Family Caregiving: Telling It Like It Is

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in all major dimensions of human experience—in the
times individuals describe as good and bad, in their
thoughts as well as their actions, and in the meanings
they attribute to their experiences. They have been
there all along, waiting to be recognized and under-
stood. Books such as these provide testimony to the
importance of religion and religious institutions in the
lives of older people and serve as superb examples
of what can be learned from creative and rigorous
scholarship on that topic.

FAMILY CAREGIVING: TELLING IT LIKE IT IS

Caring for Elderly Parents: Juggling Work, Family,
and Caregiving in Middle- and Working-Class
Families, by Deborah M. Merrill. Auburn House,
Westport, CN, 1997, 232 pp., $55.00 (cloth).
Profiles in Caregiving: The Unexpected Career, by
Carol S. Aneshensel, Leonard I. Pearlin, Joseph T.
Mullan, Steven H. Zed, and Carol J. Whitlatch. Aca-
demic Press, San Diego, CA, 1995, 385 pp., $39.95
(paper).
The Sandwich Generation: Adult Children Caring for
Aging Parents, by Charles R. Roots. Garland Pub-
ishing, New York, 1998, 150 pp., $42.00 (cloth).
Understanding Family Care: A Multidimensional
Model of Caring and Coping, by Mike Nolan, Gor-
don Grant, and John Keady. Open University Press,
Philadelphia, PA, 1996, 191 pp., $79.00 (cloth).
Your Name Is Hughes Hannibal Shanks: A Caregiver’s
Guide to Alzheimer’s, by Lela Knox Shanks. Uni-
versity of Nebraska Press, Lincoln, NE, 1996, 191
pp., $22.50 (cloth).

In the gerontological literature, much has been
written about family caregivers; normalization of the
caregiving role in an aging society, the preponder-
ance of women as caregivers, and the stresses and
burdens assumed by family caregivers have been noted.
Policy makers debate the role of family in today’s
Western society, changes in family structure, and the
appropriate role of government in provision of sup-
port services. Practitioners struggle with how to assist
confused, determined families and older persons try-
ing to make helpful decisions about care, often in
times of crises. Gerontological researchers bemoan the
seemingly dead end of much caregiver research now
that the descriptive outlines of the phenomenon have
been firmly established, and they argue for new di-
rections and explanatory paradigms. In a recent book
essay, Pillemer (1996) notes that despite years of re-
search, from the perspective of a Martian there are
many reported gaps in knowledge, families are re-
luctant to use services that do exist, and there is a
lack of demonstrated impact of supports on caregivers.
One reason for this provocative set of conclusions may
be that sufficient attention has not yet been paid to
the stories of the caregivers themselves. Rather, policy
makers, practitioners, and researchers have applied
their own “hammers” and guidelines to rectifying
assumed difficulties on a ubiquitous human experi-
ence, rather than seeking tools that match the pro-
lems identified by those most involved.

The books reviewed here represent increased at-
tention to the caregivers’ perspective. For instance,
the volume by Aneshensel and colleagues, Profiles in
Caregiving: The Unexpected Career, is a highly rigor-
ous, theoretically focused, quantitative research study.
Yet, even its abstracted quantitative findings are illus-
trated with photographs, vignettes, and statements of
caregivers gathered in a qualitative study. Does this
new focus represent a paradigm shift in caregiver re-
search? Are there useful insights for policy, practice,
and research that can be gleaned from a closer ex-
amination of caregiver perspectives?

The dominant paradigm in caregiver research is the
logical positivist perspective that interprets phenom-
ena in terms of sets of variables representing theo-
retical constructs. This type of research continues to
pervade the professional literature, especially as more
and more sophisticated methods of analysis have the
potential to enlarge our thinking and contribute to
the development of more elegant theoretical perspec-
tives. The Aneshensel book is an excellent ex-
ample of the interplay between theoretical develop-
ment and sophisticated methodology. At the same
time, the application of findings from this paradigm
improved policy options, practice interventions, and
daily caregiving choices continues to be problematic.
For example, we now know that behavior problems
of a person with dementia are a primary contribu-
tion to caregiver distress and that spouses are more
reluctant to place their dependent loved ones in an
institution than are adult children. What else do we
need to know to translate these findings into devel-
opment useful policies or interventions that address
caregiver distress or enable adult children to main-
tain care in the community longer and comfortably?
What can we learn from an emerging emphasis on
stories by caregivers that not only describe specific
caregiving experiences, but also give clues as to why
formal intervention research may not be the most suc-
cessful way to go?

