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

Ronald W. Toseland · David H. Haigler
Deborah J. Monahan *Editors*

Education and Support Programs for Caregivers

Research · Practice · Policy

Series Foreword by
Former First Lady Rosalynn Carter

Springer

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To my family Sheryl, Becky, and Stacey for their support and encouragement.

Ron

To Hayne, Frances, and Virginia for their care and support.

David

With much love and gratitude to Vernon, Sam, and Rachel for teaching me life's important lessons.

Deb

Foreword

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

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

The RCI has been at the forefront of caregiver education and support. From 1990-2005, we established a statewide network of caregiving coalitions, or CARE-NETs, throughout Georgia. CARE-NETs bring together community leaders and other key individuals to plan and coordinate local caregiver support services. Our signature curriculum, *Caring for You, Caring for Me: Education and Support for Family and Professional Caregivers*, a five-week education and support program for professional and family caregivers, was first published in 1998 with a second edition released in 2007. In 2009, we established a caregiver certification program at Georgia Southwestern State University. In this interdisciplinary program, students earn 18 college credit hours to prepare them for a caregiving career.

Whether it is by supporting CARE-NET coalitions, offering a college-level caregiver certification program, hosting an annual summit on evidence-based interventions, or forging a training partnership with Korea Digital University in Seoul, the RCI embodies my commitment to support our nation's caregivers.

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

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

The accumulated wisdom from this work is represented in the volumes that make up Springer's Caregiving Series. This series presents a broad portrait of the nature of caregiving in the United States in the 21st century. Most Americans have been, are now, or will be caregivers. With our society's increasing demands for care, we cannot expect a high quality of life for our seniors and others living with limitations due to illness or disability unless we understand and support the work of caregivers. Without thoughtful planning, intelligent policies, and sensitive interventions, there is the risk that the work of family, paraprofessional, and professional caregivers will become intolerably difficult and burdensome. We cannot let this happen.

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

Rosalynn Carter

Contents

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Chapter 1
Introduction

Deborah J. Monahan, David H. Haigler, and Ronald W. Toseland

One consequence of living longer in the twenty-first century is that most Americans will become caregivers to either their spouses or their parents, if not both. Caregiving is a genuine act of kindness to those whose lives influence our own and to whom we feel a personal sense of obligation. Although there is not a formal contractual obligation for caregiving, the bonds of filial and marital responsibility often run deep. Many individuals feel a strong moral obligation for giving care throughout the lifespan. However, the rationale for caregiving varies widely among individuals and families, whose expectations and needs often determine the extent of the perceived or actual obligation. Whether motivated by obligation or kindness, the demands of providing care to someone who is frail have considerable physical, psychological, and financial consequences for the caregiver. Supportive social and educational programs have emerged in the past two decades to help individuals and families understand and more effectively assume their caregiving responsibilities. These programs have developed in response to the burgeoning needs expressed by caregivers for information and strategies to help them to become more effective, and less overwhelmed, in their caregiving roles. In this book, we examine research findings that illuminate the efficacy of supportive and educational interventions for family caregivers.

Education and Support Programs for Caregivers: Implications for Practice, Research, and Policy is one in a series of books addressing various issues and concerns in caregiving that was commissioned and implemented through a partnership between Johnson & Johnson and the Rosalynn Carter Institute for Caregiving. This is the only book in the series to focus expressly on education and support programs to assist caregivers. The topic was selected in response to the proliferation of these programs now available to caregivers and the corresponding acknowledgment of the pressing need to expand our capacity to develop and provide such programs in the most effective manner possible. The topic is especially relevant in light of the establishment of the National Family Caregivers Support Program, funded by the

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Administration on Aging through the Older Americans Act of 2000 (Public Law 106–501), which provided funds for local organizations to develop and offer such programs much more widely than in previous years. It was considered an opportune time to put forth a single volume that explores what is currently known about education, training, and support programs for caregivers, and what knowledge is needed to facilitate the planning, implementation, and evaluation of such programs.

Following the identification of pertinent chapter topics, authors were recruited based upon their demonstrated expertise in one or more of the selected topic areas. These noted authorities were invited to participate in the preparation of this book by (1) preparing and delivering a brief presentation at an expert panel meeting at the Carter Presidential Center in Atlanta, and (2) writing their respective chapters. During the expert panel meeting, authors made brief presentations of their chapters, which were followed by discussions among all authors. This format provided an opportunity for questions about the material presented as well as collaboration on ideas to incorporate into the writing of each chapter. The chapters presented in this book, therefore, represent not only the expertise of each individual author, but also the collective wisdom and guidance of all who participated on the expert panel. In this introductory chapter, we examine the demographic data on family caregivers in the United States and trends in caregiving. We provide an overview for the analysis of the range of educational and supportive programs for caregivers, a conceptual framework for examining intervention programs, and an overview of each chapter.

Who Are the Caregivers?

In a survey of caregiving in the United States (National Alliance for Caregivers and the AARP, 2005), 44 million Americans age 18 and older provide unpaid assistance and support to adults with disabilities who live in the community. Those surveyed identified numerous tasks (e.g., activities of daily living) that they commonly performed in their caregiving role, such as helping with finances, grocery shopping, doing housework, and personal care such as assistance with dressing and bathing. Women outnumber men as caregivers (61 vs. 39%), 58% are between the ages of 18 and 49 years, and 59% work either full or part time while providing care. If you add the number of unpaid family caregivers to an adult or a child, the number has been estimated to be 65.7 million Americans (National Alliance for Caregivers-NAC, AARP, and Metlife, 2009). Caregivers provide assistance of 18–21 h per week, and nearly one in four households is involved in caregiving (Arno, Levine, & Memmott, 1999; NAC, AARP & Metlife, 2009). Usually the spouse is the first in line, followed by adult children when there is no spouse available or when the caregiving demands exceed the spouse's capacity (Cantor, 1991). Kane and Penrod (1995) assert that the majority of caregivers are the wives, husbands, daughters, and sons of the person with disabilities.

