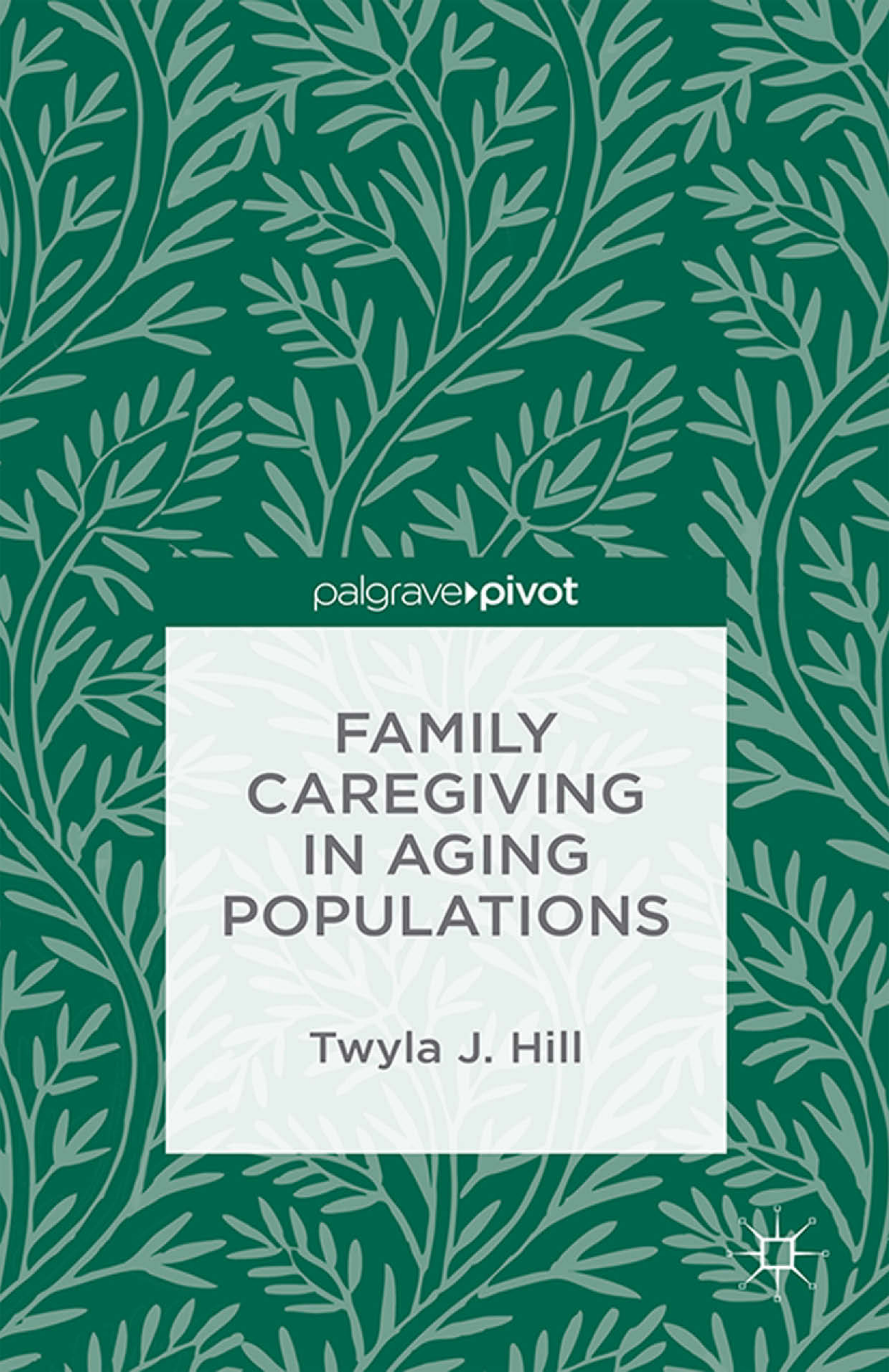

palgrave▸pivot

FAMILY CAREGIVING IN AGING POPULATIONS

Twyla J. Hill

Family Caregiving in Aging Populations

DOI: 10.1057/9781137511560.0001

Other Palgrave Pivot titles

AKM Ahsan Ullah, Mallik Akram Hossain and Kazi Maruful Islam: **Migration and Worker Fatalities Abroad**

Debra Reddin van Tuyll, Nancy McKenzie Dupont and Joseph R. Hayden: **Journalism in the Fallen Confederacy**

Michael Gardiner: **Time, Action and the Scottish Independence Referendum**

Tom Bristow: **The Anthropocene Lyric: An Affective Geography of Poetry, Person, Place**

Shepard Masocha: **Asylum Seekers, Social Work and Racism**

Michael Huxley: **The Dancer's World, 1920–1945: Modern Dancers and Their Practices Reconsidered**

Michael Longo and Philomena Murray: **Europe's Legitimacy Crisis: From Causes to Solutions**

Mark Lauchs, Andy Bain and Peter Bell: **Outlaw Motorcycle Gangs: A Theoretical Perspective**

Majid Yar: **Crime and the Imaginary of Disaster: Post-Apocalyptic Fictions and the Crisis of Social Order**

Sharon Hayes and Samantha Jeffries: **Romantic Terrorism: An Auto-Ethnography of Domestic Violence, Victimization and Survival**

Gideon Maas and Paul Jones: **Systemic Entrepreneurship: Contemporary Issues and Case Studies**

Surja Datta and Neil Oschlag-Michael: **Understanding and Managing IT Outsourcing: A Partnership Approach**

Keiichi Kubota and Hitoshi Takehara: **Reform and Price Discovery at the Tokyo Stock Exchange: From 1990 to 2012**

Emanuele Rossi and Rok Stepic: **Infrastructure Project Finance and Project Bonds in Europe**

Annalisa Furia: **The Foreign Aid Regime: Gift-Giving, States and Global Dis/Order**

C. J. T. Talar and Lawrence F. Barmann (editors): **Roman Catholic Modernists Confront the Great War**

Bernard Kelly: **Military Internees, Prisoners of War and the Irish State during the Second World War**

James Raven: **Lost Mansions: Essays on the Destruction of the Country House**

Luigino Bruni: **A Lexicon of Social Well-Being**

Michael Byron: **Submission and Subjection in Leviathan: Good Subjects in the Hobbesian Commonwealth**

DOI: 10.1057/9781137511560.0001

palgrave▸pivot

Family Caregiving in Aging Populations

Twyla J. Hill

Professor of Sociology Wichita State University

palgrave
macmillan

DOI: 10.1057/9781137511560.0001

FAMILY CAREGIVING IN AGING POPULATIONS

Softcover reprint of the hardcover 1st edition 2015 978-1-137-52067-8

First published in 2015 by
PALGRAVE MACMILLAN®
in the United States—a division of St. Martin's Press LLC,
175 Fifth Avenue, New York, NY 10010.

Where this book is distributed in the UK, Europe and the rest of the world, this is by Palgrave Macmillan, a division of Macmillan Publishers Limited, registered in England, company number 785998, of Houndmills, Basingstoke, Hampshire RG21 6XS.

Palgrave Macmillan is the global academic imprint of the above companies and has companies and representatives throughout the world.

Palgrave® and Macmillan® are registered trademarks in the United States, the United Kingdom, Europe and other countries.

ISBN: 978-1-137-51156-0 PDF
ISBN: 978-1-349-50656-9

Library of Congress Cataloging-in-Publication Data is available from the Library of Congress.

A catalogue record of the book is available from the British Library.

First edition: 2015

www.palgrave.com/pivot

DOI: 10.1057/9781137511560

To my parents, Chuck and Shirley Hill, and my sisters, Marianne and Kathy. Thank you for listening and for all your support.

DOI: 10.1057/9781137511560.0001

Contents

DOI: 10.1057/9781137511560.0001

List of Illustrations

Figures

Tables

DOI: 10.1057/9781137511560.0002

Preface

Americans are living longer than in the past and the percentage of the population that is 65 years old and older is rapidly increasing. The aging of the US pokpulation will have major impacts on family life in the twenty-first century. Older people are growing in number and also as a percentage of the American population. Since health problems tend to increase in later life, the rising proportion of the elderly has led to concerns about their impact on the health care system as a whole as well as on the costs associated with Medicare and Medicaid. Most of the assistance needed by older persons actually is provided outside of the formal health care network; however, over 75% of all help to the elderly is given by family and friends (Levine, Halper, Peist, and Gould 2010). In 2009, unpaid caregivers provided an estimated $450 billion worth of care[1] (Feinberg, Reinhard, Houser, and Choula 2011). This number will continue to increase, as both needing care and providing care became more common stages of the life course in the twentieth century (Dwyer and Coward 1992; also see Silverstein and Giarrusso 2010). Current initiatives to decrease the cost of Medicare and other health care programs should increase demands on unpaid caregivers. Therefore, family members will be increasingly likely to provide health care for the disabled or frail older adults in this century (Himes 2001). The provision of this elder care has important implications for public policy, families, and individual lives, all of which is described in this book on family caregiving in aging populations.

DOI: 10.1057/9781137511560.0003

This book focuses on the care that older persons provide to individuals their age or older. It does not cover the help that people give to younger generations, such as grandparents raising grandchildren or elderly parents taking care of a developmentally disabled adult child. Those types of care are important, but this book is about the assistance given to older persons who have health problems. I am particularly interested in those Americans 50 years and older who provide care to relatives who are 65 years and older. Research on family caregiving generally specifies the age of the care recipient, not the age of the person who provides the care, however. Also, scholars have tended to focus on the need for the care of people 65 years and over (Silverstein and Giarrusso 2010) and not on the amount of care they provide. Older adults are often caregivers. Close to half (almost 45%) of primary caregivers to other elders are 65 years and older (Wolff and Kasper 2006)—seniors assisting other seniors. While many of these care providers are spouses, more are adult children (Wolff and Kasper 2006).

The research on adult children caregivers has tended to focus on sandwich generation women—those who are middle aged (approximately 35–55 years old) with responsibilities for caring for both young children and elderly parents (Himes, Jordan, and Farkas 1996). Less than a sixth of caregivers to the elderly have children 15 years old or younger, however (Wolff and Kasper 2006). Most people who need care are 85 years old or above (National Center for Health Statistics 2007), and people in that age group generally have children who are 50 years and older. Therefore, those people who are most likely to need care are not likely to have caregivers who fit the sandwich generation definition. While the issues of the sandwich generation are important, people at a later stage in the life course are the greater number of caregivers. Their concerns are different, such as paying for children's college expenses, enjoying a newly empty nest, or planning for their own retirement. This book focuses on people who are 50 years old and over as they are the ones most likely to provide care to older family members.

Defining caregiving

To discuss family caregiving, some explanation of the terminology in the field is necessary. Definitions of caregiving vary widely (ILC-SCHSE Taskforce 2006). Researchers often have defined caregiving by the

DOI: 10.1057/9781137511560.0003

types of tasks that are needed or performed, such as assistance with medical care or with day-to-day activities. Many studies focus on assistance with particular tasks associated with the activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs). ADLs are acts such as being able to eat, bathe, or use the toilet on one's own. IADLs are abilities such as managing money, preparing a meal, or doing laundry.

Men and women often distinguish tasks differently, however. Husbands may call cooking and laundry caregiving, for example, if they became responsible for these tasks only after their spouse had become disabled, while wives rarely call those tasks caregiving (Dwyer and Seccombe 1991; also see Calasanti and Bowen 2006), which makes it difficult to compare men's and women's caregiving based on their own descriptions. Overall, though, studies have found that men and women tend to do different things, and spouses and children often perform different caregiving tasks. Therefore, the definition of caregiving needs to include a variety of jobs and recognize differences by gender and relationship (Calasanti and Bowen 2006; Russell 2007).

In addition, monetary assistance sometimes is defined as caregiving (Chappell 1990) although some researchers have defined it as support for caregiving (Cancian and Oliker 2000). Some researchers also have included talking about health and family issues as caregiving (Chappell 1990). Caregiving therefore has been defined in a variety of ways, sometimes quite narrowly and other times very broadly (ILC-SCHSE Taskforce 2006). Therefore, for this book I use an expansive definition of family caregiving, which includes physical care such as nursing and other hands-on care, direct services such as housework, coordination of care services, financial support, and emotional support such as telephone calls and discussion of issues.

Limitations of current research

What is known about racial and ethnic differences[2] in caregiving has been affected by the methods used in prior research. Hogan and Eggebeen (1995) argue that family scholars (and others) often assume that members of racial and ethnic minority groups have more access than Whites to familial care provision, but few large-scale empirical studies that analyze caregiving patterns by racial/ethnic group membership have been done (White-Means and Rubin 2008). Large random, nationally representative datasets generally have small numbers of minority group respondents, which has prevented analyses that would allow direct comparisons. Smaller studies usually focus on members of only one race or ethnicity. Comparisons therefore are difficult to make, especially for groups other than Black or White. In addition, diversity within racial or ethnic groups often is hidden; for example, Cuban Americans, Mexican Americans, and Puerto Ricans usually are categorized together as Latino/as, even though these groups have varied immigration histories, socioeconomic statuses, and cultural backgrounds. The different Asian American groups also generally are subsumed into one category. Dilworth-Anderson, Williams, and Gibson (2002) point out that White ethnic groups have distinct cultural differences that tend to be ignored as well. Whenever possible, I include what is known about particular groups, but most research on elder care has been done primarily with White respondents (Pinquart and Sörensen 2005).

Another issue is that most research on caregiving has focused on spouses and adult children as caregivers, assuming a traditional nuclear family structure (Cohen and Murray 2006). For example, few studies of caregiving in later life include gays and lesbians who are providing care to their partners. In addition, not all older people have had the same opportunities for marriage. Marriage and fertility rates tend to rise during good economic times, so some age groups are less likely to have married or to have children in later life. Also, the mere existence of these kin does not mean they are guaranteed to provide care (Barrett and Lynch 1999; Hogan and Eggebeen 1995). Changes in family structure during the past century have led to concerns about whether or not needs for care will be met during this century (Kinsella 1996; Ryan, Smith, Antonucci, and Jackson 2012). These worries are appropriate since about a third of the elderly people who need help do not receive any assistance (Wolff and Kasper 2006:346). An emphasis on traditional nuclear family members as caregivers overlooks individuals without those kinds of kin and ignores the fact that some people are not getting help. Other types of people who provide assistance, such as fictive kin or friends, also are left out when researchers focus on spousal or children caregivers. However, adult children and spouses are the most common sources of assistance for elderly people who need care.

Organization of the book

I have four goals for this book. First, by bringing together the prior research on caregiving I plan to provide a useful resource for scholars, students, service providers, and others. Second, by pointing out the increasing odds of any individual providing care to an elderly relative in the future, I want to raise our awareness of the immediate relevance of this topic. Including the variety of kin who give assistance (such as grandchildren and siblings) and the diverse ways in which care is provided (such as in caregiving teams) emphasizes that this issue touches everyone. The inclusion of employment conflicts and other labor force issues underscores the broad relationship of caregiving with societal organizations generally. Third, by highlighting how much caregiving people do in later life and the importance of that work to society, I hope to increase our overall recognition and support of their efforts. Fourth, I want to help ease the burdens family caregivers face by providing suggestions for the service providers who work with them and the policymakers who create and enact regulations that affect the provision of care to relatives.

To reach those goals, this book describes what is known about family caregiving in later life and what has not been studied. The first chapter begins with a brief discussion of the historical and current contexts of caregiving in later life in the United States. A short description of the types of health problems typical in the elderly and affecting their need for care is included. This section also describes the occurrence of needing or giving care currently and future predictions of its prevalence. The factors that affect provision of care and the consequences of furnishing that assistance are also briefly reviewed.

The second chapter covers caregiving by spouses and other intimate partners. Husbands and wives tend to provide different types of care. Caregiving has different effects, costs, consequences, and rewards for husbands and wives. Also, they receive different amounts and types of support and assistance from others. In addition, the little research on caregiving by older same sex and cohabiting partners is surveyed.

Chapter 3 discusses caregiving by adult children to older parents. Sons and daughters also generally provide different types and amounts of care, as well as receiving different amounts and types of support from others. Variations exist by race, ethnicity, socioeconomic status, and a number of other characteristics as well. More factors affect the provision of care by children than by spouses. Consequences and rewards for children are also different from the ones for spouses.

Chapter 4 summarizes what is known about caregiving by siblings, grandchildren, and other relatives (including fictive kin). It also discusses research on secondary caregivers and team caregiving. Studies of kin care within minority groups are covered in this chapter as well.

The last chapter concludes the book with a discussion of current policies regarding caregiving and policy implications. Although little federal and state legislation directly addresses familial provision of care, several policies affect people's ability and willingness to provide assistance. Programs such as Medicare and Medicaid which are aimed at care recipients indirectly impact the family members who take care of them. Social Security and pension regulations have consequences for people who leave the paid labor force to provide unpaid care work. I cover a broad variety of programs in Chapter 5.

Notes

1 This number is estimated using 42.1 million people aged 18 years old or older giving on average 18.4 hours of care per week to care recipients aged 18 years old or older, valued at $11.16 per hour.

2 Usage of terminology also differs in discussions of race/ethnicity. Terms have varied political meanings; for example, the terms Black, African American, and Black American mean distinct things to different people. Individuals and groups prefer particular terms for a variety of reasons. Knowing I cannot please everyone, I have tried to be consistent in my usage. Any offense is unintentional.

Acknowledgments

I would like to thank Susan Ferguson and Carolyn Shaw, who read the manuscript in various versions and provided many helpful comments. Also, thank you to Jennifer Wolff, Judith Kasper, and Christine Himes, who graciously gave me permission to reprint previously published tables.

DOI: 10.1057/9781137511560.0004

1

Social Context of Family Caregiving

Abstract: *The historical and current contexts of caregiving in later life in the United States are briefly discussed. A short description of the types of health problems typical in the elderly and affecting their need for care is included. This section also describes the occurrence of needing or giving care currently and future predictions of its prevalence. The factors that affect provision of care and the consequences of furnishing that assistance are also briefly reviewed.*

Keywords: aging; caregiving; disabilities; elderly; family

Hill, Twyla J. *Family Caregiving in Aging Populations*.
New York: Palgrave Macmillan, 2015.
DOI: 10.1057/9781137511560.0005.

Although family members have always had the primary responsibility for providing assistance to older family members, caregiving in later life did not become a widespread phenomenon in the United States until a few generations ago.[1] Until the middle of the twentieth century, a very small percentage of Americans lived 60 years or longer, and those that did tended to be healthy and vigorous until shortly before they died (Dwyer and Coward 1992). For example, in 1900, life expectancy at birth was 48 years for Whites and 33 years for Blacks; by 1950, it was 69 years for Whites and 61 years for Blacks. In 1950, however, those individuals who were already 65 years old could expect to live another 14 years (National Center for Health Statistics 2007). Therefore, few people needed care in later life before the latter part of the twentieth century.

In the past, if older people lived with adult children, they usually did so as household heads with control over other family members, not as dependents (Dwyer and Coward 1992; Hareven 1996). Parents moved in with children only in circumstances of dire need (Hareven 1996). People who did need care generally received it for short periods of time; individuals did not live past events like heart attacks or through lengthy periods of chronic illnesses (Dwyer 1996). Care was typically provided by spouses or children (Hareven 2001), just as it is now, but caring for the ill elderly was not a common or ongoing experience (Dwyer and Coward 1992). Higher fertility rates meant a pool of possible child caregivers was available, but generally only one child (usually a daughter) provided care (Hareven 2001), which meant that each sibling had a smaller chance of being responsible for care.

Also, life expectancy did not differ between men and women in the United States until a few generations ago. Only in the middle of the twentieth century did women's life expectancy begin to exceed men's (National Center for Health Statistics 2007). Prior to the 1950s, therefore, the proportions of older men and women were about equal. Adult daughters generally provided care (Hareven 2001) but it was provided to fathers as often as to mothers (Dwyer and Coward 1992). Now women can expect to live quite a bit longer than men. For White women, life expectancy at birth is 81 years, for White men 76 years, for Black men 71 years, and for Black women 78 years (National Center for Health Statistics 2014). Since women usually outlive men and have higher rates

---

[1] The following historical information is mostly from the White experience. We do not have much information for people of color, and what we do have is primarily about Blacks.

of health problems than men, both care recipients and care providers are often female. The gendered nature of caregiving means that older married women can expect to provide care for their spouses, and then receive care from their middle-aged or older daughters. It also means that these daughters can expect to care for their parents, perhaps their parents-in-law, and then their husbands.

Current context of family caregiving

Although Americans tend to think that we as a society are deserting our elderly in institutions, evidence does not support this stereotype (Brewer 2002). Rates of nursing home utilization have been decreasing since the 1970s for Whites but slightly rising for Blacks (National Center for Health Statistics 2007). The increase in nursing home residence for Blacks probably has more to do with the increasing ability to afford paid care rather than with being abandoned by family members. Also, relatives may still help with care after institutionalization (Gaugler, Anderson, and Holmes 2005), showing that using paid care and abandonment are not synonymous. Being in a nursing home is less common for members of minority groups overall than for Whites, however (Dilworth-Anderson, Williams, and Gibson 2002). Only 4% of Americans 65 and older are in long-term care facilities; these percentages are age-related, with only 1% of those 65–74 years old and 15% of those 85 years and older in a nursing home (Federal Interagency Forum on Aging-Related Statistics 2010:58). Therefore, most elders are still living in the community, even those seniors who need assistance.

TABLE 1.1 *Persons 65 years and older—living arrangements, 2008*

	Percent
In family households	65.1
As householder	32.3
With spouse as householder	23.1
With parent as householder	5.7
With other relative as householder	3.7
In nonfamily households	
Alone	27.4
With others	2.6
In group quarters	4.9

Source: U.S. Census Bureau 2011:Table 35.

DOI: 10.1057/9781137511560.0005

Most older adults are living with someone else. Almost two-thirds of people 65 years old and older are living with spouses or other family members, while a little over a quarter are living alone (U.S. Census Bureau 2011:Table 35). Over 5% of people 65 years old and older are living with a parent (U.S. Census Bureau 2011:Table 35). Given the age that parent must be, it seems likely that the elderly child is providing care for his or her parent. People who live in the same house are convenient potential sources of assistance.

In sum, the majority of help and health care for the elderly is provided by family members. Roughly two-thirds of those older people still living in the community receive only unpaid assistance from family members or friends, also known as informal care. Paid care, often called formal care or formal services, is almost always a supplement to informal care (He, Sengupta, Velkoff, and DeBarros 2005). The use of paid care is associated with income; those with more resources are more likely to use formal services (He et al. 2005).

Whites also are more likely to use formal care than people of color (He et al. 2005). Older people of color are more likely than Whites to experience disability, but are not more likely to receive help from children and are less likely to live in nursing homes (Dilworth-Anderson et al. 2002; Dwyer 1996). Some research finds that Native Americans and Blacks are particularly unlikely to use paid help (Dilworth-Anderson et al. 2002). Other research finds that Latino/as and Asian Americans may be more likely than Whites and Blacks to have informal rather than paid care (see Uhlenberg and Cheuk 2008:20), so it is unclear which members of minority groups are most likely to rely on family members. Older gays, lesbians, and bisexuals also tend to be in worse physical and mental health than older heterosexuals (Fredriksen-Goldsen, Kim, Elmlet, Muraco, Erosheva, Hoy-Ellis, Goldsen, and Petry 2011). They are less likely to be partnered, and may have less access to other types of familial support as well (Fredriksen-Goldsen et al. 2011), leading to concerns about how much or if informal caregiving will be available to people who are members of sexual minority groups. However, many bisexuals, gays, and lesbians have supportive chosen family and friend networks to which they can look for care (Muraco and Fredriksen-Goldsen 2011). In general, as numbers of older people increase, we can expect that family members will continue to provide most assistance. If health care costs continue to rise, we should see even more of the healthcare and caregiving burden falling on family members.

Family care is usually provided by one person, called the primary caregiver, who helps with ADLs and/or IADLs, and may manage services provided by paid help (Dwyer 1996). Sometimes other family members also provide aid to the care recipient, and these people usually are called secondary caregivers. The primary caregiver usually coordinates all assistance provided, either formal or informal (Dwyer 1996). He or she has overall responsibility for the care, even though other people may provide as much assistance (Dilworth-Anderson, Williams, and Cooper, 1999). Other models of caregiving are possible, such as a partnership style where two people contribute equally (Brewer 2002). Research has been focused on primary caregivers, however; less is known about additional people who help and other models of providing care (Brewer 2002; Dilworth-Anderson et al. 1999).

Perhaps few studies have looked at secondary and other caregivers because primary caregivers often do not have help. Less than half (47%) of primary caregivers for older adults say that they receive assistance in caregiving (Wolff and Kasper 2006:352; also see Johnson and Wiener 2006). Spouses particularly provide care alone; over two-thirds of spousal caregivers do not receive any assistance (Wolff and Kasper 2006). The percentage of sole caregivers increased from 1989 to 1999 (Wolff and Kasper 2006), which suggests that each individual caregiver will have more responsibility in the future.

Caregiving takes time, and often it is a long-term commitment. The average amount of care an individual provides is 21 hours per week, but there is wide variation. Almost half (48%) of caregivers report providing 8 hours or less of help per week, while 17% report over 40 hours (National Alliance for Caregiving 2004:6). The majority (75%) give help every day on average (Wolff and Kasper 2006:351). Many people provide care for a long time; 46% of caregivers report having done so for over four years, while only 18% say they have provided care for less than a year (Wolff and Kasper 2006:351).

The amount of care provided probably increases over the period of time for which a care recipient needs help, and cross-sectional reports do not capture that information. In the early stages of providing assistance, a caregiver may help occasionally with transportation to the doctor's office, for example, while in the later stages he or she may be spending hours with the care recipient, doing tasks like helping with feeding or bathing. It seems likely that most caregivers transition from lighter amounts of help to heavier amounts, less responsibility to more, and shorter periods of time to longer periods (see Hogan and Hogan 2009). The average length of caregiving is over four years (National Alliance for Caregiving 2004:7), so most caregivers probably experience fairly challenging situations. Therefore, providing care is an important stage in the later years of the life course for many people. It is time-consuming, like having another job, and has consequences which are described later in this chapter.

What affects the need for care?

Usually, we think about the care that older people need rather than the care they provide. Estimates vary regarding what percentage of older adults needs assistance. Approximately 10% of older persons still living at home have disabilities that require help at levels comparable to care in institutions (Dwyer and Coward 1992), which gives us a fairly low estimate. For example, in 2002, about two million older people were severely disabled and not living in institutions (Johnson and Wiener 2006). If we define needing care as an inability to perform at least one ADL or IADL, however, a higher proportion of older persons needing care is generated. "In 2004–2005, the percentage of older adults with limitation of activity ranged from 25% of 65–74 year olds to 60% of adults 85 years old and over" (National Center for Health Statistics 2007:46). A realistic estimate of the percentage that needs care is approximately one-fifth to one-third of those 65 years and older (Dwyer and Coward 1992). In other words, between 7,560,000 and 12,474,000 older Americans needed assistance in 2008 (U.S. Census Bureau 2011). These numbers will increase in the near future. The segment that is 85 years and above is the fastest growing part of the elderly population (Himes 2001), and they "have the highest rates of disability" and need the most help (Jacobsen, Kent, Lee, and Mather 2011:3).

Life expectancy and disability rates

Two important factors affecting the number of older people who need care are life expectancy and disability rates. Increasing life expectancy leads to the growth of all age groups of older adults in the population (Himes 2001), raising the numbers of people likely to need assistance. The proportion of elderly who are members of a minority group is growing as well (Alecxih 2001; Angel and Hogan 1992). Older people who are members of racial and ethnic minority groups rose from 16% of the elder population in 2000 to 21% by 2001 and are predicted to be 28% in 2030 (Administration on Aging 2012). Since older people of color are more likely to need help than Whites, this trend also increases the number needing care. For example, Latino/as have higher life expectancies at birth than Whites (Green 2005). Blacks have lower life expectancies at birth than Whites (Green 2005) but if Blacks live to 85, they have higher life expectancies (Hummer, Benjamins, and Rogers 2004; Mouton 1997). However, the disability rates of both these minority groups are higher than for Whites (Hummer et al. 2004; Santiago and Muschkin 1996), so at older ages, both Blacks and Latino/as probably are more likely to need help. Native Americans also have higher rates of disability (Fuller-Thomson and Minkler 2005). Unfortunately, reliable information for Asian Americans is not available (National Center for Health Statistics 2007). Some studies indicate that disability rates for Asian Americans are similar to those for Whites (Hummer et al. 2004). Other studies suggest their disability rates are higher than Whites, but the evidence is not conclusive (Dilworth-Anderson et al. 2002). In addition, members of most minority groups tend to have lower socioeconomic status than Whites. Disability rates are higher for those in poverty compared to people who are above the poverty line (National Center for Health Statistics 2007), so that people with lower socioeconomic status are more likely to need assistance.

Increasing longevity is also related to a rising incidence of chronic diseases affecting the need for help with ADLs and IADLs (Coward, Horne, and Dwyer 1992). Chronic illness is often accompanied by disabilities, and 80% of older adults have at least one chronic health problem; 50% have two or more (He et al. 2005:54). The occurrence of health conditions rises steeply with advancing age. The risk of having a heart or circulatory condition, for example, is 54% higher for persons 75 or older than for those 65–74 years old (He et al. 2005:54). Arthritis, hypertension, heart disease, strokes, diabetes, cancer, osteoporosis, and sensory impairments (such as vision or hearing loss) all are common health problems for older people. Rates of particular conditions vary by sex, race/ethnicity, age, income, and education (He et al. 2005:54–57). Almost 25% of Blacks 65 years and older report needing assistance with everyday activities, compared to 21% of Latino/as and 15% of non-Hispanic Whites (He et al. 2005:61). About 40% of people 80 years and

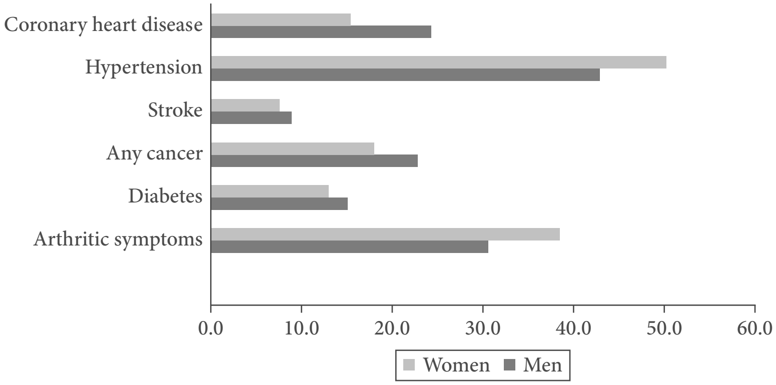

FIGURE 1.1 *Percentage of people 65 years and older with certain chronic conditions by sex, 1999–2000*

Source: He et al. 2005:56.

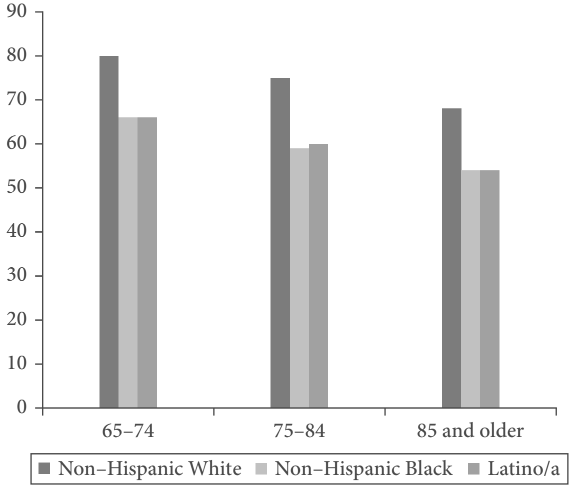

FIGURE 1.2 *Percentage of people 65 years and older reporting good to excellent health, 2006–2008*

Source: Federal Interagency Forum on Aging-Related Statistics 2010:29.

DOI: 10.1057/9781137511560.0005

over need assistance, and women are more likely than men at older ages to need help because they have higher rates of disability (He et al. 2005:60, 61). The highest rates of disability and impairment are found in the oldest-old (85 years and older) (Brault 2012). As impairment levels increase, people are more likely to receive care from family members (Coward, Cutler, and Mullens 1990). Increasing longevity therefore leads to the prediction that higher numbers of older adults will need assistance in the future.

Cognitive limitations are associated also with increasing longevity. Although most older Americans will not experience cognitive impairment, the prevalence of dementia increases with age. Up to 7% of the elderly will have dementia, with the two most common types being Alzheimer's disease and vascular dementia (Watari and Gatz 2002). Rates of Alzheimer's disease differ by sex, although women's greater longevity may be a factor in their higher rate (He et al. 2005). Men and Blacks are more likely to have vascular dementia (Watari and Gatz 2002). Some studies indicate that Japanese Americans also are more likely to have vascular dementia (Dilworth-Anderson and Gibson 1999). In addition, some evidence suggests that Native Americans are the least likely and Blacks the most likely to suffer from dementia, but in general reliable information is lacking for members of minority groups (Dilworth-Anderson and Gibson 1999; also see Manly and Mayeux 2004). Currently, over 70% of those with Alzheimer's disease are cared for at home by family and friends (He et al. 2005:57) so that family members are carrying most of the health care burden of this disease.

