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Caregiving Contexts

Cultural, Familial, and Societal Implications

Edited by
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and
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Foreword

The study of care by families to older adults is a relatively recent focus in the social and behavioral sciences. Until the late 1970s, only a handful of articles had addressed the family’s role in assisting elders. Family gerontology had instead been concerned with a different issue: the withering of traditional support for older generations. It was widely believed that older people would be left alone and lonely, living in age-segregated communities or institutional settings. Much of the research at that time sought to establish whether there was still any contact between elders and their families (e.g., Shanas, 1968). While academics were pondering these questions, ordinary people found themselves increasingly concerned about and engaged in the care of their parents and spouses. Their worries worked their way into the media, and finally to the research community (Neugarten, 1979).

Although families have always provided care, the emerging public awareness in the last 30 years reflects a substantial change in the conditions of care. In the past, caring for elders within the family was the norm, but care was rare, since most people did not live to old age, and the period of decline at the end of life was typically brief. Now, of course, life expectancy is longer and most people live to ages when it is likely that they will develop chronic illnesses and disabilities that require ongoing care. Furthermore, the same improvements in medicine and public health that have promoted long life have also extended life after the onset of disease and disability (Cassel, Rudberg, & Olshansky, 1992). As a result, more older people need care than ever before and for longer periods of time.

In light of these changes, the resilience of families is remarkable. Despite the fractures in family life caused by divorce and other problems and the declining economic resources of many working- and middle-class families, family ties to their elders have largely remained strong and they remain the main source of care, even in countries with well-developed public support programs (Shea et al., 2003).
It is not surprising, given the pressures on families, that much of the research on caregiving has been preoccupied with questions of stress and burden. This has been an important focus because of the public health implications associated with chronic stress and the need to develop reasonable systems of support to help families provide care. It was also an important step in establishing family care as a legitimate field of study and for the practical goal of obtaining research funding.

An unintended side effect of this emphasis, however, has been to decontextualize family care. The focus has been almost exclusively on a single caregiver, who has been viewed from within a relatively narrow, albeit important, frame: how stress affects health and well-being. Despite this focus, the most consistent and enduring finding in the caregiving literature from the earliest to the most current research is the heterogeneity among caregivers, caregiving families, and the stresses and outcomes they experience. There is surprisingly little attention paid to the sources of this variability, particularly how the social connections between the caregiver and his or her family, community, and the wider social milieu affect the care process and outcomes.

This volume represents a major step forward in the literature by placing its focus squarely on the caregiving context, its dimensions and how it shapes the process and outcomes of family care. The chapters locate care within the family, rather than a single individual. A husband, wife, daughter, or other family member may take on the lion’s share of responsibility, but other kin and nonkin are usually involved in giving help and support on a regular basis, and the transactions and negotiations among them are a critical dimension of the care process. The family, in turn, is embedded within a larger cultural, community, and social context. Cultural expectations affect decisions about who becomes a caregiver, who else might provide help, the meanings attributed to disability and care, willingness to make personal sacrifices in providing care, openness to outside services and support, and a variety of other issues. The community and its ecology can facilitate or hinder care through such factors as ease of access to everyday services such as groceries or health care, as well as acceptance and support. The larger social and policy context has an obvious effect on whether and in what ways caregivers and disabled elders might be supported.

These explorations of context will give us a broader view of how caregiving occurs. It will help us improve our theories about care and about the family’s role in contemporary society. An understanding of the variability in family care also can lead to development of more effective ways of supporting families. Rather than a one-size-fits-all approach, which has largely characterized social programs and public policy, we need to devise strategies that complement the heterogeneity
of families. These approaches can grow out of an understanding of the conditions under which families manage the multiple challenges of care and how some families learn to manage more effectively.

We also need to recognize that families have limited resources and ability to provide care, especially as disabilities of the person they care for become more severe. Rather than viewing the institution as the end of the process, however, the reality is that families continue to be involved. We need more thoughtful plans for incorporating families into the life of a residential setting.

Care of our elders is an enduring and yet evolving part of life. The focus on context will help us understand, support, and learn from the ways that families meet the challenges involved.

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Chapter One

Introduction:
Caregiving in Context

Adam Davey and Maximiliane E. Szinovacz

Although contexts are rarely considered, the majority of issues associated with aging of individuals and societies are socially and culturally bound. Most of the key issues—such as household structure and living arrangements; work, leisure, and retirement; and health and social policies—vary considerably from one sociocultural context to another. There is also considerable heterogeneity within contexts that has not received a great deal of attention in previous research. This volume attempts to increase our understanding of caregiving through a wide variety of contextual frameworks, as opposed to the more common disciplinary perspective.

As the baby boom cohorts move from mid-life toward old age, demand for caregivers will increase significantly, and issues surrounding caregiving will reach even greater societal significance than they already have today. Much of the existing caregiving literature has focused on the caregiver or care recipient, their relationship, and caregivers’ burdens and stress. However, fuller understanding of caregiving issues requires a broader, contextual perspective. Such a perspective is particularly important to prepare caregiving-related programs and policies for the challenges of the aging baby boom cohorts.

The objective of this volume is to present a contextual perspective on caregiving. We focus on three interrelated contexts: the sociocultural, familial, and sociopolitical. This perspective is pursued in a dual manner. First, each chapter addresses a specific caregiving context. Second, the individual chapters pay attention to contexts other than those of specific...
focus in the chapter. For example, all chapters consider selected relevant subcultural variations (race and ethnicity, gender differences, regional variations, etc.). In addition, individual chapters demonstrate linkages between different contexts, such as between cultural and familial contexts. Insights pertaining to the familial contexts of care (e.g., the familial support network) could be linked to societal-level family structural change or to cultural variations in norms about filial obligations to provide care.

As a result, the content of this book is structured somewhat differently from many other edited volumes. Each chapter begins with an introduction to the topic and a thorough review of the relevant literature. Each chapter then continues to present new data or a novel conceptualization relevant to the contexts of care. Each chapter, then, represents a unique contribution to our knowledge base that can stand on its own. Each chapter, however, also provides a contrast or counterpoint to the other contributions in this volume to illustrate the same topic from multiple vantage points, or in divergent contexts. In this way, it becomes possible to begin unpacking the various assumptions and presuppositions that guide our work or that of the dominant paradigm.

The first section addresses the sociocultural contexts of care. Uhlenberg and Cheuk use data from the Second Longitudinal Study on Aging to address the question of how the availability of caregivers is projected to change in the future, relative to today’s levels. Their analyses expand on questions of how society will be fundamentally altered by the aging of this demographically large cohort. Adding to our concerns about what will happen to programs such as Social Security and Medicare, Uhlenberg and Cheuk consider the solvency of informal care. To the extent that their assumptions and projections reflect reality, the implications of their research for the largest single source of support—informal caregivers—are sobering. The breadth of data sources they bring to bear on addressing this topic speaks volumes about the extent to which the study of aging requires an interdisciplinary perspective. Given the societal significance of the baby boom cohorts thus far, it would be surprising if they failed to exert lasting changes on formal and informal care as well.