According to data provided by the Administration on Aging in the Department of Health and Human Services (2004), 23% of households contain at least one caregiver for a relative or friend at least 50 years old. These data show that 80% of community care is provided by family caregivers. An estimate of the market value of family caregiving services by the Family Caregiver Alliance and the National Family Caregivers Association, in association with Peter Arno, suggested an approximate value of $306 billion annually (Feinberg, Wolkwitz, & Goldstein, 2006). These figures have recently been updated to $375 billion in a survey by Evercare and the National Alliance for Family Caregiving (2009). These costs are very much associated with what Bruce Vladeck (2005) characterizes as the economic implications of improving longevity.

In a report by the National Alliance for Caregiving and AARP (2004), the authors suggest that the great majority of caregivers are *helping relatives*. Data on caregivers from their national sample ($n=1{,}247$) indicate that 21% of U.S. households contain at least one caregiver (approximately 22,901,800 households); that the average duration of caregiving is 4.3 years; and that half of all caregivers perform the difficult tasks involved in assisting with activities of daily living. Findings from their report indicate that while caregivers shoulder most of the unpaid help for their relatives, paid help is more common among caregivers in higher income brackets and among those carrying the heaviest burden. When asked where they look for information about caregiving, 29% say they turn to the internet, 28% to a doctor, 15% to family or friends, and 10% to other health professionals. Where caregivers turn for help is a critical issue from a service delivery standpoint, and the basis of this book's emphasis is on supportive educational programs.

In a 50-state survey of 150 publicly funded programs conducted by the Family Caregiver Alliance in collaboration with the National Conference of State Legislatures and funded by the U.S Administration on Aging (Feinberg et al., 2006), three emerging trends were identified. The first trend is a continued development and improvement in caregiver assessment, care planning, and service delivery to ensure better client outcomes. A second trend is an increase in the consumer direction of family caregiver support services, which may include supplemental services to enable families to purchase goods and services related to care needs. The third trend involves an increasing collaboration between the aging network and the health-care system to “delay institutionalization” of the care recipient for as long as possible. The implications of these trends will be found in several chapters of this book.

Data from the 1984, 1989, 1994, and 1999 waves of the National Long Term Care Survey were analyzed to examine informal and formal care and the characteristics of family caregivers and care recipients (Spillman & Black, 2005). Researchers found that between 1984 and 1994 formal care among older community residents who received personal assistance declined dramatically (from 43% in 1994 to 34% in 1999). Furthermore, they found that a larger proportion of care recipients were relying entirely on their *informal* caregivers in 1999 than in 1994 – nearly two-thirds, compared with 57% in 1994, as a result of the decline in formal care. They concluded that the reduction in formal care for older persons would adversely affect those with a disability who had a spouse only, those who were 75 or older, and those in the highest disability level.

Consequences of Caregiving and the Emergence of Supportive Programs

Supportive educational programs have emerged as a response to both positive and negative consequences of caregiving. For some caregivers, a program is sought to increase their knowledge of how to perform their caregiving responsibilities more effectively. Their rationale for caregiving is typically positive and proactive. They experience caregiving as gratifying, and their capacity for active coping enables them to fulfill their responsibilities with vigor and resolve. For these caregivers, learning all they can about being effective in their role gives them great personal satisfaction. Many caregivers handle caregiving tasks quite well and do not interpret these new roles as problematic and these families would be characterized as resilient (McCubbin, McCubbin, & Thompson, 1993). This model of family resilience helps us to understand that many families respond to the challenge of caring for a frail relative by maintaining equilibrium during crises. These families often show more cohesion and flexibility, use open communication, and use more community resources to resolve their problems (Walsh, 1996).

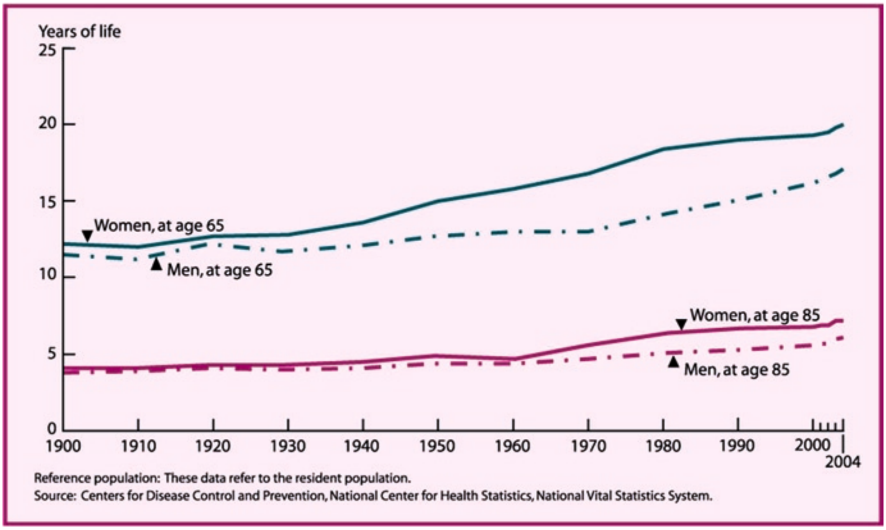
At the same time, however, even resilient families can become exhausted and experience some of the negative consequences of caregiving. Such families may experience conflict because of their differing views about *how* to provide care and *who* should give it. Moreover, some caregiving tasks leave them feeling physically and emotionally exhausted and unsure of how to take care of themselves while they provide care to a relative. Not having enough time for themselves, their own families, or their careers may lead them to feel emotionally isolated from the kind of life they had prior to becoming a caregiver. While caregiving may not initially seem burdensome, over time, the tasks may become a burden, thereby leading to unexpected emotional strains.