Effects on caregivers

While the majority of elders do not need as much care as those with cognitive problems such as Alzheimer's disease, family members still give most of the help that is received, and caregiving has been shown to have negative impacts. People who provide care tend to have worse physical and mental health than noncaregivers, for example (Johnson 2008). Negative outcomes of caregiving include depression, worsening physical health, loss of friends, family disagreements, employment conflict, and economic problems (Pearlin, Mullan, Semple, and Skaff 1990). The stress of caregiving also can lead to elder abuse (Lee and Kolomer 2007).

Research on family caregiving has tended to emphasize the burden and costs of caregiving rather than any rewards or benefits (Raschick and Ingersoll-Dayton 2004). Caregiver burden has been measured in a variety of ways (Deeken, Taylor, Mangan, Yabroff, and Ingham 2003) including distinctions between objective and subjective burden. Objective burden is the actual tasks the caregiver performs and the effects those jobs have on the finances, physical health, or social life of the caregiver. Subjective burden includes the emotional and/or psychological strain associated with the caregiving (Deeken et al. 2003:925). Perception of burden also matters; in other words, if the caregiver thinks of a job as stressful, she sees it as more of a strain than a caregiver who does not think of that task as stressful (Hooker, Monahan, Shifren, and Hutchinson 1992). The amount of burden a caregiver feels is a combination of the actual work itself, how caregiving impinges on the rest of the caregiver's life, and how the caregiver thinks about the work.

Much less research has been done in the area of rewards or benefits from caregiving (Raschick and Ingersoll-Dayton 2004). Positive outcomes of caregiving include mental health effects such as competency and feeling skilled at providing care (Pearlin et al. 1990), improvement in the relationship with the care recipient, and feelings of gratification (Raschick and Ingersoll-Dayton 2004). For example, if a husband did not previously do much cooking, but becomes responsible for it once his wife becomes ill, he may feel pride in his new skill. An adult daughter may feel closer to her parents once she starts visiting every day to help with housework. Studies of burden and/or rewards tend to use a variety of measures, so that findings are not always comparable. Perhaps the emphasis in research on the negative aspects of caregiving has obscured the benefits. However, it seems likely that the burdens do outweigh the rewards. If there are more costs than benefits to caregiving, why do people continue to take on these responsibilities?

What affects the provision of care?

Family members provide care for a number of reasons. They may help someone because of love or affection for the care recipient or a desire to reciprocate for past assistance provided by the recipient. They also can be motivated by cultural norms of obligation associated with filial or spousal responsibility. Most older couples take the marriage vows "in sickness and in health" seriously and provide help in later life without question (Harris and Bichler 1997; Mui 1995b). Young children may be taught the expectation that they will assist aging parents as part of the "family values" of their ethnic group (Hareven and Adams 1996).

Some gerontologists have applied intergenerational solidarity and exchange theories to explain why people provide care. Exchange theory argues that "interactions between individuals…reflect attempts to maximize rewards, both material and nonmaterial" (Katz, Lowenstein, Phillips, and Daatland 2005:395). Resources can include housing and money, as well as various types of assistance such as grocery shopping, child care, cooking, and nursing. Therefore, providing care can be an attempt to reciprocate or "pay back" a parent or spouse for earlier assistance. An older person could provide housing for a relative in exchange for help with housework or nursing. Also, a care recipient living in a child's home could reciprocate with money, childcare, or other types of assistance. Since exchanges between generations may never balance out equally, it may be that altruism or benevolence may be more characteristic of caregiving than reciprocity (Katz et al. 2005). Parent-child relationships are important to both generations (Umberson 1992), however, so maintaining a positive relationship through providing assistance may be a benefit in itself.

Much research has shown that adult family members exchange help and interact frequently. The intergenerational solidarity model often has been used to investigate extended family relationships (Katz et al. 2005). The model focuses on emotional closeness, similarity of opinions and values, agreement about norms (family values), geographic distance, contact (shared activities and interaction), and instrumental assistance such as gifts of money or child care (Silverstein and Bengtson 1997). However, conflict and ambiguity are normal parts of family life and recently have been included in theoretical explanations of older parent and adult child relationships (Katz et al. 2005). Ambivalence and conflict may be especially apparent during transitions, when parents and children need to renegotiate their roles and relationships. For example, when parents and children decide to coreside, be it for the support of an adult child who has lost a job or for an older parent who can no longer live alone, everyone involved has to cope with the changes living together will bring to their dealings with each other.

Of course, the individuals in an interaction or an exchange can view that interaction or exchange differently, and those perceptions affect the quality of the relationship. The older generation tends to perceive more family solidarity, while the younger generation sees more conflict. It is more important to the older parents that family relationships be positive so they are inclined to perceive them as more favorable than the younger generation does, even though consistent patterns exist of agreement on norms, frequent interaction, and emotional closeness among family members (see Bengtson and Kuypers 1971 for the seminal discussion of this "generational stake"). In other words, elderly mothers and fathers say they have better rapport with their adult children than their sons and daughters report. Adult child caregivers usually view the relationship more negatively than their parent care recipient does.

People provide care "in a cultural context in which cultural values and beliefs shape who gives care and determine whether families use formal supports and interventions" (Dilworth-Anderson and Gibson 1999:42). Overall, American culture expects that people (especially women) will take care of family members (Cancian and Oliker 2000). Latino/as and Asian Americans tend to have strong family-centered cultural beliefs; Native Americans and African Americans also often emphasize extended family networks (Dilworth-Anderson and Gibson 1999). Of course, not everyone equally shares culture; also, formal services are not equally available and/or culturally appropriate for everyone (Dilworth-Anderson et al. 2002; Li 2004). There are some patterns of which family members most often provide care, however.

For example, women are more likely to provide care than men. In 1999, over two-thirds of all primary caregivers (67%) were female (Wolff and Kasper 2006:350; also see Johnson and Wiener 2006). Although caregiving by men is becoming more common, by far the largest category of male caregivers is husbands; they are 43% of spousal caregivers (Wolff and Kasper 2006:350). Still, wives are over half of spousal caregivers and daughters are more likely than sons to help parents. Men are more likely than women to have help with providing care and to stop caregiving. Women also "spend more time providing care" than men do (Yee and Schulz 2000:160). Clearly, caregiving is gendered labor.

Availability of kin

Caregiving research generally has found that spouses are the first choice for primary caregiver and an adult child (usually a daughter) is the second choice of a care recipient (Dwyer 1996). Increasing longevity does mean more people 85 years and older will have spouses, who are the first choice for providing care. Children fill in, however, if spouses are frail and unable to provide care, which they are likely to be at that age (Montgomery 1992 as cited in Dwyer 1996). An adult child is more likely than a spouse to be the primary caregiver for a person 70 or older (Himes 2001:22). In fact, the proportion of child caregivers rose from 36% in 1989 to 41% in 1999 (Wolff and Kasper 2006:350). Therefore, the proportion of child caregivers in the future is likely to increase even though the proportion married at 85 years and older also will increase.

If an individual does not have a spouse or a child, however, that family member is not an option for caregiving. Marriage rates declined for all groups during the latter part of the twentieth century, and marriage, divorce, and fertility rates differ by racial/ethnic group (Himes 1992). These rates affect whether or not people have spouses and children available to potentially provide care. Blacks are less likely to marry than Whites, Asian Americans, or Latino/as (U.S. Census Bureau 1992; 2008). Black women are particularly unlikely to marry (Manning and Smock 2002). When Blacks do marry, they are more likely to divorce than Whites, Latino/as, or Asian Americans (U.S. Census Bureau 1992; 2008). Whites are more likely to remarry after divorce than either Latino/as or Blacks (U.S. Census Bureau 1992; 2008), so they are most likely to have a spouse in old age. Also, men are more likely to remarry than women after divorce or widowhood (Himes 1992; Kinsella 1996).

TABLE 1.2 *Marital status of people 65 years and older by sex, age, race, and Hispanic origin (in percentages), 2003*

	65–74		75–84		85 and older	
	Married	**Widowed**	**Married**	**Widowed**	**Married**	**Widowed**
Men						
Non-Hispanic White	76.4	8.3	71.3	18.1	57.8	33.6
Black	59.2	14.3	54.9	23.2	39.7	47.7
Asian American	70.2	9.6	69.7	16.6	39.2	48.8
Latino/a	72.5	7.6	65.7	17.1	49.8	33.2
Women						
Non-Hispanic White	56.6	28.8	35.3	52.3	13.1	77.8
Black	33.4	36.2	19.3	62.7	4.2	87.2
Asian American	51.8	27.1	35.1	53.7	10.7	75.5
Latino/a	48.4	25.9	31.4	53.5	17.4	74.2

Source: He et al. 2005:149, 150.

Most older men are married, compared to less than half of older women (U.S. Census Bureau 2011:Table 34), meaning that men are more likely to receive care from a spouse while women are more likely to receive care from a child or other family member. Also, older Whites are more likely to receive care from a spouse, while Blacks and Latino/as are more likely to receive care from an adult child (Himes 2001:23). Race and ethnicity therefore affect who provides care.

Smaller family sizes will contribute to increases in individual responsibility for parental caregiving. Fertility rates have decreased since the 1960s (Himes 2001), affecting sibling set size. The parents of the baby boom cohort have more children from whom to pick, which means each child is less likely to experience being a primary caregiver. The cohort just after those parents and the baby boom themselves have fewer children, however, so each child in these later cohorts will be more likely to experience providing care to an elderly parent. Fertility rates are higher for people of color than for Whites (Angel and Angel 2006), suggesting that White older adults in the future will have fewer children overall to provide care if needed. Therefore, each White child will be particularly likely to be responsible for caring for a parent.

Health status

The health of care providers is another concern, since aging is associated with health declines, and the majority of caregivers are 45 and older. In general, family caregivers are healthy. Almost two-thirds (65%) say they are in good or excellent health (Wolff and Kasper 2006:350). A third of spousal caregivers say they are in fair or poor health, however (Wolff and Kasper 2006:350), so spouses provide care even if their own health is suffering.

Regarding children, in general, people over 55 with ill parents are worse off than those with either healthy or deceased parents (Hogan, Eggebeen, and Snaith 1996). Perhaps children in poor health themselves do not provide care and another sibling steps in. Laditka and Laditka (2000) find that caregivers on average are in better health than noncaregivers, but that over a quarter of daughter and almost one-sixth of son caregivers report failing health. Therefore, at least some children already are providing care even though their own health is troubled. As average family size decreases, the ability of each child to provide care will become increasingly important.

Labor force participation

Labor force participation also affects the availability for caregiving of adult children and other family members. Responsibilities to an employer often compete with family responsibilities, particularly for women. The labor force participation rate of older women has been increasing in the past 40 years (Federal Interagency Forum on Aging-Related Statistics 2010). Older men's labor force participation decreased during the last half of the twentieth century until the 1980s (Treas 1995), stabilized, and then began to increase slightly in the 1990s (Federal Interagency Forum on Aging Related Statistics 2010). Although men over 55 years old are more likely to be in the labor force than women over 55 years old, since 1970 the percent of older women working rose while the percent of men dropped (Himes 2001). In 2003, almost half (45%) of women and over half (57%) of men between the ages of 60 and 64 were employed (He et al. 2005). This age group is likely to have parents in their eighties or older, the cohort most likely to need care. Therefore, rising labor force participation in this age group of older men and women will conflict with the availability to provide care to elderly parents.

Tensions between employment and caregiving clearly exist. Only 32% of primary caregivers for older people work (Wolff and Kasper 2006), suggesting either that people provide care because they are not in the labor force, or that they leave the labor force to provide care. Even though 85% of adult child caregivers are under 65 years old, only half work outside the home (Wolff and Kasper 2006). Also, half of employed caregivers say there are conflicts between working and caregiving (Wolff and Kasper 2006). Employers would agree; caregiving by employees is estimated to cost their employers at least $33 billion per year (Metlife Mature Market Institute 2006) through absenteeism, employee turnover, and lost productivity (Wagner 2006). These tensions increase the likelihood of leaving the labor force, which for people in their sixties or late fifties often means retirement. The age at which people leave paid employment affects income, with earlier retirement decreasing benefits (Szinovacz and Ekerdt 1996; Wakabayashi and Donato 2006). Early retirement by women and members of minority groups to provide caregiving is a cause for concern because they are particularly likely to be poor when they are elderly. As noted previously, people with lower socioeconomic status have higher rates of disability, so those individuals who retire early to provide assistance to others may be more likely to need care later themselves.

Other economic issues

Although socioeconomic status seems likely to affect the ability to provide care, little research has been done on socioeconomic differences between caregivers. As discussed earlier, care recipients with greater resources are more likely to use formal care (He et al. 2005), but only about 20% of caregivers assist someone who also receives paid help (Wolff and Kasper 2006). Wealthier caregivers are more likely to provide financial and emotional support, while caregivers from lower- and working-class families are more likely to give physical care and direct services such as cooking and cleaning (Chappell 1990). They may not have the financial resources to contribute much economic support, although many people give money as well as other forms of aid to their care recipient (National Alliance for Caregiving 2004).

In the past century, the creation of federal policies such as Social Security, Medicare, and Medicaid greatly improved the financial condition of the elderly population and reduced some dependence on family members (Dwyer and Coward 1992). Medicare and Medicaid may have decreased the need for family care provision, but the majority of help still is provided by family members and little policy exists directly addressing unpaid, informal assistance. The chief legislation in this area, the Family and Medical Leave Act, is designed for short-term caregiving, not the long-term care more often associated with aging. Although almost all Americans 65 years and older qualify for Medicare, it pays for only about half of their health care costs and primarily for doctor and hospital care (Federal Interagency Forum on Aging-Related Statistics 2010), leaving many needs unmet. Our current reliance on family members leaves providing care primarily to wives and daughters. If health care costs and the numbers of the elderly needing care increase, it seems likely that familial care provision will also rise.

Summary

The typical caregiver is female, married, between the ages of 45 and 64 years old, assists the care recipient seven days a week on average, and has been providing care for over four years (Wolff and Kasper 2006). As intergenerational solidarity theory would predict, people generally want to help their older family members and do so willingly. Society also expects family members will help out. Providing this assistance has many costs (and some rewards) for individuals. Caregivers should be supported in their efforts, as they benefit both the care recipients and society as a whole. As this chapter has explained, Americans can expect that providing care for an elderly parent while being older oneself will become even more typical in the future. About a tenth of older persons still living at home need assistance at levels like what is supplied in a nursing facility (Dwyer and Coward 1992). Their family caregivers are providing and/or supervising 24-hour care. Most people do not need that much help, however. The typical person who needs assistance is female, either married or widowed, with an average age of 80, and receives help with IADLs only (Wolff and Kasper 2006).

Not everyone who needs care gets help from family members. Wolff and Kasper (2006) estimate that about 30% of noninstitutionalized, chronically disabled older persons do not receive assistance. Perhaps these people do not have spouses, children, or other family members who can provide assistance. Research has focused on care recipients and providers, and we know little about those individuals who do not get help. In the future, increasing percentages of divorced and never married elderly are expected, leading to concerns about who will provide care for these people (Kinsella 1996). Members of the baby boom cohort will be less likely to have spouses or adult children in later life, the usual candidates for caregiving (Ryan, Smith, Antonucci, and Jackson 2012). We may see even higher proportions of the elderly in need of help but not receiving it.

The good news is that current cohorts of elderly are less disabled and in better health than earlier cohorts, and disability rates are decreasing (He et al. 2005). Hopefully, in the future, smaller percentages of older people will need care for shorter periods of time. A number of trends such as decreasing fertility rates lead to the expectation that, individually, both men and women will be more likely to provide care than in the past. By far the greatest amount of care currently is provided by female family members, however, and in the future women probably still will be more responsible for providing care than men.

2

Spousal and Intimate Partner Caregiving

Abstract: *Caregiving by spouses and other intimate partners is reviewed. Husbands and wives tend to provide different types of care. Caregiving has different effects, costs, consequences, and rewards for husbands and wives. Also, they receive different amounts and types of support and assistance from others. In addition, research on caregiving by older same sex and cohabiting partners is surveyed.*

Keywords: aging; caregiving; elderly; spouses

Hill, Twyla J. *Family Caregiving in Aging Populations.*
New York: Palgrave Macmillan, 2015.
DOI: 10.1057/9781137511560.0006.

When help is needed, spouses usually are the first choice of a care recipient for primary caregiver (Dwyer 1996). They are over a third (38%) of family caregivers for older people (Wolff and Kasper 2006). Spouses take on the primary caregiver role if they are available and capable of doing the necessary tasks, and they provide care even if the care recipient is severely impaired or if their own health is poor (Johnson and Wiener 2006; Mui 1995b; Stoller 1992). Often they accept the responsibility as a given. Most older couples take the marriage vows "in sickness and in health" seriously and provide help in later life without question (Harris and Bichler 1997; Mui 1995b). Spousal caregivers minimize difficult situations, denying problems and insisting that they can handle any circumstances (Brown and Alligood 2004). They provide more care than other family caregivers (Johnson and Wiener 2006). Husband and wife caregivers assist with a wide variety of tasks and give many hours of care, yet they generally do this work with little concern for themselves.

Why spouses and intimate partners provide care

Spouses and intimate partners provide care for the reasons given in the first chapter. They help their partner, husband, or wife because of love or affection for him or her. They may want to reciprocate for past assistance, as exchange theory would suggest. They also can be motivated by cultural norms of obligation associated with spousal responsibility. Homosexuals and heterosexuals give similar reasons for providing care, including feelings of responsibility and reciprocity (Cohen and Murray 2006; Sipes 2002). It is unknown what percentage of older people are homosexual or in same sex relationships, but it is estimated that between 2% and 10% of Americans are gay, lesbian, or bisexual (Cohen and Murray 2006; Fredriksen-Goldsen and Hoy-Ellis 2007). About 10% of same sex couples consist of partners 65 years old or older (Bennett and Gates 2004). These relationships may be more egalitarian than those of heterosexual couples, but in general, research has shown many similarities between heterosexual and homosexual relationships (DeVries 2007). For example, most coupled lesbians and gays over 50 years old say their partner would be their first choice for a caregiver (Fredriksen-Goldsen and Hoy-Ellis 2007). The partnerships of same-sex couples in marriage-like unions are as stable as those of heterosexual married couples (Rosenfeld 2014). Therefore, patterns of caregiving among homosexual partners and heterosexual spouses should be similar. We should not forget, however, that long-term homosexual partners have not been able to access benefits that have been typically offered to heterosexual married couples, such as family health insurance coverage (Coon 2007). They would have had to make extensive and expensive legal arrangements to have the inheritance and health care decision-making rights that heterosexual spouses take for granted (Porche and Purvin 2008). Also, the social and historical context in which current older homosexuals grew up probably has affected their willingness to "come out" to service and health care providers (Fredriksen-Goldsen and Muraco 2010). All of these issues undoubtedly impact caregiving for partners by members of sexual minority groups.

Little research exists on lesbian and gay caregivers, however, and the studies that have been done tend not to differentiate between people who are taking care of intimate partners, friends, or parents. Even less is known about those caregivers who identify as members of other sexual minorities such as bisexual or transgendered (DeVries 2007). Much more research on caregiving by members of sexual minority groups is needed.

Little is known about the caregiving of older heterosexual cohabiting individuals, either. Roughly 4% of unmarried men and 1% of unmarried women age 65 years and older are cohabiting (Calasanti and Kiecolt 2007), yet to date I have seen only one article on caregiving by cohabiting partners (Noel-Miller 2011). This area needs further research, as older cohabiting individuals should be likely to need care as they tend to have low levels of well-being. Cohabitors over 50 years old report higher amounts of depression, worse physical health, less social support, and fewer economic resources than older married people (Brown, Bulanda, and Lee 2005; Calasanti and Kiecolt 2007).

Needing care does not necessarily mean that a partner will provide care, however. Cohabiting relationships generally are more equitable than married relationships (Calasanti and Kiecolt 2007); for example, housework tends to be more equally shared by cohabitors than by spouses. Older cohabiting partners may not have been together for as long as older married couples; they would not have the same long history of interaction and exchange or the incentive to reciprocate for prior care. Therefore cohabitors could be less likely to provide help than spouses. Compared to married persons with a disability, cohabitors who need assistance are less likely to receive help from a partner (Noel-Miller

2011). However, cohabiting partners who do provide care spend as much time caregiving as do spouses (Noel-Miller 2011).

In addition, the likelihood of cohabitation decreases with age, suggesting that individuals who need care are not desirable partners (Brown, Lee, and Bulanda 2006). For example, many widows are not interested in remarriage or cohabitation because of the prospect of having to take care of another person (see Davidson 2001). These women feel that they have "done their duty" by caring for the husband they lived with for many years; they do not want to have to do it again (Davidson 2001:311). Older people may decide not to cohabit to avoid the chance that they will have to be a caregiver again.

Marriage as privileged status

In general, married older people are healthier and have more resources than cohabiting, widowed, divorced, or never married older persons (Brown et al. 2006). Certain categories of older people are more likely to be married than others. For example, rural older people are more likely to be married than urban older people, and thus are more likely to have a spouse available to provide care (Glasgow 2000). Marriage and divorce rates also vary by racial/ethnic group (Himes 1992), affecting the availability of spouses. Older Black men and women are less likely to be married than older Whites, for example (Himes 1992). Blacks have lower marriage rates and higher divorce rates than Whites, Asian Americans, or Latino/as (U.S. Census Bureau 1992; 2008). Whites are more likely to remarry after divorce than either Latino/as or Blacks (U.S. Census Bureau 1992; 2008). Because Whites have higher rates of marriage and remarriage, and lower rates of divorce, than other racial or ethnic groups, they are most likely to have a spouse in old age. In addition, men are more likely to remarry than women after widowhood or divorce (Himes 1992; Kinsella 1996). Less than half of older women (44%) are married, compared to about three quarters of older men (74%) (U.S. Census Bureau 2011:Table 34), so that men are much more likely to have a spouse available in later life than are women (see Table 1.2, p. 13).

In addition, not everyone has had equal opportunities for marriage. Same sex couples have not been able to legally marry. While marriage laws are changing, current older homosexual couples have faced challenges over the course of their relationship that heterosexual couples did not, such as not having access to each other's health insurance, likely affecting their health condition in old age. Because same sex couples have not had similar benefits, such as tax deductions and insurance, they have not been able to build up as much savings and other assets, leading to fewer economic resources in later life (Coon 2007). Gays and lesbians also face different challenges as partners when providing spousal care given the lack of legal recognition of their relationships (DeVries 2007) which can be an additional source of stress, especially when trying to obtain formal services (Cohen and Murray 2006).

Another issue is that marriage rates tend to rise during good economic times, so some age cohorts are less likely to have married (see Oppenheimer, Kalmijn, and Lim 1997). Also, marriage and divorce rates differ by social class. "Both men and women with better educations, job prospects and earnings are more likely to marry" than men and women with lower socioeconomic status (White and Rogers 2000:1042), and higher family income is associated with lower rates of divorce (Manning and Smock 2002). Lower marriage rates for Blacks are linked with worse economic prospects for Black men than for White men historically (Coontz 1992). Economic factors are more important for Blacks than for Whites and Latino/as when making marriage decisions (White and Rogers 2000; Manning and Smock 2002). For example, most unmarried pregnant women consider whether or not to marry the child's father, but while a White woman is somewhat more likely to marry the father of her child if he is employed than if he is unemployed, a Black woman is much more likely to marry him if he is employed (White and Rogers 2000). Although cohabiting Latinas consider their partner's employment when deciding whether or not to marry, poor Latino/as have higher marriage rates than comparable Whites (Manning and Smock 2002:1082). A number of issues affect the decision to marry, and people of different races and ethnicities may put dissimilar amounts of emphasis on those factors.

The ability to marry probably is connected to other characteristics leading to better health and more financial resources in old age, meaning that married older persons should have less need for care or better capability to pay for or otherwise obtain care. Married people tend to be in better health in general (Waite and Lehrer 2003), also suggesting less need for care in later life. The trend that women with better educations and job prospects are more likely to marry than poorer women is increasing (Goldstein and Kenney 2001), and marriage rates declined overall during the latter part of the twentieth century, suggesting that in the future there will be a greater difference in access to kin for caregiving. The better off will have larger social networks available because they will be more likely to have a spouse and children. They should also be in better health and have less need for care.

Health does affect one's ability to provide care. Most spousal caregivers (61%) say they are in good or excellent health compared to others (Wolff and Kasper 2006:350). Husband caregivers report they are in better health than wife caregivers, even though they tend to be older (Mui 1995b). Some people, however, provide care even if they are not in the best of health (Johnson and Wiener 2006). Burton, Zdaniuk, Schulz, Jackson, and Hirsch (2003:238) found that older people with lower incomes and more health risk behaviors (such as not getting enough rest, not taking prescribed medications, or missing doctor's appointments) were more likely to become spousal caregivers. Overall, spousal caregivers report worse physical and mental health than spouses who are not caregivers (Pruchno, Kleban, Michaels, and Dempsey 1990; Wallsten 2000). Older married Blacks in general are in worse health and thus begin spousal caregiving in worse health than Whites (Wallsten 2000), suggesting that health issues particularly affect the caregiving of members of minority groups. Social class also affects spousal caregiving; older middle- and upper-class couples are more likely to be in better health with less need for care. In addition, they are more likely to be able to pay for assistance than working- and lower-class couples (Stoller and Miklowski 2008:124). A wealthier couple might pay for someone to come in and help with household cleaning or personal care, such as bathing, which would be out of the financial reach of poorer couples.

Spouses are not always caregivers or primary caregivers, however, even though married older people have smaller helping networks than the unmarried elderly (Barrett and Lynch 1999; Feld, Dunkle, and Shroepfer 2004). Married older Mexican Americans often receive care from adult children rather than spouses, for example (Phillips, Torres de Ardon, Komnenich, Killeen, and Rusinak 2000). Spousal caregivers in worse health report higher levels of strain (Mui 1995b), suggesting that at some point their own health issues become a factor in deciding to stop caregiving. Also, their emphasis on self-sufficiency and not asking others for help may lead them to try to provide care past their own ability.

Statistics on spousal caregiving

Increasing age often is associated with health problems, and caregivers over 65 years old are often spouses, especially older male caregivers. The mean age of spousal caregivers is 74 (see Table 2.1; Wolff and Kasper 2006). While 85% of spousal caregivers are 65 years and older, almost half are 75 years and older (Wolff and Kasper 2006). Husband caregivers tend to be older than wife caregivers (Mui 1995b) and, according to Stone et al. (1987), husbands are the oldest subgroup of caregivers. Older married women are more likely to be in nursing homes than older married men (Stoller 1992), however, so the older age of husbands could be related to health issues that limit their ability to provide assistance. Some spouses continue to assist with care when the recipient moves to a nursing facility (Wolff and Kasper 2006); institutionalization may mean a change in the type of care provision, not necessarily stopping care. For example, a husband might stop providing hands-on assistance at home but supervise care given by paid health care workers at a nursing facility when his wife's needs become too much for his physical strength.

Spousal caregiving tends to be a lengthy, time-consuming commitment. Almost half of spousal caregivers say they have provided care for four or more years (see Table 2.2; Wolff and Kasper 2006). On average they spend 41 hours a week providing care, but there is wide variation. About a quarter say they spend 10 or fewer hours per week, while over

TABLE 2.1 *Characteristics of spouse primary caregivers, 1999*

Age, in years (%)	
14–44	1.1
45–64	10.0
65–74	37.6
75 and older	47.4
Mean age (years)	73.8
Gender (%)	
Male	42.7
Female	57.0
Perceived health status (%)	
Excellent	14.0
Good	46.9
Fair	27.1
Poor	7.1

Source: Wolff and Kasper 2006:350.

a third say they spend 40 or more (Wolff and Kasper 2006). Almost 90% say they provide help every day (Wolff and Kasper 2006:351), so for many spousal caregivers it is a full-time job without weekends off (also see Johnson and Wiener 2006). While it seems likely that the amount of care provided increases over time, almost all studies of spousal caregiving have been cross-sectional (Burton et al. 2003). Since many spouses report that they have provided care for at least four years, studies that follow caregivers for long periods of time would be helpful to provide evidence in this area.

What tasks they do

Spouses help with a variety of tasks. Over 80% report they help with shopping, transportation, and household tasks such as laundry and meal preparation, and over 50% assist with money management (see Table 2.2). In addition, over half say they help with personal care and nursing tasks such as dressing, bathing, feeding, and using the toilet, and 40% help their spouse get around inside the house (Table 2.2; Wolff and

TABLE 2.2 *Amounts and types of assistance provided by spouse primary caregivers, 1999*

Length of caregiving in years (%)	
Less than 1	18.0
1–4	30.7
More than 4	47.0
Average days per week (%)	
Less than 3	6.9
3–6	3.3
7	89.5
Average hours per week (%)	
Up to 10	24.4
More than 10 and up to 20	13.6
More than 20 and up to 40	27.4
Over 40	34.3
Specific tasks (%)	
Shopping and/or transportation	86.1
Household tasks	83.2
Finances	52.8
Personal care and/or nursing	55.7
Giving medicine	46.7
Indoor mobility	39.7

Source: Wolff and Kasper 2006:351.

DOI: 10.1057/9781137511560.0006

Kasper 2006). Also, spouses often serve as complementary caregivers when both have health conditions (Friedemann 2005). For example, a cognitively alert but physically disabled wife could manage medications for both spouses, while her more mobile husband helps her with bathing or other personal care.

A few studies have looked at how gender affects spousal performance of caregiving tasks. Since carework is primarily seen as a female job, husbands and wives might be more or less likely to do particular tasks. Even if they do similar tasks, they probably will experience these tasks differently because of societal gender expectations (Calasanti and Bowen 2006; Russell 2007). Dwyer and Seccombe (1991) found that more husbands than wives helped their spouse with getting around inside the house, getting in and out of bed, and using the toilet. More men than women also reported doing household chores such as housework, laundry, and shopping (Dwyer and Seccombe 1991); these types of jobs may be noticeable to men as they are not usually part of the male gender role. Husbands also more often reported more typically male tasks such as running errands and providing transportation (Dwyer and Seccombe 1991). In contrast, more wives than husbands reported helping with bathing, managing money, and making telephone calls (Dwyer and Seccombe 1991). Taking over the finances as a new responsibility was mentioned by several caregiving wives in Calasanti and Bowen's (2007) study, suggesting that taking on a new task highlights the carework aspect of a job.

For example, Dwyer and Seccombe (1991) found no statistically significant differences between wives and husbands on helping with eating, dressing, and preparing meals. However, in Russell's (2007) and Harris and Bichler's (1997) interviews with men giving care to wives with dementia, the task of cooking was mentioned as particularly important, even for those men who already did some of the meal preparation before their wives' illness. Cooking was definitely seen as carework by these men. Incapacity of wives probably has more effect on household labor than husbands' disability, since women generally have more responsibility for household tasks. Even when men do housework, wives are usually the managers or supervisors. Therefore, changes in the division of labor are more striking to the individuals involved when women need assistance (Calasanti and Bowen 2006; Russell 2007; Stoller 1992). More husband caregivers report assistance with housework from wife care recipients than wives do from husbands (Ingersoll-Dayton and Raschick

2004), suggesting that women continue to do such household chores as long as they are able. More research is needed to understand this issue, but apparently husbands see housework and laundry as caregiving more than wives do, probably because of the newness of the task (Calasanti and Bowen 2006). We should remember, however, that most of the older people who participated in these studies were born fairly early in the twentieth century. Gender role socialization has changed from when those people were children. More research with people born later would be helpful, as ideas about gender roles have shifted.

Societal context and gender roles

Spousal caregiving has different meanings for husbands and wives (Stoller 1992). Wives emphasize the obligation to provide care, while husbands feel they have more choice in the matter (Stoller and Miklowski 2008). In addition, men and women highlight different aspects of caregiving even if doing similar tasks. Wives perceive more responsibility for maintaining the self-esteem of their care recipient husbands (Stoller and Miklowski 2008, but see Calasanti and Bowen 2006). In contrast, husbands stress the reciprocal nature of providing care for wives who spent years nurturing them (Stoller and Miklowski 2008). General gender role expectations affect these meanings, as do husband and wife role expectations (Ingersoll-Dayton and Raschick 2004; Stoller 1992).

Of spousal caregivers, wives are more likely to report prior caregiving experience than husbands (Wallsten 2000:99). This finding is not surprising since women usually are primarily responsible for childrearing. Women also may have provided care for their own parents or for their husband's parents before taking care of their husband. Providing health care can be seen as a continuation or "natural extension" of the spousal relationship for wives (Seltzer and Li 1996:616; also see Calasanti and Bowen 2006). Women are expected to provide care in general (Cancian and Oliker 2000) so providing health care for a husband also is part of the feminine gender role.

Caregiving is not usually thought of as part of the masculine gender role, but it can be seen as "an extension of the husband role and culturally justified" (Dilworth-Anderson, Brummett, Goodwin, Williams, Williams, and Siegler 2005:S261) for two reasons. A man taking care of his wife could be viewed as an expression of male authority over women

– another type of "taking charge of another person" that is part of the role of authority figure in the family (Stoller 1992). Caregiving also can be thought of as adherence to the wedding vows and thus part of the husband role. For some men, assisting with personal care such as bathing and dressing their wives begins as a duty but becomes an expression of "love and emotional connection" (Russell 2007:15). Therefore, providing care for a wife can be accepted as masculine, even for those men with very traditional ideas about gender roles. As cultural ideas about gender roles change over time, men may become more comfortable providing assistance. Husbands with prior caregiving experience report less burden than those without such experience (Mui 1995b), so those men with less traditional gender role beliefs should find it easier to provide care. Measuring gender on a continuum of masculinity and femininity rather than as a male/female dichotomy would help us better understand the effects of spousal and same sex partner caregiving on individuals and on their relationships.

