl. II), 21–29.

Emanuel, E. J., Fairclough, D. L., Slutsman, J., Alpert, H., Baldwin, D., & Emanuel, L. L. (1999). Assistance from family members, friends, paid caregivers, and volunteers in the care of terminally ill patients. *The New England Journal of Medicine, 341*, 956–963.

Emanuel, E. J., Fairclough, D. L., Slutsman, B. A., & Emanuel, L. L. (2000). Understanding economic and other burdens of terminal illness: The experience of patients and their caregivers. *Annals of Internal Medicine, 132*, 451–459.

Field, M. J., & Cassel, C. K. (Eds.). (1997). *Approaching death: Improving care at the end-of-life*. Washington, DC: National Academy Press.

Foley, K., & Hendin, H. (Eds.). (2002). *The case against assisted suicide: For the right to end-of-life care*. Baltimore: Johns Hopkins University Press.

Foliart, D. E., Clausen, M., & Siljestrom, C. (2001). Bereavement practices among California hospices: Results of a statewide survey. *Death Studies, 25*, 461–467.

Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science and Medicine, 45*, 1207–1221.

Fox, E., Landrum-McNiff, K., Zhong, Z., Dawson, N. V., Wu, A. W., & Lynn, J. (1999). Evaluation of prognostic criteria for determining hospice eligibility in patients with advanced lung, heart, or liver disease. *Journal of the American Medical Association, 282*, 1638–1645.

General Accounting Office. (2000, September 18). *Medicare: More beneficiaries use hospice: Many factors contribute to shorter periods of use: Testimony of William. J. Scanlon* (GAO/HEHS-00-201). Retrieved September 25, 2012 from http://www.gao.gov/new.items/he00201t.pdf.

Glare, P., Virik, K., Jones, M., Hudson, M., Eychmuller, S., Simes, J., et al. (2003). A systematic review of physicians' survival predictions in terminally ill cancer patients. *British Medical Journal, 327*, 195–200.

Gochman, D. S., & Bonham, G. S. (1990). The social structure of the hospice decision. *The Hospice Journal, 6*, 15–36.

Haley, W. E., Allen, R., Reynolds, S., Chen, H., Burton, A., & Gallagher-Thompson, D. (2002). Family issues in end-of-life decision making and end-of-life care. *The American Behavioral Scientist, 46*, 284–297.

Haley, W. E., LaMonde, L. A., Han, B., Burton, A. M., & Schonwetter, R. (2003). Predictors of depression and life satisfaction among spousal caregivers in hospice: Application of a stress process model. *Journal of Palliative Medicine, 6*, 215–224.

Haley, W. E., LaMonde, L. A., Han, B., Narramore, S., & Schonwetter, R. S. (2001). Family caregiving in hospice: Effects on psychological and health functioning among spousal caregivers of hospice patients with lung cancer or dementia. *The Hospice Journal, 15*, 1–18.

Haley, W. E., Larson, D., Kasl-Godley, J., Neimeyer, R., & Kwilosz, D. (2003). Roles for psychologists in end-of-life care: Emerging models of practice. *Professional Psychology: Research and Practice, 34*, 626–633.

Haley, W. E., Levine, E. G., Brown, S. L., & Bartolucci, A. A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging, 2*, 323–330.

Hampson, L. A., & Emanuel, E. J. (2005). The prognosis for changes in end-of-life care after the Schiavo case. *Health Affairs, 24*, 972–975.

Hanson, L. C., Danis, M., & Garrett, J. (1997). What is wrong with end-of-life care? Opinions of bereaved family members. *Journal of the American Geriatrics Society, 45*, 1339–1344.

Hays, J. C., Kasl, S., & Jacobs, S. (1994). Past personal history of dysphoria, social support, and psychological distress following conjugal bereavement. *Journal of the American Geriatrics Society, 42*, 712–718.

Hogan, C., Lunney, J., Gabel, J., & Lynn, J. (2001). Medicare beneficiaries' cost of care in the last year of life. *Health Affairs, 20*, 188–195.