Johnson builds on these demographic trends by considering the factors affecting decisions individuals make regarding the choice of long-term care services—including home care, nursing home care, and informal care from children and other sources—using data from the 2002 wave of the Health and Retirement Study. This chapter and the data it presents have important implications given the considerable changes in women’s labor force participation. This chapter illustrates the extent to which economic perspectives on care have been elaborated to consider a wider range of individual, family, and social variables than would have been...
Introduction

common a decade ago. It reminds us, as well, that the costs (both real and opportunity) of care, and factors associated with variations in them, are an important and often overlooked aspect of old-age care.

Taking a slightly different approach, Silverstein, Conroy, and Gans adopt a focus that blends social psychological and economic perspectives to understand what leads one child to step forward and provide care for a mother in light of expectations about what one’s siblings will provide. The resulting analyses of data from the Longitudinal Study of Generations (LSOG) demonstrate the intricate relationships between norms and costs on each sibling’s care decisions. The central issue is that the care decisions made by one sibling have important implications for the other siblings. This should remind us that it is nearly impossible under most conditions to consider the perspective of a single actor without also considering the family context. It reminds us, as well, that some constellations of support are likely to be more satisfactory than others. As these authors demonstrate, formalized models of care can be quite useful in considering important conditions and dimensions along which care decisions vary within a single family.

The issues of population aging are truly global in their implications. In a significant extension of their previous research, Lowenstein, Katz, and Gur-Yaish examine cross-national variability in elder care using the rich data from the Old Age and Autonomy: The Role of Service Systems and Intergenerational Family Solidarity (OASIS) study. Their chapter considers both the expectations for assistance from formal and informal sources and their associations with quality of life in four European nations and Israel. Cross-national research is difficult to do well, and researchers must often rely on comparisons of data from diverse samples and measures collected with different purposes in mind. Thus, the use of OASIS data provides a good way to make cross-national comparisons directly and reliably. Their findings underscore the fact that high levels of state-provided services do not appear to deter support from informal sources. Rather, older adults receive more assistance, or at least assistance from a wider range of sources, in nations with more extensive services for older adults. Given the high observed levels of unmet need in the United States, this has important implications for aging populations.

What these chapters have in common is that they display the central role played by family in support and assistance to older adults. With this in mind, the second section of this book is devoted exclusively to considering the role of family as perhaps the most proximal context from which care emerges. It is interesting to note that, while each chapter in this section focuses on care within a single type of family relationship, the questions each seeks to address, the assumptions each brings to bear, and the methodology employed varies widely across chapters. Rather than presenting contradictory perspectives on similar issues, the diversity of
approaches highlights both the complexity of the family as a context as well as the unique perspective on family contexts that multiple methods can provide.

The chapter by Stoller and Miklowski addresses assistance provided by spouses, the most common type of helpers for married older adults. Many changes over the past 60 years have affected the institution of marriage and how couples reach old age together, but the centrality of marriage remains strong. As with so many other aspects of marriage, the implications of care are different for husbands than wives. Stoller and Miklowski are sensitive not just to gender differences, but also to how gender plays out through the multiple contexts in which individuals and couples are likely to be embedded. They carry forward the differences identified by the literature to consider a range of practical implications and recommendations that are likely to be useful when working with spouse caregivers.

Addressing a different set of relationships and their interplay, Davey and Szinovacz consider the ways in which adult children divide assistance to older parents. Using data from the Health and Retirement Study (HRS), they parse these ties in two different ways that integrate the information from the two preceding chapters. One section of the chapter addresses the issue of how siblings divide assistance to a specific parent. They examine the extent of change within these care networks over time, as well as factors associated with these changes. Considerable evidence emerges for flexibility and fluidity in these adult child care networks, and this change is not limited to children participating in a peripheral caregiver role. Another section of this chapter considers how couples divide assistance to parents (and parents-in-law). Here again, the modal situation is one in which assistance to parents is shared between husbands and wives, with lineage being the primary dimension along which responsibilities are divided; gender is an important but secondary dimension. A final section extends these analyses to consider some potential implications of changes in the care network for individual well-being. In this way, then, we can extend our understanding of filial obligation to in-law relationships as well as one's own parents, but care must be paid to social structural and demographic differences associated with one's “risk” of having a parent in need of assistance.

The implications of care for an older parent extend beyond one's siblings and spouse. Szinovacz uses a conceptual framework derived from the stress process model to organize and synthesize the diverse and disparate literature on how care affects children within the family, both directly in terms of their involvement with care and indirectly with regard to parents' involvement in care. One of the unique elements of this chapter is that it integrates first-person accounts from a qualitative
study conducted with children in caregiving families. The chapter is just as illustrative in pointing out where the considerable knowledge gaps are as it is with regard to highlighting the implications of care across three generations.

A final section of this book expands the focus to the sociopolitical contexts in which care is embedded. Chapters in this section can be seen as bridging the content and contexts of the two earlier sections, and each of the chapters either directly or indirectly addresses an aspect of the implications of social policies for caregiving. Not surprisingly, these chapters cover a wide range of content.

Whereas Johnson’s contribution in the first section of this book directs attention toward the costs for individuals of providing care directly versus indirectly via paid services or other care arrangements, Pavalko, Henderson, and Cott consider the nature of policies that can support caregivers within the workforce. Workplace elder care policies and associated benefits have generally lagged behind those for child care, and the United States has lagged behind many other industrialized nations. The authors use an ambitious scope of data resources, including the National Compensation Survey, the Current Population Survey, and the National Longitudinal Studies to provide a more comprehensive portrait of workplace policies as they pertain to caregiving. Their charting of changes in workplace policies that can support caregivers shows both progress and erosion in selected policies over time.

Broadening the consideration of policies affecting caregivers, Wisensale picks up where Pavalko and colleagues leave off. He extends the discussion to consider family care within the broader network of relevant policies in the United States such as the National Family Caregiver Support program and the Family Medical Leave Act. He also provides some comparative cross-national perspectives and concludes with the presentation of an integrative framework to unify the discussion of policy issues. There are also connections with Johnson’s chapter as Wisensale provides more detail about the nature and extent of home- and community-based services in the United States, with additional information regarding how they are financed. His chapter also points to the wide regional variations in services, as federal programs pass through state-level systems and are implemented at the local levels. Just how contextual these policies are stands out in stark relief when they are contrasted with family care policies from France, Germany, and Italy.