The couple's relationship

Many elderly couples have had long relationships that have adjusted to changes over time such as having children and moving. They also have had time to develop a strong "couple identity" – seeing themselves as part of a couple rather than as separate individuals (Badr, Acitelli, and Taylor 2007). Adapting to providing health care grows out of the prior relationship (Seltzer and Li 1996) but because of the change (usually) from reciprocity to more one-sided care, the couple's relationship may need greater adjustment at this period than at earlier stages (Greenberg, Stacy, and Penzo 2001). While some caregiving is a normal part of spousal relations, providing care because of health impairments can cause major changes in the relationship (Pearlin et al. 1990). Assisting a partner with tasks such as bathing or toileting adds a new level of interdependency and vulnerability (Carpenter and Mak 2007). Changes in responsibilities and roles such as one partner having to take on financial management or household chores that used to be the responsibility of the other partner also can occur (Carpenter and Mak 2007). Some people appreciate the opportunity to develop new skills while others resent the added work (Hepburn, Lewis, Narayan, Tornatore, Bremer, and Sherman 2002).

Caregiving potentially harms or improves the relationship (Carpenter and Mak 2007). Spousal caregiving can lead to poorer quality of the spousal relationship (Roberto and Jarrott 2008) especially for those individuals caring for people with cognitive impairments such as Alzheimer's disease. However, Seltzer and Li (1996:624) found that women "in later stages of caregiving felt greater degrees of closeness in their relationships with their husbands" compared to those in earlier stages, so that caregiving can improve the relationship. Service providers to care recipients or care providers could consider including both members of the couple in interventions such as counseling to foster couple identity and to improve the overall relationship.

Caregiving also is affected by the quality of the relationship before the need for care (Pearlin et al. 1990). A poor relationship in which one partner now needs care is likely to get worse and the caregiving will not be of good quality. For example, a spouse who has been abused in the past may take the opportunity to abuse the now dependent partner. People who have experienced violence from the care recipient are more likely to commit violence themselves (Pillemer and Suitor 1992). We cannot assume that all long-term relationships are high quality (Kramer 1993).

We also should not assume that all later life marriages have been in existence for a long time. Older people may have remarried after divorce or widowhood. Few studies, however, investigate the effects of the length of the relationship (Kramer 1993; Sherman and Boss 2007), which is problematic as not all older couples have been married many years. Remarried older people (especially men) are more likely to have a spouse as caregiver and less likely to have a child caregiver than those in their first marriage (Uhlenberg and Cheuk 2008). In addition, wives in remarriages experience greater burden than wives in first marriages (Stoller and Miklowski 2008). In particular, caregiving wives in late-life remarriages feel their complicated family situations create extra difficulties (Sherman and Boss 2007). The husband's children sometimes challenge the wife's decision making about care, for example. Length of the relationship, therefore, is an important factor in the spousal caregiving experience which deserves greater research attention.

Spousal caregivers with higher levels of couple identity feel less burden (Badr et al. 2007) and those with better relationships prior to caregiving experience caregiving as more rewarding (Greenberg et al. 2001). In contrast, spousal caregivers with poorer quality of the relationship before the need for care report lower levels of satisfaction and higher levels of depression after transitioning into spousal caregiving (Choi and Marks 2006; Kramer 1993). Long-term committed homosexual relationships do not differ in quality from long-term committed heterosexual relationships (Calasanti and Kiecolt 2007), so the effects of caregiving should be similar. Overall, higher-quality intimate relationships lead to better caregiving experiences.

Social networks and support from others

Of course, spouses have relationships with others as well. Prior to caregiving, husbands and wives tend to have different social networks; older women have more confidantes and close friends while older men have more acquaintances (Stoller 1992). Males generally have smaller social networks overall than women (Wallsten 2000). Men say they confide in their wives, while women confide in friends (Field 1999). Wives therefore feel greater losses when caregiving isolates them from friends, while husbands are more able to adjust to having less time with friends (Stoller 1992). Hepburn et al. (2002) report that both men and women complain about giving up their personal lives for caregiving, however. In addition, Mui (1995b) found that conflicts between providing care and having one's own social life were related to more strain for both men and women, although the effects were stronger for men. These findings contradict the idea that men more easily adjust to the loss of friends. Both men and women could benefit from services such as respite care that will help them maintain other friendships. Members of a social network could be sources of potential aid and comfort.

Family scholars and service providers may assume that members of racial and ethnic minority groups have larger social networks than Whites (Hogan and Eggebeen 1995). Wallsten (2000) found no difference in social network size between Black and White caregiving spouses, however, although Black spousal caregivers reported larger networks than did Black noncaregivers. In contrast, Adams, Aranda, Kemp, and Takagi (2002) found that Black spousal caregivers reported stronger social support networks than White, Mexican American, or Japanese American caregivers. These contradictory findings mean that more research is needed in this area, and that service providers and policymakers should not take it for granted that all members of minority groups have access to large social support networks.

The size of social network before caregiving can affect whether or not an individual receives assistance in providing care. Those people with larger social support groups may receive more assistance with caregiving (Wallsten 2000). In 1999, 68% of spousal caregivers said they received no help from others, which was a statistically significant increase from 1989 (Wolff and Kasper 2006). The percent of spousal caregivers who received paid assistance also decreased significantly in those ten years (Wolff and Kasper 2006); these two findings suggest that spousal caregiving responsibilities are increasing. However, average hours spent providing care also went down (Wolff and Kasper 2006), so that there may be some decreases in the amount of care work being done by individual spouses.

Most couples with health problems do not receive assistance from others (Feld, Dunkle, and Shroepfer 2005; Stoller and Cutler 1992). Feld et al. (2004) found that older married Blacks were more likely to have informal caregivers other than their spouses compared to older married Whites or Mexican Americans, but Stoller and Cutler (1992) found no difference between married Blacks and Whites. These contradictory findings could be because of the differences in the samples they used. Stoller and Cutler (1992) studied only couples with no other people living with them while Feld et al. (2004) did not limit the sample by whether or not other people were in the household. Living with other family members happens because of cultural values, economic reasons, or a combination of both. Coresidence does not necessarily mean that all household residents provide care assistance, but children or siblings or other relatives may move in with the couple to help with caregiving (see the discussion in the next chapter).

Feld et al. (2005) found the spouse as sole caregiver was most common when the care recipient was the husband, had fewer health problems, and the caregiving wife had no disabilities. When the recipient had more health issues and the caregiving spouse had ADL limitations, assistance from others was more likely (Feld et al. 2005). Also, when the wife was the care recipient and the caregiving spouse was the husband, assistance from others was more likely (Feld et al. 2005; Stoller and Cutler 1992). Husbands are more likely than wives to receive help from other family members (Feld et al. 2005; Stone et al. 1987) and to use paid assistance (Stoller 1992). Also, couples with greater financial resources or access to governmental aid have more formal helpers (Feld et al. 2004; Stoller and Cutler 1992). It appears that men, the wealthy, and those poor enough to meet government requirements find it easier to get help with caregiving.

These findings suggest a need for government assistance for all family care providers to help out wives and middle-class spousal caregivers. Perhaps a sliding fee scale could be part of such policies to increase political acceptability.

Effects of caregiving

Knowledge of the characteristics of the caregiver and the effects of caregiving also should be used to inform service provision (e.g., Bookwala, Zdaniuk, Burton, Lind, Jackson, and Schulz 2004). The factors that predict outcomes are different for husbands and wives (Mui 1995b; Pruchno et al. 1990). The effects of caregiving also differ by socioeconomic status, race/ethnicity, quality of the couple's prior relationship, and social networks (Pearlin et al. 1990); some of these effects have been described earlier. Characteristics of the care recipient and the type of transition into providing help also affect the outcomes for the caregiver, as discussed in the following section.

Characteristics of the caregiver

Husbands report lower levels of negative effects on their lives from caregiving than wives do (Adams et al. 2002; Mui 1995b; Stoller 1992). Older married women are more likely to be in nursing homes than older married men, so husbands may have a lower threshold at which caregiving overpowers their willingness or ability to provide assistance (Stoller 1992). Wallsten (2000) found, however, that husbands reported higher gratification within the relationship than wives did. Husband caregivers also reported more positive feelings about their wives who needed care than wife caregivers did about their husbands who needed assistance (Wallsten 2000). Men view caregiving more positively than women do (Adams et al. 2002), perhaps because husbands receive praise and attention for providing care, while the caregiving of wives is often unnoticed because of the social expectation that women will provide care (Stoller 1992).

Age also matters. Younger caregiving wives report higher levels of strain than older caregiving wives (Seltzer and Li 1996). Seltzer and Li (1996) argue that providing care is more accepted and expected in later life stages, so that interpretations of the caregiving role differ by age as well as by gender. If spousal caregiving is seen as a normal part of being older, it will be more stressful for a 40-year-old to take care of a disabled husband than for a 70-year-old, for example.

Characteristics of the care recipient

Many spousal caregiving studies have focused only on those people caring for husbands or wives with dementia, but assisting someone with ADLs or IADLs seems likely to affect caregivers differently. Intuitively, the needs of the care recipient should be related to how much stress the caregiver feels. More problem behaviors (such as getting up too often at night, repeated questioning, or swearing) exhibited by the care recipient are associated with more stress for both men and women caregivers (Ingersoll-Dayton and Raschick 2004). Wives report more problem behaviors of husband care recipients than husbands report of wives (Ingersoll-Dayton and Raschick 2004; Wallsten 2000). These problem behaviors are linked to dementia rather than ADLs. It would not be surprising if spouses find dealing with cognitive limitations more stressful than assisting with physical needs. Some research has found that the amount of ADL limitations of the care recipient does not affect the perception of burden for the caregiver (Mui 1995b). Spouses who assist with at least one ADL spend more time providing care than those who only help with IADLs, and ADL caregiving is associated also with the poorer health of the caregiver (Burton et al. 2003). A spouse's dementia or cognitive problems may be more upsetting than physical issues, however. More studies that investigate both characteristics of the care recipient and stress felt by the caregiver are needed, as is more research on caregivers for those people who only need help with ADLs.

Transition into caregiving

The type of illness and the speed of its onset affect the caregiver, the caregiving, and the couple's relationship (Greenberg et al. 2001). For example, sudden events such as strokes require the spouse to take on caregiving quickly, while gradual illnesses such as dementia or arthritis mean a slower adjustment. Whether the transition to caregiving was gradual or abrupt is related to the caregiver's perception of the amount of burden (Seltzer and Li 1996) and also affects the relationship between the individuals. Seltzer and Li (1996) found that wives whose caregiving had a sudden onset but longer duration reported less subjective burden than those with a sudden onset and shorter duration; they argue that wives adapt over time. Men seem to have a harder transition to the role than women (Mui 1995b). Mui (1995b) suggests that men also adapt over time; she found that men who had been caregiving longer reported less strain than men who had been providing care for a shorter time. Length of time spent providing care did not matter for women in her study, however (Mui 1995b). People probably do adjust to caregiving over time. Still, the type of illness matters. The burden of caring for someone with dementia should increase over time, while that of caring for someone who had a stroke might decrease.

Mental and physical health outcomes

Spousal caregiving is associated with physical and mental health decline over time (Burton et al. 2003). Spouses in worse health are more likely to give care, and caregiving worsens health (Hill 2011). A one-year longitudinal study found that increased caregiving is associated with increases in anxiety, depression, worse perceived own health, and increases in risky health behaviors such as not eating three meals a day, not seeing a doctor when ill, and not taking one's own medication (Beach, Schulz, Yee, and Jackson 2000). The effects of caregiving on mental health vary by race, ethnicity, and gender. Mexican American spousal caregivers report higher levels of depression than White, Black, or Japanese American caregivers (Adams et al. 2002). Feelings of depression and burden are greater for wife caregivers than husband caregivers (Adams et al. 2002; Pruchno et al. 1990). Depression leads to worse physical health, especially for wife caregivers (Pruchno et al. 1990). However, Mui (1995b) found that one's own perceived health status was more strongly related to burden for men than for women. While both men and women in poorer health felt more strain than those spousal caregivers in better health, men in worse health felt more burden than wives in worse health.

Health professionals and service providers need to keep in mind that the health of the caregiver is likely to be affected. They should not ignore the needs of the caregiver while treating the care recipient. We also should remember that spouses are the most likely of relative caregivers to become violent (Pillemer and Suitor 1992). The stress and burden of providing care, particularly with no assistance, can lead to elder abuse (Lantz 2006). Respite care and other types of support services should benefit both the care giver and the care recipient.

Typologies of spousal caregivers

A few attempts have been made to create typologies of people providing care for spouses with dementia, generally in order to improve service provision (e.g., Hepburn et al. 2002). These typologies have been created from interviews with only men, only women, or both, and little overlap exists across the typologies. Nevertheless, service providers will be better able to meet individuals' needs by recognizing that there is diversity within the types of caregivers. People will look for particular types of resources and will find different services useful.

From their interviews with men caring for wives with dementia, Harris and Bichler (1997) created five categories of husband caregivers. Some men took on caregiving as a type of profession; they treated it as a work identity. They set up a schedule for tasks just as if it were a work day. Others treated caregiving as a labor of love, in which caregiving was done out of devotion rather than duty. Their actions were an expression of their love and affection for their wives. Other husbands focused on caregiving as a responsibility to their wives – they were acting on a sense of duty. Their actions were an expression of commitment to their wives. (All these types of men love their wives, but they talk about caregiving differently.) Some of the men whose wives were in the early stage of dementia could take a team approach with their wives to caregiving. This category should be even more applicable to couples with physical rather than cognitive limitations, where they share tasks depending on who can do what.

Harris and Bichler (1997) also had a category called men in transition; these were men new to caregiving or whose wives had recently become worse. These men were struggling with taking on new tasks, learning new skills, and the psychological adjustment that goes along with these changes. These men experienced a great amount of caregiver stress and spoke of frustration with the situation rather than adjustment to it (Harris and Bichler 1997). Presumably, most men in this category will adapt over time, and will move into one of the other categories. The categories of team approach and men in transition are probably stages, rather than permanent situations.

From their interviews with White wives providing care to husbands with dementia, Brown and Alligood (2004) identified three patterns of behavior. Avoiding was "ignoring, minimizing, or denying problems as a means of coping", shouldering was utilizing personal resources to provide care without asking for help, and facing "involved acknowledging the need for help and reaching out to obtain it" (Brown and Alligood 2004:109). The first two categories (avoiding and shouldering) can be stages preceding the third (facing). Brown and Alligood (2004) argue that educational programs about services should be made available to assist caregivers in recognizing resources that could help them make sure their spouse receives the best care possible.

Hepburn et al. (2002) interviewed caregiving husbands and wives and created four categories. Relational caregivers were focused on the continuing spousal relationship; providing care was a continuation of their life together, not a new stage. In contrast, reactive spouses focused more on the changes and losses of the relationship while recognizing the added work of care provision. Instrumental caregivers were more concentrated on the chores and processes and the effects of these tasks on themselves, rather than on the relationship. Role-acquiring spouses described learning new skills and satisfaction with personal growth through caregiving. Both men and women gave answers that fit into the first three categories, while only wives' responses fell into the fourth group. It is unclear why only female respondents emphasized learning new skills in Hepburn et al.'s (2002) study, when many of Harris and Bichler's (1997) respondents spoke about it. People working with family caregivers should be alert to what issues are most important to the care providers themselves to deliver the most appropriate advice and services.

Since the needs of care recipients generally increase over time, caregivers are likely to need distinct services at different periods, and service providers should look for changes in the stages of caregiving (see Hogan and Hogan 2009). Both Harris and Bichler (1997) and Brown and Alligood (2004) recommend training of health care professionals for better communication with caregivers, including announcing the diagnosis earlier as well as listening for the needs of the spouses providing care. Hepburn et al. (2002) suggest that their typology be used to supply appropriate directed therapy, counseling, and support group activities. For example, relational caregivers would benefit more from activities including the care recipient, while those spouses in the instrumental group would gain more from the education on how to do certain tasks, and reactive spouses would find grief support groups more useful. Harris and Bichler (1997) also state that different types of support groups will be helpful to dissimilar groups of caregivers. In addition, they suggest that education programs about the specific health problem affecting their wives and about caregiving tasks such as cooking or how to hire help would be useful to husband caregivers (Harris and Bichler 1997).

Summary

Increasing longevity leads to the prediction that higher numbers of older adults will need assistance in the future. Spouses and other intimate partners will provide much of that care. Most older couples take their marriage vows seriously and provide caregiving assistance to each other without question. Spouses are the first choice for primary caregiver, are over a third of all family caregivers, and provide more care on average than other types of caregivers.

Even though a lot of research on spousal caregiving has been done, more is necessary. As Stoller (1992) pointed out over 20 years ago, cohort differences in gender role expectations means that findings from earlier and current cohorts of caregiving spouses will not apply to future cohorts, so continuing research is necessary on husbands' and wives' expectations and interpretations of the caregiver role, the tasks performed, and outcomes. Also, most research has been on those spouses who provide care for dementia patients. Much more research is necessary on husbands and wives who provide assistance with physical limitations only, as those people with cognitive problems are a fairly small percentage of the older population who need assistance. Also, caregiving for dementia patients is more stressful as well as being qualitatively different in other ways from providing help with physical needs. Therefore comparative research with people caring for recipients with a variety of needs will better represent the caregiving population.

The focus on White spousal caregivers is a continuing issue. Little research has been done with Asian American caregivers or that distinguishes between Latino/a subgroups, for example (Adams et al. 2000). Much caregiving research that includes racial and ethnic minority groups does not distinguish by relationship to the care recipient and there is reason to believe that spouses and child caregivers think about caregiving differently (Dwyer and Seccombe 1991; Seltzer and Li 1996). Also, we need more research with cohabitors and members of sexual minority groups, as discussed in the chapter. The length and quality of the relationship prior to caregiving also need more attention (Kramer 1993). More longitudinal studies are needed as well, as almost all studies of spousal caregiving have been cross-sectional (Burton et al. 2003).

The research that has been done shows that providing care for an intimate partner has implications for one's own physical and mental health. It can be a lengthy, time-consuming job with many burdens and few rewards. The men and women who do this on a daily basis should be recognized and supported in their efforts, and services should be made available to lessen the negative consequences of meeting this personal and societal obligation. These services should recognize the diversity within the types of care providers to better meet their needs. Not all husbands will want the same kind of support group, for example.

Even though a spouse is usually the first choice for a primary caregiver, some cultural groups prefer daughters over husbands as appropriate caregivers. In fact, adult children make up the highest percentage of caregivers for the elderly. The next chapter focuses on adult children assisting their elderly parents.

3

Adult Child Caregiving

Abstract: *Caregiving by adult children to older parents is described. Sons and daughters generally provide different types and amounts of care, as well as receiving different amounts and types of support from others. Variations exist by race, ethnicity, socioeconomic status, and a number of other characteristics as well. More factors affect the provision of care by children than by spouses. Consequences and rewards for children are also different than for spouses.*

Keywords: adult children; aging; caregiving; elderly

Hill, Twyla J. *Family Caregiving in Aging Populations*.
New York: Palgrave Macmillan, 2015.
DOI: 10.1057/9781137511560.0007.

Adult children and their parents usually are very important to each other throughout the life course (Umberson 1992). They talk with each other frequently, spend time with each other (and grandchildren) in activities, and help each other out in a variety of ways. In general, adult children do not expect to have to provide care for a parent (Brody 2004), but in the United States, adult children are over 40% of primary caregivers for elderly persons (Johnson and Wiener 2006; Wolff and Kasper 2006). An adult child is more likely than a spouse to be the primary caregiver for a person 70 years old or older (Himes 2001). Almost two-thirds (64%) of those assisting care recipients 85 and over are their children (Takagi, Davey, and Wagner 2013). So children, particularly daughters, provide much of the family care that is done for elderly people. The typical adult child caregiver is a married daughter between the ages of 45 and 64 years old. Typically, she aids her parent for over four years and provides assistance seven days a week with no help from anyone else (Wolff and Kasper 2006).

Much attention has been paid to the sandwich generation caregivers: women in middle age (generally defined as 35–55 years old) simultaneously caring for minor children and elderly parents. Only 11% of adult child caregivers have children under 15 years old, however (Wolff and Kasper 2006). After all, people who are 85 years old and older, those most likely to need care, generally have children who are 50 years old and older. Therefore, those people who are most likely to require help are not likely to have caregivers who fit the sandwich generation definition. We should not ignore the sandwich generation, but the problems of older adult children also need to be studied. Focusing on the concerns of the sandwich generation obscures the issues of people at a later stage in the life course and has missed important aspects of life for a great number of caregivers. Concerns later in life are different; childcare responsibilities have decreased, and while marital status and employment still impact an individual's ability to provide care, retirement decisions and one's own health also are issues.

To broaden the topics covered, Brody (2004) uses the term "women in the middle" to characterize daughter caregivers who are caught between the requirements of roles such as wife, mother, child, and employee, facing the competing demands of various family members and paid work, and trying to meet cultural expectations that women are responsible for family caregiving. This terminology includes both sandwich generation and older daughters. Even though women are more likely to be caregivers, we should not forget that many sons provide care as well, and their assistance and problems also deserve to be studied.

This chapter describes the demographics of adult child caregiving, such as what percent of adult children has a living parent and provides care. Children who are assisting their living parent are compared to those who have living parents but are not providing aid. The effects of gender, race, and ethnicity, changes in fertility rates, and divorce on adult child caregiving are covered. Motivations for providing parent care, the tasks typically done, and the amount of time spent also are discussed. Conflicts with caregiving, the health of caregivers, and the burden felt by caregivers are described, and policy issues are raised.

Fertility rates

To have a child as a caregiver, one must have had a child earlier in life, and not have outlived that child. Unlike younger cohorts, currently most people age 85 and older do have children (see Table 3.1). It is estimated that in 2010, 86% of White men and women over 85 had living children; by 2020, the proportion should increase to 89% of White men and 91% of White women (Himes 1992). In comparison, 77% of Black men and women over 85 in 2010 had children; by 2020, the percentage will rise to 84% of Black men and 85% of Black women (Himes 1992). Given declining birth rates (Himes 2001), however, the percentage of people over 85 with children is likely to decrease again after 2020. In the next decade, then, most older people will have adult children who could provide care if necessary. Whites are more likely to have children than people of color in the near future. Fertility rates currently are higher for members of minority groups than for Whites (Angel and Angel 2006), however, so that White older adults in the long-range future will have fewer children overall to provide care if needed than elderly members of minority groups (see Table 3.1).

Parental divorce

Parental divorce impacts the likelihood of adult children providing care. We know it affects the amount of contact between parents and adult children (e.g., Shapiro 2003) and undoubtedly their relationship as well. Mother's divorce does not seem to change children's helping behaviors,

TABLE 3.1 *Estimates of percentage of people over age 85 with children*

	Year	
	2010	2020
White males	86	89
Black males	77	84
White females	86	91
Black females	77	85

Source: Himes 1992:S23.

but children of divorced fathers are less likely to provide assistance to them than children of widowed fathers (Lin 2008). As percentages of divorced elderly people are increasing (Shapiro 2003), the effect that divorce decreases assistance means that more older people (especially men) potentially will not receive help from children.

From the children's perspective, declining fertility rates and smaller family sizes will contribute to increases in individual responsibility for parental caregiving. The parents of the baby boom cohort have more children from whom to pick, which means each child has lower chances of being a primary caregiver. The cohort just after those parents and the baby boom themselves have fewer children, however, so each child will be more likely to provide care to an elderly parent. In other words, those individuals born after 1965 have a higher probability of looking after a parent than people born earlier.

Having a living parent

One must have a living parent to be a parental caregiver. About a fifth of Americans 55 and older have at least one parent living (Hogan, Eggebeen, and Snaith 1996). People with more education are more likely to have a living parent (Hogan et al. 1996), suggesting that people in higher social classes have greater longevity. Life expectancy also affects proportions of people with a living parent by race and ethnicity (see Figure 3.1). By age 50, Blacks and Hispanics are less likely to have living parents than Whites, because of higher mortality rates among members of minority groups. However, members of minority groups are more likely to need assistance than Whites and to require that help at earlier ages because of higher rates of disability (Green 2005).

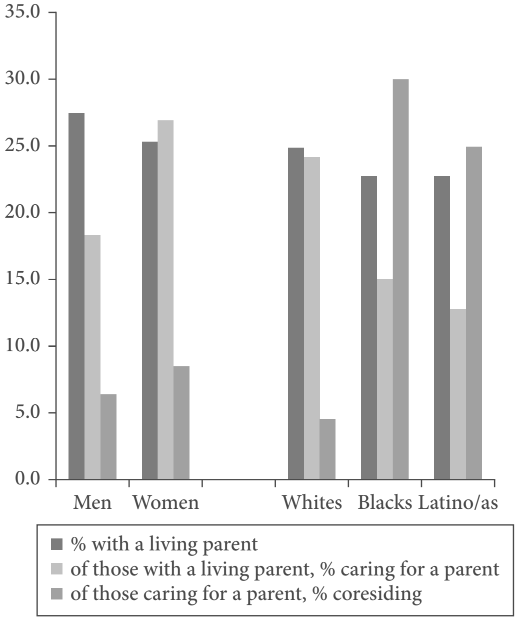

FIGURE 3.1 *Adult children, 50 years and older*

Source: The second wave of the National Survey of Families and Households (1992–1994), Bumpass and Sweet 1997; analysis by author.

Therefore, adult children of color actually may be disproportionately likely to be called upon to provide aid to their parents. Data from one point in time (such as that presented in Figure 3.1) will not show everyone who has ever cared for a parent or will help a parent; it only reports who is caregiving for a parent at that moment. So if an individual helped a parent before being 50 years old, and that parent has since died, that person's caregiving is not reflected. Accurately projecting the likelihood for different groups of people of providing care for a parent is quite complicated and beyond the scope of this book; however, for further details refer to the work of Christine Himes (1992, 1994), who has done excellent estimations.

If a person has an older parent, he or she is likely to be a caregiver for that parent at some point. For example, almost half (48%) of one sample of children 55 years and older with at least one living parent provided care (Laditka and Laditka 2000). Over one-third of White women between the ages 60 and 75 years old with a living parent are furnishing aid at any one point in time (Himes 1994). Also, daughters over 65 years old are more likely to be assisting parents than those 45–64 years old. These older women also are more likely to give care for more than 2 hours a day and for over 6 months than to provide shorter-term, less-demanding assistance to a parent (Himes, Jordan, and Farkas 1996). Thus, most adult children will give some care to elderly parents, and daughters especially are likely to be responsible for rendering help.

Comparison of caregiving adult children with those not providing care

My interest in caregiving by older adult children has led me to use the National Survey of Families and Households (Bumpass and Sweet 1997) to address some of the research questions. This random, nationally representative dataset has large enough numbers of Blacks and Latino/as to make some comparisons. The following two paragraphs compare people with a living parent who are caregivers to those individuals who have a living parent but are not providing assistance to them. This information is from the perspective of the adult child. We do not know about the health of the living parent. The parent may not need help. However, the parent may be in poor health and this child is the caregiver, another child may be helping the parent, or the parent may require assistance but is not getting it.

The adult children providing parent care are more likely to be female, more likely to be White, and more likely to be widowed than other respondents with living parents (Hill 2006). They are also a little bit older, less likely to be working, have slightly lower incomes, and report somewhat worse health (Hill 2006). Blacks and Latino/as assisting a living parent report lower average income and lower levels of education than caregiving Whites, with Latino/as reporting much lower levels of education. A smaller proportion of caregiving Blacks are married, compared to Latino/as and Whites who are assisting their parents. Females make up a larger percentage of Black caregivers than of White caregivers, but a lower percentage than of Latino/a caregivers (Hill 2006).

For Whites, respondents with a living parent but not assisting them are significantly younger than those who are helping their parents (Hill 2006). White caregiving individuals report lower average levels of health than those who are not providing care. Although White respondents who are aiding a parent are more likely to be completely retired than those who are not, there is no difference in average income. Caregiving Whites are more likely to be female than Whites who are not rendering aid. Whites who are not providing care are more likely to be married, while a higher proportion of caregiving Whites are widowed. For Blacks, age, marital status, employment, income, education, and health are not significantly different between individuals with a living parent but not providing care and Black caregivers. The only difference is that Blacks providing care are more likely to be female than those who are not helping a parent (Hill 2006).

Why adult children provide care

Adult children spend time with their parents and remain involved with them more often because of "mutual friendship and support" than because of health care needs (Umberson 1996:522), consistent with the predictions of intergenerational solidarity theory. According to Brody (2004), most children do not expect to become a caregiver for a parent. Although older parents and adult children may trade services on a regular basis, they often do not define assistance as caregiving until after a parental health crisis (Campbell and Ingersoll-Dayton 2000; Pearlin et al. 1990). A variety of reasons have been proposed for why sons and daughters provide care. As exchange theory would suggest, they may "expect to receive some reward in the future" such as an inheritance or want to reciprocate "for the years their parents spent caring for them" (Suitor, Pillemer, Keeton, and Robison 1996:234; also see Leopold, Raab, and Engelhardt 2014). Affection or love for the ailing parent also can be a motivating reason (Montgomery 1992). People may provide care for their parent to provide an example for their own children, in hopes that their children will assist them in the future if needed (Silverstein 2006). Society's expectations that adult children will provide care also are a factor (Suitor et al. 1996).

As family members, adults feel responsibility to their parents, but they also feel responsibilities to other family members, which can encourage them to provide more or less aid to parents (Piercy 1998). For example, a son might feel that he should help his mother, and that he should share this care with his sisters so that no one sibling is overburdened. On the other hand, he might feel his responsibilities to his wife and children outweigh his duties to his parents and siblings.

Of course, children provide care for a combination of reasons (Montgomery 1992). For example, most of the sons interviewed by Harris and Bichler (1997) express love for their parent, but say their filial obligation to provide care is the most important reason that they actually give assistance to their parent. Latino/as emphasize that providing care is a female task (Borrayo, Goldwaser, Vacha-Haase, and Hepburn 2007), so many Mexican American adult daughters provide care to their still married elderly mothers as a cultural duty (Phillips et al. 2000) as well as because of affection. Just as for spouses, the motivation for providing care affects the relationship between the care provider and recipient (Suitor et al. 1996) and may impact the quality of care as well. Spouses in general are more committed to providing care than are children (Piercy 2007), however, so the reason(s) children have for assisting parents are likely to have more effect on how much help is provided or for how long it is given. We cannot expect that the quality of care will be high or the amount of aid will be enough just because a family member is providing the assistance. For example, if an adult child is aiding a parent because of obligation and without affection, that person probably will provide care for a shorter period of time than someone who is motivated by both affection and obligation. A child (or other relative) also might take on caregiving as a way to access the care recipient's finances; some people financially abuse their care recipients (Lantz 2006). When the money runs out, so does the care. This situation is not common, though; most adult children provide help for less selfish reasons.

Gender

Many caregiving studies just look at women, which is somewhat appropriate given that it is primarily a women's issue. About 75% of adult child caregivers are daughters (see Table 3.2; also Mui 1995a; Stone, Cafferata, and Sangl 1987). Not only are daughters more likely to provide parent care than are sons (Kahn, McGill, and Bianchi 2011), they provide more hours of care per week than sons do (Wolf, Freedman, and Soldo 1997). Caregiving research needs to include men, nonetheless, because they are a sizeable percent of caregivers. In addition, as people have fewer children and family sizes become smaller, sons may be more likely to provide care, so including men's participation in caregiving is necessary to help predict future trends. Although the percentage of sons as primary caregiver increased from 1989 to 1999, daughters still are more likely to be caregivers than sons (Wolff and Kasper 2006; also see Johnson and Wiener 2006).

While trying to explain why daughters are more likely to provide care than sons, Matthews (2002) argues that brothers and sisters consider their responsibilities to their parents differently and therefore the composition of the sibling network is important. In her qualitative study, sons provided assistance in order to "enable their parents to maintain or reestablish self-sufficiency" (Matthews 2002:241), while daughters were more likely to view parental dependence as acceptable. In addition, sisters saw themselves as providing care within a family network, while brothers responded more individually to parental needs (Matthews 2002). Men responded to parental requests for assistance, while women monitored their parents to see if they needed any help (Matthews 2002).

TABLE 3.2 *Characteristics of adult child primary caregivers, 1999*

Age, in years (%)	
14–44	17.3
45–64	68.0
65–74	11.7
75 and older	2.1
Mean age (years)	54.5
Gender (%)	
Male	26.7
Female	73.3
Marital status (%)	
Married	56.6
Widowed	7.7
Divorced or separated	20.6
Never married	14.8
Perceived health status (%)	
Excellent	28.3
Good	40.3
Fair	21.7
Poor	4.2
Distance to care recipient (%)	
Coreside	51.0
10 minutes or less	31.9
11–30 minutes	12.4
31–60 minutes	2.1
More than 1 hour	2.3

Source: Wolff and Kasper 2006:350.