This essay seeks to examine what the voices speak-
ing in these volumes tell us about ways in which

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research on spirituality and health: A consensus report. Rockville,
MD: National Institute for Healthcare Research.
gerontological and practical professional expertise may be useful for caregivers. Four of the five books reviewed for this essay emphasize the voice of the caregiver. Two of them are authored by caregivers (Your Name Is Hughes Hannibal Shanks: A Caregiver’s Guide to Alzheimer’s, by Lela Knox Shanks, and The Sandwich Generation: Adult Children Caring for Aging Parents, by Charles R. Roots). Two others represent a combination of personal meaning and caregiving perspectives framed by theoretical perspectives of stress and coping (Understanding Family Care: A Multidimensional Model of Caring and Coping, by Mike Nolan, Gordon Grant, and John Keady) or life course interpretations (Caring for Elderly Parents: Juggling Work, Family, and Caregiving in Middle- and Working-Class Families, by Deborah M. Merrill). The Aneshensel et al. book is punctuated by caregiver quotes and pictures, but they are not integrated into the study’s presentation of results in any way.

The psychological value of telling one’s story and the belief that one’s experiences can be of value to others in similar situations have often been noted. Lela Knox Shanks illustrates the value of a good storyteller. In her story of loving family relationships, Mrs. Shanks details matter-of-factly the way she cares for her husband with dementia, respecting his unique personality and biographical history. She describes a willingness to experiment and find tailored practical solutions to the changing problems she recognizes. Her tale is a mixture of creative answers to specific problems and a determination to maintain her own sense of self and independence because she recognizes this as the only way she can truly provide care for her husband and herself. She depicts how seemingly burdensome care can become routine when coping methods are developed. The paradox of dementia caregiving—that change is constant—suggests to her that the need to remain flexible and be willing to change approaches is also constant. The Shanks family is African American, lives in Kansas, and has a long history of involvement in the civil rights movement in that state. Yet, race and culture do not play a major role in her story or care methods. Rather, her story emphasizes the basic human trials of coping with a debilitating disease instead of cultural issues, as well as a middle-class willingness to seek out community and personal resources when they are perceived as needed.

In addition, her story illustrates the inordinate complexity of coping with dementia and highlights the inadequacy of our scales and measures for capturing this complexity in a constantly changing environment of care. The inadequacy of “one-size-fits-all” interventions based on single-variable interpretations of complex processes are also noted. Mrs. Shanks comments that “the ongoing needs of caregivers are too constant and often too desperate to rely on periodic informal training” (p. 142). Intervention research suggesting that individual counseling approaches may be more successful than group-based interventions receives indirect support in her descriptions of the idiosyncratic ways in which she made things work for herself and her family. Yet the financial costs of providing different types of respite for herself also illustrate the need for a better balance between public and private sources of support.

The Shanks story is about a spouse caregiver and her family. The Roots book focuses on adult children caring for aging parents, the so-called “sandwich generation,” and represents the limit of individual need to publish personal discomforts. Growing out of personal experience with providing care to his grandmother because his mother was absorbed in caring for a seriously ill spouse, the author, a minister, has obviously struggled to give broader meaning to his experiences. But the book is a pastiche of selected self-disclosures, compilations of advice taken from other sources, ad hoc research summaries, and discussions of the role of the church. The desired audience is not targeted, and the advice is brief and disconnected. Gerontologists and family caregivers will learn little from this book.

Nolan, Grant, and Keady, British nursing researchers, appear motivated by a desire to present a more holistic conceptualization of caring. Their perspective is based on the stress-coping literature, emphasizing the role of personal meaning for caregivers in coping with difficult life events. The authors claim to provide a multidimensional model of family care based on integration of selected portions of the caregiving literature and grounded descriptions by caregivers of their experiences. Describing the holistic and transactional nature of caregiving, they highlight the underlying purposes of providing care, caregiving satisfactions, and coping mechanisms of caregivers of diverse patient populations. A secondary theme is implications for service delivery and planning of interventions. The authors’ longitudinal model briefly describes changes over time in cognitive or psychological terms from the caregiver’s perspective, such as “taking it on,” “getting through it,” and “turning it over.” These terms provide a colloquial counterpart to the similar stages of role acquisition, role enactment, and role disengagement proposed by Aneshensel and her coauthors, suggesting some congruence on the broad outlines of the caregiving process over time.