Jacobs, D., Mazure, C., & Prigerson, H. (2000). Diagnostic criteria for traumatic grief. *Death Studies, 24*, 185–199.

Kayser-Jones, J., Schell, E., Lyons, W., Kris, A. E., Chan, J., & Beard, R. L. (2003). Factors that influence end-of-life care in nursing homes: The physical environment, inadequate staffing, and lack of supervision. *The Gerontologist, 43*, 76–84.

King, D. A., Kim, S. Y. H., & Conwell, Y. (2000). Family matters: A social systems perspective on physician-assisted suicide and the older adult. *Psychology, Public Policy, and Law, 6*, 434–451.

Kwak, J., & Haley, W. E. (2005). Current research findings on end-of-life decision making among racially/ethnically diverse groups. *The Gerontologist, 45*, 634–641.

Kwak, J., Salmon, J. R., Acquaviva, K. D., Brandt, K., & Egan, K. A. (2007). Benefits of training family caregivers on experiences of closure during end-of-life care. *Journal of Pain and Symptom Management, 33*, 434–445.

Larson, D. G., & Tobin, D. R. (2000). End-of-life conversations. *Journal of the American Medical Association, 284*, 1573–1578.

Lunney, J. R., Lynn, J., & Hogan, C. (2002). Profiles of elderly Medicare decedents. *Journal of the American Geriatrics Society, 50*, 1108–1112.

Lynn, J. (2000). Learning to care for people with chronic illness facing the end of life. *Journal of the American Medical Association, 284*, 2508–2511.

Lynn, J. (2001). Serving patients who may die soon and their families: The role of hospice and other services. *Journal of the American Medical Association, 285*, 925–932.

Lynn, J., & Harrold, J. (1999). *Handbook for mortals: Guidance for people facing serious illness*. New York: Oxford Press.

McMillan, S. C., Small, B. J., Weitzner, M., Schonwetter, R. S., Tittle, M., Moody, L., et al. (2006). Impact of coping skills intervention with family caregivers of hospice patients with cancer: A randomized clinical trial. *Cancer, 106*(1), 214–222.

Miller, S. C., Gozalo, P., & Mor, V. (2000). *Use of Medicare's hospice benefit by nursing home residents*. Providence, RI, USA: Center for Gerontology and Health Care Research, Brown University. Retrieved September 25, General Accounting Office. 2012 from http://aspe.hhs.gov/daltcp/reports/nufares.htm.

Miller, S. C., Gozalo, P., & Mor, V. (2001). Hospice enrollment and hospitalization of dying nursing home patients. *The American Journal of Medicine, 111*, 38–44.

Miller, S. C., Mor, V., Gage, B., & Coppola, K. (2000). Hospice and its role in improving end-of-life care. *Annual Review of Gerontology and Geriatrics, 20*, 193–223.

Minino, A. M., & Smith, B. L. (2001). *Deaths: Preliminary data for 2000 (National Vital Statistics Reports; vol. 49, no. 12)*. Hyattsville, MD: National Center for Health Statistics.

Mittelman, M. S., Ferris, S. H., Shulman, E., Steinberg, G., & Levin, B. (1996). A family intervention to delay nursing home placement of patients with Alzheimer's disease: A randomized controlled trial. *Journal of the American Medical Association, 276*, 1725–1731.

Mouton, C. P., Espino, D. V., Esparza, Y., & Miles, T. P. (2000). Attitudes toward assisted suicide among community-dwelling Mexican Americans. *Clinical Gerontologist, 22*, 81–92.

Murphy, K., Hanrahan, P., & Luchins, D. (1997). A survey of grief and bereavement in nursing homes: The importance of hospice grief and bereavement for the end-stage Alzheimer's disease patient and family. *Journal of the American Geriatrics Society, 45*, 1104–1107.

National Hospice and Palliative Care Organization. (2001). *NHPCO facts and figures.* Alexandria, VA: Author.

National Hospice and Palliative Care Organization. (2005). *NHPCO facts and figures: Hospice Care in America*.

Neimeyer, R. A. (2000). Searching for the meaning of meaning: Grief therapy and the process of reconstruction. *Death Studies, 24*, 541–558.