With all of this information as ground work, Sundström, Malmberg, Castiello, del Barrio, Castejon, Tortosa, and Johansson remind us that there is often at least as much variation in the nature and extent of services for old-age care within countries as between them. These authors present in-depth information about home- and community-based services
across a wide variety of European nations, organized into three broad categories along geographical and ideological-political dimensions. What emerges is a sense of the rich array of services—some directed toward older adults, others directed toward supporting family members, and still others nascent or nonexistent. Going beyond a simple survey of policies and services, the authors proceed to a more in-depth comparison of two contrasting nations: Sweden and Spain. The rich set of analyses they present draw from a wide variety of data sources within countries (such as the Levels of Living survey in Sweden), and across nations (such as the SHARE study, designed to mirror the HRS in the United States, and the EUROFAMCARE project). One of the most striking features of their in-depth comparisons is that policies emerge out of specific family contexts as much as families respond to the policies that are available. Formal services rarely appear to supplant support by families, but at their best they can encourage and sustain the help that families do provide. In every nation considered, families were the primary source of support for older adults, although they need not do so on their own. That services begin to strain under the rapidly aging population in the Nordic countries can be readily seen in the changing mix of formal and informal support to older adults.

In preparing a volume such as this one, it was never our aim to be comprehensive. We hope instead that we have succeeded in presenting views on caregiving for older adults from as wide a range as possible. It is not until we begin to shift figure and ground in dialectic fashion that the centrality, yet tremendous variability, in the contexts from which care emerges can be fully appreciated. Our consideration of the three interrelated contexts of culture, family, and society can help to broaden perspectives on caregiving and to lay a solid foundation for the next generation of dialogue on policy, research, and practice of caregiving.

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SECTION I

Sociocultural Contexts
In recent years, a great deal of attention has focused on issues related to the rapid aging of the U.S. population that is anticipated as the baby boom cohorts enter old age. Journalists, aging researchers, and policymakers are interested in the social, economic, political, and health implications associated with the expected doubling of the size of the older population between 2010 and 2040. So far, the greatest attention has been paid to the challenges associated with funding the Social Security program. The key issue here involves the changing ratio of the working population to the retired population receiving old-age pensions. Obviously, changes will be required in the pay-as-you-go Social Security program as the ratio of workers (those paying the Social Security tax) to beneficiaries drops from 3.3 in 2005 to 2.0 in 2040. The challenge of funding the existing Medicare program in the face of population aging is even greater. The issue for Medicare involves not only the same change in the ratio of workers paying taxes to retirees receiving benefits, but also the anticipated continuing inflation in per capita health care costs. Recent projections show that, by 2028, Medicare will cost more than Social Security (Palmer & Saving, 2005).

Still another issue related to population aging, and the focus of this chapter, involves providing care for older people who cannot function independently. Despite receiving less attention, the challenges of caring for the dependent older population in coming decades are no less formidable than those facing the Social Security and Medicare programs. The challenges of
caring for the frail elderly population in the future involve not only funding for long-term care but also the supply of caregivers. Most of the care that older people currently receive comes from unpaid caregivers—family members and other informal caregivers (Knickman & Snell, 2002; Rein & Salzman, 1995; Stone, 2000). For example, 65% of older people receiving help with activities of daily living who live in the community rely exclusively on informal care, and an additional 30% rely in part on informal care. In other words, about 95% of older people outside of institutions who rely on others for daily assistance are receiving that care, wholly or in part, from unpaid sources (Knickman & Snell, 2002). Should we assume that this high level of informal caregiving will be available for the future population of dependent older people?

The future supply of informal caregivers is an important issue because of its economic implications and its relationship to quality of care. The economic significance of informal care can be seen from estimates of the economic value of the informal caregiving that occurs in the United States—$196 billion in 1997. By comparison, national spending for nursing home care was $83 billion in that year, and spending on paid home health care was $32 billion. (Arno, Levine, & Memmott, 1999). Even without any change in the frequency of care being provided by unpaid sources, the cost of long-term care would be expected to increase rapidly because of population aging. If, in addition, there is a shift away from using informal care toward using formal care, we could experience even greater growth in public and/or out-of-pocket expenditures for long-term care. Currently, about 60% of formal long-term care is paid for by public sources, and 40% is paid for out of pocket (Knickman & Snell, 2002).

In addition to the economic concern, a decline in the availability of informal caregivers could have a negative effect on the quality of care received. First, unavailability of informal care increases the risk of institutionalization (Lo Sasso & Johnson, 2002). Most people strongly feel that quality of life is enhanced by living at home rather than in an institution, and physical and mental health outcomes tend to be better for those receiving care outside of institutions (Uhlenberg, 1997). Moreover, there are widespread concerns that the quality of care provided by home health aides tends to be inferior to that provided by family members (Wiener & Hanley, 1992).

This chapter explores how the supply of informal caregivers for the disabled older population may change as the population ages over coming decades. We first review what is known about informal caregiving and how recent changes in the older population may affect the future need for caregivers. Then we examine what currently predicts whether an older disabled person receives formal versus informal long-term care. Finally,
we look at how projected changes in the sociodemographic characteristics of both the older and the younger populations may challenge the existing caregiving arrangements that rely so heavily on informal care.

BACKGROUND

How Many Need Assistance?

Because the prevalence of frailty and disability increases in later life, a substantial proportion of the older population must depend on others for daily care. Several large, national surveys over the past 20 years provide information about the number and characteristics of both the users and the providers of long-term care for disabled older persons. For example, the National Long-Term Care Survey (NLTCS) has collected information from about 17,000 older people. In this survey, a user of long-term care is defined as anyone receiving help for activities of daily living (ADLs) or instrumental activities of daily living (IADLs) due to a disability or health problem lasting at least 3 months (Spillman, 2004). The ADLs in this definition were bathing, dressing, eating, walking, transferring, and toileting; the IADLs were preparing meals, telephoning, shopping, and managing money. The NLTCS found that about 16% of the population over age 65 in 1999 was receiving long-term care (Spillman, 2004). Among the 5.5 million older people receiving long-term care in 1999, 30% were in institutions, and 70% were community residents.

The probability of an older person receiving long-term care varies a great deal depending on the person’s age. The age pattern of receiving long-term care is shown in Table 2.1. Among the young-old (aged 65–74), about 7% were receiving long-term care in 1999, and most of those (84%) were community residents. But among those over age 90, the need for daily assistance is very different—63% are users of long-term care, and only slightly more than half of these are still living outside of institutions. The strong relationship of disability with age has led some to suggest that caregiving research should focus on the population over age 80. However, the situation looks quite different when we examine the age distribution of all long-term care users. Because the total number of people in each age category declines steeply with age, it turns out that 42% of all older long-term care users are less than 80 years of age. Because a significant proportion of long-term care users are in the young-old category and because these individuals are the most likely to be receiving care from informal caregivers, we include all persons over age 65 in this study.
Changing Age Composition and the Ratio of Potential Caregivers to Older Care Receivers

A number of factors will influence the future demand for care by older persons and the supply of people available to provide that care. Perhaps the most obvious factor that will affect the ratio of potential caregivers to care receivers is the shifting age composition of the population. This does not mean that demography is destiny (Friedland & Summer, 1999), but it recognizes that population aging should not be ignored in discussions of how to meet caregiving needs in the future. A simple way of seeing the implications of the changing age composition is to calculate the ratio of potential caregivers to care receivers, assuming that the age-specific rates of care receiving do not change. As discussed below, this assumption may not be realistic. However, showing the results of projections using this assumption demonstrates the relevance of population age composition for future caregiving needs.