There are many useful observations about caregivers’ experiences in this book, including recognition of the importance of the apparently trivial and mundane events that can assume much significance, especially as social opportunities for caregivers appear to contract (p. 103). Other paradoxes of caregiving are noted: for example, satisfactions with caregiving can provide an important stress-buffering role, but also may bind caregivers to situations which, perhaps, should not be sustained. The authors conclude that there is a need to follow new theoretical, methodological, and empirical routes to a more holistic understanding of family care, but they provide few specific suggestions on how to travel. They do provide, however, a set of conceptual stepping stones for those who are seeking ways to describe caregiving experiences in a family context.

The Merrill book examines social class, a dimension often missing from caregiving studies. Based on 50 in-depth interviews with White working- and
middle-class adult child caregivers, the author, a sociologist, draws on a life course perspective to organize, describe, and interpret her findings. The caregivers’ stories form the backdrop of the text with descriptions of the interface of caregiving responsibilities with work roles, sibling relationships, family life, and career choices. Themes are illustrated by personalized accounts that once again convey the variability in caregiving situations. Most of the volume represents the author’s synthesis of expectations drawn from previous research to identify class, ethnic, and gender differences in patterns of caregiving in the context of the caregivers’ lives, restricting the power of the caregivers’ stories.

The relationship between adult child caregiver and parent (care receiver) becomes more apparent in this book than in many others. The dependence of the caregiving career on the ups and downs in the health status of the parents is graphically evident. Especially in working-class families, the parents are the ones who often choose which of their children will become identified as the primary caregiver. Because many of the elderly parents are not cognitively impaired, their stories become as important as the caregivers’ to the ongoing caregiver career. Although this factor often is given lip service in discussion sections, studies based primarily on caregiver data often obscure this basic element. In addition, many of the generalizations made by researchers about the relevance of gender, ethnic, and class differences in patterns of care are more carefully nuanced in this text. For example, Merrill found that among many working-class families, sons play active roles in providing direct care. Furthermore, cultural values, even more than financial considerations, appear to be a major contributing factor in many service-use decisions. Thus, these caregiving stories add to our knowledge of the complexity of caregiving choices.

Profiles in Caregiving, by Aneshensel and colleagues, seeks to address research, clinical, educational, and family audiences at one turn. As indicated earlier, the authors aim to enliven and ground their theoretical perspectives and quantitative findings from a three-year longitudinal survey of dementia caregivers by using photographs and quotes from caregivers, and by providing useful chapter summaries of results and discussions. The resulting volume may not completely satisfy any one audience, but offers much for those who pore through the dense text. The unifying concepts are the caregiver career and stress process theory. As noted, the caregiver career is portrayed in three stages: role acquisition, role enactment, and role disengagement. Within each of these stages, the building blocks of stress process theory—primary and secondary stressors, stress proliferation, and stress containment (moderators of stress)—are described and their causal paths carefully analyzed in terms of short-term change over one year and long-term change over a three-year period. The use of both time periods adds a great deal to our knowledge of the caregiving career, as positive and negative changes are not necessarily sustained over three years and new forms of adaptation emerge.

The primary limitation, as in most quantitative work, is the gap between the rich conceptual model and the more limited operationalization of the concepts that were used in the survey. Measures of many of the concepts, especially psychosocial resources such as social support, are weak and not sufficiently multidimensional. Yet the detailed emphasis on how stress can proliferate over time and affect be affected by intrapsychic strains and role constraints is an important contribution to stress research.

The empirical results are complex, vary by career stage, and are not easily summarized. As is typical in large surveys of primary caregivers, most of the role dimensions examined are necessarily individualistic, not family focused. The findings bear out many of the anecdotal caregiver comments found in the other books. For example, institutionalization of the patient with dementia did not have significant effects on changes in family strain, and among those who continued to provide in-home care, role captivity increased family conflict (p. 232). The longitudinal perspective once again demonstrates that caregiving for persons with dementia needs to be fluid in nature to cope with the inevitable decline. Working through the detailed findings provides many rich possibilities for clinical insights into caregiving issues in general and, more specifically, in the form, content, and timing of interventions at different stages of the caregiving career. Chapter 12 details some of these possibilities and presents a brief review of the literature citing service delivery obstacles. Although the findings are applicable only to caregivers of persons with dementia, this research monograph provides a model for longitudinal, quantitative studies of other types of caregiving. Given the unique aspects of caregiving for persons with dementia, the exportability of the stress proliferation model to other caregiving situations is an important issue.