Neimeyer, R. A. (Ed.). (2001). *Meaning reconstruction and the experience of loss*. Washington, DC: American Psychological Association.

Nolen-Hoeksema, S., McBride, A., & Larson, J. (1997). Rumination and psychological distress among bereaved partners. *Journal of Personality and Social Psychology, 72*, 855–862.

Nuland, S. B. (1994). *How we die: Reflections on life's final chapter*. New York: Knopf.

Osterweis, M., Solomon, F., & Green, M. (Eds.). (1984). *Bereavement: Reactions, consequences and care*. Washington, DC: National Academy Press.

Owen, J. E., Goode, K. T., & Haley, W. E. (2001). End-of-life care and reactions to death in African-American and white family caregivers of relatives with Alzheimer's disease. *Omega, 43*, 349–361.

Pearlin, L. I., Mullin, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*, 583–594.

Prigerson, H. G., Frank, E., Kasl, S. V., Reynolds, C. F., Anderson, B., Zubenko, G. S., et al. (1995). Complicated grief and bereavement-related depression as distinct disorders: Preliminary empirical validation in elderly bereaved spouses. *The American Journal of Psychiatry, 152*, 22–30.

Prohaska, T. R., & Glasser, M. (1996). Patients' views of family involvement in medical care decisions and encounters. *Research on Aging, 18*, 52–69.

Puchalski, C. M., Zhong, Z., Jacobs, M. M., Fox, E., Lynn, J., Harrold, J., et al. (2000). Patients who want their family and physician to make resuscitation decisions for them: Observations from SUPPORT and HELP. *Journal of the American Geriatrics Society, 48*(5 Suppl), S84–S90.

Rando, T. A. (Ed.). (2000). *Clinical dimensions of anticipatory mourning: Theory and practice in working with the dying, their loved ones, and their caregivers*. Champaign, IL: Research Press.

Roscoe, L. A., Osman, H., & Haley, W. E. (2006). Implications of the Schiavo case for understanding family caregiving issues at the end-of-life. *Death Studies, 30*(2), 149–161.

Salmon, J. R., Kwak, J., Acquaviva, K. D., Brandt, K., & Egan, K. (2005). Transformative aspects of caregiving at life's end. *Journal of Pain and Symptom Management, 29*(2), 121–129.

Sankar, A. (1999). *Dying at home: A family guide for caregiving*. Baltimore: Johns Hopkins University Press.

Schonwetter, R. S., Han, B., Small, B. J., Martin, B., Tope, K., & Haley, W. E. (2003). Predictors of six-month survival in patients with dementia: An evaluation of hospice Medicare guidelines. *The American Journal of Hospice & Palliative Care, 2*, 105–113.

Schulz, R., Gallagher-Thompson, D., Haley, W. E., & Czaja, S. (2000). Understanding the interventions process: A theoretical/conceptual framework for intervention approaches to caregiving. In R. Schulz (Ed.), *Handbook on dementia caregiving* (pp. 33–60). New York: Springer.

Schulz, R., Mendelsohn, A. B., Haley, W. E., Mahoney, D., Allen, R. S., Zhang, S., et al. (2003). End of life care and the effects of bereavement among family caregivers of persons with dementia. *The New England Journal of Medicine, 349*, 1936–1942.

Schulz, R., Newsom, J. T., Fleissner, K., DeCamp, A. R., & Nieboer, A. P. (1997). The effects of bereavement after family caregiving. *Aging & Mental Health, 1*, 269–282.

Singer, P. A., Martin, D. K., & Kelner, M. (1999). Quality end-of-life care: Patients' perspectives. *Journal of the American Medical Association, 281*, 163–168.

Sorensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist, 42*, 356–372.

Terry, P. B., Vettese, M., Song, J., Forman, J., Haller, K. B., & Miller, D. J. (1999). End-of-life decision making: When patients and surrogates disagree. *Journal of Clinical Ethics, 10*, 286–293.