To calculate the ratio of potential caregivers to older people in need of care, one must estimate both the numerator and the denominator. Although caregivers can be any age, the population aged 35–64 can be used as an approximation of the potential supply of caregivers. Spillman and Pezzin (2000) estimate that about 75% of potential family caregivers were in this age category in 1994, and most formal caregivers are in this age category. The projected size of the population aged 35–64 at future dates comes from the middle-range projections provided by the U.S. Census Bureau (2000). The projected number of older people in need of care is obtained by applying the age-specific rates of receiving long-term care given in Table 2.1 to the projected size of the population in each age category.

The results of this exercise in calculating the ratio of potential caregivers to long-term care receivers are shown in Table 2.2. If current patterns of disability persist, the number of persons aged 35–64 per older disabled person will fall from 18.8 in 2000 to 8.6 in 2040. This striking change occurs because the proportion of the total population in the 35–64 age category declines (from 39% in 2000 to 34% in 2040), the proportion of the total population in the 65 and over category increases (from 13% to 20%), and the proportion of the older population over age 85 increases (from 12% to 19%). Other things being equal, population aging would greatly increase the need for caregivers. If the availability of family members to provide unpaid care should decline, there could be a tremendous increase in the demand for geriatric health care workers. Before discussing potential changes in the availability of informal caregivers, we consider the possibility that the demand for care might decline.
TABLE 2.1  Persons Aged 65 and Older Receiving Long-Term Care, 1999 National Long-Term Care Survey

<table>
<thead>
<tr>
<th>Age</th>
<th>Population (in thousands)</th>
<th>Percent receiving long-term care</th>
<th>Percent receiving long-term care in community</th>
<th>Percent receiving long-term care in institutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>65–69</td>
<td>9,443</td>
<td>5.7</td>
<td>5.0</td>
<td>0.7</td>
</tr>
<tr>
<td>70–74</td>
<td>8,785</td>
<td>8.8</td>
<td>7.2</td>
<td>1.7</td>
</tr>
<tr>
<td>75–79</td>
<td>7,305</td>
<td>13.6</td>
<td>10.1</td>
<td>3.5</td>
</tr>
<tr>
<td>80–84</td>
<td>4,797</td>
<td>24.8</td>
<td>17.3</td>
<td>7.4</td>
</tr>
<tr>
<td>85–89</td>
<td>2,601</td>
<td>39.8</td>
<td>24.8</td>
<td>15.0</td>
</tr>
<tr>
<td>90–94</td>
<td>1,133</td>
<td>59.8</td>
<td>33.7</td>
<td>26.1</td>
</tr>
<tr>
<td>95 and older</td>
<td>396</td>
<td>72.1</td>
<td>35.7</td>
<td>36.4</td>
</tr>
<tr>
<td>Total</td>
<td>34,459</td>
<td>15.9</td>
<td>11.1</td>
<td>4.8</td>
</tr>
</tbody>
</table>

- Receipt of long-term care is defined as receiving human assistance or standby help with at least one of six activities of daily living (ADLs) or being unable to perform at least one of eight instrumental activities of daily living (IADLs) without help. The ADLs included are eating, transferring, toileting, getting around inside, dressing, and bathing. The IADLs are meal preparation, grocery shopping, light housework, laundry, financial management, taking medication, telephoning, and getting around inside.
- This does not include about 1.3 million persons with disabilities who do not receive chronic help but who use special equipment to manage their disabilities.
- This includes about 1.5 million persons in nursing homes and slightly more than 150,000 persons in other care facilities.


TABLE 2.2  Projection of Potential Caregivers and Long-Term Care Receivers

<table>
<thead>
<tr>
<th>Year</th>
<th>Caregivers (population aged 35 to 64)</th>
<th>Long-term care receivers aged 65 and older</th>
<th>Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>106,061,000</td>
<td>5,642,000</td>
<td>18.8 to 1</td>
</tr>
<tr>
<td>2020</td>
<td>121,657,000</td>
<td>8,448,000</td>
<td>14.4 to 1</td>
</tr>
<tr>
<td>2040</td>
<td>129,665,000</td>
<td>15,077,000</td>
<td>8.6 to 1</td>
</tr>
</tbody>
</table>

Source. Calculated from Table 2.1 and U.S. Census Bureau (2000).
Trends in Demand for Care

An assumption of no change in rates of using long-term care in coming decades could be wrong. If age-specific disability rates decline, then the number of old people needing assistance would not increase as rapidly as projected above. Greater use of assistive technology and higher education levels could reduce the need for caregivers for the population with disabilities. A starting place for considering these possibilities is an examination of recent trends.

The trend in age-specific use of long-term care is clear. Data from the NLTCS show that the proportion of older people receiving care has declined in recent years, from 14.6% in 1984 to 12.8% in 1989, 11.6% in 1994, and 10.7% in 1999. This downward trend occurred despite some aging of the older population, which, other things being equal, would have increased the use of long-term care. The next question that researchers ask, of course, is why these data show such a large decline in the use of long-term care.

Part of the answer to why the need for caregivers declined is straightforward—there was a notable decline in disability rates from 1982 to 2005. Although a number of studies have examined this issue, there is not full agreement over how much improvement there was in underlying capacity. Generally, disability studies report that rates of IADL disability have declined (Freedman et al., 2004), and these declines appear to be driven by increased levels of education, greater use of assistive technology, and changes in environmental accommodations (Freedman & Martin, 1999; Spillman, 2004). Findings on changes of rates of ADL disability are mixed; several studies show no significant change in ADL disability rates, but two studies show declines (Freedman et al., 2004; Manton, Gu, & Lamb, 2006). Thus, in recent years, IADL disability rates have declined and ADL disability rates may have as well.