In other words, daughters give aid to parents if they think their parents need help, while sons wait to be asked.

Quantitative analysis of the National Survey of Families and Households supports Matthew's arguments (Hill and Tiemeyer 2013). Men with sisters do provide more care than only sons or men with only brothers. This finding suggests that sisters form a family caregiving network and include their brothers in it, while men with only brothers do not create such an arrangement. However, having only sisters or brothers does not affect how much care daughters provide, indicating that gender of their siblings matters much more for sons than for daughters. Also, about the same percent of only sons provide care as do men with only brothers, reinforcing the importance of sisters for men's sibling caregiving network (Hill and Tiemeyer 2013). Parents of sons should not need any less care than parents of daughters, so it does look like women help parents if they think parents need assistance, and sons provide aid when asked by their sisters or their parents.

Matthews (2002) also states that in general men and women have different ideas about what is "best practice" for parental caregiving. Since women have been responsible for familial caregiving, daughters have cultural support for their ideas being more powerful in the family system and an advantage for winning out in family discussions of what should be done, which means they generally become the primary caregiver (Matthews 2002). Even when brothers give a great deal of assistance to parents, sisters tend to manage the care provision (Hequembourg and Brallier 2005). This situation is not always the case, however. Some sons take charge of the family caregiving decision making (Harris and Bichler 1997), which fits well with the masculine role. The structure of the sibling group as well as the geographic location of the ill parent impacts which child becomes the care manager.

Children who live closer to parents are more likely to provide aid than children who live farther away (Koh and McDonald 2006; Leopold et al. 2014). Men and women on average live about the same distance from their parents, but women travel farther to provide instrumental types of assistance such as housework or transportation (Tiemeyer and Hill 2010). Also, both sex of the parent and of the child affect whether or not help is provided. Mothers are more likely to receive assistance than fathers from children (Tiemeyer and Hill 2011). However, a larger proportion of sons than daughters help their fathers (Tiemeyer and Hill 2011). Also, sons play a larger role in the networks of fathers than of mothers and a slightly higher percentage of males over 85 report help from sons than do females 85 and older (Coward, Cutler, and Mullens 1992; but see Leopold et al. 2014). If they have both male and female children, men may prefer to receive help from their sons rather than from their daughters. Therefore, both men and women should be included in future caregiving studies.

Race and ethnicity

Many caregiving studies have been of White daughters. People of color are about 22% of all adult child caregivers, however (Stone et al. 1987:621), and their contributions should not be overlooked. Black women in particular are expected to give help to elderly family members, at least partially because older Blacks have high rates of chronic diseases (Williams, Dilworth-Anderson, and Goodwin 2003). Therefore, a larger proportion of Black elderly need help compared to Whites. Many Black primary caregivers for elderly family members are daughters assisting their mothers (Williams and Dilworth-Anderson 2002).

Familial care provision often is presumed to be more available to members of racial and ethnic minority groups than Whites (Hogan and Eggebeen 1995). Unfortunately, few empirical studies that analyze caregiving patterns by racial or ethnic group membership have been done (White-Means and Rubin 2008). Since the availability and actual provision of care by adult children is affected by marriage and fertility rates, marital status, health, and employment, all of which differ by race and ethnicity, studies that compare caregiving patterns by racial and ethnic group membership would be helpful but are difficult to do. Because subgroup sample sizes tend to be very small in random, nationally representative datasets, analyses that would allow direct comparisons are not possible. Smaller studies usually include only members of one racial or ethnic group, and these studies often do not separate caregivers by familial relationship. Comparing patterns of caregiving of diverse groups is therefore difficult. (The next chapter reviews studies of family caregiving that do not categorize the caregivers by relationship.)

In general, studies suggest Black adult children help older parents more than White adult children do, although some studies have had conflicting results regarding whether race and ethnicity affect help given to parents (Dilworth-Anderson et al. 2005). For example, Hogan and Eggebeen (1995) did not find variations between older Blacks and Whites in access to support from adult children or in actual aid given by them. However, while most older people say they have someone who will help them in an emergency, many of those who need help are not getting it (Hogan and Eggebeen 1995). The expectation of assistance and actual availability of help are two different things.

In contrast, White-Means and Rubin (2008) did find different patterns of caregiving assistance by race. In their study, employment affects help with ADLs, IADLs, and finances for Blacks, but only affects ADL assistance for Whites. Employment increases aid with finances from Black children, but lessens help with ADLs and IADLs. Employment decreases ADL assistance from White children, but does not affect aid with IADLs or finances (White-Means and Rubin 2008). Since employment decreases help with ADLs for both Blacks and Whites, individuals presumably find that caregiving (especially ADL assistance) and paid work compete for their time. Why employment increases financial aid to parents from Blacks but not Whites is not clear. Another study found that Black and Latino/a couples "are more likely than White couples to provide parents with financial assistance, or both money and time" (Shuey and Hardy 2003:428). In this case, there were no differences between the likelihood of providing assistance with personal care. Perhaps members of minority groups are more likely to share money with family members than are Whites.

Since the findings from different studies contradict one another, the relationships between race and ethnicity and caregiving by adult children are unclear. Beliefs about familial obligations seem to matter. One study found that racial differences in parental support were not significant when measures of cultural ideas of filial responsibility and of rewards from giving assistance to family members were included (Fingerman, VanderDrift, Dotterer, Birditt, and Zarit 2011). More research needs to include such cultural factors, as they can affect the amounts of stress, burden, and reward people feel while providing care.

What tasks they do

Older people primarily desire emotional support such as attention, visits, and telephone conversations from their children, rather than help with things such as cleaning or bathing (Brody 2004). Unfortunately, emotional support is not always measured in caregiving studies. We do know that adult children help with a variety of tasks, as shown in Table 3.3. Almost all say they help with shopping and/or transportation, 75% with household tasks such as laundry and meal preparation, and over half with money management. In addition, a large minority say they help with personal care and nursing tasks such as dressing, bathing, feeding, and using the toilet, as well as with the taking of medicine; a third assist with getting around inside the house (Wolff and Kasper 2006). While studies have not found gender differences in the proportion helping with money management, daughters are more likely to help with household labor and personal care such as nursing, and sons with home maintenance and transportation (Dwyer and Seccombe 1991; Montgomery 1992; Stone et al. 1987).

These differences are not strictly because of gender, however. For example, Witt (1994) found differences between urban and rural children; a higher proportion of rural daughters do more “traditional” female tasks such as housework and meal preparation, while a larger percentage of urban daughters help with finances. A greater proportion

TABLE 3.3 *Amounts and types of assistance provided by adult child primary caregivers, 1999*

Length of caregiving in years (%)	
Less than 1	16.7
1–4	31.2
More than 4	47.2
Average days per week (%)	
Less than 3	17.4
3–6	12.0
7	69.5
Average hours per week (%)	
Up to 10	37.8
More than 10 and up to 20	20.5
More than 20 and up to 40	19.5
Over 40	21.2
Specific tasks (%)	
Shopping and/or transportation	88.8
Household tasks	75.1
Finances	55.8
Personal care and/or nursing	43.6
Giving medicine	39.6
Indoor mobility	33.3

Source: Wolff and Kasper 2006:351.

of urban sons help with meal preparation and housework than do rural sons (Witt 1994). Gender role socialization undoubtedly impacts what jobs people do. Just as for spouses, new research is necessary to see if changes in gender roles have affected the division of tasks for children.

Many adult children provide this care with no support from either paid or unpaid sources. Almost half (48%) of adult children primary caregivers in 1999 report receiving no assistance, a large and statistically significant increase from 28% in 1989 (Wolff and Kasper 2006). About one-fifth (22%) have paid assistance, which is less than 28% in 1989 (Wolff and Kasper 2006), suggesting that the use of paid help is decreasing. Assistance from secondary caregivers also is declining (Spillman and Pezzin 2000). The amount of responsibility of adult child caregivers seems to be increasing. One possible factor could be increasing participation in paid employment by women; female relatives who might otherwise have provided secondary caregiving support are busy working for pay. Wolff and Kasper (2006) also speculate that Medicare policy changes may have participated in the decline. After 1997, fewer personal care home health services were eligible for reimbursement, discouraging the use of this type of paid assistance. If this kind of care was replaced, it was probably done by unpaid caregivers, which would help explain the decrease in the use of paid help.

Time spent providing care

Almost half of adult children caregivers report they have been providing care for over four years (see Table 3.3; Wolff and Kasper 2006). Another third say they have been assisting their parent between one and four years. Seventy percent state they give help seven days a week (see Table 3.3). Almost 40% report providing assistance for less than 10 hours a week, however, with the other 60% fairly evenly split between the categories of 10–20 hours, 21–40 hours, and more than 40 hours a week (see Table 3.3). Therefore, most adult child caregivers provide care for a number of years, and for a considerable amount of time per week.

Children who live closer to parents are more likely to provide assistance (Koh and McDonald 2006), and some adult children are on call 24 hours a day. About half of child caregivers share a home with their parent, and almost a third live within ten minutes of the care recipient (see Table 3.2;

Wolff and Kasper 2006). Sons and daughters are equally likely to coreside with their parents (Stone et al. 1987; also see Figure 3.1).

Parents and adult children may live together for a variety of reasons (see Dilworth-Anderson and Gilbson 1999; Janevic and Connell 2001). People may coreside for economic reasons such as for reducing housing costs. The cultural norms of some racial and ethnic groups anticipate that older and younger generations will live together. Grandparents sometimes live with their children and grandchildren to provide childcare while the middle generation is working. Adult children sometimes live with their parents to make intensive caregiving more convenient. Also, people might coreside because they like spending a lot of time together, or for a combination of these reasons. Older parents and adult children often live together to benefit both generations, and the arrangement may have begun before the parent needed help (Koh and McDonald 2006).

Blacks and Latino/as are more likely to coreside with elderly parents/care recipients than Whites (see Figure 3.1). Dilworth-Anderson and Gibson (1999) argue that family-centered cultural values encourage Black primary caregivers to live with their care recipients. Many racial and ethnic groups emphasize familial relationships (Dilworth-Anderson and Gibson 1999) and members of minority groups also tend to be worse off than Whites, so it can be hard to tell whether cultural values or economic factors are the most important reason for coresidence (Janevic and Connell 2001). Studies which inquire when and why coresidence began would be helpful in discovering which reasons are more important.

Conflicts with caregiving

Having to provide care for a parent is not something adult children expect to do at any point in their lives. "In effect, younger caregivers say 'I'm too young for this'; middle aged caregivers say 'I thought I would be free at this stage of my life'; and older daughters say 'I'm too old; I'm old myself'" (Brody 2004:70). Adult children always have other obligations that clash with parental caregiving. For example, having paid employment conflicts with obligations to a parent. Full-time workers are less likely to become caregivers than their siblings (Leopold et al. 2014). Also, studies of sandwich generation caregivers have shown that responsibilities to one's own children and one's spouse impact an individual's ability to provide assistance to parents. Only 18% of adult child caregivers have coresident children under the age of 15 (Wolff and Kasper 2006), though, so most (82%) are not members of the sandwich generation as it is typically defined. Even if children are over 18, however, they still require some time, attention, and money. Many adult children caregivers are probably concerned with sending their own children to college, for example. Financial assistance given to needy parents would decrease the amount of money available for the third generation. Obligations to a spouse also get in the way of assisting parents. Married adult children are less likely to give practical help to their parents than unmarried children (Sarkisian and Gerstel 2008) and are less likely to become caregivers (Leopold et al 2014). Our societal expectations that husbands and wives will be each other's primary support reduce their availability to other family members.

Other roles also affect the ability to provide care, amounts of care provided, or feelings of stress and burden. For example, half of adult child caregivers are employed for pay (Wolff and Kasper 2006:352), which undoubtedly impacts their caregiving. Conflicts with paid employment affect both daughters and sons. For example, caregiving sons with more control over their work hours reported less stress from providing care than those men with less flexibility (Harris and Bichler 1997). Caregiving also affects employers, as it is estimated to cost businesses about $33.6 billion a year (MetLife Mature Market Institute 2006). Companies lose money because caregiving responsibilities diminish workers' productivity; also, employees often take time off, reduce their hours, or leave their jobs because of providing care (Wagner 2006). Businesses lose skilled employees and have to train new ones. Therefore, employers have reasons to come up with policies to reduce conflicts between working for pay and taking care of older family members. Allowing flexible work hours would reduce turnover, as having control over one's time should reduce feelings of overload for both men and women.

Flexible leave arrangements should also help. For example, long-distance caregivers face geographic constraints which can require extended visits to the care recipient's location (Baldock 2000; Harrigan and Koerin 2007). It can be hard to know the status of someone living miles away. Parents may not give a child all the details of their health in order to preserve their independence, or in order not to worry or inconvenience their son or daughter (Harrigan and Koerin 2007). A parent's hospitalization or accident often is when an adult child becomes aware of the need for help. When a crisis occurs, an adult child will rush to a parent's side, usually requiring time off from work. In addition, the caregiving child often has to spend extended amounts of time at the parent's location because finding "appropriate services and monitoring them can be problematic" (Harrigan and Koerin 2007:14). Although many long-distance caregivers are secondary caregivers, between a third and a half are primary caregivers (Koerin and Harrigan 2002). These people especially will need flexible working arrangements to enable them to both keep their job and perform their caregiving responsibilities.

Access to other sources of income such as a pension or a spouse's support also has an effect on someone's ability to assist a parent. Adult children with higher incomes are more likely to provide care in general, for example (Hill 2007). "Greater financial resources increase the odds of giving money to a parent, but affluence is not related to providing" help with eating, dressing, or other activities of daily living (Shuey and Hardy 2003:428). Therefore, socioeconomic status affects whether or not adult children aid their aging parents financially, but they provide instrumental help regardless of wealth. Perhaps some individuals assist with personal care because they do not have spare monetary resources, while others are able to give instrumental assistance because their financial position allows them to have the time to do so.

Societal expectations of appropriate gendered behavior undoubtedly also affect individual's actions. For example, more daughters than sons report that they quit working to become a caregiver (Stone et al. 1987). Access to other resources probably has an effect on an individual's ability to give up paid employment, however. Sons providing care are less likely to be working for pay and more likely to be married compared to other men with a living parent (Triana and Hill 2004). These findings suggest that having other sources of support, both familial and economic, make it easier to give assistance to an ill parent.

Health

The health of care providers is another concern. Although daughter caregivers report being in better health than noncaregivers (Himes, Jordan, and Farkas 1996), in general people over 55 with sick parents are in worse physical health than those with either dead or healthy parents (Hogan et al. 1996). Some research finds that children in worse health are more likely to provide care, compared to others with a living parent (Hill 2005; Koh and McDonald 2006). In contrast, Laditka and Laditka (2000) find that 27% of daughter and 16% of son caregivers report failing health even though caregivers on average are in better health than noncaregivers. Perhaps if a sibling is available, people in poor health do not provide care. If they do not have a brother or sister who can step in, they assist their parent no matter the state of their own health.

Within each racial and ethnic group, women report poorer health than men of the same race or ethnicity (Santiago and Muschkin 1996). Overall, elderly Latino/as and Blacks have disproportionately worse health than Whites (Green 2005). Latino/as report worse health than Whites, but better than Blacks (Santiago and Muschkin 1996), so Black women are likely to be in the worst health. Still, they are likely to be caregivers. Black daughters are at risk for providing care, no matter what other characteristics they have, and in general, women with a living parent are more likely to provide care than men (Hill 2006).

Gender of child and parent both affect the mental health of caregivers. Daughters overall feel more emotional strain than sons (Mui 1995a). Of respondents with a living father, caregivers to fathers report higher levels of depression than those who are not caregivers, while caring for a mother is not associated with the level of depression for those with a living mother (Chumbler, Pienta, and Dwyer 2004). For those children providing care for their fathers, being married and/or employed decreases symptoms of depression, suggesting that these roles buffer the strain of caregiving (Chumbler et al. 2004). However, Seltzer and Li (1996) argue that roles such as employee or wife conflict with caregiving for women. Having other roles may work differently for sons and daughters, but we need more comparative studies to answer that question.

Race and ethnicity also can affect how caregivers' mental health is impacted. For example, Harwood, Barker, Cantillon, Loewenstein, Ownby, and Duara (1998) found little difference in depression between Latino/a daughters and sons who are helping their parents, even though women in general are more depressed than men, and female caregivers have worse mental health than male caregivers. In other words, caregiving Latino sons in their study are just as depressed as the Latina daughters. Since providing care usually is a female task in Latino/a culture, the contradiction with gendered expectations probably explains a portion of the greater depression experienced by Latino son caregivers.

Stress and burden

A number of things affect the level of strain felt by adult children caregivers, including disruptive behaviors of the care recipient and family disagreement about what should be done for the care recipient (Kang 2006). Limitations on the caregiver's life because of caregiving (such as less time with friends or other family members), the caregiver's perception of overload, and whether or not respite care is available also impact the amount of burden caregivers feel (Kang 2006). This is an issue because large amounts of strain and burden can be related to elder abuse by caregivers. For example, disruptive behavior of the care recipient, such as not cooperating with dressing or being fed, can lead to frustration and sometimes violence on the part of the care provider (Pillemer and Suitor 1992). Cultural barriers against using care options outside the family may add to the stress felt by adult children caregivers (Lantz 2006). Sibling relationships also can be sources of stress, as sisters and brothers may disagree about what should be done, who should provide care, and if the help being given is acceptable (Connidis and Kemp 2008; Kwak, Ingersoll-Dayton, and Kim 2012; Roff, Martin, Jennings, Parker, and Harmon, 2007).

Some evidence suggests that child caregivers for people of color feel more strain than children who assist White care recipients (Kang 2006; Mouton 1997) but other research has found that Whites feel more burden. For example, White daughters report more emotional strain than daughters of color, but there is no significant differences by race or ethnicity for sons (Mui 1995a). Perhaps variations across studies of how burden is measured have affected the findings, or stress factors may differentially affect members of distinct racial and ethnic groups.

Similarly, there are conflicting findings regarding burden felt by gender. Daughters may feel more caregiving strain than sons (Mui 1995a). After things such as involvement with other roles and interference with personal life are controlled for, however, gender does not seem to contribute to the amount of emotional strain (Mui 1995a). Other research also has found no differences in the amount of strain (Cicirelli 1992). Societal expectations of sons and daughters and the components of the gendered roles probably affect the level of stress. Cicirelli (1992) suggests that caregiving is not part of the expected role for sons, leading to greater psychological strain when they do provide care. So even if they objectively do less than daughters, they should feel more burdened by what they do since parent caregiving is not a normal part of the son role. Daughters, however, should feel less stress even when they actually do more as parent caregiving is part of the gendered expectations for them.

Different things lead to stress for sons and daughters. For daughter caregivers, the quality of the relationship with their parent, the amount of interference with their personal life, and interference with their paid work are predictors of strain (Mui 1995a). For sons, parental behavior problems, less assistance from others with caregiving, and interference with their personal life are predictors (Mui 1995a). These differences between daughters and sons may be related to gendered expectations of caregiving in which men anticipate receiving more assistance with providing care or expect to furnish less care overall, while women are more concerned with the quality of family relationships (Mui 1995a; Umberson 1992). Women also have more responsibilities overall, leading to more conflicts between caregiving, work and other roles (Mui 1995a). Whether or not a woman is a mother or employed does not seem to affect whether or not she provides care to a parent (Himes et al. 1996) but those roles probably affect her level of stress or feeling overwhelmed.

Married daughters report more conflicts with caregiving but fewer negative effects than widowed, divorced, or never-married women, primarily because of having more sources of support (Brody 2004). For example, married women have obligations to husbands that conflict with the responsibilities to parents, but usually also receive from their husbands emotional support (and other types of aid) for the parental caregiving. Widowed, divorced, and never-married women often have fewer other people to rely on for assistance than married women do (Brody 2004) so they probably receive less support and feel more burden.

The parent/adult child relationship is affected by the length of time spent in caregiving. Types of care needed and/or provided also alter the relationship between the parent and the caregiving child. “Some older people need so much support that it can consume many hours a week and be stressful as well” (Brody 2004:35). Daughters who have provided care for longer report more burden and “a more distant relationship with their mother or father” than other caregiving daughters (Seltzer and Li 1996:624). In addition, many parents who receive assistance from children also provide help in return, but little is known about how this affects the parent-child relationship (Ingersoll-Dayton, Neal, and Hammer 2001). Greater amounts of time together provide more opportunities for conflict, and parents and adult children may have different expectations about which tasks should be done, how, and for whom (Brody 2004). A mother and daughter may have differing ideas about how laundry should be done, for example, or a father might expect more (or fewer) in person visits from his son.

The relationship between the adult child and the parent is also affected by role reversal, which is a problem for both men and women. Providing transportation and personal care (such as bathing), tasks that their parents did for them, particularly disrupt the relationship between parent and child (Harris and Bichler 1997; Seltzer and Li 1996). Since almost all adult children help with transportation, this is an arena in which service providers could both fill a need and help improve relationships. Provision of personal care such as bathing also is an obvious domain for formal services.

Daughters experience more caregiving costs than sons, but the same level of caregiving rewards (Raschick and Ingersoll-Dayton 2004). Costs are things such as the caregiver feeling exhausted, lacking time for him- or herself, and having more to do than he or she can handle. Rewards are emotions such as feeling good about oneself and appreciating life (Raschick and Ingersoll-Dayton 2004). Other positive aspects of caregiving are being able to reciprocate for parents' care of them as a child, having "a sense of purpose and satisfaction from simply being able to provide care to their parents, and the opportunity to provide a role model for their own children" (Harris and Bichler 1997:108). Since the unpleasant features of relationships are more prominent "to individuals than are the positive aspects" (Umberson 1996:516), the stress and burden of caregiving probably outweigh the rewards for most adult child caregivers.

Compared to spouses, "adult children experience more rewards" when providing care (Raschick and Ingersoll-Dayton 2004:321; also see Kang 2006). Adult children also report less hours of care on average, more use of formal services, and more availability of respite care than spousal caregivers, but the same amount of strain (Kang 2006). Also, children report more limitations on their personal lives (such as reduced time with other family members or friends) than spouses do (Kang 2006), but interference with one's personal life predicts strain for both spousal and child caregivers (Mui 1995a, 1995b). These findings suggest that adult children feel that providing care to parents is more stressful than spouses think providing care to each other is, since even with more assistance children are equally stressed. Perhaps some of this burden is felt because adult children caring for their parents often have more social roles than spousal caregivers do. Adult children caregivers are often employees, spouses, and parents while caregiving spouses are less likely to be employed or to have obligations to children.

Occupying multiple roles either leads to extra stress and burden for a caregiver, or buffers the care provider from stress (Chumbler et al. 2004). Too many obligations cause feelings of overload. However, the roles other than caregiver are sources of support or of personal growth (Chumbler et al. 2004), and the caregiver role itself offers benefits such as new skills and confidence (Roberto and Jarrott 2008). Support groups potentially could provide affirmation for adult children who are helping their parents, and respite care could supply relief.

Age and policy issues

Compared to others with a living parent, older adult children are more likely to provide care (Hill 2006). The largest age category for adult children providing care is 45–64 years old (see Table 3.3), with a mean age of 55 years old (Wolff and Kasper 2006). However, about one-third of adult child caregivers are over 60 years old and about a fifth are between the ages of 60 and 65 years old (Mui 1995a; Stone et al. 1987). These ages are when people are making retirement decisions, having implications for their own later financial security. The timing of retirement affects income; people who retire earlier have lower benefits (Szinovacz and Ekerdt 1996; Wakabayashi and Donato 2006), and caregiving in later life increases the odds of leaving paid employment (Moen 2001). Women are particularly in danger of poor financial status in later life (Himes 2001) so early retirement by women to provide caregiving (either to an elderly parent or spouse) is a cause for alarm.

Similar retirement issues arise for people of color. For men, Blacks and Latino/as have less income in retirement than Whites (Hogan, Kim, and Perucci 1997), so early retirement for caregiving would also be of concern – not only for them but also for spouses who would be affected by their pension or Social Security income. While one study of Black caregivers found that most of the adult child caregivers were working, the unemployed caregivers reported being unable to look for work because of their care responsibilities (Bullock, Crawford, and Tennstedt 2003). Presumably those providing more care to parents have less time to work for pay. Some caregivers apply for Social Security at age 62 to have more time to give to their parent. Those people who take Social Security benefits early tend to be in worse health than those who take benefits at their full retirement age (Ozawa and Choi 2002), and early benefits are lower, so that those in worse health in their fifties and sixties are likely to be in worse economic situations in even later life. Those individuals who provide care to parents are more likely to retire and to be in worse economic situations afterward (Hill 2007). In other words, those who are most likely to need assistance will be less likely to be able to pay for it, placing more burden on family members and repeating the cycle.

Summary

If they have a living parent, most adult children will assist that parent at some point. In particular, daughters are very likely to provide parental care. This caregiving usually takes place when children are in their fifties or older, since people are most likely to need help at later ages such as 85 years old and older. Adult children are motivated to help their parents by affection, societal norms of obligation, the desire to reciprocate for the care their parents gave them, expectations of inheritance, or a combination of these reasons.

The gender composition of the sibling network affects the caregiving of sons; men with sisters provide more care to parents than only sons or men with only brothers. Whether a woman has sisters or brothers does not affect how much care she provides, however. Children assist with a wide variety of tasks from money management to nursing care. Daughters are more likely to help with household chores and personal care (such as dressing or bathing) while sons are more likely to help with transportation and home maintenance.

On average, adult children help their parents over ten hours a week, and for four years or more. Almost half of adult child primary caregivers do not have any assistance with providing care. Most either live within ten minutes of the parent they are helping, or they coreside with the care recipient. Blacks and Latino/as are more likely than Whites to live with their elderly parents and to give them financial aid. Other relationships between race, ethnicity, and caregiving are unclear.

Paid employment and obligations to one's own spouse and children are important factors that conflict with providing care to a parent. Also, if an adult child is in poor health, his or her ability to help a parent is limited. In turn, providing care to a parent can negatively impact an individual's health. Adult child caregivers feel more strain and burden than spousal caregivers do, but they also experience more rewards.

Just as for spouses, more current research is necessary regarding which tasks children do while caring for elderly parents. Witt's (1994) findings that rural and urban residence affects task provision suggests that gender role socialization drives what jobs people do, and changes in gender roles have occurred since the 1980s datasets that Witt (1994) and Dwyer and Seccombe (1991) used. In addition, we need more comparative studies with larger numbers of members of minority groups. Surprisingly, we also know little about economic or social class differences between adult child caregivers.

Most studies of adult child caregivers focus on one primary caregiving child and the parental care recipient, overlooking other family members who also provide care (Hequembourg and Brallier 2005). Many adult children act as secondary caregivers and support their siblings or parents (e.g., Pearlin, Pioli, and McLaughlin 2001), yet their contributions (and the costs they bear) are not always apparent in research. We need more studies that include the entire sibling set (Mathews 2002). As we see in the next chapter, few studies address team and secondary caregiving.

Spouses and adult children make up the majority of caregivers for older adults. A fifth of primary caregivers, however, are other types of relatives or are unrelated to the care recipient. Other relatives (such as siblings and daughters-in-law) are quite often secondary caregivers as well. The next chapter explores their contributions.

4

Caregiving by Other Relatives, Secondary Caregivers, and Members of Minority Groups

Abstract: *Caregiving by siblings, grandchildren, and other relatives (including fictive kin and ex-spouses) is discussed. Research on secondary caregivers and team caregiving also is reviewed. Studies of kin care within sexual and racial/ethnic minority groups are covered as well.*

Keywords: aging; caregiving; LGBT elderly; minority elderly; siblings

Hill, Twyla J. *Family Caregiving in Aging Populations.*
New York: Palgrave Macmillan, 2015.
DOI: 10.1057/9781137511560.0008.

Little research exists on caregiving by siblings, grandchildren, daughters-in-law, and other relatives (including friends and fictive kin), even though they are about a fifth of all primary caregivers (Wolff and Kasper 2006). In addition, not much is known about secondary caregivers or team caregiving, as research has tended to focus on the primary caregiver alone. While the most common family caregiving system is the primary caregiver model, often other people are involved in care provision, and their contributions should be acknowledged (see Keith 1995).

This chapter first discusses what is known about other relatives who serve as caregivers in general, and then covers siblings, daughters-in-law, grandchildren, and friends and fictive kin specifically. Secondary caregivers, team caregiving, and caregiving networks are the next topics. The chapter then turns to research on members of minority groups as caregivers. Much research regarding care provision by members of minority groups does not specify relationship to the care recipient. Therefore, some of the caregivers in these studies may be spouses or adult children, but the proportion of these family members compared to other kin is not reported. Studies of members of minority groups or the rarer relationship types of caregivers are important because they can alert us to differences and similarities in caregiving experiences across groups. Such research also obscures differences within groups, however. For example, we cannot assume that a son-in-law and daughter-in-law or Latina wife and a Latina daughter will be affected similarly by providing care.

Other relative caregivers

This category is made up of all relatives other than a spouse or child, and includes friends and fictive kin. In 1999, other relatives were about 20% of all primary caregivers (Wolff and Kasper 2006:350). Almost half of these care providers share a home with the care recipient and another quarter live within ten minutes (see Table 4.1; Wolff and Kasper 2006). Therefore, most other relative caregivers live quite close to their care recipient; perhaps they became caregivers because of the geographic proximity. However, maybe they live nearby because of affection for the care recipient, which also would make them a candidate for caregiver. Motivations for these care providers include familial obligations and affection, similar to spouse and adult child caregivers. Some obligations

TABLE 4.1 *Characteristics of other relative primary caregivers, 1999*

Age, in years (%)	
14–44	17.6
45–64	41.1
65–74	12.3
75 and older	14.9
Mean age (years)	57.1
Gender (%)	
Male	19.4
Female	74.8
Marital status (%)	
Married	48.1
Widowed	14.1
Divorced or separated	13.3
Never married	15.2
Perceived health status (%)	
Excellent	28.5
Good	35.6
Fair	23.1
Poor	3.4
Distance to care recipient (%)	
Coreside	48.2
10 minutes or less	24.5
11–30 minutes	17.0
31–60 minutes	1.3
More than 1 hour	0.6

Source: Wolff and Kasper 2006:350.

may outlast legal bonds; some ex-wives report they assist their ex-husbands because their children are unwilling or unable to provide help, or because their ex-husband has no other potential caregiver (Cooney, Proulx, Snyder-Rivas, and Benson 2014). Qualitative research with rural caregivers for older relatives shows no differences between spouses, adult children, siblings, or grandchildren in feelings of responsibility (Langner 1993), so similar reasons motivate familial caregivers, whatever the relationship.

Three quarters of other relative primary caregivers are female, and almost half are married (see Table 4.1; Wolff and Kasper 2006), suggesting that many of these caregivers are daughters-in-law. In 1999, the mean age was 57 years old, with most between the ages of 45 and 64 years old (see Table 4.1). This age group is the largest category for adult child caregivers as well, leading me to think that many of the other

DOI: 10.1057/9781137511560.0008

relative primary caregivers have a similar generational position relative to their care recipient; in other words, they probably are daughters-in-law or sons-in-law. However, over a quarter of other relative caregivers are 65 years old and over. These oldest other relative caregivers may be siblings, cohabiting partners, or ex-spouses.

Forty percent of these other relative primary caregivers have been providing assistance for over 4 years, with another 30% helping between one and four years (see Table 4.2; Wolff and Kasper 2006). Over half assist the care recipient seven days a week. Most, however, give aid ten or less hours per week on average (see Table 4.2). A fifth provide care over 40 hours a week, so other relative caregivers tend to either help a little or a lot. They assist with shopping or transportation, household tasks, personal care and nursing, administration of medicine, indoor mobility, and finances (see Table 4.2). Not surprisingly, a smaller percentage (30%) helps with financial management than spouses (53%) or children (56%). Otherwise the kinds of tasks with which they help their care recipient are not that different.

Other relative caregivers are the most likely to receive assistance; although 34% report no help at all, 43% report help from other family

TABLE 4.2 *Amounts and types of assistance provided by other relative primary caregivers, 1999*

Length of caregiving in years (%)	
Less than 1	21.6
1–4	30.1
More than 4	41.0
Average days per week (%)	
Less than 3	28.2
3–6	13.6
7	55.4
Average hours per week (%)	
Up to 10	41.7
More than 10 and up to 20	16.3
More than 20 and up to 40	19.4
Over 40	20.4
Specific tasks (%)	
Shopping and/or transportation	76.0
Household tasks	72.1
Finances	29.7
Personal care and/or nursing	44.6
Giving medicine	36.9
Indoor mobility	29.8

Source: Wolff and Kasper 2006:351.

or friends, and almost a quarter (24%) report paid assistance (Wolff and Kasper 2006:352). Only 12% have coresiding children under 15 years old, and just over a third (34%) are employed for pay (Wolff and Kasper 2006:352). Both of these percentages are less than for adult child caregivers, suggesting that these other relative caregivers have fewer competing obligations than adult children. Perhaps they are more willing to provide care because they have less responsibilities in other areas.