These emotional strains may become even more complex and difficult to manage if caregivers have feelings of guilt or anger directed at themselves, other family members, or at their situation in general. Families often experience negative financial consequences of caregiving if they need to reduce their hours of paid work or forego employment to provide care. At the same time, there may be unexpected increases in the costs associated with their relative's illness, such as physician, medical, and pharmaceutical expenses or delays in processing insurance reimbursements and difficulties in dealing with insurance and provider organizations (Toseland & Smith 2001). These strains can lead to psychological or health problems and to the need for professional educational and supportive programs. Thus, educational and psychoeducational interventions have been designed to decrease family burden at the same time that they seek to increase family functioning (Biegel & Schulz, 1999).

Demographic Trends Affecting Family Caregiving

Several recent demographic trends also have important implications for family caregiving. These include increases in (1) longevity, (2) the prevalence of chronic diseases, (3) the percentage of people over 65 with memory impairments,

(4) expenditures for health care, and (5) the diversity of the population. The 2008 *Report on Older Americans: Indictors of Well-being*, prepared by the Federal Inter-Agency Forum on Aging-Related Statistics, indicates that Americans are living longer than ever before and that life expectancies at both age 65 and age 85 have increased (also see the 2004 and 2006 reports). Under current mortality conditions, people who survive to age 65 can expect to live an average of nearly 18.7 more years, while the life expectancy of people who survive to age 85 today is about 7.2 years for women and 6.1 years for men. However, Olshansky, Goldman, Zheng, and Rowe (2009, page 858) argue that "official government forecasts of survival, life expectancy, and aging for the U.S. population may have been significantly underestimated." Increased longevity with its concomitant increase in exposure to risk of adverse events is often associated with the need for social and health-care services and the supportive assistance of family caregiving. For example, individuals with developmental disabilities, especially those with Down syndrome, are also living longer, and will have increased needs for family caregiving (Fig. 1.1).

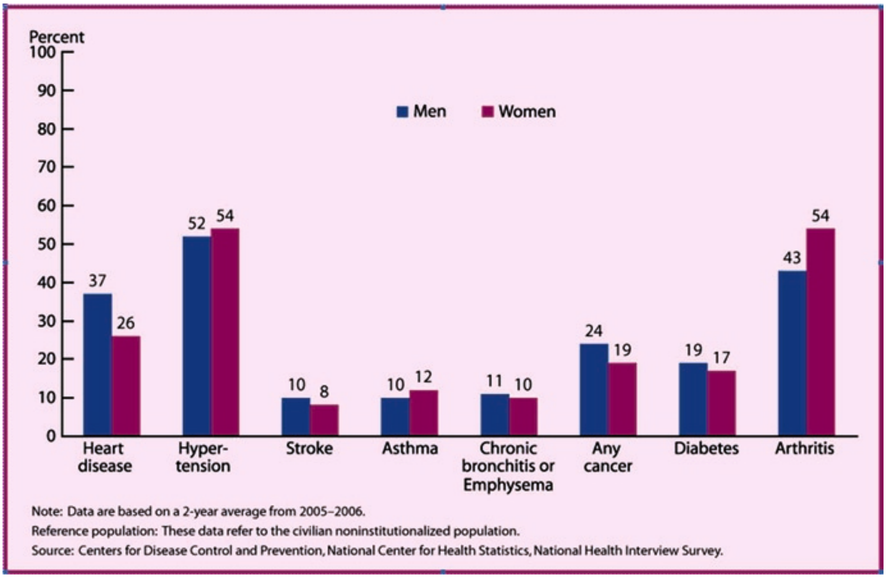


Reference population: These data refer to the resident population.
Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics System.

Fig. 1.1 Life expectancy at ages 65 and 85, by sex, selected years 1900–2004

A second trend, mainly reflecting increased exposure to risk due to longevity, is the increase in chronic illnesses (i.e., diseases that are long term and that are rarely cured). Chronic diseases such as heart disease, stroke, cancer, and diabetes are among the most common and costly health conditions. Chronic health conditions negatively affect quality of life, contributing to declines in functioning and increased inability to remain in the community. These conditions often lead to the need for family caregiving. The percentage of people age 65 and over that reported having selected chronic conditions is shown in Fig. 1.2.