As noted already, one factor contributing to the decline in IADL disability rates is the rising levels of education in the older population from 1984 to 1999. The other major factor is an increase in the use of assistive technology during this time. The NLTCS found that the percentage of disabled people using “assistive devices only” increased from 13.4% in 1984 to 25.8% in 1999 (Federal Interagency Forum on Aging-Related Statistics, 2004), and the National Health Interview Survey on Disability found a substantial age-adjusted increase in the use of assistive devices (e.g., wheelchairs, walkers, leg braces, and canes) during this time as well (Russell, Hendershot, LeClere, Howie, & Adler, 1997). The use of assistive technology not only allows some people to avoid dependency, but also is associated with a decline in hours of personal care (Hoenig, Taylor, & Sloan, 2003), time and difficulty in performing tasks
Demographic Change

(Mann, Ottenbacher, Frass, Tomita, & Granger, 1999), and residual disability (Agree, 1999; Verbrugge, Rennert, & Madans, 1997). Given that many people still do not use assistive technology (Mann, Hurren, & Tomita, 1993) and have unmet needs (Edwards & Jones, 1998), it is possible that use of assistive technology will continue to increase and thereby further reduce the demand for personal care.

Because educational attainment and assistive technology are likely to increase in the future, the demand for IADL caregiving is likely to decrease. However, recent trends suggest that demand for the more intensive ADL care is likely to continue at its current level unless ADL disability rates begin to drop (Spillman, 2004).

Looking ahead, some researchers argue that disability rates might increase as new cohorts enter old age in coming decades. The reason for this gloomy forecast is the much-publicized increasing rates of obesity among younger adults after 1980. The proportion of adults under age 75 who were obese doubled, from 15% to 30%, in the period from 1976–1980 to 1999–2002 (National Center for Health Statistics, 2005). Because of the strong relationship between obesity and disability (Gregg et al., 2005; Strum, Ringel, & Andreyeva, 2004), there is concern that increasing obesity rates among cohorts entering old age in the years ahead could lead to increasing rates of disability (Reynolds, Saito, & Crimmins, 2005; Strum et al., 2004). It is not clear that rising levels of obesity at younger ages will translate into greater prevalence of disability at older ages (Gregg et al., 2005; Preston, 2005; Williamson, 2003). However, it is noteworthy that, while disability rates were falling for older people between 1984 and 1996, they were increasing for the adult population under age 60—that is, for those cohorts that were experiencing large increases in rates of obesity (Lakdawalla, Bhattacharya, & Goldman, 2004). As these cohorts enter old age in coming decades, one cannot assume that they will have lower rates of chronic disability than those who preceded them.

Who Provides Care?

Who currently provides care for the millions of older long-term care users? A useful way to approach this question is to distinguish four types of long-term care users. The most studied category consists of those who receive paid care because they reside in long-term care institutions. In 1999, 30% of all elderly long-term care users were living in institutions, and 70% were residing in the community (Spillman, 2004). Elderly long-term care users residing in the community can be divided into three categories: those who rely on formal (paid) care, those who rely on informal (unpaid family and friends) care, and those who use a
combination of formal and informal care. A majority of those living in the community relies solely on informal caregivers, and another large proportion relies on a combination of informal and formal caregivers. Only 5% of all long-term care users live in the community and rely exclusively on formal care providers (Spillman & Pezzin, 2000). Thus, the distribution of all long-term care users by type of caregiver is as follows: 35% rely wholly on formal care (30% in institutions and 5% in the community), 25% use both formal and informal care, and 40% depend wholly on informal care. This means that almost two-thirds of all disabled older people in the population are receiving all or part of their caregiving from informal sources in the community. Clearly, these informal caregivers—unpaid relatives and friends—play an enormously significant role in meeting the needs of older people who are no longer able to function independently.

In the United States there exists a hierarchy in preferences for who should provide informal care, with spouses and children being called upon for help before other relatives, friends, or neighbors (Cantor, 1980). By far the most important sources of informal caregivers are the spouses and children of older disabled people (Stoller & Martin, 2002; Stone, Cafferata, & Sangl, 1987; Wolff & Kasper, 2006). Furthermore, in recent years the proportion of all informal caregivers who are spouses and children has increased. Therefore, the discussion of informal caregiving in this chapter will focus on the children and spouses of older people.

How has the distribution across types of caregivers been changing? The proportion of people using “formal care only” has increased slightly since the 1980s. Although the proportion of older people living in nursing homes declined from 5.4 to 4.3% between 1985 and 1999, the proportion living in the community who used formal care exclusively increased from 5.1 to 8.5% (Federal Interagency Forum on Aging-Related Statistics, 2004). However, over this time period, there was no clear trend in the use of “informal care only.” The proportion of older people in the community using informal care alone declined from 68.9% in 1984 to 57.1% in 1994 but then increased to 65.5% by 1999 (Federal Interagency Forum on Aging-Related Statistics, 2004). The proportion using both formal and informal care followed the reverse pattern, increasing and then decreasing.

During these years, the changes in use or nonuse of formal care to supplement informal care are likely related to changes in Medicare coverage of home health care. In the late 1980s, several court decisions expanded Medicare’s home health care coverage. People who were receiving home health care visits received more visits, and people who did not have home health care visits began to have them. The increase in home health care likely accounts for the reduction in reliance on only informal care observed from 1984 to 1994, as more people utilized the home
health care visits covered by Medicare. The increased use of Medicare-funded home health care in this period resulted in a massive upsurge in Medicare costs. Subsequently, steps were taken to curtail the use of home health care. In 1997, the Balanced Budget Act limited Medicare coverage of home health care, and this change explains both the decline in home health care visits after 1997 and the increase in informal care use only by 1999 (Federal Interagency Forum on Aging-Related Statistics, 2004; Health Care Financing Administration, 1999; Scanlon, 1997).

The point to be emphasized here is that informal caregiving continues to be extremely important in meeting the needs of disabled older people. But we can anticipate that demographic forces will challenge the existing arrangements. Substantial changes in the size and composition of cohorts of both care users and care providers are on the horizon. Before examining these demographic changes, we carefully examine the factors other than policy that promote informal versus formal caregiving for disabled persons.

PREDICTING USE OF FORMAL VERSUS INFORMAL CARE

As mentioned previously, the availability of informal caregivers has important implications for those receiving care and for the public cost of providing care to older people. In anticipating how the supply of informal caregivers might change in coming decades, it is useful to know what characteristics of older dependent people are related to their use of paid versus unpaid caregivers. We briefly summarize the findings of previous research on this subject. Then we present findings from our multivariate analysis of data from the second Longitudinal Study on Aging (LSOA II). This analysis will provide more detail on the differences in the use of unpaid care across individuals with different characteristics.

Past Studies

A recent analysis of data from the 2002 Health and Retirement Survey by Johnson and Wiener (2006) provides information on the bivariate relationship between selected characteristics of care receivers and their use of paid versus unpaid care. The results are unsurprising, if one assumes that the probability of using informal care is related to the degree of disability and to the resources available to the dependent person. As severity of the disability requiring assistance increases, measured as number of ADLs, the reliance on informal care decreases. An important resource for an older person can be family members, such as a spouse and adult children. As expected, among older disabled people, the unmarried are more likely
than the married to rely on paid care, and the childless are more likely than those who have children to use paid caregivers. Economic resources to purchase help might also be expected to influence whether a person makes use of formal caregiving. Using education as a proxy for economic resources, the Johnson and Wiener study shows that those with a college education are more likely than those with less education to use formal caregiving. However, the relationship between income and use of paid care is curvilinear. Those in or near poverty and those in the highest income category are more likely than those in the middle income category to use paid caregivers. This income pattern probably exists because low-income older people have access to paid home health care services through Medicaid, and high income older people have adequate resources to purchase care, but those in the middle lack adequate resources to purchase care.