Reflecting on the stories presented in these books leads me to the observation that perhaps gerontologists have reified the concept of caregiver, removing it from its situational context. The stories of family members offer different conceptions of “caregiving.” Some emphasize the role of the family member with its associated domains of love and obligation to care; others focus on the caregiving tasks, often not as additive burdens but as activities to encompass in daily life. Others focus on role constrictions and webs of sibling and family relationships. From the individual and family caregiver perspective, families facing care for a dependent older person perceive themselves facing problems in living. With the onset of dependency, they face a new imbalance in the customary ups and downs of family relationships, one that has to be interpreted and managed in some way. The ways chosen are reflective of community options, previous patterns of family decision making, coping strategies, values, and abilities to be flexible and respond to unanticipated contingencies. There are no obvious right ways to provide or receive care, or to fully control the situation to achieve true homeostasis or avoid some behavioral and psychological disturbances.
In the social and psychological sciences, we struggle to integrate the subjective and objective elements of experience, yet rarely articulate our underlying conceptions of social agency and decision making. Pescosolido and Kronenfeld (1995), in a recent review of the status of research in medical sociology, call for paradigmatic changes in our study of the dependency process and the ways that individuals and families use lay, folk, and formal healing systems. They argue for more attention to the dynamic processes of care that “link individuals in all their psychological complexity to institutions and social context in all their structural complexity” (p. 18). Furthermore, they call for greater attention to our assumptions of rational choice as the foundation of individual, family, and institutional decision making. The need to take negotiated solutions and value preferences into account is emphasized. Listening to the caregivers “tell it as it is” in the books reviewed in this essay verifies the need for a new integration of subject and method that goes beyond the oft-noted distinctions between quantitative and qualitative research. Both approaches are needed to operationalize and elaborate the situationally based concepts of career and life course that are emphasized in these new books. But we haven’t yet found the methodological or conceptual mechanisms to adequately capture diversity in the midst of empirical generalizations.

This challenge has special relevance for gerontologists as we straddle science and practice and policy. What are we about in an applied field? Is our goal to develop knowledge that can be used to make peoples’ lives better? Is our goal to develop more valid theoretical interpretations of phenomena on the principle that basic research into normal and customary human behavior is needed before applications can be meaningfully derived—there is nothing as practical as a good theory? Given the variability in individual and family care situations, does the concept of formal interventions devised by professionals, with built-in assumptions of replicability, efficiency, and effectiveness, make any sense at all? Our difficulty in identifying successful interventions for family caregivers suggests the importance of flexible and individualized solutions to individualized perceptions of problems and solutions—perceptions that may be far removed from what professional definitions or the capacity of social institutions can provide. Abel (1990) and Braithwaite (1996) argue that the individualized stress-process model has had limited success in creating interventions that successfully alleviate caregiver distress. Reasons include family ties, family traditions, and designation of frailties and care activities primarily as stressors to be changed or appraised differently, rather than as dynamic aspects of most individuals’ lives. Caregivers’ stories suggest that the basic reason for the limited effectiveness of most interventions is that stress is inherent in the caregiving role. The ability of caregivers, like other human beings, to cope with adversity through personal change and stress-management approaches may be inherently limited (Abel, 1990).

Gerontologists’ most important contribution should be the development of new paradigms of interpretation of caregiving experiences—paradigms that can come to grips with chronic illness and its impact on individuals and families. Clearly, an important shift has begun, as we have gone beyond the task-centered descriptions of family caregiving to recognizing the family context and personal meanings attached to caring for dependent family members. We do not yet, however, have a way of capturing into a unifying theory of family caregiving the many small, but important, ongoing negotiations and strategies that make up many of our caregivers’ stories. What we do have is growing evidence at all levels that families continue to struggle as best as they can, muddling through to provide care for those in need. The challenge of integrating diverse individual and family experiences with the perspectives of service and professional providers in useful theoretical models remains.

A second challenge to think about is how to organize society so that caregiving responsibilities are humanely and justly distributed (Braithwaite, 1996). We do not yet have a way to convince policy makers that investing in family caregiving issues is useful or cost-effective in the long run. On the one hand, the assumption of many policy makers that families are the appropriate source of care for impaired family members is supported by many of the caregivers’ stories. Caregivers suggest that they are willing, for the most part, to provide needed assistance and do not expect formal services to substitute for what they are doing, but they do want help from others with their activities when they desire it. Such help ideally would provide ways to enhance the caregiver’s own sense of competence and self-efficacy, rather than just remove objective burdens of care. Yet, such help is clearly not available. The broad focus, limited access, and fragmentation of services that are not easily integrated into established family care patterns are recurring themes in family caregiving stories. The paradox of current long-term care policies, in which the importance of family care is stressed—even though reimbursements and service eligibility focus only on the individual older person—seems to lead many caregivers to opt out of the formal service arena. Resolving this paradox in the context of coherent caregiving and family social policies is one of gerontology’s most important tasks.

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References