A third demographic trend is the increase in the percentage of people age 65 and over with moderate or severe memory impairment (Fig. 1.3). Memory skills are

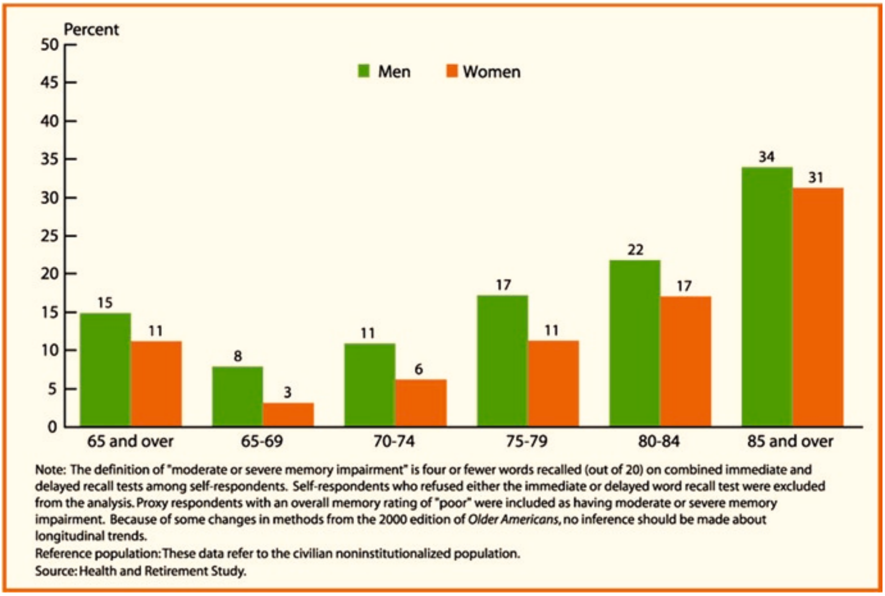


Note: Data are based on a 2-year average from 2005–2006.

Reference population: These data refer to the civilian noninstitutionalized population.

Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Health Interview Survey.

Fig. 1.2 Percentage of people age 65 and over who reported having selected chronic conditions, by sex, 2005–2006



Note: The definition of "moderate or severe memory impairment" is four or fewer words recalled (out of 20) on combined immediate and delayed recall tests among self-respondents. Self-respondents who refused either the immediate or delayed word recall test were excluded from the analysis. Proxy respondents with an overall memory rating of "poor" were included as having moderate or severe memory impairment. Because of some changes in methods from the 2000 edition of *Older Americans*, no inference should be made about longitudinal trends.

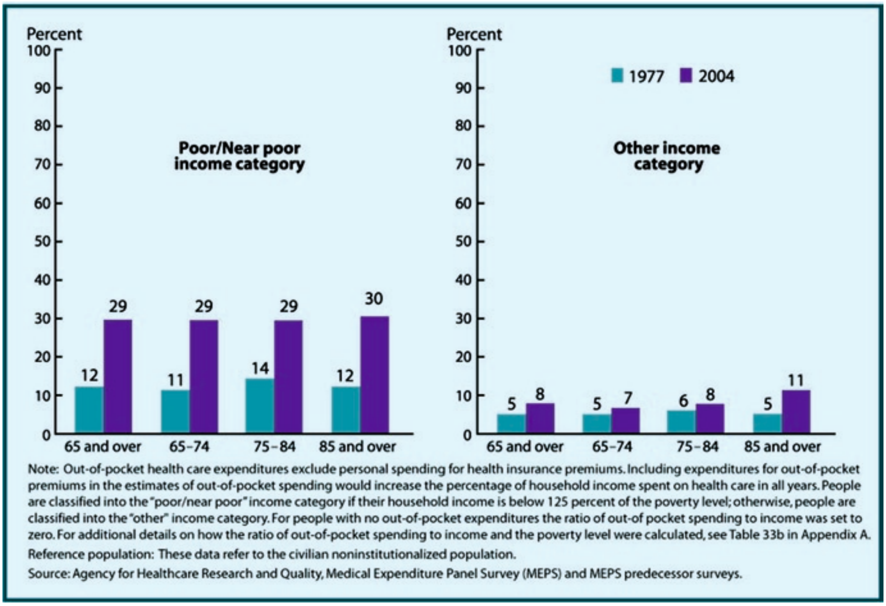
Reference population: These data refer to the civilian noninstitutionalized population.

Source: Health and Retirement Study.

Fig. 1.3 Percentage of people age 65 and over with moderate or severe memory impairment, by age group and sex, 2002 important to general cognitive functioning and enable older adults to live independently. Low cognitive functioning (e.g., memory impairment) is a major risk factor for needing assistance with daily functioning, and typically these are the tasks provided by family members. Much of the early work on family caregivers was directed at understanding the needs of caregivers providing care to relatives with serious memory problems or cognitive impairment.

A fourth trend is the large and increasing out-of-pocket expenditures for health care. Serious implications of these increasing expenditures include service use and access to care as well as quality of life and health status. Another implication of rising expenditures is that there are inadequate resources for other necessities. The percentage of household income that is allocated to health-care expenditures is a measure of the health-care expense burden placed on older people and their family caregivers (see Fig. 1.4).

The increasing diversity of the U.S. population is a fifth trend that poses significant challenges for professionals in reaching vulnerable groups and responding to their unique needs for services. It is expected that 33–39% of the elderly population in the United States by the year 2050 will be members of minority groups (Federal Interagency Forum on Aging Related Statistics, 2008; Markides & Miranda, 1997). Because minority caregivers tend to have lower incomes, less education, and to be in poorer health than white caregivers (Pruchno, Patrick, & Burant, 1997), their



Note: Out-of-pocket health care expenditures exclude personal spending for health insurance premiums. Including expenditures for out-of-pocket premiums in the estimates of out-of-pocket spending would increase the percentage of household income spent on health care in all years. People are classified into the "poor/near poor" income category if their household income is below 125 percent of the poverty level; otherwise, people are classified into the "other" income category. For people with no out-of-pocket expenditures the ratio of out-of pocket spending to income was set to zero. For additional details on how the ratio of out-of-pocket spending to income and the poverty level were calculated, see Table 33b in Appendix A.