Other studies report findings consistent with those described above. For example, being unmarried and/or having fewer children increases the risk of an older disabled person receiving care in an institution (Crystal, 1982; Freedman, 1999). Childless older people have been shown to rely more on formal care (Boaz & Muller, 1994; Crimmins & Saito, 1993; Zimmer & Kwong, 2003).

Further Analysis

To extend our understanding of the determinants of using informal care, we use a simple model (shown in Table 2.3) to predict the use of paid caregiving by dependent older persons living in the community. First, consistent with findings reported above, we expect formal care to be used more often when the level of care required is greater. The logic of this argument is that informal caregivers may be less able or willing to provide care that requires special skills and/or is more physically demanding. Second, based on economic reasoning, we expect that the likelihood of purchasing care increases as the resources needed to purchase care increase. Third, again consistent with previous findings, we expect that use of formal care increases as the supply of kin (spouse, children, and siblings) decreases. Finally, several standard control variables (sex, age, race/ethnicity) are included in the model, although we do not hypothesize what effects they might have. Using this multivariate model, we examine the effect of each variable controlling for other related variables, and we can address questions regarding how much difference particular variables make.

Data

The data used in this analysis come from the first wave of the second Longitudinal Study on Aging, conducted in conjunction with the 1994
TABLE 2.3 Odds Ratios for Logistic Regression of Use of Paid Caregiving by Dependent Older People on Independent Variables (N = 2,884)

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Odds ratio</th>
<th>Predictor</th>
<th>Block</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of activities of daily living</td>
<td>1.13 **</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of instrumental activities of daily living</td>
<td>0.99 **</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>1.20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>0.97</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>0.40 ***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>0.42 *</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other race</td>
<td>0.92</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>0.60 ***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>College</td>
<td>1.44 *</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing education</td>
<td>0.85</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married, spouse present</td>
<td>0.41 ***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married, spouse not present</td>
<td>1.19 ***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing marital status</td>
<td>0.66</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 children</td>
<td>1.72 **</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 children</td>
<td>0.85</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 children</td>
<td>1.10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 or more children</td>
<td>0.76</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of siblings</td>
<td>0.93 *</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


* p < .05. ** p < .01. *** p < .001.

National Health Interview. The sample for the study was obtained through a stratified multistage sample design and is representative of the civilian noninstitutionalized population, age 70 and older, in the United States in 1994–1995. A total of 9,447 respondents had face-to-face interviews. Information on disability, type of health care, demographic characteristics, family structure, and living arrangements were collected in the interviews. Our analysis is based on the 2,884 respondents who reported that they were receiving help with activities of daily living (ADLs or IADLs) and for whom crucial information was not missing (347 cases were dropped because of missing information).

The dependent variable in the analysis is dichotomous—whether the older person’s primary caregiver was a paid caregiver or an informal...
caregiver. One-fourth of the weighted sample (25.6%) had a paid caregiver, while three-fourths (74.4%) had an informal caregiver. With this outcome variable, we use logistic regression and report odds ratios in Table 2.3. The independent and control variables in the regression equation are coded as follows:

*Age:* A continuous variable from 70 to 99 and over. The last category is coded as 99. The mean age of the weighted sample is 79.4.

*Level of disability:* The sum of ADL and IADL disabilities. The means of the weighted sample are 0.5 ADLs and 1.4 IADLs.

*Sex:* A dummy variable, with 1 being female. Seventy % of the weighted sample is female.

*Race/ethnicity:* A nominal variable with mutually exclusive categories of White, Black, Hispanic, Asian, and other race. Eighty-two percent of the weighted sample is White, 9% is Black, 4% is Hispanic, 1.7% is Asian, and 2.6% is other race.

*Education:* Coded as less than high school, high school but not college, college, or missing information. The mean level of education for the weighted sample is 10.5 years.

*Marital status:* The four categories are not married, married and the spouse is present in the household, married but the spouse is not present in the household, and missing marital status. In the weighted sample, 59% is not married, 39% is married and the spouse is present in the household, 1% is married but the spouse is not present in the household, and 1% is missing marital status.

*Children:* Number of living children are coded as 0, 1, 2, 3, 4+. Twelve % of the weighted sample has no child, 19% has one child, 23 percent has two children, 18% has three children, and 28% has four or more children.

*Siblings:* Number of living siblings. The mean of the weighted sample is 1.9 siblings.

**Results**

The results of the logistic regression analysis are shown in Table 2.3. After briefly describing these results, we examine the magnitude of selected differences. First, the control variables age and sex do not have a significant effect on using paid versus informal care, net of the other variables in the model. Regarding race/ethnicity, there is no difference between Blacks and Whites, but Hispanics and Asians were more likely than Whites to rely on informal caregivers. As expected,
people with more ADLs are more likely than people with fewer ADLs to use paid care.

Of greater interest for our purposes are the effects of resources possessed by older people. Net of other variables, older people who receive care are more likely to use paid care when they have more education rather than less education. This finding fits with our expectation that those with more economic resources (indicated by higher levels of education) are more likely to pay for care. The variables we are most interested in are related to the supply of potential kin caregivers: marital status, number of children, and number of siblings. All three of these variables have a significant effect on informal caregiving. Those who are not married, and hence do not have a spouse who can provide care, are more likely to use paid care than those who are married. People with no children are more likely to rely on paid care than those who have at least one child. People with one child are more likely to pay for care than those who have four or more children. However, those with two or three children were not more likely than those with only one child to use only informal caregiving. This suggests that greater attention should be given to childlessness than to number of children when discussing implications of demographic change for supply of informal caregiving. Finally, people with fewer siblings are more likely than those with many siblings to pay for care. Thus, each aspect of family structure is a significant predictor, in the direction expected, of whether a disabled older person receives care from paid sources.

We next looked more closely at married people to see if there are differences between those who are remarried and those who are in their first marriage (analysis not shown). Compared to those who are in their first marriage, remarried people are more likely to have a spouse caregiver. This is especially true for men. One possible explanation is that men who remarry, compared to those in first marriages, may be more likely to have spouses who are younger and healthier than they are. On the other hand, compared to people in their first marriage, those who are remarried are less likely to have a child as their caregiver. Overall, the differences between these groups in spousal and in child caregiving roughly balance out, so that remarried long-term care users were about as likely as those in first marriages to have a spouse or a child as caregivers.