The percentage of other relative caregivers compared to spouse and children caregivers is lower for non-Hispanic Whites than for people of color (Stone, Cafferata, and Sangl 1987:621). According to some studies, primary caregivers of Black elderly persons are more likely to be other relatives than those for older Whites (Lum 2005) or for Latino/as (Cox and Monk 1996) and perhaps in comparison to caregivers from any other racial or ethnic group. This finding lends support to the idea that members of minority groups can call upon relatives other than spouses and children, but it does not necessarily mean that they have larger numbers of caregivers overall. For example, Lum (2005:17) found that Blacks are less likely and Latino/as more likely to have caregivers than Whites. Therefore Black elderly may have the most unmet needs for care, even though a greater percentage of Black primary caregivers are other relatives.

Sibling caregivers

Some caregiving research has focused on specific types of other relatives, such as siblings. Elderly adults commonly think of their brothers and sisters as resources for assistance if needed, but they do not often serve as caregivers (Cicirelli, Coward, and Dwyer 1992:332). Siblings are estimated to be less than 10% of primary caregivers (Bedford 1996:211). White (2001:563) found that a lot of sibling assistance occurs after age 70 between siblings who live fairly close to each other, however. Many older adults feel close to their siblings and sibling relationships are more important in old age than in earlier years (Van Volkom 2006). Most brothers and sisters are willing to give help in later life, even though few actually have to provide aid. They also say they can call upon their siblings for help (Cicirelli 1995). Sisters and brothers assist each other because of emotional closeness or norms of familial obligation (Eriksen and Gerstel 2002).

Older people without children or spouses are more likely to receive help from siblings (Cicirelli 1995:117; also Eriksen and Gerstel 2002;

Miner and Uhlenberg 1997; Van Volkom 2006). Never married individuals may have built up relationships with other siblings over the course of their lifetimes that make them especially able to call on those sisters and brothers if help is needed (Cicirelli 1995). As baby boomers have fewer children but more siblings than members of other age cohorts, brothers and sisters should become more important sources of support in the near future.

Siblings provide help more often in ways such as emotional support (talking with each other), transportation, and housekeeping, rather than nursing or personal care (Cicirelli 1995). Women, those with higher education, and those with more brothers and sisters are more likely to give and receive assistance (Eriksen and Gerstel 2002; Van Volkom 2006; White 2001). Rural respondents are more likely to receive support than urban respondents (Miner and Uhlenberg 1997). If a person feels emotionally closer to a sibling, he or she gives that person more assistance, so the quality of relationship also matters (Eriksen and Gerstel 2002).

Blacks are more likely to be caregivers for sisters and brothers than Whites (Mui and Morrow-Howell 1993). Black and White siblings give somewhat different types of assistance; while Whites and Blacks are equally likely to provide most kinds of aid, Blacks more often help with transportation while Whites provide assistance with shopping and decision making (Suggs 1989). Blacks are more likely than Whites to say they give emotional support to a brother or sister (Miner and Uhlenberg 1997). Older respondents are less likely to give instrumental support (such as transportation or household chores) than emotional support, reflecting their own abilities (Miner and Uhlenberg 1997). The state of their own health affects what kind of care and the duration of assistance that siblings can give (Cicirelli 1995). Those brothers and sisters who are in poor health themselves probably are not able to give much help, or they may have to stop assisting a sibling.

Those siblings who live near to one another are more likely to provide help to one another (Miner and Uhlenberg 1997), but perhaps they live closer to one another because they are more attached to one another in the first place. People with more sisters and brothers are more likely to live close to a sibling, and those individuals without a living parent, child, or spouse also are more likely to live close to a sibling (Miner and Uhlenberg 1997). Blacks and Latino/as have more siblings, and live closer to their brothers and sisters, than Whites or Asian Americans (Miner and Uhlenberg 1997; Reidmann and White 1996). Adult Blacks and

Latino/as more often live with siblings than Whites or Asian Americans do (Reidmann and White 1996). However, Mexican Americans are more likely to live with sisters or brothers than Puerto Ricans, showing that variations occur across different Latino/a groups (Reidmann and White 1996:112).

Also, noncoresiding Latino/as and Blacks are less likely to assist their brothers or sisters than Asian Americans or Whites (Reidmann and White 1996:117). Those Blacks and Latino/as with higher incomes actually exchange more assistance than poorer siblings (Reidmann and White 1996). Wealthier respondents are more likely to give emotional, but not instrumental, support (Miner and Uhlenberg 1997). Social class affects sibling assistance, therefore, particularly for Blacks and Latino/as (Reidmann and White 1996:123).

In some cases, sisters or brothers take over as primary caregivers for people with lifelong health problems. Although parents are usually the primary care provider(s) to an individual with mental illness, as parents age and die, siblings often assume these duties (Earl 2006; also see Lohrer, Lukens, and Thorning 2007). Sisters, those geographically close, and those without living parents, are more likely to provide care to a mentally ill brother or sister (Lohrer et al. 2007). Most studies of siblings caring for someone with mental illness have been of Whites and Blacks; little is known about members of other groups (Earl 2006), so these findings may or may not apply to them.

Providing care has costs for siblings. Just as for spouses and adult children, lack of respite care and more conflict with one's own life means more strain for a brother or sister primary caregiver (Mui and Morrow-Howell 1993). Higher burden is also related to lower quality of relationship with the care recipient (Mui and Morrow-Howell 1993). These findings show the similarity of caregiving effects for spouses, adult children, and siblings. People who are being cared for by siblings tend to be less impaired than those receiving care from a spouse, however, and sibling caregivers are more likely to be receiving assistance than spousal caregivers (Mui and Morrow-Howell 1993). Not surprisingly, therefore, spouses report higher levels of strain than sisters or brothers (Mui and Morrow-Howell 1993).

While brothers and sisters are a fairly small percentage of caregivers now, the proportion probably will increase. Older people in the future may be less likely to have spouses and children, so that sisters and brothers will be called upon more often to act on their willingness to provide assistance (see Cicirelli et al. 1992). Sisters in particular should be a higher percentage of caregivers in the future.

Daughter-in-law caregivers

Currently, daughters-in-law probably make up a large proportion of other relatives providing care, although the percentage is unknown. Qualitative research has found that many of them assist parents-in-law without daughters, suggesting that they take on these duties because they are the only female relative available (Merrill 1993). Also, daughters-in-law sometimes provide care as a replacement for sons, taking on tasks for their husbands as part of the marital relationship (Globerman 1996; Strauss 2013). Daughters-in-law also help with the same number of ADLs and IADLs as daughters, which could mean that they are taking on “a role similar to that of daughters”, and not simply helping out their husband (Merrill 1993:87). They spend less time on average providing assistance compared to daughters, however (Merrill 1993).

In general, daughters-in-law feel less obligated to provide care than daughters (Peters-Davis, Moss, and Pruchno 1999). The quality of the relationship with the care recipient affects how both daughters and daughters-in-law feel about providing care; the better the relationship, the less burden and more satisfaction is reported (Peters-Davis et al. 1999). For daughters-in-law, the length and quality of the relationship with the care recipient may be more important factors than the obligatory nature of kin ties (Merrill 1993; Peters-Davis et al. 1999). Affection for the elderly person makes a daughter-in-law more willing to meet cultural obligations to provide care (Peters-Davis et al. 1999).

Shuey and Hardy (2003:428) found that couples, regardless of race or ethnicity, “appear more responsive to the needs of the matrilineal parent than to the needs of the patrilineal parent”, suggesting that women are more likely to help their mothers than their mothers-in-law. However, non-White couples are more likely to provide assistance to both sets of parents if there is need than are White couples (Shuey and Hardy 2003). Perhaps norms of in-law obligations are stronger for members of minority groups than for Whites.

Patriarchal cultures often include expectations that daughters-in-law will cater to the needs and desires of older mothers-in-law (Murti 2006). While cultural differences exist regarding anticipated care provision from daughters-in-law, Murti’s (2006) interviews with South Indian

Hindu widows suggest that living in America tends to increase expectations of daughters but not decrease expectations of daughters-in-law; both daughters and daughters-in-law are supposed to provide care to older women, therefore. Some studies of Chinese American and Filipino American caregivers also indicate that living in the United States increases expectations of daughters, but daughters-in-law are still seen as culturally appropriate care providers (see Jones, Zhang, and Meleis 2003; Lan 2002). Some groups may anticipate particular daughters-in-law to be primary caregivers (e.g., the wife of the eldest son), but in general American daughters-in-law feel pressure to furnish assistance. The obligation of female relatives to provide care is very strong across many groups, however, as is seen later in the chapter.

Grandchildren caregivers

Grandchildren are about 8% of all caregivers, both primary and secondary (Robert Wood Johnson Foundation 2003). Although grandchild caregivers are generally under 40, they are mentioned here because grandchildren often are secondary caregivers, especially when the elderly care recipient is brought into a household so that an adult child can provide care (Szinovacz 2003). Young and adolescent grandchild caregivers usually live with the grandparent(s) who need care, while adult grandchild caregivers are less likely to coreside with their care recipient (see Fruhauf, Jarrott, and Allen 2006; Fruhauf and Orel 2008). Grandchild caregivers often provide the same types of help as spouses or adult child caregivers such as personal care and assistance with household tasks (Fruhauf and Orel 2008). A common assignment for young grandchildren is to watch their grandparent and let the primary caregiver (usually their mother) know if she is needed (Fruhauf and Orel 2008). While this task might seem simple to the primary caregiver, grandchildren find this duty somewhat stressful (Fruhauf and Orel 2008).

Grandchildren experience both benefits and costs for providing care. Rewards of caregiving are increased time and a deeper relationship with the grandparent (Fruhauf et al. 2006:904–905). Adolescents who help with caregiving report that some rewards are added time with their siblings, more shared family activities, and increased bonding with their mother (usually the primary caregiver) (Beach 1997). They also say that greater empathy for elderly persons and finding friends who are supportive of caregiving are benefits of taking care of their grandparent

(Beach 1997). There are some negative effects of caregiving, however. Grandchildren experience stressors such as time constraints and restrictions in their ability to go to work or school (Fruhauf et al. 2006). Early obstructions such as these would limit their ability to obtain an education, get a job to provide for themselves in midlife, or to finance their own retirement, just as for other family caregivers.

Adult grandchildren may be primary caregivers if the middle generation is unable to provide care or is not present. For example, the care recipient's child may have died from cancer or while serving in the military. They may be in jail or in very poor health themselves. In those situations, an adult grandchild (or other relative) often will step in. An 85-year-old is likely to have grandchildren who are in their thirties or forties. These caregiving grandchildren are likely to have similar issues as sandwich generation adult child caregivers.

Friend and fictive kin caregivers

Although friends and fictive kin are estimated to be assisting between 5% and 20% of older people (Barker 2002; LaPierre and Keating 2013), little systematic research has been done with this group of caregivers (Himes and Reidy 2000). Some of these people are the only care providers for a care recipient; others are part of caregiving networks that include other friends, the care recipient's family, and/or the caregiver's kin (Barker 2002). For example, "LGBT older adults ... have distinct support networks, relying heavily on partners and friends, most of a similar age, to provide assistance and help as they age" (Fredriksen-Goldsen et al. 2011:3).

Just as for relatives who are providing care, most friends who give assistance are female (Barker 2002). Female friends providing care tend to be older and are more likely to be unmarried and unemployed than women providing care to family members (Himes and Reidy 2000). Friends give less hours of care and for shorter periods compared to relatives (Himes and Reidy 2000). "(W)omen who are older and unmarried are more likely to develop support networks outside their families, increasing their chances of both receiving care from nonfamily members and providing such care themselves" (Himes and Reidy 2000:330). In Barker's (2002) study of friend caregivers, many care recipients did not have living relatives. These findings suggest that people look to others to provide care when biological family members are not available.

Divorced men in particular may have few options. Cooney et al. (2014) interviewed 21 ex-wives who were primary caregivers. These women often experienced problems with service providers who did not recognize them as family members. Because "few norms exist for what constitutes appropriate behavior between former spouses," the ex-wives faced disapproval from some family members and coworkers (Cooney et al. 2014:86). They also questioned their own reasoning, but generally felt their ex-husbands did not have other potential caregivers available. Ex-spouses probably are very different from other types of nonrelative caregivers, due to their shared marital history with the care recipient. As the percentage of the elderly who are divorced increases, ex-spouse caregivers may become more common.

Some friends and fictive kin provide care because they had close relationships with the care recipient prior to his or her need for care, but others have been just acquaintances (Barker 2002). Geographic proximity and a predisposition to providing care are the most important factors in why nonrelatives give assistance (Barker 2002; Nocon and Pearson 2000). These people are motivated by "seeing an otherwise unfilled need," a feeling of "moral duty" and of "being a good neighbor" (Barker 2002:S164). Also, many nonkin caregivers say they provide assistance as an expression of their religious beliefs (Barker 2002; Nocon and Pearson 2000). Neighbors may provide help with home maintenance as a way of preserving real estate values (LaPierre and Keating 2013). These reasons are somewhat different from the motivations that relatives report. For members of sexual minority groups, however, friends are often chosen family members, and many older unpartnered lesbians and gays say they would request caregiving assistance from friends (Cahill, Ellen, and Tobias 2002). For some LGBT care recipients, friends may be the only sources of help (Muraco and Fredriksen-Goldsen 2011). Therefore, we would expect their motivations to be the same as relatives' motivations.

The types of assistance provided ranges from giving emotional support (talking with each other and giving advice) to personal care such as bathing or helping with medication (Barker 2002). The most frequent types of aid are emotional support and transportation (Barker 2002; also see Himes and Reidy 2000). Shopping and home maintenance are also common (LaPierre and Keating 2013). Some nonrelatives provide extensive amounts of care; Barker (2002) found that in some instances friend care providers live with the care recipient because intensive care is needed. Most nonkin caregivers, however, provide less demanding assistance. While the help they give may not be strenuous, it is often very useful, such as when they check on the care recipient and report to a long-distance caregiver (see Koerin and Harrigan 2002). Fictive kin, friend, and neighbor caregivers often act as secondary caregivers while a female relative is the primary caregiver (Barker 2002). The ability of friends to be primary caregivers probably is limited. They will not have the capacity to make decisions for and about the care recipient unless they are specifically named in legal documents, such as power of attorney (Fredriksen-Goldsen et al. 2011).

Secondary caregivers

Less than half of primary caregivers receive assistance (Wolff and Kasper 2006). However, secondary caregivers provide important support, help, and respite when they are present. While the primary caregiver has responsibility for managing the care, and usually provides most of it, secondary caregivers can help with all sorts of tasks including personal care, emotional support, and transportation (see Keith 1995). Many adult children are secondary caregivers assisting spouses (Pearlin et al. 2001); in other words, they are helping a parent (or step-parent) provide care to the other parent. Sisters and brothers also serve as secondary caregivers to spouses; they may aid a sibling to care for his or her spouse or help their brother- or sister-in-law to care for their sibling (Cicirelli 1995). In some cases, the daughter-in-law (or son-in-law) is the primary caregiver while the adult child provides assistance (Strauss 2013). The little research that exists on sons-in-law suggests that they are usually secondary caregivers, assisting and supporting their wives in caring for her parents (Kleban, Brody, Shoonover, and Hoffman 1989; also see Globerman 1996). Black men provide more help than White or Latino sons-in-law (Szinovacz and Davey 2008).

For adult child secondary caregivers, the amount of impairment of the care recipient, the health of the caregiving parent, or the closeness of the relationship do not affect involvement in caregiving even though we would expect these characteristices to have some effects (Pearlin et al. 2001:247). Factors such as financial status, paid employment, being married, and having minor children do impact who becomes a secondary caregiver and how much assistance they provide. The greater the feeling of financial insecurity the adult child has, the less involved in secondary caregiving he or she will be (Pearlin et al. 2001:247). Reduction of job commitments, however, is related to more secondary caregiving involvement. Pearlin et al. (2001) speculate that people who feel they can reduce their hours of paid work without endangering their financial security will do so to help out a parent, even as a secondary caregiver. Having one's own children and being married also reduce the amount of caregiving assistance provided (Pearlin et al. 2001:247). Obligations to one's own spouse and children get in the way of providing care to other family members.

Geographic location also affects whether one is a primary or secondary caregiver. Many long-distance caregivers are secondary caregivers, helping someone who lives closer to the care recipient (Koerin and Harrigan 2002). Some of the ways long-distance secondary caregivers help are by traveling to provide respite care, paying for services, being involved in making decisions, or by making arrangements for formal care (Harrigan and Koerin 2007; Koerin and Harrigan 2002). Negotiating with the on-site caregiver how to help can be a source of stress for both the long-distance and on-site individuals (Harrigan and Koerin 2007). Geographic distance does not prevent all assistance but makes it more difficult to be a primary caregiver. As communication technologies change, however, it is becoming easier for long-distance caregivers to provide emotional support to the care recipient and other care providers (see Baldock 2000 and Harrigan and Koerin 2007).

Pearlin et al. (2001) find that secondary caregiving strains marital and parental roles, conflicts with paid work, and limits social life. Also, daughters experience more conflicts with paid work and more constriction of social life than sons, which is probably related to gender role expectations (Pearlin et al. 2001:248, 249). Higher levels of caregiving lead to higher levels of depression and worse physical health, but the effects are indirect, through the disruption of marital and parental roles and the conflicts with paid work (Pearlin et al. 2001:249–251). Therefore, secondary caregiving also has costs, though not as many as primary caregiving.

Team caregiving and caregiving networks

A secondary caregiver can be one individual assisting a primary caregiver or be a member of a caregiving team. Caregiving teams are formed by families in response to the needs and circumstances of all family members, not just the needs of the care recipient (Brewer 2002; Piercy

1998). They include at least two family members (usually more) who provide assistance to the person who needs help and give support to each other (Brewer 2002). The number of family members, gender composition of the kin network, and geographic location of relatives affect the organization of the caregiving team (Keith 1995). Characteristics of the care recipient also impact the structure of the caregiving network. For example, Black care recipients with more disabilities or more children living nearby usually have more care providers, while those with less financial resources have fewer (Dilworth-Anderson et al. 1999).

Values held by the family members also are an important factor. Desires for fairness, unwillingness for any particular person to be overburdened, and feelings of responsibility to other relatives promote team caregiving (Keith 1995; Piercy 1998). Women are usually the primary caregivers, but sometimes a son will be the person in charge of the team (Keith 1995). Team members are often siblings, the spouse of the primary caregiver, and/or grandchildren of the care recipient (Pyke and Bengtson 1996). Ethnic minority families more often have team caregiving than Whites (Dilworth-Anderson et al. 2002).

Although caregiving sources tend to remain stable, they can alter, and very few studies have addressed changes in caregiving networks (Peek, Zsembik, and Coward 1997). Once an individual becomes a care recipient, several transitions are possible. Someone receiving only informal care may stop getting care, or begin receiving formal care as well as informal care, for example (Peek et al. 1997). The primary caregiver may change (from a spouse to an adult child, perhaps) or secondary caregivers may stop or start providing support. Szinovacz and Davey (2007, 2013) found that about half of adult child caregiving networks experience change. The care teams of male recipients alter more than those of female care recipients (Peek et al. 1997:347). White networks are more stable than Black or Latino/a networks, as are female-only networks compared to those teams that include men (Szinovacz and Davey 2007, 2013). Large networks tend to shrink (Szinovacz and Davey 2007, 2013). Since most studies look at caregiving at only one point in time and focus on the primary caregiver, the amount of team caregiving that happens is apt to be undercounted. The amount of change in caregiving networks also probably is underestimated. Much more research is needed on secondary and team caregiving.

Such studies could help answer the question whether members of minority groups are more likely than Whites to have more different types of relatives who provide care or to have greater numbers of people they can call upon. Only if they have more secondary caregivers, or more team caregiver groups (in other words, more caregivers in total), would they have larger networks than Whites. Lum (2005), whose study included members of a number of Latino/a groups, found that elderly Latino/as have more types of caregivers and larger caregiving networks than Whites or Blacks. However, Dietz (1997), whose sample was only of older Mexican Americans, found that many of them were not receiving help with their needs. In another study comparing Mexican Americans to non-Hispanic Whites, Mexican American caregivers reported smaller networks than Whites (Phillips, Torres de Ardon, Komnenich, Killeen, and Rusinak 2000). Perhaps Mexican Americans have smaller networks than Cuban Americans or Puerto Ricans. The types of people in the sample clearly affect the research findings. Therefore, while some Latino/as may have larger networks than Whites, other Latino/as, and members of other minority groups, may not. For example, a study of Pacific Islander caregivers found that "many of the caregivers were the only family member providing any sort of care to their loved one... despite the presence of other adult family members in the home" (Kaholokula, Saito, Mau, Latimer, and Seto 2008:285). Results from a number of studies therefore suggest that members of minority groups may not have access to larger caregiving networks than Whites.

Another sampling issue is that sometimes studies consist of only care recipients and other studies include both elderly people who are and are not receiving care. This difference might explain why Lum (2005), who included both care recipients and people needing assistance but not receiving it, found that Black elderly were the least likely to receive care, while Dilworth-Anderson, Williams, and Cooper (1999) in a study of only Black care recipients found that about three quarters of them had at least two caregivers. Perhaps Blacks are at more risk than Whites for not receiving care, but those who do receive care have larger networks. These differences in what kinds of people are in the samples mean that it is difficult to compare the varied and contradictory findings. Questions are still unanswered regarding actual network size and availability of caregivers for older persons. Service providers need to be aware that team caregiving is a possibility and not assume that there is just one caregiver. They also should be open to changes in caregiving networks to facilitate the best outcomes for the care recipient.

Members of minority groups

Much research regarding care provision by members of minority groups does not distinguish relationship to the care recipient. Some studies of minority caregivers do specify relationship to the care recipient; results from those studies have been discussed earlier. The following findings are from studies which either do not differentiate by relationship type or by whether the respondent is a primary or secondary caregiver. Although these studies obscure differences by kin or caregiver type, they do give us important information about the experience of minority group members. Since the book is primarily organized by relationship to the care recipient, these findings do not fit elsewhere. This section is arranged by type of minority group.

Sexual minority caregivers

Older members of sexual minority groups probably do a lot of caregiving for other elders. One large study of bisexuals, gays, and lesbians 50 years old and older found that 45% were presently providing care to a partner, biological family member (usually a parent), or friend (Shippy 2007). In another study, 67% had assisted someone in the past five years (Grossman, D'Augelli, and Dragowski 2007). Studies of lesbian and gay caregivers generally do not differentiate between spousal, friend, and parent caregivers. Also, these studies rarely discuss racial or ethnic differences, although most LGBT research has focused on non-Hispanic Whites. Research on gay caregivers has tended to focus on men providing care for someone with AIDS (Cohen and Murray 2006), who often become caregivers while relatively young (Wight 2002; also see Sipes 2002). Sexual orientation is seldom included as a variable in research, however, so homosexuals undoubtedly provide care for people with a variety of needs and illnesses.

Lesbians feel more caregiving burden than gays (Shippy 2007), similar to findings for women and men in the general population. Lesbians are more likely to do traditional female tasks than gays (Cohen and Murray 2006), so gender roles matter. Lesbians are more likely to provide care for those 65 years and older, while gays are more likely to provide care for working age adults (Fredriksen 1999), suggesting that gays primarily provide care for their partners, while lesbians take on caregiving for a variety of family members. Both lesbians and gays also help out friends and obtain assistance in return. Giving and receiving help are highly correlated (Grossman, D'Augelli, and Dragowski 2007). Grossman et al. (2007) suggest that this illustrates exchange theory in practice. "Not having traditional kin to depend on when they need help, the participants in this study 'know' that providing care is an investment in receiving care when one needs it" (Grossman et al. 2007:31).

Although in many ways the caregiving experience is similar for heterosexuals and homosexuals, gays and lesbians often face challenges from policy, organizations, and other family members who make providing care more difficult, particularly care to a partner (Cohen and Murray 2006; Hash and Cramer 2003). Lesbian and gay partners generally do not have the same legal decision-making rights as heterosexual spouses, for example. They also are not eligible for the federal family leave program, as discussed in the next chapter. In addition, medical staff sometimes treat them differently because of their sexual orientation (Shippy 2007). Discrimination against LGBT care recipients and their caregivers results in higher levels of depression for both (Fredriksen-Goldsen, Kim, Muraco, and Mincer 2009).

Also, LGBT care recipients are at higher risk for not receiving appropriate medical care in the first place; many have been denied care or received inferior care (Fredriksen-Goldsen et al. 2011). Within this group, differences exist; older bisexual women "are less likely to have a primary physician or healthcare provider than lesbians" (Fredriksen-Goldsen et al. 2011:4). Over a fifth of older LGBT adults have not disclosed their gender identity or sexual orientation to their health care provider, which "can lead to failure to diagnose serious medical problems" and prevents discussion about health risk factors (Fredriksen-Goldsen et al. 2011:5). Fear of discrimination therefore can compound medical problems and reduce the amount of appropriate care.

For those homosexuals providing care to a member of their family of choice, a majority are providing care to their partner (Shippy 2007). Of those providing care to a friend, gays generally provide care to another man, while lesbians provide care to both men and women (Cantor, Brennan, and Shippy 2004 cited in Cohen and Murray 2006). For lesbians and gays providing care to a member of their family of origin, most are providing care for females, often parents or siblings (Cantor et al. 2004 cited in Cohen and Murray 2006). Similar to spousal caregivers, lesbian, gay, and bisexual caregivers often have chronic health issues of their own, affecting their ability to provide great amounts or certain types of care (Muraco and Fredriksen-Goldsen 2011). Since adult child caregivers are rarely asked about sexual orientation, we do not know whether homosexuals are less, as, or more likely to provide care for a parent than heterosexuals. About a third of lesbian and gay caregivers report their families expect "more of them because of their sexual orientation," however (Shippy 2007:44), so they may be more likely to be parental caregivers than heterosexuals. One study did find that LGBT Baby Boomers are somewhat more likely to be caregivers than their heterosexual counterparts (MetLife 2010). Including sexual orientation as a research variable is an obvious step to knowing more about the caregiving experience for homosexuals.

Also, research has tended to apply findings from lesbians, gays, and/or bisexuals to transgendered persons as well, which is not always appropriate (Williams and Freeman 2007; also see Fredriksen-Goldsen and Muraco 2010). Some issues are similar; for example, transgendered persons report discrimination from medical personnel, such as insults or jokes regarding their identity (Williams and Freeman 2007). Health issues related to transitioning from one gender to the other are specific to transgendered persons, however, and they may be more likely to be isolated from biological family members and other sources of caregiving support. Health care providers and care recipients also may be less willing to accept transgendered persons as caregivers (Williams and Freeman 2007), causing obstacles when they do try to provide care for an older family member. In addition, LGBT members of racial or ethnic minority groups may face discrimination "including a lack of acceptance within the predominantly White organized LGBT community," which may limit their access to caregiving resources; the effects of this have not been explored (Coon 2007:118). In general, more research is necessary to understand the caregiving of members of all gender and sexual minority groups.

Black caregivers

Most studies of Black caregivers do specify relationship to the care recipient and therefore are discussed elsewhere in this book. Some studies of Black caregivers differentiate by sex but not kin type, however. In general, Black women provide more care than White women or Black men, but feel less burden (Martin 2000). Williams, Dilworth-Anderson, and Goodwin (2003) found a wide range of strain levels in their study of Black female caregivers, however. Caregivers with worse health, more education, or who lived with the care recipient felt more strain (Williams et al. 2003). Therefore, policymakers and service providers should not assume that providing care comes easily for or has little cost to Black women. Also, few studies that compare Black caregivers to those from other backgrounds discuss diversity within groups, although regional, rural/urban, immigration history, and other differences likely exist. For example, recent immigrants from Africa probably will not have much in common with Blacks whose families have been in America for centuries. Acknowledging these differences would support better service provision.

Latino/a caregivers

Undoubtedly, differences exist across Latino/as by ethnicity, region, and immigration history, but almost all studies group them into one category (see Ayalon and Huyck 2001; Magilvy, Congdon, Martinez, Davis, and Averill 2000; Passmore and Cummins 2004). They may be of Mexican, Puerto Rican, Cuban, or other background or from Central or Southern America. While Mexican Americans make up about two-thirds of Latino/as, people within that group differ on nativity status (whether or not they were born in the United States) as well. Because of the diversity of Latino/as, we should be careful about making generalizations.

Some studies have found that Latino/a caregivers employ formal services less than members of other racial and ethnic groups, which seems to be more because of cultural reasons than to having less need for services (Passmore and Cummins 2004). Use of paid services can be seen as avoiding culturally assigned responsibilities (Cox and Monk 1993; Passmore and Cummins 2004), limiting usage of this form of assistance even when it is available. Elderly Mexican Americans who use formal services are more likely to live alone (Dietz 1997), suggesting either that they have fewer caregivers available or that they (or their family members) do not view the utilization of formal services as culturally inappropriate.

Many Latina caregivers are women helping parents or parents-in-law, as Latina daughters often provide care rather than Latino husbands (Ayalon and Huyck 2001; also see Cox and Monk 1996). Cultural expectations of females as caregivers inhibit spousal care by men and encourage daughters of impaired women to provide care rather than their husbands. Latino/as providing care to older family members report greater depression than non-Hispanic Whites (Harwood et al. 1998:343) and more stress than Blacks (Cox and Monk 1996:98). Cultural norms of what is due to elders increase the amount of burden felt by caregivers, if they feel they cannot provide enough or the right kinds of care, ask for support, or discuss their feelings with others (Cox and Monk 1996; Passmore and Cummins 2004). Fulfilling expectations also can be a source of pride and cushion the amount of stress felt by caregivers, however (Phillips et al. 2000).

For Latino/as, culture seems to affect the provision of care as well as feelings of stress and burden (Cox and Monk 1993; Passmore and Cummins 2004; Phillips et al. 2000). Cultural expectations regarding appropriate caregivers sometimes exclude some relatives from providing care, even if they are willing to take on some duties that the assigned caregivers find difficult or impossible to do. For example, Passmore and Cummins (2004) quote a respondent whose mother and aunt did not allow her (or anyone else) to participate in caring for her grandmother, even though they were unable to provide all the care the grandmother needed. The mother and aunt felt that they should be the caregivers, because of cultural norms, and shut out others who were willing to help. Therefore, culture may actually reduce the amount of care received in some cases. Awareness by service providers of cultural differences and how they might affect provision of aid should help ensure better outcomes for care recipients.

Asian American caregivers

The term Asian American also lumps together people of many different regional backgrounds and with diverse immigration histories. The families of some people of Asian descent have been in America for over a century, while others have arrived since the changes in immigration law in the late twentieth century. In general, Asian cultures emphasize the "interdependence of family members" (Li 2004:247). Of course, there is cultural diversity within and across groups (Yeo 2008). For example, regional differences regarding familial obligations exist within China, which immigrants probably brought with them to America (Hsueh, Hu, and Clarke-Ekong 2008). Similar to caregivers with other backgrounds, Asian Americans generally are expected to and are willing to take care of older family members (Li 2004). The norm of filial piety, in which younger family members are obligated to provide care to older family members, is common across many Asian cultures and may even be intensified in Asian Americans (Jones, Zhang, and Meleis 2003). This cultural value plays out in a variety of behaviors, however. Also, while Asian cultures tend to be patrilineal, exposure to American norms may mean more flexibility in what is seen as acceptable fulfillment of obligations.

For Vietnamese Americans, filial piety "discourage(s) use of non-family long-term care services," particularly formal services (Yeo, UyenTran, Hikoyeda, and Hinton 2001:146). When a care receiver needs a lot of assistance, family members providing care look to extended relatives, particularly women, to help. This evidence suggests that this group has larger caregiving networks than other groups. In addition, if a care recipient lacks appropriate female relatives, fulfilling the norm of filial piety means a male becomes the primary caregiver even though Vietnamese gender roles prescribe that women provide personal care and men assist with financial support and decision making (Yeo et al. 2001). This is also the case for Hmong Americans, for whom the patrilineal extended family is very powerful (Gerdner, Tripp-Reimer, and Yang 2008). Therefore, filial obligation overrides gender role norms for some groups, particularly if paid assistance is not seen as a suitable option.

In contrast, some Chinese Americans see paying for high-quality care as acceptably fulfilling filial piety obligations (Lan 2002). Utilizing government services and funds, on the contrary, is not a viable substitute for providing care. The logic seems to be "that the more one pays, the more one cares" but "the more public funds one receives, the less one cares" (Lan 2002:832). Financial status affects usage of services, however; Chinese Americans with less financial resources are more willing to apply for aid (Hsueh et al. 2008). Chinese American sons are more likely to choose formal services, while daughters are more likely to expect that all siblings will help provide care before seeking assistance from paid providers (Hsueh et al. 2008). Also, for Chinese Americans, daughters are more willing to take on care provision and therefore may be replacing daughters-in-law as the culturally most appropriate female relative (see Hsueh et al. 2008; Jones et al. 2003). Gender roles therefore are more important than the traditional patrilineal roles for this group. As many of these studies have small samples, however, findings from one group of Chinese Americans may not apply to another group because of socioeconomic status, immigration history, or other factors.

Feeling that they are fulfilling their cultural obligation to provide care reduces stress and caregiver burden for South Asian American caregivers (people originally from India or Pakistan) and Chinese American caregivers (Gupta and Pillai 2000; Hsueh et al. 2008). These findings may also apply to members of other Asian American groups. However, competing demands such as employment can make the observance of filial piety another source of stress (Gerdner et al. 2008; Jones et al. 2003; Yeo et al. 2001). These results are similar to findings for Latino/as, as reported previously. Also, similar to patterns among Latino/as, daughters are seen as more appropriate caregivers than husbands among Hmong Americans (Gerdner et al. 2008), suggesting that familial roles also matter.