The SUPPORT Investigators. (1995). A controlled trial to improve the care of seriously ill hospitalized patients: The study to understand the prognoses and preferences for the outcomes and risks of treatment. *Journal of the American Medical Association, 274*, 1591–1598.

Tilden, V. P., Tolle, S. W., Nelson, C. A., & Fields, J. (2001). Family decision-making to withdraw life-sustaining treatments from hospitalized patients. *Nursing Research, 50*, 105–115.

Weinstein, S. M. (2001). Integrating palliative care in oncology. *Cancer Control, 8*, 32–35.

Worden, J. W. (2001). *Grief counseling and grief therapy: A handbook for the mental health practitioner* (3rd ed.). New York: Springer Publishing Company.

Yang, Z., Norton, E. C., & Stearns, S. C. (2002). Longevity and health care expenditures: The real reasons older people spend more. *Journal of Gerontology, Series B: Psychological Sciences & Social Sciences, 55B*, S2–S10.

Zearson, J., Sterns, S., & Hanson, L. (2000). Access to palliative care and hospice in nursing homes. *Journal of the American Medical Association, 284*, 2489–2494.

Chapter 10
Perspectives on Caregiving Across the Life Span: Current Status and Future Directions

Rhonda J.V. Montgomery and Ronda C. Talley

Although the division of this book into two parts is consistent with a general perception that caring for children is a process distinct from that of caring for adults, the common elements of the caregiving experience become clear when we pay attention to the themes that emerge from all of the chapters. The unique experiences and challenges of caregiving that parents and other caregivers encounter as children develop and mature from infancy through late childhood were described in Part I. These chapters also identify several aspects of the caregiving experience that are shared by caregivers who attend to the needs of children across the spectrum of developmental stages. Similarly, the chapters in Part II of the book focused on the unique and common experiences of caregivers who attend to the needs of adults in early, middle, and old age, including those who are at the end of life. The insights about the unique challenges associated with each stage of life highlight the ubiquitous change that characterizes the caregiving experience while the elements of caregiving identified as common to all groups provide a foundation for understanding caregiving as normative familial role that prevails across the life span. Here we summarize six themes that highlight the extent to which the role of caregiver is assumed and experienced in a similar manner regardless of the characteristics of the care recipient.

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Caregivers Are Predominately Female Family Members

The most basic fact about caregivers is that the large majority is family members, and most of them are women. As Mzarek (Chap. 2) noted, in all cultures, care for children is primarily provided by women, most often mothers or sisters. Gonyea (Chap. 7) made a similar observation noting that the vast majority of persons who care for relatives with chronic disabilities are women, most of whom are wives, daughters, and daughters-in-law. The preponderance of women as caregivers largely reflects societal expectations. Indeed, in there is a tacit expectation that new mothers handle the lion's share of infant care tasks. And, Gonyea (Chap. 7) provided an in-depth discussion of the corresponding expectations placed on women to serve as caregivers for older adults.

Associated with this societal expectation for women to provide care is an array of negative consequences both for society and individuals. Indeed, it can be argued that the expectation that women will be caregivers has impeded the development and delivery of support services. Moreover these societal expectations and the overwhelming prevalence of women as caregivers translate to a higher probability for women to live lives with high levels of stress, and often depression, due to the demands of family care and competing demands of employment.

Caregiving Changes Over Time

Variation and change in the caregiving role is a second theme that emerged from the chapters focused on care for children and was echoed in the chapters focused on care for adults. The types of tasks that caregivers assume and the ways in which they perform these tasks are influenced by the needs of the care recipient and social and cultural norms associated with familial roles.

The authors of the chapters in Part I emphasized the need for caregivers to adapt and change their tasks and roles as the physical and emotional needs of a child change. This link between functional level of the care recipient and care tasks is also described in the chapters focused on caregiving for adults. As the levels of physical and mental disability increase caregivers assume more responsibility and often take on more complex care tasks, which include direct care, assistance with decision making, and emotional support. In Chap. 6, Givens and his colleagues also identified a link between the type and intensity of care involvement and the frequency and severity of symptoms of care recipient.