In addition to knowing that marital status and number of children have a significant effect on the probability of using paid care, we also want to know how much of a difference these particular variables make. To get a sense of the magnitude of the effects, we take a typical respondent (average values for age, race/ethnicity, education, disability level,
and number of siblings), vary the marital status and number of children, and calculate predicted probabilities of using paid versus unpaid care for men and women. Figure 2.1 shows the results of this exercise. First, having children has a large impact on using paid care, especially for women. For example, married women with no children are twice as likely as those with four or more children to use paid care (28% versus 12%). Similarly, the fewer children that unmarried women have, the more likely they are to rely on paid care. Forty-six percent of unmarried women without children used paid care compared to 24% of unmarried women with four or more children. In contrast to women, the number of children has relatively little impact on the probability of men using paid versus unpaid care.

The second finding highlighted in Figure 2.1 is the critical influence of marital status for both men and women. Controlling for number of children, marital status has a significant effect on the likelihood that an older long-term care user receives help from a paid caregiver. As one might expect, the impact of being married is greater for men than women. For example, among childless people, being unmarried increases the likelihood of using paid care by 2.5 times for men, compared to 1.3 times for women. Similarly, for those who have one child, being unmarried increases the likelihood of using paid care by 2.5 times for men, compared to 1.8 times for women.

FIGURE 2.1 Percent of long-term care users predicted to use a paid caregiver, by sex, marital status, and number of children, with control variables held constant at their means.

Source: Authors’ calculation from 1994–1995 second Longitudinal Study on Aging (LSOA II).
To summarize the key findings from our analysis, older people are more likely to use formal care than informal care when they

- have higher education,
- are not married,
- are childless,
- have few children compared to many, and
- have few siblings.

DEMOGRAPHIC CHANGE

The characteristics of the older population change as new cohorts enter old age and replace the cohorts who previously occupied the older age categories. Assuming that the individual-level characteristics that predict use of formal versus informal caregivers persist, these changing characteristics of the older population could alter the extent to which older people in the future will rely on family and kin as caregivers. How will the characteristics that affect the use of informal care by older people—education, marital status, and number of children—change in coming decades? To answer this question we will focus on expected change among older White women between 2000 and 2040, recognizing that subsequent analyses should complete the projections for other segments of the future older population.

Data

To illustrate changes in the older population in coming decades, we focus on three age categories (70–74, 80–84, and 90–94) in the years 2000, 2020, and 2040. To estimate the distribution of older White women in these years by education, marital history, and number of children, we begin with data from around 2000 provided by the U.S. Census Bureau. For example, among White women aged 70–74 in 2000 (survivors of the birth cohort of 1926–1930), 15% were college graduates, 4% were never married, and 11% were childless (see Figures 2.2, 2.3, and 2.4). In 2020, this cohort born in 1926–1930 will have aged into the 90–94 age category, and we assume that these characteristics of the cohort will not have changed. That is, the characteristics of women aged 90–94 in 2020 is projected to be the same as for women aged 70–74 in 2000. The assumption of no change in the distribution across characteristics as a cohort ages is not entirely plausible because there is likely to be differential survival by these characteristics. For example, we should expect survival to be positively related to educational achievement, so the
proportion with low education should decline with time and the proportion with high education should increase. Nevertheless, this approach of assuming no change in cohort characteristics as they age in later life provides a reasonable approximation to what can be anticipated.

To project the characteristics of younger age categories in 2020 and 2040, we start with data from 2000 for the appropriate cohort. For example, women who will be 80–84 years old in 2040 are in the birth cohort of 1956–1960, which was aged 40–44 in 2000. By assuming that women have completed their education and childbearing by age 40, we project that these characteristics of this cohort will not change as it ages. In projecting its marital history in 2020 and 2040, we assume that age-specific transition rates will resemble those existing around 2000. For Census Bureau data on education for various cohorts of White women around 2000, see Day and Bauman (2000); for data on marital history, see Kreider (2002); and for data on fertility, see National Center for Health Statistics (2003).

**Educational Change**

As shown in Figure 2.2, we anticipate a substantial increase in the educational levels of older women, reflecting the very different school experiences in earlier life of the cohorts that will replace the contemporary older population. In 2000, four times as many women aged 80–84 had less than a high school education than had a college education. By 2040, this ratio will be reversed, because five times as many will be college-educated as will have less than a high school education. Assuming that educational differences in use of paid care persist, other things being equal, the coming large increase in the educational levels of the older population should significantly increase the future demand for paid caregivers. Because education is associated with lower rates of disability, there could be a lower demand for caregiving among individuals in an age category. Nonetheless, more people who become disabled will have high education levels and therefore will be more likely to demand paid care.

**Marital Status Changes**

The proportion of older people who have never married is expected to slightly increase over the next 40 years, as shown in Figure 2.3. The effect of this change, of course, will be to decrease the supply of potential spouse caregivers. However, the expected increase in the proportion of older White women who never marry (for example, an increase from 5% of women aged 80–84 in 2000 to 7% in 2040), is too small to have much impact on the overall supply of informal caregivers.
In contrast to the experience of White women, the retreat from marriage in recent decades by younger Black women has been dramatic—a third of all Black women aged 40 in 2000 may never marry (Blau, 2007). This racial contrast suggests that discussions of future spouse caregiving need to carefully consider racial/ethnic differences.

FIGURE 2.2 Educational attainment of White women by age: 2000, 2020, 2040.

Source: Day and Bauman (2000).

FIGURE 2.3 Marital status of White women by age: 2000, 2020, 2040.

Source: Kreider (2002).
Probably a more important factor affecting the future supply of spouse caregivers is the declining gender gap in age at marriage and in life expectancy. Gender differences in median age at first marriage declined over the 20th century, and the gender gap in life expectancy declined since 1970 (Federal Interagency Forum on Aging-Related Statistics, 2004). Consequently, married couples who enter old age in the future can anticipate spending fewer years widowed, which implies an increase in the supply of potential spouse caregivers. These changes are reflected in the increase between 1990 and 2000 in the proportion of older women who were married (Kreider & Simmons, 2003) and in the forecast by the Social Security Administration that the proportion of married persons over age 85 will increase in coming years (Siegel, 1996).

Potentially the most important change in marital patterns affecting future informal caregiving, however, is neither the increase in percent who never marry nor the decrease in length of widowhood. It is the expected dramatic increase in the proportion of women who have their first marriage end in divorce that could most alter current caregiving arrangements (Uhlenberg, Cooney, & Boyd, 1990). In 2000, about 20% of ever-married women aged 80–84 had experienced divorce; in 2040 it will be nearly 50%. The crucial question is what effect divorce in earlier life has on availability of informal caregivers in later life.