Studies of single ethnicities can provide findings such as certain Asian American groups emphasize the gender of the type of kin when selecting a caregiver, while others stress familial line over gender. Clearly, such variations point out the dangers of broad categorizations such as Asian American or Native American. Since these groups comprise very small percentages of the American population, it is unlikely that the diversity of the subgroups can be represented in quantitative studies.

Native American caregivers

Native Americans are perhaps the most diverse and least studied group (Jervis and Manson 2002). The over 500 tribal groups differ culturally and historically; also, geographic location affects access to services. For example, Alaska Natives in remote Northern villages probably have less access to services than Native Americans elsewhere (Jervis and Manson 2002). Most of what is known is from studies of those Native Americans who live on reservations, but urban members of the same tribe may have very different experiences (Jervis and Manson 2002). Results from studies of one tribe are often generalized to all Native Americans (Dilworth-Anderson and Gibson 1999), which is inappropriate given the diversity of this population.

Since Native Americans develop chronic health conditions at fairly early ages, they “may be more likely to serve as caregivers, they may provide care for relatively longer periods of time, and they may provide care for others while experiencing their own health concerns” (Evans-Campbell, Fredriksen-Goldsen, Walters, and Stately 2007:77). Females often are seen as more appropriate caregivers than males, similar to the expectations of other cultural groups (Hennessy and John 1996). However, "Native LGBTQT-S (lesbian, gay, bi-sexual, transgender, queer, or two-spirit...) people often have specific cultural roles and responsibilities tied to caregiving" (Evans-Campbell et al. 2007:78). They may be viewed as the most suitable individuals to provide assistance (Evans-Campbell et al. 2007). Fulfilling these community expectations for giving care to elders is a source of anticipation and pride (Evans-Campbell et al. 2007). These caregivers sometimes experience discrimination when dealing with non-Native service providers based on both cultural and sexual orientation characteristics (Evans-Campbell et al. 2007), making their situations more stressful.

The concept of "caregiver burden" as developed from studies of White caregivers does not necessarily translate to different cultural groups. Since many Native American groups see intergenerational caregiving as an expectation, any "burden" "may have more to do with the level of un-anticipated role stress or resource stress...than to the actual caregiving activity per se" (Evans-Campbell et al. 2007). Hennessy and John (1995) found that Pueblo Indian caregivers do experience burden, but perceive and express it somewhat differently from Whites. For example, other obligations (such as paid employment) that get in the way of providing care are viewed as burdens, rather than the caregiving itself, and values promoting social harmony inhibit showing unhappiness with the situation. While some families provide care as a team, generally there is one primary caregiver who would like more support from other family members, similar to Pacific Islanders (Kaholokula et al. 2008) and Whites (Hennessy and John 1995, 1996; also see Evans-Campbell et al. 2007). Reservation-dwelling care providers often deal with worse living conditions and fewer available services than urban Pueblo Indians or Whites would experience (Hennessy and John 1995, 1996), adding to their stress.

Native Americans who are more engaged with traditional culture may be more likely to be caregivers (Goins, Spencer, McGuire, Goldberg, Wen, and Henderson 2011). "[C]ultural values that mandate caregiving to elderly relatives...no matter how frail the recipient" (Hennessy and John 1996:288) are both a source of strain and of satisfaction. Providers of assistance are happy that they are fulfilling these norms but also feel unqualified to provide medical care and that they do not have enough personal resources to provide the best care possible (Hennessy and John 1996). Cultural values affect which characteristics of the caregiving situation are perceived as causing burden; these norms also impact how the care provider interprets the effects of care provision on him/herself (John, Hennessy, Dyeson, and Garrett 2001), similar to findings for Latino/as and Asian Americans. In addition, Pueblo Indian care providers want services that would support and supplement familial care (Hennessy and John 1996) such as culturally appropriate respite care and training in ways to cope with problematic behavior of the care recipient. Members of other tribes, racial categories, and ethnic groups probably also desire such services delivered in culturally suitable ways, which should increase usage.

Summary

In conclusion, women usually are seen as the most appropriate caregivers, regardless of culture or type of kin. Also, the repeated finding that those people who live closer to the frail older person are more likely to provide care than other potential caregivers highlights the possibility that people live geographically closer to each other because they are emotionally more attached. Emotional and geographic closeness seem to be inter-related, and both are related to providing care. It seems likely that relatives (and friends) who are emotionally close also prefer geographic closeness, but more research is needed to know definitively which comes first, and also which is more important for care provision.

People assist elderly relatives for similar reasons, including affection and norms of family obligation, whatever their kinship status. Neighbor and friend caregivers, however, report somewhat different motivations such as seeing an unmet need for care. Other relative primary caregivers report less strain overall than spouse or adult children caregivers, but the burden they feel should not be overlooked. Also, providing care impacts their paid employment and affects their ability to finance their retirement, just as it does for adult children caregivers.

Conflicts between providing care and working for pay exist for everyone. Although primary caregivers do most family caregiving, secondary caregivers assist in a variety of ways and also experience costs from providing care. Spouses of caregivers and adult children and grandchildren of care recipients are important sources of support for primary caregivers. Studies of caregiving networks and how caregiving arrangements change over time would be helpful in answering the questions about the size of support networks and whether or not members of minority groups have more access to caregiving.

Members of minority groups are more likely than Whites to have an other relative as their primary caregiver. Clearly, cultural expectations affect who helps frail family members and how that care is provided. As discussed in this chapter, culture may actually reduce the amount of care in some cases. Also, fulfilling cultural values may be somewhat protective for caregivers' mental health, but care providers still feel stress and burnout, which should not be ignored. Therefore, policymakers and service providers should not assume that providing care has few costs for minority caregivers, or that elderly members of minority groups automatically will receive help from family members. Service providers and policymakers also should be aware that cultural acceptability of paid care and government services varies by ethnicity and social class.

More attention needs to be paid to differences by kinship status within minority groups; although most groups emphasize familial responsibility, little attention has been paid to differences by family role. For example, Latino/as and Hmong Americans emphasize females as caregivers, but it would be instructive to look at expectations for daughters and daughters-in-law to explore how ideas about kin type and gender interact. In addition, investigating variations in norms regarding caregiving for White, Latino, and Hmong husbands would be helpful. Also, more attention should be paid to diversity within groups. Differences between Latino/as of Puerto Rican, Cuban, Mexican, and other descent are likely, as are dissimilarities between members of different Native American tribes and between Asian Americans of Chinese, Japanese, Korean, Vietnamese, or other descent.

The question also arises if we should emphasize similarities between caregivers or differences. Many commonalities exist, but to enable and encourage use of services, diversity needs to be honored. A balance between the two should be found to promote the best care possible for recipients and to reduce the burden felt by caregivers. Policymakers responsible for legislation regarding caregiving also should respect these similarities and differences. The next chapter covers a variety of legislation; while only a few policies directly impact family members who provide aid, many more affect both care recipients and caregivers.

5

Current Policy Regarding Caregiving and Policy Implications

Abstract: *Discusses current policy regarding caregiving and policy implications. Although little federal and state legislation directly address familial provision of care, several policies affect people's ability and willingness to provide assistance. Programs such as Medicare and Medicaid, which are aimed at care recipients, indirectly impact the family members who take care of them. Social Security and pension regulations have consequences for people who leave the paid labor force to provide unpaid care work.*

Keywords: aging; aging policy; caregiving; employment policy; health policy; retirement policy

Hill, Twyla J. *Family Caregiving in Aging Populations.*
New York: Palgrave Macmillan, 2015.
DOI: 10.1057/9781137511560.0009.

As the previous chapters have shown, family members provide a lot of assistance to elderly relatives. Informal caregivers provide over 75% of care worth an estimated $450 billion yearly (Feinberg et al. 2011; Levine, Halper, Peist, and Gould 2010). As discussed in Chapter 1, the likelihood of any one individual providing care to an older family member is increasing. Also, as an aging society, America is facing rising numbers and percentages of people who will need care. Health care costs are increasing as well. Health care policy tends to be focused on formal, paid care. Few policies directly address unpaid, informal assistance. This combination of circumstances calls for a broad look at legislation addressing health care and caregiving.

Although few US policies focus on informal caregiving, a wide range affect it. For example, Medicaid and Medicare are health care policies, but are about care recipients rather than caregivers. Nevertheless, their existence has undoubtedly affected the need for family care provision. In addition, policies that are about caregiving quite often are not used by people assisting older relatives, either because they are not aware of the program or they do not know the policy applies to them. As a case in point, the Family and Medical Leave Act is specifically aimed at caregivers, but tends to be viewed as legislation that benefits new parents rather than helping people who are caring for elderly family members (Wisensale 2008). This chapter first covers policies that directly target caregivers. Then it describes policies that affect people's ability and/or willingness to provide care. Third, policies that impact both care recipients and their caregivers are reviewed. Policy implications are discussed as well. The chapter ends with an overall review and conclusion to the book.

Policies specifically about caregiving

The Family and Medical Leave Act of 1993 (FMLA) gives workers time off to care for an ill parent, spouse, or child, a newly born or adopted child, or their own serious health problem. The person is allowed up to 12 weeks off in any one year, and the leave is not paid (Wisensale 2008). Friends, cohabiting or same sex partners providing care are not eligible for these benefits as the caregiver must be related by blood, marriage, or adoption to the care recipient. Because the FMLA legislation applies only to people with at least 1,250 hours or a year of service to companies

DOI: 10.1057/9781137511560.0009

with at least 50 workers, it covers only about 60% of American employees (Wisensale 2008). The FMLA offers some job security and improves employee retention (Pavalko, Henderson, and Cott 2008) so the policy benefits both employers and employees. However, many people cannot afford to take time off without pay.

California is the only state that has a paid leave program; it is funded by employee contributions, is partial wage replacement, and allows for only six weeks of leave (Wisensale 2008; also see Family Caregiver Alliance 2007). The FMLA and the California program provide solutions for short-term care needs, but not long-term care, which is what many older people need and many family caregivers provide. Only about a quarter of employees who take time off under the FMLA do so to care for an ill family member, and almost all of these are women (Pavalko et al. 2008). Undoubtedly, many people who are assisting an older spouse or parent do not use the FMLA.

A federal policy does exist that is more focused on long-term care, but it is not well known. The National Family Caregivers Support Program (NFCSP) was started in 2001 under the Older Americans Act. It is federally funded, but is administered at the state level and implemented through the Area Agencies on Aging. This program offers benefits supporting family caregivers, including provision of information about available community programs and assistance in accessing services, respite care, and counseling, among other things (Feinberg and Newman 2006; Wisensale 2008). Unlike most policies, this program does include extended LGBT family members in its definition of relatives, providing access to support groups, caregiver training, respite care, and other services to caregivers who are same sex partners or other chosen family members (Fredriksen-Goldsen and Hooyman 2007; Grant 2010). While the states offer a variety of programs, respite care is the most common (Feinberg, Newman, Gray, and Kolb 2004). For a comprehensive breakdown by the state of the services offered, see Feinberg et al. (2004).

The NFCSP has increased the amount of supportive services available to caregivers since its enactment (Feinberg and Newman 2006). Over a third of the states did not provide programs for caregivers until after federal funds were available through the NFCSP (Feinberg et al. 2004). Services and accessibility are inconsistent within and across states, however, and many needs are still unmet. Most people are not aware of the program, which is seen by many NFCSP administrators as a major reason more people do not utilize the services (Feinberg and Newman 2006). The administrators also report that inadequate funding is a problem (Feinberg et al. 2004). As is the case for many government programs, the NFCSP is underfunded and the recession made the situation worse. The funding amount for 2010 was just over $154 million, down $2 million from 2007 (Administration on Aging 2011). Without more funding, the Area Agencies on Aging will be unable to expand services aimed at family caregivers.

However, in 2009, the federal government did add funding for the Lifespan Respite Care Program, specifically to improve caregivers' access to respite care (The Arc 2015). The Administration on Aging provided grants to state agencies working with statewide respite care organizations or coalitions to enhance and expand respite services. This program was funded for $2.5 million a year from 2009 to 2012 (The Arc 2015). As of this writing, the Act had not yet been reauthorized. Expansion of respite services would be helpful for people who provide care to disabled individuals of all ages, not just older family members.

Policies impacting people's ability and/or willingness to provide care

The prior policies are designed to support family caregiving, once a person has chosen to do so. Other policies affect their willingness and ability to become a caregiver. People are motivated to provide care for relatives in later life by a variety of reasons such as affection, a desire to reciprocate, a feeling of obligation, or expectations of an inheritance. The context in which people make decisions affects their options and shapes their choices, however, so that policies not explicitly about caregiving impact whether or not people provide assistance. For example, Caputo (2005) found that caregiving by adult daughters was affected by parental intentions to leave them something in their will. Therefore, programs such as Medicare and Social Security that help to maintain parents' resources probably increase children's motivations to provide assistance (Caputo 2005).

Leave policies such as the FMLA obviously impact caregiving decisions; other workplace policies also affect employee's options. At least 13% of the paid labor force is involved in caring for the elderly (Wagner 2006). Many of these people report that assisting older family members has affected their performance at work, because of having to take time off, adjust their work hours, et cetera, and some employees (6%) left the workforce because of caregiving (National Alliance for Caregiving 2004). Along with family leave, workplace policies such as flexible hours, paid vacation time, and paid sick leave are used by and valuable to caregivers (Pavalko et al. 2008). Access to family leave has increased since the 1990s, but the availability of benefits such as paid vacation and sick leave has declined (Pavalko et al. 2008). These trends lead to concerns about people's ability to provide care for family members and keep working for pay. Health insurance policy also is important, as most people cannot afford health insurance without an employer subsidy (Pavalko et al. 2008). While the 2010 health care reform (the Affordable Care Act) will affect individuals' options, many people will not choose to leave their job to provide care unless they have some other way to get health insurance.

Possible sources of income are also a factor in decisions about care provision. In some states and under certain circumstances, people can receive payment for providing care to a family member. The Medicaid Cash and Counseling Demonstration and Evaluation (MCCDE) project began in 1998 in three states: Florida, New Jersey, and Arkansas. The experimental project allowed care recipients to manage their own care. Among the options was the decision of whom to hire: care recipients were permitted to employ either family members or others to provide care.

Analyses of the MCCDE project have found generally positive results (Kunkel, Applebaum, and Nelson 2003–2004; Simon-Rusinowitz, Mahoney, Loughlin, and Sadler 2005). No differences in health outcomes exist between care recipients who hire family members and those who engage others. In addition, those who employ family members "reported less unmet need for personal care" compared to care recipients who hire strangers (Simon-Rusinowitz et al. 2005:98). Family workers provide care during more flexible hours than other providers, and both the recipients and workers report high levels of satisfaction with the care arrangements (Simon-Rusinowitz et al. 2005). Because of these positive findings, the project was expanded. In 2005, federal Medicaid guidelines were changed to make it easier for states to include what is called a Cash and Counseling option (Cash & Counseling 2007).

People in favor of paying family caregivers point to the positive results from the MCCDE program as well as from studies of similar projects.

They “argue that it is a way to strengthen, expand, and sustain the natural support system” (Kunkel et al. 2003–2004:74). Paying family caregivers also means they can continue earning Social Security credits as well as perhaps saving for retirement (Simon-Rusinowitz, Mahoney, and Benjamin 2001). In addition, care recipients like the program because it gives them control over how help is provided and who does the care, which helps them maintain their autonomy (Simon-Rusinowitz et al. 2001).

In contrast, critics of paying relatives to provide care worry about the potentials for fraud, poor care, and abuse (Blaser 2001). Care recipients and providers could conspire to defraud the program. Family caregivers potentially would have less training than other health care workers, and therefore would provide worse care. Family members might be abusive, or exploit the care recipient in order to receive the payments, denying the elder person more appropriate care. Critics also point out the increase in monetary cost to the state of paying family caregivers for the work they used to provide for free (Blaser 2001). However, those in favor of the program argue that strangers also can be abusive or exploitative. Analysis of the MCCDE has found few cases of abuse or fraud. In addition, the majority of the family workers had given assistance before their care recipient had enrolled in the program, and were currently “providing care for more hours than those for which they were paid” (Simon-Rusinowitz et al. 2005:99; also see Kietzman, Benjamin, and Matthias 2013), suggesting that care recipients and their caregivers are not likely to exploit the program.

The Cash and Counseling state grants ended in 2009 (National Resource Center for Participant Directed Services n.d.). The 15 states involved continued their programs, and other states began similar projects. Running such programs through Medicaid, however, means that care recipients must meet strict requirements of needing assistance, reducing the likelihood of serving large numbers of people. Allowing all care recipients to choose their workers would cause the costs to be the same whether the caregiver was a family member or not. Also, low-paid, low-skilled health care jobs are high-turnover positions, and family members potentially would be a more consistent source of care than strangers (see Bradham 2000). Overall, payment of family members to provide assistance seems like a good strategy, but the extension of such benefits from Medicaid to Medicare probably is not politically feasible. There has been some discussion of federal tax credits for caregiving

(Family Caregiver Alliance 2007; also see Bradham 2000), which may be more politically acceptable.

Some policies that are not specifically about health care or caregiving also affect caregiver decisions and outcomes. Adult children are the majority of care providers for the elderly, as shown in the third chapter. About a fifth of adult child caregivers are between the ages of 60 and 65 years old (Mui 1995a), when people are making retirement decisions. Their options and choices at this point in their lives will affect their own later financial well-being. Caregiving in later life increases the likelihood of retirement (Moen 2001), and giving up work earlier decreases benefits (Szinovacz and Ekerdt 1996; Wakabayashi and Donato 2006). Women and people of color are particularly likely to be in poverty in their own later years so early retirement by these types of people to assist someone else is cause for worry. Currently, the way Social Security and pension benefits are calculated rewards continuous participation in the paid labor force (see Clark, Burkhauser, Moon, Quinn, and Smeeding 2004). For example, computation of Social Security payments includes averaging an individual's wages for the 35 years of highest earnings (see Clark et al. 2004:173–174 for a clear and detailed description of the entire formula). Therefore, if adult children reduce their hours or leave the labor market to provide care, they are decreasing their own retirement resources. In the long run, this reduction in savings impacts the country's future as well. These individuals will have less money to spend on goods and services in their own old age, reducing the size of the overall economy.

Most US policies emphasize participation in the market economy (Folbre 2004). As policies reinforce that, they discourage people from caregiving. Individuals will decide not to assist an older family member if leaving the labor force to provide care costs too much either in current or future economic resources. This pressure to remain in the job market may weaken societal norms such as familial obligations and altruism (see Folbre 2004). There has been congressional discussion of allowing family caregivers to receive Social Security credit for the time spent in providing unpaid care (Family Caregiver Alliance 2007). This new way to qualify would increase the overall cost of Social Security but also would reward people for fulfilling commitments to family members. Changing the Social Security program is a very touchy subject politically, so the addition of this qualification seems unlikely.

Policies that affect the care recipient and the caregiver

Numerous state and local programs exist that support care recipients and therefore caregivers. Examples of these services are nutrition and meal programs, adult day care and respite care programs, information and referral services, home health care, and transportation (see Conner 2000). Many of these programs and services are provided by the agencies in the aging network, created through the Older Americans Act originally enacted in 1965 (Gelfand 2006). At the federal level, there is the Administration on Aging, which gathers statistics on aging issues, sponsors programs for the elderly, and sets policies for the state and local agencies. Each state has an Office on Aging, which oversees the local Area Agencies on Aging. Each Area Agency on Aging has its own plan for serving local elderly persons; this diversity of programming allows for services to be targeted to the needs of residents in that area (Gelfand 2006). Therefore, availability of these programs varies widely both across and within states (see Giunta and Scharlach 2009). These services tend to directly support the care recipient, reducing caregiver responsibilities and burden.

Scholars and service providers generally suggest that the availability and accessibility of these programs should be increased and improved. Provision of these services must respect the diversity of the caregiver population, however. For example, gender appropriate services should be provided. Many programs are aimed at women, and unintentionally can discourage men from participating. Men might feel uncomfortable in support groups, for example. However, differences exist by age, race/ethnicity, sexual orientation, and other characteristics that affect how men (and women) view caregiving and want services delivered (Femiano and Coonerty-Femiano 2002; also see Harris and Bichler 1997). Recognition of diversity within groups is important, because service usage varies by race, ethnicity, and cultural context (Giunta and Scharlach 2009).

Cultural views of the aging process and of dementia affect if and how caregiving is provided as well as attempts to find services for the care recipient (Dilworth-Anderson and Gibson 1999; Evans-Campbell et al. 2007). For instance, what medical practitioners diagnose as dementia may be viewed as spiritual experiences by some cultural groups. Policymakers should not assume that elderly members of minority groups automatically will receive help from family members, or that providing care comes easily for or has little cost to minority caregivers. Although culture seems to differentially affect caregiving and stress, a major similarity across groups is that services have to be provided in culturally appropriate ways. Caregiving members of minority groups need supportive programs such as information and referral services, transportation, respite care, and others; the lack of usage appears to be more because of barriers rather than due to not needing or wanting services. For example, a Southern California study found that language is often an obstacle; a bilingual (Korean and English) health care center reached many more Asian Americans than other centers in the project which primarily used English (Chow, Ross, Fox, Cummings, and Lin 2000).

Language is just one of the possible barriers. In another study of Asian American caregivers, over half "reported that supportive services provided did not meet the needs presented by older adults" (Li 2004:254). Differences in food practices and culturally appropriate behaviors were mentioned in a number of studies as affecting the acceptability of services. For example, "Interpersonal relations with healthcare providers were a notable barrier...for Pacific Islanders" (Kaholokula, Saito, Mau, Latimer, and Seto 2008:287; also see Angel and Angel 1997 and Li 2004). The communication style of Pacific Islander patients is quite different from the style of their physicians and medical staff, and this clash works against the patients' compliance with doctors' recommendations. Pacific Islanders generally are not assertive and the health care providers tend to be hurried and abrupt. The medical staff should respect the communication style of Pacific Islanders to ensure patients get the needed care (Kaholokula et al. 2008).

Fear of discrimination is another barrier to the utilization of services, and training in culturally appropriate provision of services should help to increase usage. "Educational interventions with service providers are crucial because of the stigma, misinformation, and discrimination often exhibited by health and human services professionals toward" LGBT care recipients and caregivers (Fredriksen-Goldsen and Hooyman 2007:137). Training program staff in cultural competency should improve service provision for other historically disadvantaged groups as well.

Cultural inappropriateness is more of a problem than cost and affordability; in general, wealthier people can pay for the services while low-income clients have access to funding through programs (Li 2004). Therefore, services such as home health care, congregate meals, and respite care all need to be delivered with recognition of racial, ethnic, social class, sexual identity, and within group diversity for maximum usage and benefits to the care recipients and caregivers (Angel and Angel 1997). The success of programs such as On Lok in San Francisco shows that this can be done. On Lok provides a wide range of ethnically appropriate services, including adult day care, medical treatment, and housing facilities. Its achievements have made it a model for the Medicare Program of All-Inclusive Care for the Elderly (PACE), with many sites nationwide. Some of these programs have been more successful than others, however (Angel and Angel 1997). To succeed, such programs have to be carefully adapted to the community and the clientele. They also demand a great deal of commitment and effort from the management and staff (Angel and Angel 1997).

Funding for these services is a crucial factor as well. For example, On Lok receives money from Medicare, Medicaid, and private insurance companies. The regulations governing what these organizations will pay for greatly influence the options available to elderly individuals. In general, policies such as Medicare and Medicaid that directly affect the care recipient indirectly impact caregivers by altering the accessibility and use of paid care. For example, when the Medicare eligibility requirements and reimbursement practices for home health care were tightened, utilization of these services declined. The decrease was at least partially because of agencies limiting their acceptance of new patients (McCall, Korb, Petersons, and Moore 2003). It seems likely that these paid services were either replaced by family care or not provided.

Because Medicare covers about 97% of older Americans, its impact on elderly individuals and the health care industry is huge. A person becomes eligible for Medicare by being 65 years old and having worked in a job that paid Medicare taxes or by being married to an eligible person. Medicare is funded by federal taxes and premiums paid by those in the program (Clark et al. 2004). Only about half of health care costs are covered, however, meaning that a sizable amount is paid by the care recipient or family members.

The other major federal health care program that affects the elderly is Medicaid. A person becomes eligible for Medicaid by falling below certain income and asset levels. Medicaid is funded jointly by the federal government and the states, and the program varies widely across states (Clark et al. 2004). Although Medicaid was intended to assist the poor, it has become an old-age program because it pays for long-term institutional care, and Medicare does not. Many of the elderly who need nursing home care qualify for Medicaid after spending most of their own resources on their medical needs.

Cuts in Medicare and Medicaid have led to increasing loads being placed on informal caregivers, including very technical medical care in some cases (Harrington Meyer and Herd 2007). In addition, out-of-pocket health care expenses can be a lasting and disastrous strain on individuals and family members (Harrington Meyer and Herd 2007; South and Bradham 2000). Some expenses may be tax-deductible (Alzheimer's Association 2007). Meeting the qualifications can be tricky, however, and most people probably are not aware of the possibility for family members to take expenses for taking care of an elderly person as a deduction off their own taxes. Hopefully, the Affordable Care Act will reduce costs for care recipients and their care providers. The new focus on prevention should improve the average enrollee's health (Kaplan 2011), which should decrease many individuals' expenses. However, the Act's decreased spending for Medicare Advantage plans and other overall cuts are likely to limit health care options for many seniors (Kaplan 2011), which may increase some costs for individuals and the families.

Long-term care, which is a major component of health care costs, also places great demands on families. Most long-term care is provided by relatives to older persons still living in the community. The monetary cost is primarily paid by individual and family resources and Medicaid. Currently, Medicaid pays for about 45% of long-term care costs (Clark et al. 2004). Medicaid primarily funds institutional care such as that provided in nursing homes. Moving into a nursing home is generally a last resort, meaning the burden and cost of care remain on family members while a long-term care recipient remains in the community.

Long-term care insurance has been proposed as a solution. However, individuals tend to think they are at low risk of needing long-term care, and the cost of the insurance puts it outside the reach of many people (Bradham 2000). Long-term care insurance currently pays only for about 11% of all long-term care costs (Clark et al. 2004). The need for long-term care is likely to increase, and if long-term care insurance is going to be part of the solution, it will have to be affordable. Also, it will have to pay for in-home services, which is what most people prefer.

The Affordable Care Act included the Community Living Assistance Services and Supports Plan (CLASS), which would have been a voluntary insurance program (Kaiser Family Foundation 2010; Miller 2012).

Working adults would have been able to pay premiums through payroll deductions or directly to the government and would have been eligible for benefits after five years of contributions. The cash benefits would have been based on the degree of disability and could have been used for services provided either in the home or in an institution (Kaiser Family Foundation 2010). The CLASS program was projected to reduce both state and federal Medicaid costs (Chernof 2011). The program did not go into effect; government analyses predicted that it would not be financially practical because of the funding design (Miller 2012). The CLASS program may have been educational for those people involved in the discussion of long-term care reform, however (Miller 2012). Financing long-term care is a major challenge facing the insurance industry as well as the government. Clearly, this issue of long-term care is related to policies in a number of areas such as health care, federal programs such as Medicaid, and the insurance industry, even if informal caregiving is not explicitly included in these policies.

Policy implications

Since family members provide the majority of help for older persons, it would seem that government policy should bolster and assist their efforts (Campbell and Ingersoll-Dayton 2000). This reinforcement of society's anticipation that we will meet obligations to kin is not the case, however. In general, relatives are expected to provide assistance to older family members, but few supports or rewards exist for doing so. Current American policy actually tends to discourage caregiving through penalizing people who leave paid employment (see Folbre 2004). Also, many laws that provide benefits for families exclude people in same sex relationships, making it even more difficult for them to be caregivers (see Fredriksen-Goldsen and Hooyman 2007).

This situation affects individuals, both care recipients and caregivers. Some people do not get care at all. Many frail elderly do not get appropriate care. Care providers experience stress and burden and will have fewer future resources because of their current duties. This state of affairs also has effects on families. The relationship between the recipient and his or her care provider(s) may be harmed. The relationship of the primary caregiver with other family members probably suffers. The decrease in future resources also affects others. Income lost or resources

DOI: 10.1057/9781137511560.0009

spent on caregiving are not available to pay for children's college costs, for example. This situation also impacts businesses. Elder care provision is estimated to cost employers $33.6 billion a year through its effects on workers' job performance (MetLife Mature Market Institute 2006). It also affects the country as a whole by reducing the productivity of employees. If people leave the paid labor force, the loss of their skills and their wages affects the economy (Wagner 2006). In addition, the negative effect of caregiving on the provider's health increases future health care costs (Harrington Meyer and Herd 2007; Wagner 2006), which will impact us all.

As the American population ages, an increasing number and proportion of people will need assistance. Policies at all levels can encourage or discourage family members to help. Employers have incentives to provide family-friendly policies. Caregiving affects employers because of absenteeism, lost productivity, and turnover of employees (Wagner 2006). Expanding access to paid leave and flexible hours would be beneficial for both employees and employers. State and federal programs such as payment of caregivers or tax credits for caregiving would support familial assistance and might decrease future health care costs (see Bradham 2000; Caputo 2005). As another example, the Area Agencies on Aging potentially are places where services for caregivers and care receivers could be coordinated; with proper organization and enough funding, they could become "one stop shops" for managing care.

Legislators also should look for the effects of policy on caregiving more generally. Currently, policies such as Social Security are designed to give benefits to people who participate in the paid labor force, or to people who are dependents of "breadwinners." Caregiving could be recognized as work that benefits society in the same way labor force participation is viewed, and time spent providing care could be counted toward these entitlements (see Cancian and Oliker 2000). These changes would encourage altruism and support fulfillment of familial obligations.

Also, answers for those people who need care and do not receive assistance must be found. Currently, about 30% of those elderly who require help do not get care (Wolff and Kasper 2006). As discussed in Chapter 1, several societal trends are likely to increase that percentage. Fewer individuals will be available to provide care in the future because of decreases in marriage and fertility rates and increases in divorce and labor force participation, while rising longevity means more persons will need assistance. These people should not be ignored.

One source of solutions is the programs and policies of other nations. A full review is beyond the scope of this chapter, but some authors have evaluated elder care policies and outcomes in a number of countries (see Linsk, Keigher, Simon-Rusinowitz, and England 1992 and Sundstrom, Malmberg, Castiello, del Barrio, Castejon, Tortosa, and Johansson 2008 for examples). A wide variety of programs are in place. For example, Germany and Austria pay family members to provide care (Sundstrom et al. 2008), similar to the Cash and Counseling project described earlier. Many European countries have government-funded home help services; the types of assistance vary from house cleaning to personal care to some medical treatment (Sundstrom et al. 2008). Some countries tie eligibility for services to a means test; others do not (Sundstrom et al. 2008). Legislators should assess these programs for applicability to the US context as well as for how well these policies have worked in these other nations.

The United States has increasing costs of health care and pays more for health care than other countries, but Americans do not receive better care than people in those nations (Peterson and Burton 2007). Other industrialized, comparable countries cover more of the costs for their citizens (South and Bradham 2000). Policymakers should look at the experience of those nations, as privatization and deregulation of the health care system here have not cut costs either for society or for individuals (Harrington Meyer and Herd 2007). Hopefully, both care recipients and care givers will benefit from the Affordable Care Act reforms, but the impact of those changes on family caregiving is still unclear.

This overview has shown that policies in a number of areas clearly influence individuals and families in later life. Legislation regarding health care affects both care recipients and care providers. Programs designed for caregivers support individuals' efforts to help their elderly family members, but diversity of the clientele needs to be recognized to ensure these services are useful. Retirement and employment regulations influence the ability and willingness of people to assist elderly relatives. In general, American policy discourages caregiving, even though familial and cultural norms anticipate we will provide aid to our relatives. This situation increases the stress and burdens of the many individuals who do choose to fulfill those obligations to family members.

Conclusion

As this book has shown, older family members give a lot of care to aging relatives as well as needing assistance in later life. Demographic and societal trends affect the availability of family members to provide care, which leads to concerns about who will give aid to older people in the future. Many similarities exist across caregivers, but because every family is unique, every caregiving situation is different. Individual factors such as health and employment affect provision of care, along with structural factors such as policy and the economy. Both the need for care and the likelihood of providing care are predicted to increase in the near future. Each of us is likely to render aid to an elderly relative at some point.

That help probably will be provided in our own later years. Although most research on family caregiving has focused on the need for care of people 65 years and over (Dwyer and Coward 1992; Silverstein and Giarrusso 2010), almost half of primary caregivers to other elders are 65 years and older (Wolff and Kasper 2006). Most people who need care are 85 years old or over (National Center for Health Statistics 2007), and people in that age group generally have spouses who are close to their own age and children who are 50 years and older. Over three-quarters of caregivers to the elderly are spouses and adult children (Wolff and Kasper 2006). Therefore, this book has focused on people who are 50 years old and over as they are the ones most likely to assist older family members.

Care recipients generally prefer spouses (or other intimate partners) for caregivers, and husbands and wives provide the most intensive caregiving of all relatives who provide aid. Most elderly couples fulfill the marriage vows without question. The jobs spouses do differ by sex, however. More husbands report helping with housework, while more wives say they help with money management. These differences probably reflect gender role socialization. Spouses take on tasks as their partners are unable to do them, and because the jobs are new, they think of the duties as caregiving rather than as household responsibilities. Gender role expectations also affect the meanings husbands and wives assign to providing care; women emphasize their obligations, while men feel they have more choice in the matter.