Reference population: These data refer to the civilian noninstitutionalized population.

Source: Agency for Healthcare Research and Quality, Medical Expenditure Panel Survey (MEPS) and MEPS predecessor surveys.

Fig. 1.4 Out-of-pocket health-care expenditures as a percentage of household income, among people age 65 and over, by age and income category, 1977 and 2004 needs may be greater and different in some respects from those of more advantaged groups. Developing interventions for these caregivers will require sensitivity to cultural norms of caregiving. More sophisticated outreach efforts will be necessary to successfully recruit minority caregivers into educational and supportive programs, and more attention will need to be paid to the types of measures used to evaluate the efficacy of these programs for minority caregivers as well as in the development of the measurement tools to evaluate their efficacy (Toseland & Smith, 2001; Toseland & McCallion, 1997).

Range of Educational and Supportive Programs

Programs developed in support of caregivers are quite varied and have emerged over the past two decades to ease the burden of providing both short- and long-term caregiving for family members. Many programs provide respite or time off from the demands of caregiving. Quite often, programs are a combination of public, voluntary, and private social services developed by professionals such as nurses, social workers, educators, and other health-care providers. Respite programs typically provide time off for caregivers, while support groups offer educational training and emotional support from other caregivers as well as from professionals. Some programs are standalone, community-based programs; others are developed to serve an existing clinical program. Still others are a combination of both. Many programs offer telephone reassurance and referrals, while some offer on-line computer-based internet referrals and assistance. In addition, some programs offer explicit training for family caregivers; others concentrate their efforts on providing information and referral services. In the ensuing chapters of this book, these educational and support programs for caregivers are reviewed and analyzed, using the following conceptual framework.

Conceptual Framework

Conceptual frameworks guide researchers and practitioners in their analysis of the various components of intervention programs. This book introduces a wide range of supportive educational programs for caregivers, their organizational structure, and implementation methods. The conceptual framework selected for this book considers programs from the standpoint of current and future trends in professional practice, research, and education as well as policy and advocacy. In most of the chapters, the conceptual framework analyzes four questions about supportive educational programs for caregivers.

1. How does the actual caregiving experience inform our professional knowledge about interventions for caregivers?
2. What have we learned from the empirical research literature about the effectiveness/efficacy of a range of intervention programs designed for caregivers?

3. What do the specialized educational and training programs tell us about how caregivers learn about their roles and responsibilities?
4. How can advocacy and social policy initiatives for caregivers support their goals of providing humane services to frail, chronically ill adults?

By using this conceptual framework, we are able to more critically evaluate the efficacy of these programs and help other educators, practitioners, and researchers who plan to replicate them or develop new interventions.

Organization of the Book

In Chap. 2, Maryam Navaie writes about "Accessibility of caregiver education and support programs: Reaching hard-to-reach caregivers." She acknowledges that although family caregivers provide a tremendous amount of care to loved ones, they often carry out these activities with little or no formal training, which may exacerbate their stress. She suggests that differential access to education and support programs leads to some caregivers being underserved and at risk for serious negative consequences that may affect the care recipient. She concludes that as education and support programs continue striving to serve family caregivers, more creative and tailored avenues of service delivery are necessary to engage the many hard-to-reach, underserved, and unsupported caregivers that could benefit from participation.

In Chap. 3, "Utilization patterns of caregiver education and support programs," Deborah Monahan describes how studying utilization patterns can help us to understand service needs. She notes that whether programs are underutilized or overutilized tells us something about the demand, quality, satisfaction, and ultimately the specific service needs of caregivers. Her chapter covers such topics as who attends education and support group programs, what specific interventions are used, and the implications of attendance at these programs. She speculates that as baby boomers enter retirement and some become chronically ill over the next several decades, the incidence and prevalence of older caregivers needing supportive educational services is likely to increase. She cautions that given the likelihood of continuing constraints on the expansion of professionally provided services, much of the growing burden of care will have to be absorbed by family members and other informal systems of caregiving.

In Chap. 4, Timothy Elliot discusses "Education and support programs for family caregivers: Current practices across health-care scenarios." He notes that family caregiving in the United States occurs within several important societal changes that impinge directly upon the experience and adjustment of persons living with chronic and debilitating health conditions. These conditions include escalating health-care costs, an increasingly older population, an increasing number of chronic health conditions, and an increased life expectancy. He argues that family caregivers experience a wide range of problems that may not relate specifically to instrumental tasks associated with caregiving per se, but may reflect problems in managing family life, resources and responsibilities, and in role changes imposed by health conditions. In his review of community and home-based programs, he infers that family caregivers and care recipients benefit from problem-solving-based interventions provided in telephone interactions. He also notes that educational and training needs will ebb and flow over time, influenced by the dynamic processes that characterize the trajectories of caregivers.

In Chap. 5, Carole Cox discusses the role of "Ethnic, cultural, and gender issues in conducting caregiver education and support groups." She acknowledges that ethnic groups are, in themselves, bound by a shared culture that dictates values, beliefs, traditions, and norms for behavior. She states that "culture gives meaning to the experience of caregiving and even to interventions such as support groups that can assist caregivers." She also notes that ethnicity and culture shape the way individuals perceive and interact within education and support groups. She urges practitioners to understand the ways in which caregivers view authority, power, and gender relationships because these perspectives may affect participation rates in educational programs. For example, she notes that professionals must become aware of their own perspectives about gender roles and their involvement in caregiving activities in order to ensure that their own biases and attitudes do not affect participation by men in caregiver education and support programs.