The impact of divorce on availability of children to provide care seems clear. Compared to married people, divorced people are more likely to use paid care and less likely to rely on children for care when they are disabled. The negative effect of divorce on children as caregivers is true for both men and women, but especially for men (Cooney & Uhlenberg, 1990; Hagestad, 1986; Marks, 1991). The decreased strength of father-child relationships in later life resulting from divorce (Uhlenberg, 1993) reflects the consequences of fathers not coresiding with their children during childhood (Furstenberg, 1990; Seltzer & Bianchi, 1988). Theoretically, those who remarry after divorce could expand their supply of child caregivers by adding stepchildren (Wachter, 1997). However, findings from our analysis (discussed above) replicate results from other studies that show that remarried people are less likely than people in first marriages to use any child caregivers (Marks, 1991). Remarried people may be more likely than divorced people to receive care from children, but they are less likely to receive such care than people in first marriages (Knickman & Snell, 2002). Thus, the increasing prevalence of divorce among cohorts that will occupy the older ages after 2020 or 2030 is a major demographic force working to decrease the supply of child caregivers in the future.

In addition to decreasing the availability of children to provide care, divorce can also decrease availability of spouses to provide care. Clearly this is the case for those who divorce and do not remarry. However, as shown above, people who remarry are somewhat more likely than
people who stay in first marriages to rely on a spouse caregiver. This is especially true for men. Thus, remarriage can moderate the negative impact of increasing divorce on the availability of informal caregivers. However, the rate of remarriage has been decreasing steadily since 1960 (Bramlett & Mosher, 2002). The persistent high rate of divorce in recent decades, when combined with a decreasing rate of remarriage, produces an expected large increase in the proportion of people whose marital status in old age will be divorced. Thus, the overall effect of changing marital patterns on the use of informal caregivers in coming decades will almost certainly be negative.

**Changes in Number of Children**

The significant decline in the number of children that baby boomers had compared to the cohorts that precede them will produce a large change in the number of living adult children available to provide long-term care for older parents in the future. The total fertility rate of cohorts that produced the baby boom was over 3.0, compared to about 2.0 for the baby boom cohorts (National Center for Health Statistics, 2003). As shown in Figure 2.4, when the mothers of the baby boom are in greatest need of caregiving (i.e., when they are over age 80 around 2020), more than a fourth of them will have at least four children. However, 20 years later when baby boomers are over age 80, only 10 percent of them will have four or more children. There will also be an increase in the proportion of those over age 70 who are childless between 2020 and 2040. This change in family size is significant because older people with fewer living children tend to use paid care more often, as indicated in Figure 2.1. Also, women with fewer children are more likely to be cared for in institutions (Crystal, 1982; Freedman, 1999). Thus, the decrease in the number of children per capita among older long-term care users can be expected to increase the demand for paid caregivers in coming decades.

However, the effect of declining fertility on the use of child caregivers by older adults should not be exaggerated. The most important contrast in availability of having a child caregiver is between the childless and those with at least one child. Those who have one child are less likely than those with two children to have a child who provides care, but the difference is less than that between the childless and the mothers with one child (Uhlenberg, 1993; Zimmer & Kwong, 2003). At higher parities, there are diminishing returns associated with having more children, so that differences between those with four or more compared to those with two or three are small. As shown in Figure 2.4, the proportion of women over age 80 who are childless is not expected to increase—it will be lower in 2020 than it was in 2000 and will be about the same in 2040 as in 2000. The big change in family size will be the decrease in the proportion of women
with large families, but, as noted above, those with four or more children rely on paid caregivers only slightly less often than those who have one or two children. It is a significant advantage to have a daughter if one wants to receive long-term care from a child (Rein & Salzman, 1995; Stone, 2000), and the odds of having a daughter increase with the number of children born.

In conclusion, the smaller average family size for women who will occupy the oldest age categories by 2040 will reduce the supply of informal caregivers for dependent older persons, but not dramatically. In addition, decline in fertility across cohorts will result in older people in the future having fewer siblings, nephews, nieces, and grandchildren available for caregiving. Although these other kin constitute a relatively smaller proportion of family caregivers than spouses and children, their shrinking numbers will have some additional impact on the supply of informal caregivers.

**Changes in Characteristics of Younger Cohorts**

The future availability of informal caregivers depends not only on changing characteristics of the older population but also on changing characteristics
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of the cohorts that will comprise the younger population. High rates of divorce and declining rates of remarriage among these cohorts may decrease the availability of adult children to provide care (Uhlenberg, 1994) because divorced women who maintain separate households tend to have less time and money to invest in caregiving. Also, increasingly, the daughters of older people are in the labor force, which decreases the time and energy that they have for caregiving (Doty, Jackson, & Crown, 1998; Pavalko & Artis, 1997). Research has shown that when daughters provide care in addition to being employed, their parent tends to receive less informal care and more formal care (Doty et al., 1998). In addition, longer life expectancy and later age at childbearing mean that more parents in need of care in the future will have adult children who also are old. Adult children who are themselves old may be less able or willing to care for their parents who are very old than are middle-aged children with old parents. On the other hand, adult children who are old will also more likely be retired, and therefore they may be more available to provide care than their younger, working counterparts.

CONCLUSION

Population aging over the next several decades will challenge existing social institutions in a number of ways. As long as growing old is associated with withdrawal from the labor force, increasing health problems, and growing risks of disability, the challenges of dealing with Social Security, Medicare, and long-term care issues will all occur at about the same time. There is no reason to expect that social institutions cannot adapt to meet these challenges, but substantial changes will need to begin soon. The ratio of older people to working-age people will occur abruptly after 2010 as the baby boom cohorts arrive at old age with very different educational and family experiences than those of the contemporary older population.

This chapter has explored the challenges ahead to the current arrangement of relying on kin for almost two-thirds of the long-term care received by older disabled people. Some disabled people rely on paid care more than on informal care by family members. Individuals are at higher risk of using paid care when they have high disability levels, have resources to pay for care, and/or lack family members to provide informal care. Those most able to pay for care either have high incomes or receive Medicaid benefits because of low income. People who are divorced, unmarried, childless, and/or have a small extended family are more likely to rely on paid care because they have fewer family members available for assistance. Cohorts of Black women entering old age have a high proportion who are unmarried and are therefore more likely to rely
on paid care. Hispanics and Asians, on the other hand, are less likely to rely on paid care and are more likely to rely on informal care.

As fewer people arrive at old age with stable marriages and large families, the availability of informal caregivers will shrink. Further, as educational levels among older people increase, we can expect the demand for formal care to increase, although this may be offset by the fact that people with higher educational levels are less likely to become disabled in the first place. But the forces that point to an increase in demand for paid care relative to informal care will occur at the same time as the overall ratio of older retired persons to workers is increasing. In this context, several important questions will need to be answered. How much growth in the geriatric workforce will be needed to meet the demands of the future disabled older population? How will the nation’s resources be allocated to pay for geriatric care? And who will pay for the increase in formal care?

REFERENCES


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