Caregiving Leads to Change in Relationships and Identity

A third theme that emerged is the dynamic nature of the relationship between caregivers and care recipients. In Part I, which focused on care for children, we were reminded of the observation made by Seltzer and Ryff (1994) that, "family well-being and caregiving demands evolve over time and what happens at one stage obviously is influenced by earlier stages and, in turn, influences later ones." This notion is reflected in the fact that infancy not only provides an opportunity for babies to develop, but also for mothers and fathers to embrace new feelings and new roles. for further human development.

Blancher (Chap. 3) also emphasized the reciprocal nature of change in the dyadic relationship for caregivers when she wrote, "parents are both recipients of, and contributors to, their children's developing changes. These changes during middle childhood shape the primary goals and tasks associated with parenting during this time period." Similarly in her discussion of late childhood, Wong (Chap. 4) observed that the movement in late childhood toward greater independence and autonomy requires parents to release their control.

The themes of change and relationship maintenance were also woven into the chapters focused on care for adults. Givens et al., (Chap. 6) emphasized the importance of viewing family caregiving within a historical context stating that the bonds of affection and reciprocity that sustain caregiving take root in past relationships. They also noted that changes in the patient condition that stem from remissions necessitate changes in caregiver responsibilities and continued negotiation of roles. Haley (Chap. 9) emphasized the unique transition that family members make when they serve as their relatives' surrogates to voice health care needs and make end-of-life decisions. The changing nature of the dyadic relationship was presented as a core principle of the theoretical framework articulated by Montgomery and Kosloski (Chap. 8) which asserts that caregivers go through a process of identity change.

Caregiving Is Accompanied By Stress and Burden

Although the provision of care for dependent individuals by family members is often viewed as normative, caregiving is frequently accompanied by many stressors and strains that can have an impact on the caregiver's well-being. In Part I, the difficulties that parents encounter during each stage of a child's development were identified along with the costs that caregivers can incur in their own personal well-being. The level of stress experienced by caregivers, however, is not uniform for parents and the authors identified several characteristics of the children that influence level of parental stress. These included the developmental age, the level of dependency, and the behaviors of the child. Additionally several caregiver characteristics were identified as factors influencing the caregiving experience. In particular, maternal employment and single parenthood were identified as factors that exacerbate the burdens of care. Women employed outside the home experience considerable role overload as they attempt to perform several competing roles effectively and simultaneously (Blacher, Chap. 3). The consequences of this role overload include negative impacts on women's health and well-being and on their relationships with their spouses. Culturally based values and experiences were also identified as factors that influence stress levels. In particular, culture was shown to affect access to social and formal supports, which in turn affected the level of stress experienced by caregivers. Each of these observations about stress and caregiving was repeated in Part II. Citing a large body of evidence, the authors discussed the emotional, physical, and financial costs associated with caring for adults. In particular they identified the level of functional dependency as a major factor that affects the type and intensity of care tasks that are performed by their caregivers. At the same time, the authors agreed that there is an inconsistent relationship between measures of the care recipient's functional condition and stress. This fact indicates that the level of stress experienced by caregivers is not solely dependent upon the physical needs of the care recipient. Rather, a range of characteristics of the caregiver, the care recipient, and the care context influence the level of stress. In Chap. 6, Givens and his colleagues examined living arrangements, the length of time that a person spends in the caregiving role, age, sex, and physical health of the caregiver as factors affecting stress. The authors also discussed role conflicts and role tension that are most acute among early adult caregivers who are juggling care tasks with responsibilities for young children and employment demands. Special attention was given to the stress that stems from discrepancies that caregivers may experience between their expectations for their role and the physical and emotional tolls that care tasks incur. In a similar manner, Gonyea (Chap. 7) emphasized the influence of caregivers' expectations on the level of stress and role conflict for midlife caregivers. These expectations are often grounded in familial roles. Gender, race, and cultural beliefs were all shown to be linked with differences in the caregiving experience. In Chap. 8, Montgomery and Kosloski noted the cyclical nature of caregiver stress and burden and link it to an identity change process that caregivers experience over their caregiving career.