In Chap. 6, Meridean Maas and Janet Specht review the "Caregiver support groups: Led by peers, professionals or both." They describe the characteristics of successful support group leaders and successful support group programs. They note that whether support groups are peer-led or professionally led, the keys to effective leadership are the training of the leader, caregiver participation, and a focus on caregivers' needs. They urge group leaders to assist caregivers to understand and reflect on their current situations by promoting an accepting atmosphere and an open expression of ideas within the group. They note that this can be done by assisting caregivers to identify and meet their own needs, helping them reinforce their coping skills, and to facilitating their problem-solving skills.

In Chap. 7, "Telehealth and family caregiving: Developments in research, education, policy, and practice" Robert Glueckauf and La Tonya Noel reviews the role of telehealth in supporting family caregivers. They discuss how recent advances in telecommunication technologies can provide an alternative vehicle for meeting the needs of family caregivers for information, education, and support that may not be readily available in their communities. They argue that caregivers are increasingly turning to the internet for information about their loved one's medical condition and for strategies to enhance their coping skills and emotional well-being. They posit that the technologically savvy baby boomers are likely to choose the internet as the medium of choice in obtaining information about caregiving and support. They recommend that additional efforts be made to educate caregivers about how to use computers and the internet as a source of information and support for their caregiving efforts.

In Chap. 8, Kathryn McGrew presents "Education and support outcome sustainability: A conceptual framework." She argues that the sustainability of caregiver education and support program outcomes is the most important *and* the least attended to of all program variables in education and support practice, research, education, policy and advocacy. She notes that consumers, providers, and sponsors of programs want their investment in programs to pay off in positive and enduring ways. She mentions that short-term outcomes are only beneficial if they can be sustained over time, and she addresses how caregivers can sustain the immediate positive outcomes of education and support programs in order to achieve intermediate and long-term outcomes. She presents a framework for sustaining and generalizing change efforts by describing five sustainability tests that should be addressed by all caregiver education and training programs.

In Chap. 9, Ronald Toseland, Tamara Smith, and Kimberly McClive-Reed consider the importance of "Evaluating the effectiveness of caregiver education and support programs." The authors discuss eight domains that should be addressed when evaluating caregiver education and support programs: aims, background, theory, participants, design, caregiver program, measurement, data analysis, and human subjects. They note that theoretical perspectives, such as the Lazarus and Folkman (1984) stress, appraisal, and coping theory, provide the mechanisms whereby program impacts on caregivers, care recipients, or others in caregivers' support networks can be measured. They acknowledge that although standardized measures are available to measure caregiver outcomes, there are times when nonstandardized measure may be the only option available to capture the aims of the education or support program (e.g., when collecting data about participants' knowledge of local community services and resources). In their discussion of data analysis, they review baseline comparisons, differential attrition, outliers, transformations, approaches to longitudinal analysis, and analytic approaches for censored data. Toseland and colleagues suggest that in future evaluations of caregiver support groups, power and sample size issues should be considered.

In Chap. 10, the concluding chapter, we offer recommendations for improving the current and future direction of education and support programs for caregivers. We offer recommendations in four areas: (1) professional practice, (2) education and training, (3) research, and (4) policy and advocacy. These recommendations will hopefully improve the support and education caregivers and care recipients receive in the twenty-first century.

Overall, the chapters in this book contribute to our understanding of how to plan, implement, and evaluate caregiver education and support group interventions. The authors have provided an overview of current trends and practices in caregiver education and support programs. They also make cogent suggestions for future practice, research policy and advocacy with regard to caregiver education and support programs in the twenty-first century.

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Chapter 2
Accessibility of Caregiver Education and Support Programs: Reaching Hard-to-Reach Caregivers

Maryam Navaie

Although family caregivers provide a tremendous amount of care to loved ones, they often carry out these activities with little to no formal training (McDonald, Stetz, & Compton, 1996; Navaie-Waliser et al., 2001; Navaie-Waliser, Feldman, et al., 2002). Lack of training and support for the caregiver often exacerbates the caregiver's distress (Knight, Lutzky, & Macofsky-Urban, 1993; Gallo, Reichel, & Andersen, 1995; Schmall, 1995). Recent studies have shown that family caregivers experience considerable anxiety about the provision of care (Hennessy, John, & Anderson, 1999; Miller, Shewchuk, Elliot, & Richards, 2000; Silliman, Bhatti, Khan, Dukes, & Sullivan, 1996), have difficulty coping with psychological needs of patients and themselves (Hennessy et al., 1999), have concerns about decision making and communication problems with secondary support systems and the formal health-care system (Hennessy et al., 1999; Silliman et al., 1996), and feel less than adequately prepared to take on challenging tasks such as medication management (Miller et al., 2000).

