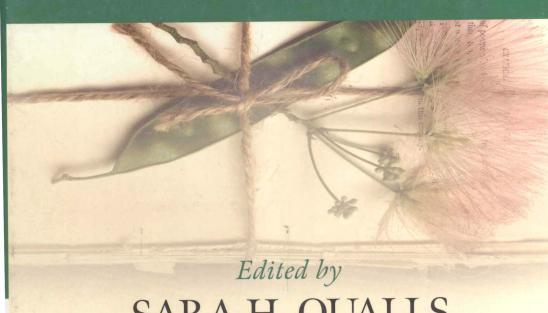
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AGING FAMILIES AND CAREGIVING



SARA H. QUALLS STEVEN H. ZARIT

Aging Families and Caregiving

Edited by
Sara Honn Qualls
Steven H. Zarit





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Preface

AGING FAMILIES AND CAREGIVING

Families are so important within the lives of older persons that they often are part of mental health assessment and treatment, whether explicitly or implicitly. Families are hidden victims of devastating diseases such as Alzheimer's disease (Zarit, Orr, & Zarit, 1985) and are the primary caregiving service providers of older adults (see Chapter 4, this volume). Yet, families are so much more than caregivers to older adults. They are the primary social network for older persons, accounting for nearly all of the confidants reported by older adults (see Chapter 1, this volume). Families receive both emotional and instrumental support from older adults who have provided similar assistance throughout the entire lifespan of their offspring. Families give back more than they receive only when parents reach very late life. In short, families of older adults are linked in complex, reciprocally beneficial, and challenging relationships that are powerful and meaningful.

This book is included in Wiley's Clinical Geropsychology series precisely because families are so critical to the well-being of older adults. The book series parallels and grows out of an annual Clinical Geropsychology conference held in Colorado Springs each summer (www.uccs.edu/geropsy). The conference provides advanced training to experienced mental health providers seeking postlicensure learning opportunities related to geriatric mental health. About midconference, the presenters built on the conference curriculum to create the content of the book you hold in your hands. The annual "author dinner" has become a highlight of the conference because it offers experts in the field the opportunity to build a book that can guide clinicians who are relatively new to geriatric work. Essentially, the entire set of presenters engages in the same task that the cochairs faced in structuring the conference: how to focus what is known in a very large field into the background knowledge underlying clinical skills.

Stephens and Franks describe families' process of providing care to persons with chronic illness in Chapter 4; and Liu and Gallagher-Thompson review the effects of caring for persons with dementia on their family members in Chapter 5. Each chapter summarizes a vast and confusing literature, providing structure that offers clinicians a framework for engaging families effectively in their practice.

The second section of the book addresses clinical services for families engaged in care of an older person. J. Zarit provides a rich clinical introduction to assessment and intervention with caregiving families encountered in clinical practice in Chapter 6. S. Zarit reviews the empirical research literature, drawing conclusions about how clinicians might use that literature to guide their work in Chapter 7. Qualls and Noecker describe a family therapy intervention designed specifically for caregiving families in Chapter 8. Finally, Norris addresses the complex issues that arise in working with family caregivers within long-term care residences in Chapter 9. These chapters are rich with clinical illustrations, guidance, tips for practice, and encouragement to persevere in the face of significant clinical complexity.

The next section of the book provides the background in social services and policy that clinicians need to know in order to practice effectively with older adults and their families, who almost inevitably will need more than just mental health resources. Among the more vexing tasks of expanding practice to work with any new population is figuring out the "lay of the land" of services that various clients will need. The topography of geriatric social services is shaped by policy and regulation at the federal, state, and local levels. Elmore and Tally provide a fascinating overview of federal policy issues that influence family care for older adults and clinicians working with caregiving families in Chapter 10. Auxier provides a practical guide to the diverse array of services available within most communities in Chapter 11. Giunta and Scharlach address variations and trends across states in the funding and structuring of social services in Chapter 12. The complex interplay among federal and state regulations ultimately shape the richness and format of local services and thus are key components of the knowledge base needed by geriatric mental health providers.