Finally, in Chap. 9, Haley outlines the heavy work load the family members assume for persons at the end of life, noting that stress is particularly high when there is an absence of advance directives to guide family members in their surrogate role as decision maker for end of life cares. The stresses of caregiving are often exacerbated for this group by the frustration of dealing with unresponsive health care systems and anticipatory grief related to their loved one's pending death.

Caregiving Has a Positive Side

In addition to noting the negative aspects of caregiving, a number of positive outcomes for caregivers were identified for caregivers across the life span including, a sense of competency, gratification, self-satisfaction, self-esteem, a sense of mastery and a gain in the meaning and life. These gains were even reported for caregivers attending to the needs of relatives at the end of life. Despite this growing recognition of positive outcomes, there was agreement among the authors that there is a need for more information about factors that lead to these positive experiences, and mechanisms for creating conditions to foster and enhance these experiences.

Mechanism for Supporting Caregivers

Just as there are numerous similarities in the caregiving experience between those who attend to the needs of children and those who care for adults, there are similarities between the two groups in their need for support services. A common need of caregivers of dependants of all types is the need for educational programs. Caregivers of children could benefit from programs that enhance their knowledge about human development and parenting skills. Caregivers assisting older adults and those with developmental disabilities could benefit from programs that offer information about normal aging and disease processes. Equally important, several of the chapters noted the value of teaching caregivers practical skills to ease care tasks and coping skills to ease the emotional costs that are associated with care. Additionally, Haley (Chap. 9) discussed the growing need for caregivers to learn more about end-of-life care and the legal and ethical issues that surround this care.

The most frequently recognized and articulated need of all caregivers is the need for reliable substitute caregivers. Regardless of the age or disability level of the care recipient, caregivers benefit from respite that is provided by paid and informal care workers in family homes and in day care centers. Yet, the lack of appropriate substitute caregivers was a lament articulated throughout this book. Sadly, our culture does not value caregiving and we do not pay for it. The dilemmas surrounding the search for substitute childcare are manifold. They relate to the fact that in the USA it is the economic engine that drives our childcare policies and products. Unfortunately child care is not recognized as an opportunity for promoting the development and well-being of children or the individuals who care for them. The paucity of high quality child care is well documented as is the paucity of high quality elder care. Even when it comes to end-of-life care, our society tends to devalue caregiving. The need for trained, qualified direct care workers is pervasive, due to both the growing numbers of elders in need of care and the absence of benefits and low wages that such workers receive.

In addition to benefiting from educational programs and respite services, caregivers for persons of all ages are reported to benefit from counseling and support groups. Just as parents of special needs children have been shown to benefit from support groups, Givens (Chap. 6) and Gonyea (Chap. 7) noted the benefits of support groups for caregivers of persons who have suffered from strokes, cancer, Parkinson's disease, or Alzheimer's disease. Similarly there is strong evidence that the inclusion of counseling and support services for family members in hospice programs is extremely beneficial. Citing evidence that bereaved caregivers can remain highly distressed for up to 4 years after death of a relative, Haley (Chap. 9) asserts that there is especially a need among caregivers for grief counseling to deal with the bereavement process.

Finally, the importance of conducting assessments to clearly identify the specific needs of caregivers and thereby effectively target support services was recognized by several authors. A major challenge for professionals working with caregivers is contending with the changing circumstances of caregivers that lead to corresponding changes in the need for services. Haley (Chap. 9) argued that “ideally, systems of care should support the needs of patients and families from diagnosis through treatment, living with life threatening illness, disease progress, and end of life.” The challenge of matching services with care needs as they change is directly addressed by Montgomery and Kosloski in Chap. 8 as they discussed the practice implications of their Caregiver Identity Change Theory.

Summary

Clearly, family members prevail as the primary caregivers of dependent persons of all ages in our society. Although their caregiving responsibilities and experiences are uniquely linked to the type of dependency or disability of the care recipient, there is great commonality in the caregiving experience for family members who care for persons of all ages. To fully support caregivers it is important to focus on these common elements of the experience and begin to design and implement support systems that will build on common strengths and address common needs.

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