Increasing family caregivers' confidence and competence requires training in the skills they need to provide care. Past studies have repeatedly shown that family caregivers often express interest in, and have a need for, education and support programs (National Alliance for Caregiving & American Association for Retired Persons, 1997; Navaie-Waliser et al., 2001; Navaie-Waliser, Feldman, et al., 2002). Despite their expressed interests and needs, however, only between 30 and 60% of "eligible" family caregivers actually use education and support programs (Anderson et al., 2000; Boothroyd, Kuppinger, Evans, Armstrong, & Radigan, 1998; Cox, 1999; Gallagher-Thompson, Solano, Coon, & Arean, 2003; Laditka, Pappas-Rogich, & Laditka, 2001; Morgan, Semchuk, Stewart, & D'Arcy, 2002; Pedlar & Smyth, 1999). Differential access to education and support programs has been reported, with some caregivers being harder to reach than others (Braithwaite, 1998). The practice and policy implications of not reaching or engaging caregivers with needs can have serious and negative consequences for the caregiver, the care

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recipient, and the long-term care system. Given increasingly limited resources, family caregiver support and educational interventions that fail to reach their target populations are inadvertently wasting scarce resources, leaving caregivers in need feeling unsupported and more isolated, and escalating the vulnerability of care recipients who rely on a significant amount of dependent care from loved ones.

The purpose of this chapter is to provide (1) a comprehensive review of the literature to highlight (a) the benefits of family caregiver education and support programs, (b) the various operational definitions of hard-to-reach family caregivers, and (c) the common characteristics of hard-to-reach family caregivers; (2) an overview of barriers to accessing caregiver education and support programs; and (3) recommendations for future directions in practice, research, education/training, and policy/advocacy that could enhance the accessibility of caregiver education and support programs.

Literature Review

The Benefits of Family Caregiver Education and Support Programs

Meta-analytic and integrated reviews of family caregiver education and support intervention studies conducted during the past two decades can be categorized into three groups: (a) *psychosocial and support group programs* that primarily focus on helping caregivers develop the knowledge base needed to assume caregiving tasks and coping with their responsibilities; (b) *educational and skills training programs* that aim to help caregivers improve care recipient outcomes, such as daily functioning, behavioral management, cognitive stimulation, and social skills; and caregiver outcomes including better ability to problem solve, manage care provision, cope with stress, learn to relax, and experience life satisfaction; and (c) *family or individual psychotherapy programs* that focus on improving caregivers' emotional/mental health and coping by employing various counseling strategies (e.g., cognitive/behavioral vs. psychodynamic, grief counseling vs. cognitive/behavioral, problem solving vs. emotional expression, professional counseling vs. peer counseling) (Acton & Kang, 2001; Brodaty, 1992; Bourgeois, Schulz, & Burgio, 1996; Farran, 2001; Glueckauf, Ketterson, Loomis, & Dages, 2004; Sorensen, Pinquart & Duberstein, 2002; Toseland & Rossiter, 1989; Visser-Meily, van Heugten, Post, Schepers, & Lindeman, 2005; Whittier, Scharlach, & Dal Santo, 2005).

Most caregiver education and support interventions have been multifaceted, incorporating several types of caregiver support strategies. An overview of these past studies suggests that participation in family caregiver education, training, and support programs is beneficial as evidenced by improvements in caregivers' understanding of disease processes and symptom recognition; reduced social isolation; improved ability to deal with emotional and practical problems of caregiving; enhanced coping skills; increased confidence in performing caregiving tasks; improved communication and problem solving skills; reduced feelings of depressions; better management of care recipients' problem behaviors, anxiety and anger; reduced caregiver strain, stress, and burden; and improved quality of life (Belmin, Hee, & Ollivet, 1999; Brodaty, 1992; Buckwalter et al., 1999; Corbeil, Quayhagen & Quayhagen, 1999; Corcoran & Gitlin, 1992; Gerdner, Hall, & Buckwalter, 1996; Gitlin, Corcoran, Winter, Boyce & Hauck, 2001; McMillan et al., 2006; Mohide et al., 1990; Ripich, 1994; Robinson & Yates, 1994; Sorensen et al., 2002; Teri, 1999). By directly enhancing caregiver skills, knowledge, and coping abilities, family caregiver education and support programs also benefit care recipients whose health and well-being rely heavily on their family caregivers (Whittier et al., 2005).

Operational Definitions of Hard-to-Reach Caregivers

When considering which family caregivers are typically hard to reach, various operational definitions have been used in the literature (Fig. 2.1). In general, caregivers, who are difficult to contact at one or more stages of the program delivery process are considered hard to reach. Typically, however, caregivers are not considered hard to reach until multiple outreach efforts have been unsuccessful. There are three key stages of caregiver education and support program delivery processes. Each stage presents a relatively unique set of challenges that impact the ability of programs to successfully contact caregivers, including (1) identification of caregivers, (2) recruitment of caregivers, after they have been identified, and (3) engagement of caregivers on an ongoing basis.