The final section of the book represents an emerging area of knowledge for mental health providers—the use of technology to improve quality of care and quality of life. Two chapters explore innovative approaches for addressing key challenges in family caregiving that have been developed by psychologists working across the boundaries of basic science and business solutions. In Chapter 13, Williams and Lewis describe a technological approach to helping elders participate in the electroniccommunication network used by family members without requiring the elder to learn to use a computer or even a cell phone. The simple fax-type machine allows elders to submit handwritten materials, photographs, or other family artifacts that are scanned and sent to family members' e-technology of choice. Williams and Lewis have developed rich behind-the-scenes support systems to facilitate communication, if desired by users. These are but two of a myriad of technological innovations available to promote independence among family members and elders, support care demands, and foster well-being during the elder-care phase of family life. Other solutions are highlighted by organizations such as the Center for Aging Services Technologies that attempt to make technology more accessible to providers who can pass them along to families.

The first challenge addressed in Chapter 14 is managing multiple care providers, keeping good records, and advocating for coordinated care, which are some of the more complex challenges faced by family caregivers. Electronic health record systems are a hot area of innovation intended to support providers in providing higher quality of care, yet patients and families often are kept outside the official record-keeping system. In Chapter 14, Blechman provides an excellent orientation to the different types of electronic records, their strengths and weaknesses for older adults and their caregiving families, along with an introduction to a new technical solution to these challenges. She introduces characteristics of the next generation of electronic records by demonstrating how her person-centric personal health record extends beyond archiving to support coordination of care among diverse and dispersed health, social service, and residential providers. The second challenge is keeping older family members well-integrated into informal family communication

channels that are increasingly occurring through technologies not yet embraced by most elders.

Finally, S. Zarit addresses the future of family caregiving in the Epilogue.

We hope you find this book challenges some of your assumptions, opens doors to new ways of practicing, and provides useful information that will influence your clinical practice. Regardless of the setting in which you provide services, or the services you provide to older adults, we hope this book helps you always *think family* when working with a client or patient in clinical practice.

REFERENCES

- Qualls, S. H., & Knight, B. G. (2006). *Psychotherapy for depression in older adults*. New York: Wiley.
- Qualls, S. H., & Smyer, M. A. (2007). Changes in decision-making capacity in older adults: Assessment and intervention. Hoboken, NJ: Wiley.
- Zarit, S. H., Orr, N. K., & Zarit, J. M. (1985). The hidden victims of Alzheimer's disease: Families under stress. New York: New York University Press.

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CHAPTER

1

Who Are the Aging Families?

ROSEMARY BLIESZNER

Adults typically grow old within multigenerational families. Ties with relatives are mostly positive experiences that supply companionship, provide numerous forms of support, and lend meaning to life. Of course, close relationships can include conflict and distress, as well. This chapter is introductory to the rest of the volume on interventions aimed at problematic aspects of late-life family ties. It sets the stage for the other discussions by focusing on the diversity of older adults' family structures and interactions. First is a detailed look at the definition of family for elderly persons, including illustrations of a range of family structures. Next is information about different types of old-age family ties. The final section addresses numerous personal, sociocultural, and historical influences on the nature of family interactions in the later years of life.

DEFINING OLDER ADULTS' FAMILY

Everyone has an intuitive idea of what the term *family* means; but when people articulate their views, many different perspectives become apparent. For example, individuals differ on how broad and permeable they consider the boundaries of family to be, with some viewing family as a fairly small and fixed group and others having a more encompassing

and even shifting perspective on who is included. Understanding what people mean by *family* is crucial for psychologists because the definition influences who is important to patients, who is involved with them as they seek help, and who professionals consider when developing treatment and intervention plans.

Traditionally, anthropologists and sociologists used the term *family* to denote the nuclear family unit, composed of married partners and their children and situated within the larger kinship network (i.e., the group of all other relatives) (Adams, 1968). Another term for nuclear family is *family of procreation*, used to distinguish the married partners in each new nuclear family from their *family of origin*, comprising their parents and siblings. One problem with this traditional conception of family and its application in social science research and professional practice is that it marginalizes old people. That is, adult children belong to their parents' family of procreation, but their parents belong to the adult children's extended kin system, not to their family. This way of thinking about family leads some researchers and professionals to forget that old people both have relatives and are other peoples' relatives!