Most caregiving spouses do not report support from other people, but husbands are more likely to get assistance from a secondary caregiver than are wives. The physical and mental health of spousal

DOI: 10.1057/9781137511560.0009

caregivers declines over time, so providing care to an intimate partner can be detrimental. While there has been little research on caregiving by homosexuals or cohabiting partners, similar patterns of obligation, intensive assistance, and burden as seen in heterosexual married couples seem likely to exist.

Adult children (particularly daughters) are the largest proportion of caregivers. Sons and daughters also have different views on caregiving, as well as doing dissimilar sorts of tasks. Men wait for their parents (or their sisters) to ask them to do something, while women provide aid if they think it is necessary. Daughters do more personal care and housework, while sons help with transportation and home maintenance. Gender role socialization undoubtedly affects these variations. Paid employment limits both men's and women's ability to provide assistance. Obligations to spouses and children also affect parental caregiving. However, having greater financial resources allows adult children to do more for parents.

In general, women who provide parental care report worse health and more strain than caregiving men. A poor relationship with the care recipient and interference with their employment predict more stress for daughters, while parental behavior problems and less assistance from others are related to more burden for sons. For both men and women, caregiving for their parents negatively impacts their marriages, their jobs, and their futures.

Other relatives also serve as caregivers to elderly family members; sometimes as primary caregivers, but also as supportive secondary caregivers or as part of a team. These family members are also motivated by affection and obligations to kin, just as are spouses and adult children. In general, the amount of care other relatives provide is less than that given by adult children and intimate partners, but some other relatives do supply time-consuming and intensive assistance. Also, the amount of strain and burden overall reported by spouses and adult children is greater than that reported by other relative primary caregivers. Giving aid to older people conflicts with paid employment, other familial obligations, and saving for retirement for other relatives, just as it does for adult children.

Minority group members are more likely than Whites to have an other relative be their primary caregiver. Women usually are preferred sources of aid, although in some cases, cultural norms of familial obligations will expect a male relative to take over. While fulfilling cultural expectations buffers feelings of burden for many caregivers, members of minority groups assisting older relatives still feel strain. Also, we cannot assume that elderly minority group members have family members who can provide aid, as some research shows they are actually less likely to receive assistance than Whites.

The research on older family caregivers has shown that differences and similarities exist across types of relationships, gender, race, and ethnicity. For example, motivations for providing care are similar across types of relationships. Most people want to help their elderly relatives because of affection and norms of familial obligation. Individuals providing aid tend to live nearer to the care recipient than other potential caregivers do, but it is unclear whether emotional closeness or geographic closeness is the primary reason for this finding. All people who provide care report experiencing strains because of assisting elderly family members, but in general, primary caregivers and adult children caring for parents feel more burden. Women spend more time on care work than men, while men more often receive help with providing care. Assisting relatives conflicts with paid employment for everyone. More availability of respite care and payment for services such as in-home care would reduce burden on caregivers, whatever their relationship to the care recipient.

While we know a lot about family caregiving in later life, this book has highlighted some areas which require further study. For example, additional research is needed on caregivers who are members of minority groups, cohabitors, or other understudied relationship types like sons-in-law. New studies should be done to bring the research on gendered task performance and differences by social class up to date. Studies which recognize the diversity within racial and ethnic groups also would be helpful. Because past research has focused on primary caregivers alone, more research on caregiving teams and secondary caregivers is also desirable, as their contributions probably have been underestimated. Caregiving changes over time, usually from less intense to more burdensome, and cross-sectional research does not capture these alterations. More longitudinal studies are necessary to explore these changes for primary caregivers and for caregiving networks.

This book has pointed out the contributions caregivers make to individual care recipients, families, and society as a whole. US policy could and should explicitly recognize the value of caregiving to society. As much research has shown, female family members over 50 years of age do most of the caregiving for the elderly. These women receive some benefits but bear more burdens for providing this care. There are immediate personal costs such as stress; there are also long-term costs such as health impacts and lower retirement benefits. American society presumes that family members (mostly women) will provide care for older adults but does not reward them for fulfilling those cultural expectations. Instead, people should be supported for taking care of relatives, whether elderly or not. Doing so will strengthen values of altruism and familial obligation; it also will help reduce the financial cost to society over time.

References

Adams, Brad, Maria P. Aranda, Bryan Kemp, and Kellie Takagi. 2002. "Ethnic and Gender Differences in Distress among Anglo American, African American, Japanese American, and Mexican American Spousal Caregivers of Persons with Dementia". *Journal of Clinical Geropsychology*, 8(4):279–301.

Administration on Aging. 2011. "National Family Caregiver Support Program (OAA Title IIIE)". <http://www.aoa.gov/AoARoot/Aof_Programs/HCLTC/Caregiver/index.aspx>. Accessed July 25, 2011.

Administration on Aging. 2012. "A Profile of Older Americans: 2012". < http://www.aoa.gov/Aging_Statistics/Profile/2012/docs/2012profile.pdf>. Accessed November 21, 2014.

Alecxih, Lisa. 2001. "The Impact of Sociodemographic Change on the Future of Long-Term Care". *Generations*, 25(1):7–11.

Alzheimer's Association. 2010. "Tax Deductions and Credits". <http://www.alz.org/carefinder/planning/planning4.asp>. Accessed June 17, 2010.

Angel, Jacqueline Lowe and Dennis P. Hogan. 1992. "The Demography of Minority Aging Populations". *Journal of Family History*, 17(1):95–115.

Angel, Ronald J. and Jacqueline L. Angel. 1997. *Who Will Care for Us? Aging and Long-Term Care in Multicultural America.* New York, NY: New York University Press.

Angel, Ronald J. and Jacqueline L. Angel. 2006. "Diversity and Aging in the United States". Pages 94–110 in Robert H. Binstock and Linda K. George, eds. *Handbook of*

DOI: 10.1057/9781137511560.0010

Aging and the Social Sciences, Sixth Edition. New York, NY: Academic Press.

Arc, The. 2015. "Lifespan Respite Care Program". <http://www.thearc.org/page.aspx?pid=3379>. Accessed January 26, 2015.

Ayalon, Liat and Margaret Hellie Huyck. 2001. "Latino Caregivers of Relatives with Alzheimer's Disease". *Clinical Gerontologist*, 24(3/4):93–106.

Badr, Hoda, Linda K. Acitelli, and Cindy L. Carmack Taylor. 2007. "Does Couple Identity Mediate the Stress Experienced by Caregiving Spouses?" *Psychology and Health*, 22(2):211–229.

Baldock, Cora Vellekoop. 2000. "Migrants and Their Parents: Caregiving from a Distance". *Journal of Family Issues*, 21(2):205–224.

Barker, Judith C. 2002. "Neighbors, Friends, and Other Nonkin Caregivers of Community-Living Dependent Elders". *Journal of Gerontology: Social Sciences,* 57B(3):S158–S167.

Barrett, Anne E. and Scott M. Lynch. 1999. "Caregiving Networks of Elderly Persons: Variation by Marital Status". *The Gerontologist*, 39(6):695–704.

Beach, Diane L. 1997. "Family Caregiving: The Positive Impact on Adolescent Relationships". *The Gerontologist*, 37(2):233–238.

Beach, Scott R., Richard Schulz, Jennifer L. Yee, and Sharon Jackson. 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.

Bedford, Victoria Hilkevitch. 1996. "Sibling Relationships in Middle and Old Age". Pages 201–222 in Rosemary Blieszner and Victoria Hilkevitch Bedford, eds. *Aging and the Family: Theory and Research*. Westport, CT: Praeger Publishers.

Bengtson, Vern L. and Joseph A. Kuypers. 1971. "Generational Difference and the Developmental Stake". *Aging and Human Development*, 2:249–260.

Bennett, Lisa and Gary J. Gates. 2004. "The Cost of Marriage Inequality to Gay, Lesbian and Bisexual Seniors". Human Rights Campaign Foundation. <www.hrc.org>. Accessed July 8, 2008.

Blaser, C. Jean. 2001. "The Case against Paid Family Caregivers: Ethical and Practical Issues". Pages 278–285 in Martha B. Holstein and Phyllis Mitzen, eds. *Ethics in Community-Based Elder Care*. New York, NY: Springer Publishing Company, Inc.

Bookwala, Jamila, Bozena Zdaniuk, Lynda Burton, Bonnie Lind, Sharon Jackson, and Richard Schulz. 2004. "Concurrent and Long-Term Predictors of Older Adults' Use of Community-Based Long-Term Care Services: The Caregiver Health Effects Study". *Journal of Aging and Health*, 16(1):88–115.

Borrayo, Evelinn A., Gali Goldwasser, Tammi Vach-Haase, and Kenneth W. Hepburn. 2007. "An Inquiry into Latino Caregivers' Experience Caring for Older Adults with Alzheimer's Disease and Related Dementias". *Journal of Applied Gerontology*, 26(5):486–505.

Bradham, Douglas D. 2000. "Critical Issues in Health Care for the US Elderly: Beyond the Millennium". Pages 98–188 in Susan Orpett Long, ed. *Caring for the Elderly in Japan and the US: Practices and Policies*. New York, NY: Routledge.

Brault, Matthew W. 2012. "Americans with Disabilities: 2010". *Current Population Reports*, P70–P131. Washington, DC: U.S. Census Bureau.

Brewer, Loretta. 2002. "Families that Care: A Qualitative Study of Families Engaged in the Provision of Elder Care". *Journal of Gerontological Social Work*, 39(3):41–56.

Brody, Elaine M. 2004. *Women in the Middle: Their Parent Care Years*. New York, NY: Springer Publishing Company, Inc.

Brown, Janet Witucki and Martha Raille Alligood. 2004. "Realizing Wrongness: Stories of Older Wife Caregivers". *Journal of Applied Gerontology*, 23(2):104–119.

Brown, Susan L., Jennifer Roebuck Bulanda, and Gary R. Lee. 2005. "The Significance of Nonmarital Cohabitation: Marital Status and Mental Health Benefits among Middle-Aged and Older Adults". *The Journals of Gerontology: Social Sciences*, 60B(1):S21–S29.

Brown, Susan L., Gary R. Lee, and Jennifer Roebuck Bulanda. 2006. "Cohabitation among Older Adults: A National Portrait". *The Journals of Gerontology: Social Sciences*, 61B(2):S71–S79.

Bullock, Karen, Sybil L. Crawford, and Sharon L. Tennstedt. 2003. "Employment and Caregiving: Exploration of African American Caregivers". *Social Work*, 48(2):150–162.

Bumpass, Larry L. and James A. Sweet. 1997. "National Survey of Families and Households: Wave 1, 1987–1988" [Computer file]. ICPSR version. Madison, WI: University of Wisconsin, Center for Demography and Ecology (producer), 1997. Ann Arbor, MI: Inter-University Consortium for Political and Social Research (distributor), 1997.

Burton, Lynda C., Bozena Zdaniuk, Richard Schulz, Sharon Jackson, and Calvin Hirsch. 2003. "Transitions in Spousal Caregiving". *The Gerontologist*, 43(2):230–241.

Cahill, Sean, Mitra Ellen, and Sarah Tobias. 2002. "Family Policy: Issues Affecting Gay, Lesbian, Bisexual and Transgender Families". The Policy Institute of the National Gay and Lesbian Taskforce. <http://www.thetaskforce/org/downloads/reports/reports/FamilyPolicy.pdf> Accessed February 17, 2012.

Calasanti, Toni and Mary Elizabeth Bowen. 2006. "Spousal Caregiving and Crossing Gender Boundaries: Maintaining Gendered Identities". *Journal of Aging Studies*, 20:253–263.

Calasanti, Toni and K. Jill Kiecolt. 2007. "Diversity among Late-Life Couples". *Generations*, 31(3):10–17.

Campbell, Ruth and Berit Ingersoll-Dayton. 2000. "Variations in Family Caregiving in Japan and the US". Pages 231–247 in Susan Orpett Long, ed. *Caring for the Elderly in Japan and the US: Practices and Policies.* New York, NY: Routledge.

Cancian, Francesca M. and Stacey J. Oliker. 2000. *Caring and Gender*. Thousand Oaks, CA: Pine Forge Press.

Caputo, Richard K. 2005. "Inheritance and Intergenerational Transmission of Parental Care". Pages 107–127 in Richard K. Caputo, ed. *Challenges of Aging on U.S. Families: Policy and Practice Implications*. Binghamton, NY: The Haworth Press, Inc.

Carpenter, Brian D. and Wingyun Mak. 2007. "*Caregiving Couples*". Generations, 31(3):47–53.

Cash & Counseling. 2007. "Program Overview". <http://www.cashandcounseling.org/about>. Accessed June 25, 2010.

Chappell, Neena L. 1990. "Aging and Social Care". Pages 438–454 in Robert H. Binstock and Linda K. George, eds. *Handbook of Aging and the Social Sciences*, Third Edition. San Diego, CA: Academic Press.

Chernof, Bruce. 2011. "The Three Spheres of Aging in America: The Affordable Care Act Takes on Long-Term-Care Reform for the 21st Century". *Generations*, 35(1):45–49.

Choi, Heejeong and Nadine F. Marks. 2006. "Transition to Caregiving, Marital Disagreement, and Psychological Well-Being". *Journal of Family Issues*, 27(12):1701–1722.

Chow, Tiffany W., Leslie Ross, Patrick Fox, Jeffrey L. Cummings, and Keh-Ming Lin. 2000. "Utilization of Alzheimer's Disease Community

Resources by Asian-Americans in California". *International Journal of Geriatric Psychiatry*, 15:838–847.

Chumbler, Neale R., Amy Mehraban Pienta, and Jeffrey W. Dwyer. 2004. "The Depressive Symptomatology of Parent Care among the Near Elderly: The Influence of Multiple Role Commitments". *Research on Aging*, 26(3):330–351.

Cicirelli, Victor G. 1992. "Siblings as Caregivers in Middle and Old Age". Pages 84–101 in Jeffrey W. Dwyer and Raymond T. Coward, eds. *Gender, Families, and Elder Care*. Newbury Park, CA: Sage Publications.

Cicirelli, Victor G. 1995. *Sibling Relationships across the Life Span*. New York, NY: Plenum Press.

Cicirelli, Victor G., Raymond T. Coward, and Jeffrey W. Dwyer. 1992. "Siblings as Caregivers for Impaired Elders". *Research on Aging*, 14(3):331–350.

Clark, Robert L., Richard V. Burkhauser, Marilyn Moon, Joseph F. Quinn, and Timothy M. Smeeding. 2004. *The Economics of an Aging Society*. Malden, MA: Blackwell Publishing.

Cohen, Harriet L. and Yvette Murray. 2006. "Older Lesbian and Gay Caregivers: Caring for Families of Choice and Caring for Families of Origin". *Journal of Human Behavior in the Social Environment*, 14:275–298.

Conner, Karen A. 2000. *Continuing to Care: Older Americans and Their Families*. New York, NY: Falmer Press.

Connidis, Ingrid Arnet and Candace L. Kemp. 2008. "Negotiating Actual and Anticipated Parental Support: Multiple Sibling Voices in Three-Generation Families". *Journal of Aging Studies*, 22:229–238.

Coon, David W. 2007. "Exploring Interventions for LGBT Caregivers: Issues and Examples". Pages 109–128 in Karen I. Fredriksen-Goldsen, ed. *Caregiving with Pride*. The Haworth Press, Inc.

Cooney, Teresa, M., Christine M. Proulx, Linley A. Snyder-Rivas, and Jacquelyn J. Benson. 2014. "Role Ambiguity among Women Providing Care for Ex-Husbands". *Journal of Women and Aging*, 26(1):84–104.

Coontz, Stephanie. 1992. *The Way We Never Were: American Families and the Nostalgia Trap*. New York, NY: Basic Books.

Coward, Raymond T., Stephen J. Cutler, and Russell A. Mullens. 1990. "Residential Differences in the Composition of the Helping Networks of Impaired Elders". *Family Relations*, 39:44–50.

Coward, Raymond T., Claydell Horne, and Jeffrey W. Dwyer. 1992. "Demographic Perspectives on Gender and Family Caregiving". Pages 18–33 in Jeffrey W. Dwyer and Raymond T. Coward, eds. *Gender, Families, and Elder Care*. Newbury Park, CA: Sage Publications.

Cox, Carole and Abraham Monk. 1993. "Hispanic Culture and Family Care of Alzheimer's Patients". *Health and Social Work*, 18(2):92–100.

Cox, Carole and Abraham Monk. 1996. "Strain among Caregivers: Comparing the Experiences of African American and Hispanic Caregivers of Alzheimer's Relatives". *International Journal of Aging and Human Development*, 43(2):93–105.

Davidson, Kate. 2001. "Late Life Widowhood, Selfishness and New Partnership Choices: A Gendered Perspective". *Aging and Society*, 21:297–317.

Deeken, John F., Kathryn L. Taylor, Patricia Mangan, K. Robin Yabroff, and Jane M. Ingham. 2003. "Care for the Caregivers: A Review of Self-Report Instruments Developed to Measure the Burden, Needs, and Quality of Life of Informal Caregivers". *Journal of Pain and Symptom Management*, 26(4):922–953.

DeVries, Brian. 2007. "LGBT Couples in Later Life: A Study in Diversity". *Generations*, 31(3):18–23.

Dietz, Tracy L. 1997. "Family and Formal Assistance with Activity Limitations: Who Helps the Mexican American Elderly?". *Hispanic Journal of Behavioral Sciences*, 19(3):333–352.

Dilworth-Anderson, Peggye and Brent E. Gibson. 1999. "Ethnic Minority Perspectives on Dementia, Family Caregiving, and Interventions". *Generations*, 23(3):40–45.

Dilworth-Anderson, Peggye, Sharon Wallace Williams, and Theresa Cooper. 1999. "Family Caregiving to Elderly African Americans: Caregiver Types and Structures". *Journal of Gerontology: Social Sciences*, 54B(4):S237–S241.

Dilworth-Anderson, Peggye, Ishan Canty Williams, and Brent E. Gibson. 2002. "Issues of Race, Ethnicity, and Culture in Caregiving Research: A 20-Year Review (1980–2000)". *The Gerontologist*, 42(2):237–272.

Dilworth-Anderson, Peggye, Beverly H. Brummett, Paula Goodwin, Sharon Wallace Williams, Redford B. Williams, and Ilene C. Siegler. 2005. "Effect of Race on Cultural Justifications for Caregiving". *Journal of Gerontology: Social Sciences*, 60B(5):S257–S262.

Dwyer, Jeffrey W. 1996. "The Effects of Illness on the Family". Pages 401–421 in Rosemary Blieszner and Victoria Hilkevitch Bedford, eds. *Aging and the Family: Theory and Research.* Westport, CT: Praeger.

Dwyer, Jeffrey W. and Karen Seccombe. 1991. "Elder Care as Family Labor: The Influence of Gender and Family Position". *Journal of Family Issues*, 12(2):229–247.

Dwyer, Jeffrey W. and Raymond T. Coward. 1992. "Gender, Family, and Long-Term Care of the Elderly". Pages 3–17 in Jeffrey W. Dwyer and Raymond T. Coward, eds. *Gender, Families, and Elder Care*. Newbury Park, CA: Sage Publications.

Earl, Tara R. 2006. "Mental Health Care Policy: Recognizing the Needs of Minority Siblings as Caregivers". *Journal of Human Behavior in the Social Environment*, 14(1/2):51–72.

Eriksen, Shelley and Naomi S. Gerstel. 2002. "A Labor of Love or Labor Itself: Care Work among Adult Brothers and Sisters". *Journal of Family Issues*, 23(7):836–856.

Evans-Campbell, Teresa, Karen I. Fredriksen-Goldsen, Karina L. Walters, and Antony Stately. 2007. "Caregiving Experiences among American Indian Two-Spirit Men and Women: Contemporary and Historical Roles". Pages 75–92 in Karen I. Fredriksen-Goldsen, ed. *Caregiving with Pride*. The Haworth Press, Inc.

Family Caregiver Alliance. 2007. "Archived Federal Legislation". <http// www.caregiver.org/caregiver/jsp/print_friendly.jsp?nodeid=789>. Accessed June 17, 2010.

Federal Interagency Forum on Aging-Related Statistics. 2010. *Older Americans 2010: Key Indicators of Well-Being*. Washington, DC: U.S. Government Printing Office.

Feinberg, Lynn Friss and Sandra L. Newman. 2006. "Preliminary Experiences of the States in Implementing the National Family Caregiver Support Program: A 50-State Study". Pages 95–113 in Francis G. Caro, ed. *Family and Aging Policy*. New York, NY: The Haworth Press, Inc.

Feinberg, Lynn Friss, Sandra L. Newman, Leslie Gray, and Karen N. Kolb. 2004. *The State of the States in Family Caregiver Support: A 50-State Study*. San Francisco, CA: Family Caregiver Alliance.

Feinberg, Lynn, Susan C. Reinhard, Ari Houser, and Rita Choula. 2011. "Valuing the Invaluable: 2011 Update, The Economic Value of Family Caregiving in 2009". AARP Public Policy Institute. <http://www.aarp.org/ppi.> Accessed July 28, 2011.

Feld, Sheila, Ruth E. Dunkle, and Tracy Schroepfer. 2004. "Race/Ethnicity and Marital Status in IADL Caregiver Networks". *Research on Aging*, 26(5):531–558.

Feld, Sheila, Ruth E. Dunkle, and Tracy Schroepfer. 2005. "When Do Couples Expand Their ADL Caregiver Network Beyond the Marital Dyad?". *Marriage and Family Review*, 37:27–44.

Femiano, Sam and Aimee Coonerty-Femiano. 2002. "Principles and Interventions for Working Therapeutically with Caregiving Men: Responding to Challenges". Pages 337–358 in Betty J. Kramer and Edward H. Thompson, Jr, eds. *Men as Caregivers: Theory, Research, and Service Implications*. New York, NY: Springer Publishing Company, Inc.

Field, Dorothy. 1999. "Continuity and Change in Friendships in Advanced Old Age: Findings from the Berkeley Older Generation Study". *International Journal of Aging and Human Development*. 48(4):325–346.

Fingerman, Karen L., Laura E. VanderDrift, Aryn M. Dotterer, Kira S. Birditt, and Steven H. Zarit. 2011. "Support to Aging Parents and Grown Children in Black and White Families". *The Gerontologist*, 51(4):441–452.

Folbre, Nancy. 2004. "Disincentives to Care: A Critique of U.S. Family Policy". Pages 231–259 in Daniel Patrick Moynihan, Timothy M. Smeeding, and Lee Rainwater, eds. *The Future of the Family.* New York, NY: Russell Sage Foundation.

Fredriksen, Karen I. 1999. "Family Caregiving Responsibilities among Lesbians and Gay Men". *Social Work*, 44:142–155.

Fredriksen-Goldsen, Karen I. and Nancy R. Hooyman. 2007. "Caregiving Research, Services, and Policies in Historically Marginalized Communities: Where Do We Go from Here?" Pages 129–145 in Karen I. Fredriksen-Goldsen, ed. *Caregiving with Pride*. The Haworth Press, Inc.

Fredriksen-Goldsen, Karen I. and Charles P. Hoy-Ellis. 2007. "Caregiving with Pride: An Introduction". Pages 1–13 in Karen I. Fredriksen-Goldsen, ed. *Caregiving with Pride*. The Haworth Press, Inc.

Fredriksen-Goldsen, Karen I., Hyun-Jun Kim, Anna Muraco, and Shawn Mincer. 2009. "Chronically Ill Midlife and Older Lesbians, Gay Men, and Bisexuals and Their Informal Caregivers: The Impact of the Social Context". *Sexuality Research and Social Policy*, 6(4):52–64.

Fredriksen-Goldsen, Karen I., and Anna Muraco. 2010. "Aging and Sexual Orientation: A 25-Year Review of the Literature". *Research on Aging*, 32(3):372–413.

Fredriksen-Goldsen, Karen I., Hyun-Jun Kim, Charles A. Emlet, Anna Muraco, Elena A. Erosheva, Charles P. Hoy-Ellis, Jayn Goldsen, and Heidi Petry. 2011. *The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults*. Seattle, WA: Institute for Multigenerational Health.

Friedemann, Marie-Luise. 2005. "Couples Taking Care of Each Other: Does Ethnicity Matter?". *Report of the National Council on Family Relations (Family Focus Section)*, 50(3):F27–F28.

Fruhauf, Christine A., Shannon E. Jarrott, and Katherine R. Allen. 2006. "Grandchildren's Perceptions of Caring for Grandparents". *Journal of Family Issues*, 27(7):887–911.

Fruhauf, Christine A. and Nancy A. Orel. 2008. "Developmental Issues of Grandchildren Who Provide Care to Grandparents". *International Journal of Aging and Human Development*, 67(3):209–230.

Fuller-Thomson, Esme and Meredith Minkler. 2005. "Functional Limitations among Older American Indians and Alaska Natives: Findings from the Census 2000 Supplementary Survey". *American Journal of Public Health*, 95(11):1945–1948.

Gaugler, Joseph E., Keith A. Anderson, and Heidi H. Holmes. 2005. "Family-Based Intervention in Residential Long-Term Care". *Marriage and Family Review*, 37:45–62.

Gelfand, Donald E. 2006. *The Aging Network: Programs and Services*. New York, NY: Springer Publishing Company, Inc.

Gerdner, Linda A., Toni Tripp-Reimer, and Deu Yang. 2008. "Perception and Care of Elder Hmong Americans with Chronic Confusion or Tem Toob". *Hallym International Journal of Aging*, 10(2):111–138.

Giunta, Nancy and Andrew Scharlach. 2009. "Caregiver Services: Resources, Trends, and Best Practices". Pages 241–267 in Sarah Honn Qualls and Steven H. Zarit, eds. *Aging Families and Caregiving*. Hoboken, NJ: John Wiley and Sons, Inc.

Glasgow, Nina. 2000. “Rural/Urban Patterns of Aging and Caregiving in the United States”. *Journal of Family Issues*, 21(5):611–631.

Globerman, Judith. 1996. “Motivations to Care: Daughters- and Sons-in-Law Caring for Relatives with Alzheimer’s Disease”. *Family Relations*, 45(1):37–45.

Goins, R. Turner, S. Melinda Spencer, Lisa C. McGuire, Jack Goldberg, Yang Wen, and Jeffrey A. Henderson. 2011. “Adult Caregiving among American Indians: The Role of Cultural Factors”. *The Gerontologist*, 51(3):310–320.

Goldstein, Joshua R. and Catherine T. Kenney. 2001. “Marriage Delayed or Marriage Forgone? New Cohorts Forecasts of First Marriage for U.S. Women”. *American Sociological Review*, 66(4):506–519.

Grant, Jaime M. 2010. “Outing Age 2010: Public Policy Issues Affecting Lesbian, Gay, Bisexual and Transgender Elders”. The Policy Institute of the National Gay and Lesbian Taskforce. <http://www.thetaskforce/org/downloads/reports/reports/outingage_final.pdf> Accessed February 17, 2012.

Green, Carole A. 2005. “Race, Ethnicity, and Social Security Retirement Age in the US”. *Feminist Economics*, 11(2):117–143.

Greenberg, Sarah, Maria G. Stacy, and Jeanine A. Penzo. 2001. “Spousal Caregiving: In Sickness and in Health”. *Journal of Gerontological Social Work*, 35(4):69–82.

Grossman, Arnold H., Anthony R. D’Augelli, and Eliza A. Drogowski. 2007. “Caregiving and Care Receiving among Older Lesbian, Gay, and Bisexual Adults”. Pages 15–38 in Karen I. Fredriksen-Goldsen, ed. *Caregiving with Pride*. The Haworth Press, Inc.

Gupta, Rashmi and Vijayan K. Pillai. 2000. “Elder Care Giver Burden in South Asian Families in the Dallas-Fort Worth Metropolitan Area”. *Hallym International Journal of Aging*, 2(2):93–104.

Hareven, Tamara K. 1996. “Historical Perspectives on the Family and Aging”. Pages 13–31 in Rosemary Blieszner and Victoria Hilkevitch Bedford, eds. *Aging and the Family: Theory and Research.* Westport, CT: Praeger.

Hareven, Tamara K. 2001. “Historical Perspectives on Aging and Family Relations”. Pages 141–159 in Robert H. Binstock and Linda K. George, eds. *Handbook of Aging and the Social Sciences*, Fifth Edition. San Diego, CA: Academic Press.

Hareven, Tamara K. and Kathleen J. Adams. 1996. “The Generation in the Middle: Cohort Comparisons in Assistance to Aging Parents in

DOI: 10.1057/9781137511560.0010

an American Community". Pages 272–293 in Tamara K. Hareven, ed. *Aging and Generational Relations over the Life Course: A Historical and Cross-Cultural Perspective*. New York, NY: Walter de Gruyter and Co.

Harrigan, Marcia P. and Beverly B. Koerin. 2007. "Long-Distance Caregiving: Personal Realities and Practice Implications". *Reflections: Narratives of Professional Helping*, 13(2):5–16.

Harrington Meyer, Madonna, and Pamela Herd. 2007. *Market Friendly or Family Friendly?: The State and Gender Inequality in Old Age*. New York, NY: Russell Sage Foundation.

Harris, Phyllis Braudy and Joyce Bichler. 1997. *Men Giving Care: Reflections of Husbands and Sons.* New York, NY: Garland Publishing, Inc.

Harwood, Dylan G., Warren W. Barker, Marc Cantillon, David A. Loewenstein, Raymond Ownby, and Ranjan Duara. 1998. "Depressive Symptomatology in First-Degree Family Caregivers of Alzheimer Disease Patients: A Cross-Ethnic Comparison". *Alzheimer Disease and Associated Disorders*, 12(4):340–346.

Hash, Kristina M. and Elizabeth P. Cramer. 2003. "Empowering Gay and Lesbian Caregivers and Uncovering Their Unique Experiences through the Use of Qualitative Methods". *Journal of Gay and Lesbian Social Services*, 15(1/2):47–63.

He, Wan, Manisha Sengupta, Victoria A. Velkoff, and Kimberly A. DeBarros. 2005. *65+ in the United States: 2005.* Washington, DC: U.S. Census Bureau.

Hennessy, Catherine Hagan, and Robert John. 1995. "The Interpretation of Burden among Pueblo Indian Caregivers". *Journal of Aging Studies*, 9:215–229.

Hennessy, Catherine Hagan, and Robert John. 1996. "American Indian Caregivers' Perceptions of Burden and Needed Support Services". *Journal of Applied Gerontology*, 15(3):275–293.

Hepburn, Kenneth, Marsha L. Lewis, Suzanne Narayan, Jane B. Tornatore, Karin Lindstrom Bremer, and Carey Wexler Sherman. 2002. "Discourse-Derived Perspectives: Differentiating among Spouses' Experiences of Caregiving". *American Journal of Alzheimer's Disease and Other Dementias*, 17(4):213–226.

Hequembourg, Amy and Sara Brallier. 2005. "Gendered Stories of Parental Caregiving among Siblings". *Journal of Aging Studies*, 19:53–71.

Hill, Twyla J. 2005. "Trends in Senior Children Caregiving: Comparisons of the First and Second Wave of the NSFH". Paper presented at the Annual Meeting of the American Sociological Association, Philadelphia, PA.

Hill, Twyla J. 2006. "Senior Children Caregiving: Variations by Race/Ethnicity". Paper presented at the Annual Meeting of the American Sociological Association, Montreal, Quebec, Canada.

Hill, Twyla J. 2007. "Constraints and Consequences: Older Adult Children Providing Care to Elderly Parents". Paper presented at the 2007 Annual Meeting of the American Sociological Association, New York, NY.

Hill, Twyla J. 2011. "Spousal Caregiving in Later Life: Predictors and Consequences". *Report of the National Council on Family Relations (Family Focus Section)*, 56(1):F15–F16.

Hill, Twyla J. and Stacy Tiemeyer. 2013. "Who Will Take Care of Mom and Dad? Sibling Set Composition and Caregiving". *Report of the National Council on Family Relations (Family Focus Section)*, 58(4):F17–F18.

Himes, Christine L. 1992. "Future Caregivers: Projected Family Structures of Older Persons". *Journal of Gerontology: Social Sciences*, 47(1):S17–26.

Himes, Christine L. 1994. "Parental Caregiving by Adult Women: A Demographic Perspective". *Research on Aging*, 16(2):191–211.

Himes, Christine L. 2001. "Elderly Americans". *Population Bulletin*, 56(4).

Himes, Christine L., Anne K. Jordan, and Janice I. Farkas. 1996. "Factors Influencing Parental Caregiving by Adult Women: Variations by Care Intensity and Duration". *Research on Aging*, 18(3):349–370.

Himes, Christine L. and Erin B. Reidy. 2000. "The Role of Friends in Caregiving". *Research on Aging*, 22(4):315–336.

Hogan, Dennis P. and David J. Eggebeen. 1995. "Sources of Emergency Help and Routine Assistance in Old Age". *Social Forces*, 73(3):917–936.

Hogan, Dennis P., David J. Eggebeen, and Sean M. Snaith. 1996. "The Well-Being of Aging Americans with Very Old Parents". Pages 327–346 in Tamara K. Hareven, ed. *Aging and Generational Relations over the Life Course: A Historical and Cross-Cultural Perspective*. New York, NY: Walter de Gruyter and Co.