Another problem is that the traditional definition tends to pathologize family structures in African American, Native American, and other minority families that differ in composition from the mainstream patterns (Dilworth-Anderson, Burton, & Johnson, 1993). The chosen families of gay and lesbian persons who cannot legally marry are overlooked in the traditional definition (Savin-Williams & Esterberg, 2000), as are those of single adults (Amato, 2000; DePaulo, 2006). Families belonging to the minority by virtue of their racial ethnic group, class, single status, or sexual orientation often have open and fluid boundaries, with friends and neighbors (*fictive kin*), distant relatives, and older family members playing roles they might not play in traditional nuclear families (e.g., assuming parenting or caregiving responsibilities).

The U.S. Census Bureau perpetuates a narrow conception of family ("a group of two or more people who reside together and who are related by birth, marriage, or adoption"), which implicitly omits elders who reside in a different *household* ("all the people who occupy a housing unit as their usual place of residence") from that of their children, grandchildren, or

siblings (U.S. Census Bureau, 2006). Although the Census definitions of family and household serve demographic functions, they are not very useful for capturing the essence of family that is most meaningful to people on a day-to-day basis: the functional and emotional aspects of relationships. Not only do the functional and emotional aspects of family ties often lend more meaning in everyday life than the formal structural dimensions do, they are also the chief reasons for individuals and families to seek assistance from psychologists. Even so, family interactions and the feelings family members hold for one another are connected to the different kinds of family structures, not dissociated from them. Thus, the purpose of this chapter is to provide an overview of important structural features of contemporary families in which older adults participate. Chapter 2 addresses specific family functions in greater detail.

We need to define family in such a way as to recognize old members as active participants. What is an alternative to the traditional definition of family as limited to the nuclear unit? Developing a definition that encompasses the experiences of older adults requires attending not only to the relatives with whom they interact regularly regardless of household status, but also to those who have psychological importance, even though they may be estranged or no longer living, and to fictive or chosen kin. With these considerations in mind, Victoria Bedford and I created the following definition of family: "A family is a set of relationships determined by biology, adoption, marriage, and . . . social designation, and existing even in the absence of contact or affective involvement, and in come cases, even after the death of certain members" (Bedford & Blieszner, 2000, p. 160). Our intention was to capture the experiences of many types of families and many personal perspectives, including both latent and potential family or family-like relationships. The implication of this definition is that it becomes crucial to ask individuals whom they consider to be part of their family, rather than assuming who belongs (which assumption would likely be based on the traditional nuclear family definition).

The necessity and importance of taking a broad perspective on family is illustrated by research that colleagues and I completed with older adults living independently in the community. We were curious about older adults' perspectives on contemporary family issues. We also wanted

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to learn about similarities or differences over generations in patterns of family life reflecting a continuum from traditional to nontraditional orientations. We coded as traditional or conventional the ideal nuclear family structure with its sequence of family events encompassing one heterosexual marriage, followed by birth of children, and enduring until the death of one spouse. Although this family type is often idealized by lay people, politicians, and professionals, it represents only 6% of the U.S. population (Jackson, Brown, Antonucci, & Daatland, 2005). In contrast, we coded any other pattern of family life as nontraditional or postmodern. Examples include families experiencing divorce, remarriage, gay or lesbian relationships, pregnancy before or outside of marriage, nonmarital cohabitation, singlehood, and the like (Allen, Blieszner, Roberto, Farnsworth, & Wilcox, 1999). We conducted detailed, in-depth interviews with 45 older women and men. We applied a comprehensive open-coding data-analysis process to transcripts of the interviews and used extensive verification procedures to identify themes related to family patterns.