Hogan, Paul and Lori Hogan. 2009. *Stages of Senior Care: Your Step-by-Step Guide to Making the Best Decisions*. New York, NY: The McGraw-Hill Companies.

Hooker, Karen, Deborah Monahan, Kim Shifren, and Cheryl Hutchinson. 1992. "Mental and Physical Health of Spouse Caregivers: The Role of Personality". *Psychology and Aging*, 7(3):367–375.

Hsueh, Kuei-Hsiang, Jie Hu, and Sheilah Clarke-Ekong. 2008. "Acculturation in Filial Practices among U.S. Chinese Caregivers". *Qualitative Health Research*, 18(6):775–785.

Hummer, Robert A., Maureen R. Benjamins, and Richard G. Rogers. 2004. "Racial and Ethnic Disparities in Health and Mortality among the U.S. Elderly Population". Pages 53–94 in Norman B. Anderson, Randy A. Bulatao, and Barney Cohen, eds. *Critical Perspectives on Racial and Ethnic Differences in Health in Late Life*. Washington, DC: National Academies Press.

ILC-SCHSE Taskforce. 2006. "Caregiving in America". <http://www.caregiverslibrary.org/portals/0/CGM.Caregiving%20in%20America-Final.pdf>. Accessed January 19, 2015.

Ingersoll-Dayton, Berit, Margaret B. Neal, and Leslie B. Hammer. 2001. "Aging Parents Helping Adult Children: The Experience of the Sandwiched Generation". *Family Relations*, 50:262–271.

Ingersoll-Dayton, Berit and Michael Raschick. 2004. "The Relationship between Care-Recipient Behaviors and Spousal Caregiving Stress". *The Gerontologist*, 44(3):318–327.

Jacobsen, Linda A., Mary Kent, Marlene Lee, and Mark Mather. 2011. "America's Aging Population". *Population Bulletin*, 66(1).

Janevic, Mary R. and Cathleen M. Connell. 2001. "Racial, Ethnic, and Cultural Differences in the Dementia Caregiving Experience: Recent Findings". *The Gerontologist*, 41(3):334–347.

Jervis, Lori L. and Spero M. Manson. 2002. "American Indians/Alaska Natives and Dementia". *Alzheimer Disease and Associated Disorders*, 16 (Supplement 2):S89–S95.

John, Robert, Catherine Hagan Hennessy, Timothy B. Dyeson, and Mario D. Garrett. 2001. "Toward the Conceptualization and Measurement of Caregiver Burden among Pueblo Indian Family Caregivers". *The Gerontologist*, 41(2):210–219.

Johnson, Richard W. 2008. "Choosing between Paid Elder Care and Unpaid Help from Adult Children: The Role of Relative Prices in the Care Decision". Pages 35–69 in Maximiliane E. Szinovacz and Adam Davey, eds. *Caregiving Contexts: Cultural, Familial, and Societal Implications*. New York, NY: Springer Publishing Company, Inc.

Johnson, Richard W. and Joshua M. Wiener. 2006. “A Profile of Frail Older Americans and Their Caregivers”. Washington, DC: The Urban Institute. <http://www.urban.org/UploadedPDF/311284_older_americans.pdf>. Accessed January 19, 2015.

Jones, Patricia S., Xinwei Esther Zhang, and Afaf I. Meleis. 2003. “Transforming Vulnerability”. *Western Journal of Nursing Research*, 25(7):835–853.

Kahn, Joan R., Brittany S. McGill, and Suzanne M. Bianchi. 2011. “Help to Family and Friends: Are There Gender Differences at Older Ages?” *Journal of Marriage and Family*, 73:77–92.

Kaholokula, Joseph Keawe’aimoku, Erin Saito, Marjorie K. Mau, Renee Latimer, and Todd B. Seto. 2008. “Pacific Islanders’ Perspectives on Heart Failure Management”. *Patient Education and Counseling*, 70:281–291.

Kaiser Family Foundation. 2010. “Health Care Reform and the CLASS Act”. <http://www.kff.org/healthreform/upload/8069.pdf> Accessed June 11, 2012.

Kang, Suk-Young. 2006. “Predictors of Emotional Strain among Spouse and Adult Child Caregivers”. *Journal of Gerontological Social Work*, 47 (1/2):107–131.

Kaplan, Richard L. 2011. “Older Americans, Medicare, and the Affordable Care Act: What’s Really In It for Elders?” *Generations*, 35(1):19–25.

Katz, Ruth, Ariela Lowenstein, Judith Phillips, and Svein Olav Daatland. 2005. “Theorizing Intergenerational Family Relations: Solidarity, Conflict, and Ambivalence in Cross-National Contexts”. Pages 393–420 in Vern L. Bengtson, Alan C. Acock, Katherine R. Allen, Peggye Dilworth-Anderson, and David M. Klein, eds. *Sourcebook of Family Theory and Research.* Thousand Oaks, CA: Sage Publications.

Keith, Carolyn. 1995. “Family Caregiving Systems: Models, Resources, and Values”. *Journal of Marriage and the Family*, 57(1):179–189.

Kietzman, Kathryn, A. E. Benjamin, and Ruth E. Matthias. 2013. “Whose Choice? Self-Determination and the Motivations of Paid Family and Friend Caregivers”. *Journal of Comparative Family Studies*, 44(4):519–540.

Kleban, Morton H., Elaine M. Brody, Claire B. Schoonover, and Christine Hoffman. 1989. “Family Help to the Elderly: Perceptions of Sons-in-Law Regarding Parent Care". *Journal of Marriage and the Family*, 51:303–312.

Koerin, Beverly B. and Marcia P. Harrigan. 2002. "P.S. I Love You: Long-Distance Caregiving". *Journal of Gerontological Social Work*, 40 (1/2):63–81.

Koh, Sun-Kang and Maurice McDonald. 2006. "Financial Reciprocity and Elder Care: Interdependent Resource Transfers". *Journal of Family and Economic Issues*, 27:420–436.

Kramer, Betty J. 1993. "Marital History and the Prior Relationship as Predictors of Positive and Negative Outcomes among Wife Caregivers". *Family Relations*, 42(4):367–375.

Kunkel, Suzanne R., Robert A. Applebaum, and Ian M. Nelson. 2003–2004. "For Love and Money: Paying Family Caregivers". *Generations*, 27(4):74–80.

Kwak, Minyoung, Berit Ingersoll-Dayton, and Jeungkun Kim. 2012. "Family Conflict from the Perspective of Adult Child Caregivers: The Influence of Gender". *Journal of Social and Personal Relationships*, 29(4):470–487.

Laditka, James N. and Sarah B. Laditka. 2000. "Aging Children and Their Older Parents: The Coming Generation of Caregiving". *Journal of Women and Aging*, 12(1/2):189–204.

Lan, Pei-Chia. 2002. "Subcontracting Filial Piety: Elder Care in Ethnic Chinese Immigrant Families in California". *Journal of Family Issues*, 23(7):812–835.

Langner, Suzanne R. 1993. "Ways of Managing the Experience of Caregiving to Elderly Relatives". *Western Journal of Nursing Research*, 15(5):582–594.

Lantz, Melinda S. 2006. "Elder Abuse and Neglect". Pages 352–354 in Richard Schulz, ed. *The Encyclopedia of Aging*, Fourth Edition. New York, NY: Springer Publishing Company, Inc.

LaPierre, Tracey A. and Norah Keating. 2013. "Characteristics and Contributions of Non-kin Carers of Older People: A Closer Look at Friends and Neighbors". *Ageing and Society*, 33:1442–1468.

Lee, Minhong and Stacey Kolomer. 2007. "Design of an Assessment of Caregivers' Impulsive Feelings to Commit Elder Abuse". *Research on Social Work Practice*, 17(6):729–735.

Leopold, Thomas, Marcel Raab, and Henriette Engelhardt. 2014. "The Transition to Parent Care: Costs, Commitments, and Caregiver Selection among Children". *Journal of Marriage and Family*, 76:300–318.

Levine, Carol, Deborah Halper, Ariella Peist, and David A. Gould. 2010. "Bridging Troubled Waters: Family Caregivers, Transitions, and Long-Term Care". *Health Affairs*, 29(1):116–124.

Li, Hong. 2004. "Barriers to and Unmet Needs for Supportive Services: Experiences of Asian-American Caregivers". *Journal of Cross-Cultural Gerontology*, 19:241–260.

Lin, I-Fen. 2008. "Consequences of Parental Divorce for Adult Children's Support of Their Frail Parents". *Journal of Marriage and Family*, 70:113–128.

Linsk, Nathan L., Sharon M. Keigher, Lori Simon-Rusinowitz, and Suzanne E. England. 1992. *Wages for Caring: Compensating Family Care of the Elderly*. New York, NY: Praeger Publishers.

Lohrer, Steven P., Ellen P. Lukens, and Helle Thorning. 2007. "Economic Expenditures Associated with Instrumental Caregiving Roles of Adult Siblings of Person with Severe Mental Illness". *Community Mental Health Journal*, 43(2):129–151.

Lum, Terry Y. 2005. "Understanding the Racial and Ethnic Differences in Caregiving Arrangements". *Journal of Gerontological Social Work*, 45(4):3–21.

Magilvy, Joan K., Joann G. Congdon, Ruby J. Martinez, Renel Davis, and Jennifer Averill. 2000. "Caring for Our Own: Health Care Experiences of Rural Hispanic Elders". *Journal of Aging Studies*, 14(2):171–190.

Manly, Jennifer J. and Richard Mayeux. 2004. "Ethnic Differences in Dementia and Alzheimer's Disease". Pages 95–141 in Norman B. Anderson, Randy A. Bulatao, and Barney Cohen, eds. *Critical Perspectives on Racial and Ethnic Differences in Health in Late Life.* Washington, DC: National Academies Press.

Manning, Wendy D. and Pamela J. Smock. 2002. "First Comes Cohabitation and Then Comes Marriage? A Research Note". *Journal of Family Issues*, 23(8):1065–1087.

Martin, Cathy D. 2000. "More Than the Work: Race and Gender Differences in Caregiving Burden". *Journal of Family Issues*, 21(8):986–1005.

Mathews, Sarah H. 2002. "Brothers and Parent Care: An Explanation for Sons' Underrepresentation". Pages 234–249 in Betty J. Kramer and Edward H. Thompson, eds. *Men as Caregivers: Theory, Research, and Service Implications.* New York, NY: Springer Publishing Company, Inc.

McCall, Nelda, Jodi Korb, Andrew Petersons, and Stanley Moore. 2003. "Reforming Medicare Payment: Early Effects of the 1997 Balanced Budget Act on Postacute Care". *The Milbank Quarterly*, 81(2):277–303.

Merrill, Deborah M. 1993. "Daughters-in-Law as Caregivers to the Elderly: Defining the In-Law Relationship". *Research on Aging*, 15(1):70–91.

MetLife. 2010. "Still Out, Still Aging: The MetLife Study of Lesbian, Gay, Bisexual, and Transgender Baby Boomers". <https://www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-still-out-still-aging.pdf>. Accessed January 16, 2015.

MetLife Mature Market Institute. 2006. "The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business". <http://www.caregiving.org/data/Caregiver%20Cost%20Study.pdf>. Accessed May 1, 2008.

Miller, Edward Alan. 2012. "The Affordable Care Act and Long-Term Care: Comprehensive Reform or Just Tinkering around the Edges?" *Journal of Aging and Social Policy*, 24:101–117.

Miner, Sonia and Peter Uhlenberg. 1997. "Intragenerational Proximity and the Social Role of Sibling Neighbors after Midlife". *Family Relations*, 46(2):145–153.

Moen, Phyllis. 2001. "The Gendered Life Course". Pages 179–196 in Robert H. Binstock and Linda K. George, eds. *Handbook of Aging and the Social Sciences*, Fifth Edition. San Diego, CA: Academic Press.

Montgomery, Rhonda J. V. 1992. "Gender Differences in Patterns of Child-Parent Caregiving Relationships". Pages 65–83 in Jeffrey W. Dwyer and Raymond T. Coward, eds. *Gender, Families, and Elder Care*. Newbury Park, CA: Sage Publications.

Mouton, Charles P. 1997. "Special Health Considerations in African-American Elders". *American Family Physician*, 55(4):1243–1253.

Mui, Ada C. 1995a. "Caring for Frail Elderly Parents: A Comparison of Adult Sons and Daughters". *The Gerontologist*, 35(1):86–93.

Mui, Ada C. 1995b. "Multidimensional Predictors of Caregiver Strain among Older Persons Caring for Frail Spouses". *Journal of Marriage and the Family*, 57(3):733–740.

Mui, Ada C. and Nancy Morrow-Howell. 1993. "Sources of Emotional Strain among the Oldest Caregivers: Differential Experiences of Siblings and Spouses". *Research on Aging*, 15(1):50–69.

Muraco, Anna and Karen Fredriksen-Goldsen. 2011. " 'That's What Friends Do': Informal Caregiving for Chronically Ill Midlife and

Older Lesbian, Gay, and Bisexual Adults". *Journal of Personal and Social Relationships*, 28(8):1073–1092.

Murti, Lata. 2006. "At Both Ends of Care: South Indian Hindu Widows Living with Daughters and Daughters-in-Law in Southern California". *Globalizations*, 3(3):361–376.

National Alliance for Caregiving. 2004. "Caregiving in the U.S.". <http://www.caregiving.org/data/04finalreport.pdf>. Accessed July 20, 2010.

National Center for Health Statistics. 2007. "Health, United States, 2007, with Chartbook on Trends in the Health of Americans". <http://www.cdc.gov/nchs/data/hus/hus07.pdf>. Accessed July 20, 2010.

National Center for Health Statistics. 2014. "Health, United States, 2013, with Special Feature on Prescription Drugs". <http://www.cdc.gov/nchs/data/hus/hus13.pdf>. Accessed January 16, 2015.

National Resource Center for Participant Directed Services. No date. "Cash and Counseling". <http://www.bc.edu.schools/gssw/nrcpds/cash_and_counseling.html/about>. Accessed January 16, 2015.

Nocon, Andrew and Maggie Pearson. 2000. "The Roles of Friends and Neighbours in Providing Support for Older People". *Ageing and Society*, 20:341–367.

Noel-Miller, Claire M. 2011. "Partner Caregiving in Older Cohabiting Couples". *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 66(3):341–353.

Oppenheimer, Valerie Kincade, Matthijs Kalmijn, and Nelson Lim. 1997. "Men's Career Development and Marriage Timing during a Period of Rising Inequality". *Demography*, 34(3):311–330.

Orpett Long, Susan. 2000. "Introduction". Pages 1–15 in Susan Orpett Long, ed. *Caring for the Elderly in Japan and the US: Practices and Policies.* New York, NY: Routledge.

Ozawa, Martha N. and Young Choi. 2002. "The Relationship Between Pre-Retirement Earnings and Health Status in Old Age: Black-White Differences". *Journal of Gerontological Social Work*, 38(4):19–37.

Passmore, Susan Racine and Julie Jo Cummins. 2004. "Elder Caregiving on the U.S./Mexican Border: The Impact of the Changing Hispanic Family on the Informal Caregiving System". *Journal of Mental Health and Aging*, 10(2):131–143.

Pavalko, Eliza K., Kathryn A. Henderson, and Amanda Cott. 2008. "Workplace Policies and Caregiving". Pages 195–214 in Maximiliane E. Szinovacz and Adam Davey, eds. *Caregiving Contexts: Cultural,* *Familial, and Societal Implications*. New York, NY: Springer Publishing Company, Inc.

Pearlin, Leonard I., Joseph T. Mullan, Shirley J. Semple, and Marilyn M. Skaff. 1990. "Caregiving and the Stress Process: An Overview of Concepts and Their Measures". *The Gerontologist*, 30(5):583–594.

Pearlin, Leonard I, Mark F. Pioli, and Amy E. McLaughlin. 2001. "Caregiving by Adult Children: Involvement, Role Disruption, and Health". Pages 238–254 in Robert H. Binstock and Linda K. George, eds. *Handbook of Aging and the Social Sciences*. San Diego, CA: Academic Press.

Peek, Chuck W., Barbara A. Zsembik, and Raymond T. Coward. 1997. "The Changing Caregiving Networks of Older Adults". *Research on Aging*, 19(3):333–361.

Peters-Davis, Norah D., Miriam S. Moss, and Rachel A. Pruchno. 1999. "Children-in-Law in Caregiving Families". *The Gerontologist*, 39 (1):66–75.

Peterson, Chris L. and Rachel Burton. 2007. "U.S. Health Care Spending: Comparison with Other OECD Countries". Congressional Research Service. <http://assets.opencrs.com/rpts/RL34175_20070917.pdf>. Accessed June 10, 2010.

Phillips, Linda R., Esperanza Torres de Ardon, Pauline Komnenich, Mary Killeen, and Ramona Rusinak. 2000. "The Mexican American Caregiving Experience". *Hispanic Journal of Behavioral Sciences*, 22(3):296–313.

Piercy, Kathleen W. 1998. "Theorizing about Family Caregiving: The Role of Responsibility". *Journal of Marriage and the Family*, 60(1):109–118.

Piercy, Kathleen W. 2007. "Characteristics of Strong Commitments to Intergenerational Family Care of Older Adults". *Journal of Gerontology: Social Sciences*, 62B(6):S381–S387.

Pillemer, Karl and J. Jill Suitor. 1992. "Violence and Violent Feelings: What Causes Them among Family Caregivers?". *Journal of Gerontology: Social Sciences*, 47(4):S165–S172.

Pinquart, Martin and Silvia Sörensen. 2005. "Ethnic Differences in Stressors, Resources, and Psychodogical Outcomes of Family Caregiving: A Meta-Analysis". *The Gerontologist*, 45:90–106.

Porche, Michelle V. and Diane M. Purvin. 2008. " 'Never in Our Lifetime': Legal Marriage for Same-Sex Couples in Long-Term Relationships". *Family Relations*, 57:144–159.

Pruchno, Rachel A., Morton H. Kleban, J. Eileen Michaels, and Norah P. Dempsey. 1990. “Mental and Physical Health of Caregiving Spouses: Development of a Causal Model”. *Journal of Gerontology: Psychological Sciences*, 45(5):P192–199.

Pyke, Karen D. and Vern L. Bengtson. 1996. “Caring More or Less: Individualistic and Collectivist Systems of Family Eldercare”. *Journal of Marriage and the Family*, 58(2):379–392.

Raschick, Michael and Berit Ingersoll-Dayton. 2004. “The Costs and Rewards of Caregiving among Aging Spouses and Adult Children”. *Family Relations*, 53(3):317–325.

Riedmann, Agnes and Lynn White. 1996. “Adult Sibling Relationships: Racial and Ethnic Comparisons”. Pages 105–126 in Gene H. Brody, ed. *Sibling Relationships: Their Causes and Consequences*. Norwood, NJ: Ablex Publishing Corporation.

Robert Wood Johnson Foundation. 2003. *A Portrait of Informal Caregivers in America, 2001*. Portland, OR: FACCT—The Foundation for Accountability. <http://www.rwjf.org/files/newsroom/2001FacctSurvey.pdf>. Accessed February 2, 2009.

Roberto, Karen A. and Shannon E. Jarrott. 2008. “Family Caregivers of Older Adults: A Life Span Perspective”. *Family Relations*, 57(1):100–111.

Roff, Lucinda Lee, Shadi S. Martin, Lisa K. Jennings, Michael W. Parker, and Dana K. Harmon. 2007. “Long Distance Parental Caregivers’ Experiences with Siblings: A Qualitative Study”. *Qualitative Social Work*, 6(3):315–334.

Rosenfeld, Michael J. 2014. “Couple Longevity in the Era of Same-Sex Marriage in the United States”. *Journal of Marriage and Family*, 76(5):905–918.

Russell, Richard. 2007. “Men Doing ‘Women’s Work’: Elderly Men Caregivers and the Gendered Construction of Care Work”. *Journal of Men’s Studies*, 15(1):1–18.

Ryan, Lindsay H., Jacqui Smith, Toni C. Antonucci, and James S. Jackson. 2012. “Cohort Differences in the Availability of Informal Caregivers: Are the Boomers at Risk?”. *The Gerontologist*, 52(2):177–188.

Santiago, Anna M. and Clara G. Muschkin. 1996. “Disentangling the Effects of Disability Status and Gender on the Labor Supply of Anglo, Black, and Latino Older Workers”. *The Gerontologist*, 36(3):299–310.

Sarkisian, Natalia and Naomi Gerstel. 2008. "Till Marriage Do Us Part: Adult Children's Relationships with Their Parents". *Journal of Marriage and Family*, 70(2):360–376.

Seltzer, Marsha Mailick and Lydia Wailing Li. 1996. "The Transitions of Caregiving: Subjective and Objective Definitions". *The Gerontologist*, 36(5):614–626.

Shapiro, Adam. 2003. "Later-Life Divorce and Parent-Adult Child Contact and Proximity: A Longitudinal Analysis". *Journal of Family Issues*, 24(2):264–285.

Sherman, Carey Wexler, and Pauline Boss. 2007. "Spousal Dementia Caregiving in the Context of Late-Life Remarriage". *Dementia*, 6(2):245–270.

Shippy, R. Andrew. 2007. "We Cannot Go It Alone: The Impact of Informal Support and Stressors in Older Gay, Lesbian, and Bisexual Caregivers". Pages 39–51 in Karen I. Fredriksen-Goldsen, ed. *Caregiving with Pride*. The Haworth Press, Inc.

Shuey, Kim and Melissa A. Hardy. 2003. "Assistance to Aging Parents and Parents-in-Law: Does Lineage Affect Family Allocation Decisions?". *Journal of Marriage and Family*, 65(2):418–431.

Silverstein, Merril. 2006. "Intergenerational Family Transfers in Social Context". Pages 165–180 in Robert H. Binstock and Linda K. George, eds. *Handbook of Aging and the Social Sciences*, Sixth Edition. New York, NY: Academic Press.

Silverstein, Merril and Vern L. Bengtson. 1997. "Intergenerational Solidarity and the Structure of Adult Child-Parent Relationships in American Families". *American Journal of Sociology*, 103(2):429–460.

Silverstein, Merril and Roseann Giarrusso. 2010. "Aging and Family Life: A Decade Review". *Journal of Marriage and Family*. 72:1039–1058.

Simon-Rusinowitz, Lori, Kevin J. Mahoney, and A. E. Benjamin. 2001. "Payments to Families Who Provide Care: An Option That Should Be Available". Pages 286–296 in Martha B. Holstein and Phyllis Mitzen, eds. *Ethics in Community-Based Elder Care*. New York, NY: Springer Publishing Company, Inc.

Simon-Rusinowitz, Lori, Kevin J. Mahoney, Dawn M. Loughlin, and Michele DeBarthe Sadler. 2005. "Paying Family Caregivers: An Effective Policy Option in the Arkansas Cash and Counseling Demonstration and Evaluation". Pages 83–105 in Richard K. Caputo, ed. *Challenges of Aging on U.S. Families: Policy and Practice Implications*. Binghamton, NY: The Haworth Press, Inc.

Sipes, Carolyn Sidwell. 2002. "The Experiences and Relationships of Gay Male Caregivers Who Provide Care for Their Partners with AIDS". Pages 151–189 in Betty J. Kramer and Edward H. Thompson, Jr., eds. *Men as Caregivers: Theory, Research, and Service Implications*. New York, NY: Springer Publishing Company, Inc.

South, Brett R. and Douglas B. Bradham. 2000. "From the New Deal to the New Millennium: Bridging the Gap in Us Aging and Health Policy". Pages 52–81 in Susan Orpett Long, ed. *Caring for the Elderly in Japan and the US: Practices and Policies.* New York, NY: Routledge.

Spillman, Brenda C. and Liliana E. Pezzin. 2000. "Potential and Active Family Caregivers: Changing Networks and the 'Sandwich Generation' ". *The Milbank Quarterly*, 78(3):347–374.

Stoller, Eleanor Palo. 1992. "Gender Differences in the Experiences of Caregiving Spouses". Pages 49–64 in Jeffrey W. Dwyer and Raymond T. Coward, eds. *Gender, Families, and Elder Care*. Newbury Park, CA: Sage Publications.

Stoller, Eleanor Palo and Stephen J. Cutler. 1992. "The Impact of Gender on Configurations of Care among Married Elderly Couples". *Research on Aging*, 14(3):313–330.

Stoller, Eleanor Palo and Casey Schroeder Miklowski. 2008. "Spouses Caring for Spouses: Untangling the Influences of Relationship and Gender". Pages 115–131 in Maximiliane E. Szinovacz and Adam Davey, eds. *Caregiving Contexts: Cultural, Familial, and Societal Implications*. New York, NY: Springer Publishing Company, Inc.

Stone, Robyn, Gail Lee Cafferata, and Judith Sangl. 1987. "Caregivers of the Frail Elderly: A National Profile". *The Gerontologist*, 27(5):616–626.

Strauss, Judy R. 2013. "Caregiving for Parents and In-Laws: Commonalities and Differences". *Journal of Gerontological Social Work*, 56:49–66.

Suggs, Patricia K. 1989. "Predictors of Association among Older Siblings: A Black/White Comparison". *American Behavioral Scientist*, 33(1):70–80.

Suitor, J. Jill, Karl Pillemer, Shirley Keeton, and Julie Robison. 1996. "Aged Parents and Aging Children: Determinants of Relationship Quality". Pages 223–242 in Rosemary Blieszner and Victoria Hilkevitch Bedford, eds. *Aging and the Family: Theory and Research.* Westport, CT: Praeger.

Sundstrom, Gerdt, Bo Malmberg, Mayte Sancho Castiello, Elena del Barrio, Penelope Castejon, Maria Angeles Tortosa, and Lennarth

Johansson. 2008. "Family Care for Elders in Europe: Policies and Practices". Pages 235–267 in Maximiliane E. Szinovacz and Adam Davey, eds. *Caregiving Contexts: Cultural, Familial, and Societal Implications*. New York, NY: Springer Publishing Company, Inc.

Szinovacz, Maximiliane. 2003. "Caring for a Demented Relative at Home: Effects on Parent-Adolescent Relationships and Family Dynamics". *Journal of Aging Studies*, 17:445–472.

Szinovacz, Maximiliane and Adam Davey. 2007. "Changes in Adult Child Caregiver Networks". *The Gerontologist*, 47(3):280–295.

Szinovacz, Maximiliane and Adam Davey. 2008. "The Division of Parent Care between Spouses". *Ageing and Society*, 28:571–597.

Szinovacz, Maximiliane and Adam Davey. 2013. "Changes in Adult Children's Participation in Parent Care". *Ageing and Society*, 33:667–697.

Szinovacz, Maximiliane and David J. Ekerdt. 1996. "Families and Retirement". Pages 375–400 in Rosemary Blieszner and Victoria Hilkevitch Bedford, eds. *Aging and the Family: Theory and Research*. Westport, CT: Praeger.

Takagi, Emiko, Adam Davey, and Donna Wagner. 2013. "A National Profile of Caregivers for the Oldest-Old". *Journal of Comparative Family Studies*, 44(4):473–490.

Tiemeyer, Stacy and Twyla J. Hill. 2010. "Adult Child Caregiving Tasks and Gendered Division of Labor". Paper presented at the 2010 Annual Meeting of the American Sociological Association, Atlanta, GA.

Tiemeyer, Stacy and Twyla J. Hill. 2011. "Helping Out Parents: Does Sex of the Parent Affect Which Child Helps with Particular Tasks?". Paper presented at the 2011 Annual Meeting of the Pacific Sociological Association, Seattle, WA.

Treas, Judith. 1995. "Older Americans in the 1990s and Beyond". *Population Bulletin*, 50(2).

Triana, Natalie and Twyla J. Hill. 2004. "Sons as Caregivers". Paper presented at the Sociological Society Annual Meetings, Kansas City, MO.

Uhlenberg, Peter and Michelle Cheuk. 2008. "Demographic Change and the Future of Informal Caregiving". Pages 9–33 in Maximiliane E. Szinovacz and Adam Davey, eds. *Caregiving Contexts: Cultural, Familial, and Societal Implications*. New York, NY: Springer Publishing Company, Inc.

Umberson, Debra. 1992. “Relationships between Adult Children and Their Parents: Psychological Consequences for Both Generations”. *Journal of Marriage and Family*, 54(3):664–674.

Umberson, Debra. 1996. “Demographic Position and Stressful Midlife Events: Effects on the Quality of Parent-Child Relationships”. Pages 493–531 in Carol D. Ryff and Marsha Mailick Seltzer, eds. *The Parental Experience in Midlife*. Chicago, IL: The University of Chicago Press.

U.S. Census Bureau. 1992. *Marriage, Divorce, and Remarriage in the 1990s (Current Population Reports P23–180)*. Washington, DC: U.S. Government Printing Office.

U.S. Census Bureau. 2008. *Statistical Abstract*. Washington, DC: U.S. Government Printing Office.

U.S. Census Bureau. 2011. *Statistical Abstract*. Washington, DC: U.S. Government Printing Office.

Van Volkom, Michele. 2006. “Sibling Relationships in Middle and Older Adulthood: A Review of the Literature”. *Marriage and Family Review*, 40(2/3):151–170.

Wagner, Donna L. 2006. “Families, Work, and an Aging Population: Developing a Formula that Works for the Workers”. Pages 115–125 in Francis G. Caro, ed. *Family and Aging Policy*. New York, NY: The Haworth Press, Inc.

Waite, Linda J. and Evelyn L. Lehrer. 2003. “The Benefits from Marriage and Religion in the United States: A Comparative Analysis”. *Population and Development Review*, 29(2):255–275.

Wakabayashi, Chizuko and Katharine M. Donato. 2006. “Does Caregiving Increase Poverty among Women in Later Life? Evidence from the Health and Retirement Survey”. *Journal of Health and Social Behavior*, 47:258–274.

Wallsten, Sharon S. 2000. “Effects of Caregiving, Gender, and Race on the Health, Mutuality, and Social Supports of Older Couples”. *Journal of Aging and Health*, 12(1):90–111.

Watari, Kecia and Margaret Gatz. 2002. “Dementia: A Cross-Cultural Perspective on Risk Factors”. *Generations*, 26(1):32–38.

White, Lynn. 2001. “Sibling Relationships over the Life Course: A Panel Analysis”. *Journal of Marriage and Family*, 63(2):555–568.

White, Lynn and Stacy J. Rogers. 2000. “Economic Circumstances and Family Outcomes: A Review of the 1990s”. *Journal of Marriage and the Family*, 62:1035–1051.

White-Means, Shelley I. and Rose M. Rubin. 2008. "Parent Caregiving Choices of Middle-Generation Blacks and Whites in the United States". *Journal of Aging and Health*, 20(5):560–582.

Wight, Richard G. 2002. "AIDS Caregiving Stress among HIV-Infected Men". Pages 190–212 in Betty J. Kramer and Edward H. Thompson, Jr, eds. *Men as Caregivers: Theory, Research, and Service Implications*. New York, NY: Springer Publishing Company, Inc.

Williams, Mark E. and Pat A. Freeman. 2007. "Transgender Health: Implications for Aging and Caregiving". Pages 93–108 in Karen I. Fredriksen-Goldsen, ed. *Caregiving with Pride*. The Haworth Press, Inc.

Williams, Sharon Wallace and Peggye Dilworth-Anderson. 2002. "Systems of Social Support in Families Who Care for Dependent African American Elders". *The Gerontologist*, 42(2):224–236.

Williams, Sharon Wallace, Peggye Dilworth-Anderson, and P. Y. Goodwin. 2003. "Caregiver Role Strain: The Contribution of Multiple Roles and Available Resources in African-American Women". *Aging and Mental Health*, 7(2):103–112.

Wisensale, Steven K. 2008. "Caregiving Policies in the United States: Framing a National Agenda". Pages 215–233 in Maximiliane E. Szinovacz and Adam Davey, eds. *Caregiving Contexts: Cultural, Familial, and Societal Implications*. New York, NY: Springer Publishing Company, Inc.

Witt, Judith LaBorde. 1994. "The Gendered Division of Labor in Parental Caretaking: Biology or Socialization?" *Journal of Women and Aging*, 6(1/2):65–89.

Wolf, Douglas A., Vicki Freedman, and Beth J. Soldo. 1997. "The Division of Family Labor: Care for Elderly Parents". *The Journals of Gerontology: Social Sciences*, 52B:102–109.

Wolff, Jennifer L. and Judith D. Kasper. 2006. "Caregivers of Frail Elders: Updating a National Profile". *The Gerontologist*, 46(3):344–356.

Yee, Jennifer L. and Richard Schulz. 2000. "Gender Differences in Psychiatric Morbidity among Family Caregivers: A Review and Analysis". *The Gerontologist*, 40(2):147–164.

Yeo, Gwen. 2008. "Family Caregiving for Elders with Dementia in Three Asian American Populations". *Hallym International Journal of Aging*, 10(2):85–89.

Yeo, Gwen, Jane Nha UyenTran, Nancy Hikoyeda, and Ladson Hinton. 2001. "Conceptions of Dementia among Vietnamese American Caregivers". *Journal of Gerontological Social Work*, 36(1/2):131–152.

Index

DOI: 10.1057/9781137511560.0011

DOI: 10.1057/9781137511560.0011