We were not surprised to find that whereas 60% of the older adults had lived according to a conventional family model themselves, only 22% of their offspring had done so. Specifically, 15 female and 6 male elderly respondents reported the traditional pattern in their own lives but structural diversity in the families of their adult children. However, the other 24 cases reflected less typical patterns of family life. For 10 females and 4 males, both they and their adult children had nontraditional family structures, depicting the greatest complexity and variety of families in the sample. These families included as many chosen kin ties as legal and biological family ties, they portrayed egalitarian relationships, and they reflected adaptation to events and situations such as divorce, mental illness, incarceration, and death. For example, one man began rearing two young sisters-in-law right after he got married because his new wife's (and her sisters') mother died at that time. He considered those girls his daughters. Other elders and their offspring reared stepchildren or stepgrandchildren who were not biological kin, reared grandchildren after they thought their active parenting days were finished, or had friends playing more significant roles in their lives than their biological relatives. Atypically, another five females and one male reported that

both they and their offspring had followed the conventional model of family life. Finally, most unusual of all were the four females who had experienced some type of structural diversity in their own lives but had children whose lives were conventional in that none had divorced and all were rearing their own children with their original spouses.

Contrary to ageist stereotypes, we found that the older adult participants mostly were accepting of nontraditional family patterns in their offspring's lives. Those who expressed intolerance of a certain lifestyle (e.g., biracial marriage, gay or lesbian partnership) actually had not experienced it within their own families. Moreover, some of the participants had themselves been living nontraditional lifestyles, demonstrating family structure heterogeneity in the older adult population. Thus, our findings show that older adults are not necessarily conservative or "set in their ways" and do not necessarily oppose social change. Based on their experiences, many clearly did not believe the traditional nuclear family is the only successful type of family life.

Discovering a wide range of family patterns across the generations in a sample drawn from small cities, towns, and rural areas in southwest Virginia suggests the likelihood of uncovering much diversity in the families of older adults from other locations, if researchers were only to ask the right questions. In fact, once a discussion starts about family (broadly defined), family history, and life events, elders often reveal very interesting situations and experiences that may not be apparent at first glance.

The information in this section provides a rationale for using a broad and inclusive definition of family. Research findings from a study of older adults revealed their acceptance of diverse family structures. The following section highlights typical family ties comprising older adults' family structures.

TYPES OF FAMILY TIES IN LATE LIFE

Depending on longevity of the oldest family members and spacing of successive generations, it is possible for contemporary families to contain four or even five generations for the first time in history. Thus, some older adults will still have surviving parents as the oldest generation

in the family. Looking within their own generation, they are likely to have a spouse or romantic partner as well as siblings in their family. Succeeding generations probably include children, grandchildren, and possibly great-grandchildren.

Older adults with living parents assume regular responsibility for helping them to the extent they can, given their own functional health, geographic location, and financial circumstances. If they live close enough, they are likely to check on their older parents daily, prepare meals, provide shopping and transportation assistance, and complete household chores for them (Blieszner, Roberto, & Singh, 2002).

Although the majority of older men in the United States are married (72%), the proportion is smaller for older women (42%), who are more likely to be widowed (43% of older women vs. 14% of older men). Thus, over half (55%) of older adults live with a spouse, but nearly a third (30%) live alone due to widowhood, separation, or divorce (U.S. Census Bureau, 2007). Spouses and partners provide emotional support, companionship, and direct care to one another, and they help foster better physical and psychological health in each other (Connidis, 2001).

Sibling ties are a unique dimension of late-life family structure because siblings share potentially the longest-enduring close relationship of all (see Bedford, 1995). Studies using the National Survey of Families and Households show that adults tend to have at least monthly contact with their siblings for 60 or more years of adulthood and usually consider siblings as potential sources of support even if they do not actually help each other very often, particularly in advanced old age. Sister-sister relationships are strongest, and having living parents increases contact, affection, and exchanges of support among siblings (White, 2001; White & Reidmann, 1992).

Eighty percent of persons aged 65 years or more are parents (Connidis, 2001). Relationships with their adult children usually involve reciprocal exchanges of social and emotional support, shared leisure activities and companionship, and assistance with household chores throughout the adult years. Parents are more likely to provide financial assistance to their children than the reverse, however. As parents' functional health diminishes, they may receive more instrumental support and assistance