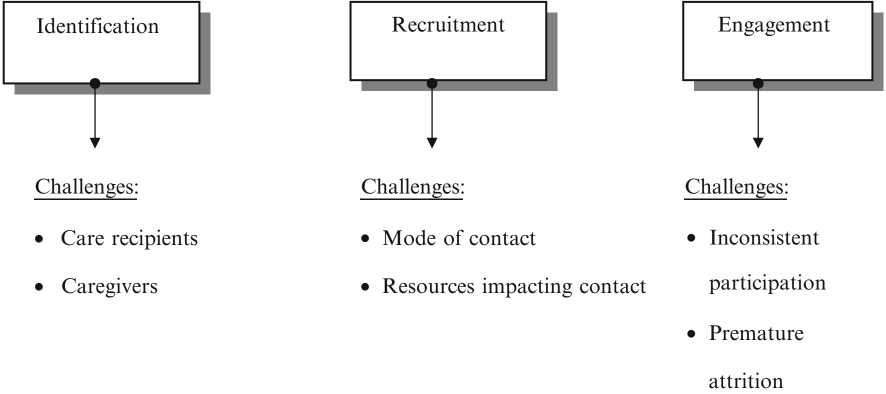

Fig. 2.1 Defining hard-to-reach caregivers: a conceptual model

During the *identification* stage, programs tend to rely principally on care recipients to identify their primary (i.e., caregivers providing the most care) or secondary family caregivers. Therefore, if care recipients are reluctant to provide identifying information about their caregivers, those caregivers would be "labeled" as hard to reach (Coe & Neufeld, 1999). Under certain circumstances (e.g., when care recipients are cognitively impaired), programs may have direct access to persons who are either providing direct care or coordinating care for care recipients. However, research has revealed major challenges in providing outreach to family caregivers, even when formal providers believe they have already identified the caregiver to whom they could target services (Hoffmann, 2002; Kutner, 2001). Terms such as "hidden" or "unacknowledged" caregivers have recently been used by researchers, practitioners, and policymakers to refer to persons who do not consider themselves as caregivers, albeit they provide unpaid care to a family member or friend. Recent studies have revealed that the term caregiver does not invoke a common understanding, resulting in many caregivers not automatically identifying themselves as such even when they take on caregiving responsibilities (Kutner, 2001; National Alliance for Caregiving & Center for Productive Aging, 2003; Navaie-Waliser et al., 2001). These reports have found that approximately 15% of persons who carry on various caregiving activities are not self-identifying as family caregivers (Hoffmann, 2002; Kutner, 2001). This significant level of caregiver disconnect from caregiver terminology points to the issue that a relatively large fraction of caregivers are unfamiliar with the definition of the term, dislike being labeled as a caregiver, have a reluctance to give any name or title to what they do, and object to any term that is used to "label" themselves (National Family Caregivers Association & National Alliance for Caregiving, 2001). Most of these studies point to the common finding that when the term "caregiver" is used, it resonates with unacknowledged caregivers to be someone who gets paid for the care they provide (National Family Caregivers Association & National Alliance for Caregiving, 2001). Among these unacknowledged caregivers, disproportionate groups are men and racial/ethnic minorities (Kutner, 2001). Identifying oneself with the term "caregiver" has been found as one of the most significant predicators in determining the extent to which persons become proactive in seeking resources to facilitate their caregiving roles (Hoffmann, 2002; National Family Caregivers Association, 2001). Therefore, many hard-to-reach caregivers who do not self-identify as caregivers often do not seek out needed education and support services.

After caregivers have been identified, programs are faced with the task of recruitment and engagement. During the *recruitment* stage, the mode of contact used by programs can affect their ability to effectively reach caregivers. The most common forms of outreach typically used by caregiver education and support programs are telephone, in-person meetings, newsletters, and print materials distributed by mail to either the care recipient's or the caregiver's home, and technology-based contact (e.g., telehealth networks, videophones). Reviews of past studies have shown in-person contact with caregivers to be the most effective recruitment strategy and distribution of print materials by mail to be the least successful (Sorensen et al., 2002). The choice of recruitment strategy is driven most often by financial and other resource limitations. Unfortunately, the most cost-efficient recruitment approach often results in the inability to contact a high number of hard-to-reach caregivers. The recruitment phase is not only contingent upon the methods used to reach potential participants, but much of the success of recruitment depends on personal attributes of the caregivers themselves. Studies have shown that service-seeking actions among caregivers are heralded by caregiver appraisals of changes in their physical or emotional health and associated control over the health risk of the care recipient (Brown, Chen, Mitchell, & Province, 2007; Murphy et al., 2007). Moreover, results from Murphy et al. (2007) show that willingness to participate in support programs is a result of the confluence between the caregiver's recognition of the need for help and becoming aware of the available support service. Timeliness of recruitment, therefore, plays a major role in the success of enrollment.

Once family caregivers have been identified and successfully recruited, programs must help caregivers overcome the many barriers that could impact their ongoing participation. The *engagement stage* of caregiver education and support programs may last from a week to several weeks (Sorensen et al., 2002). Depending on the duration and length of a program, some caregivers can remain engaged while others become hard to reach because of either inconsistent participation or by premature attrition. As shown in Fig. 2.2, among the many approaches of services delivery used by education and support programs, those programs most likely to have difficulty reaching family caregivers are non-home-based services which often present logistical barriers to consistent participation (Acton & Kang, 2001; Brown et al., 1999; Chambers & Connor, 2002; Colantonio, Cohen, & Pon, 2001; Rosswurm, Larrabee, & Zhang, 2002).

Common Characteristics of "Hard-to-Reach" Caregivers

To develop a richer understanding of why many caregiver education and support programs face the challenge of extending services to hard-to-reach caregivers, it is helpful to examine what the literature reveals as shared characteristics among such caregivers. These common characteristics can be categorized into four main domains: (a) sociodemographic attributes, (b) social and environmental contexts, (c) service delivery system factors, and (d) emotional and physical health attributes. Despite the categorization of these characteristics, it is important to recognize that many of the factors affecting caregivers' ability or decision to participate in education and support programs are often interrelated and point to a complex set of issues that are not easily overcome.

Sociodemographic Characteristics

A review of the literature suggests that hard-to-reach caregivers tend to be racial/ethnic minorities, living in poverty, younger than 55 years of age, employed, and male (Anderson et al., 2000; Bullock, Crawford, & Tennstedt, 2003; Coe & Neufeld,

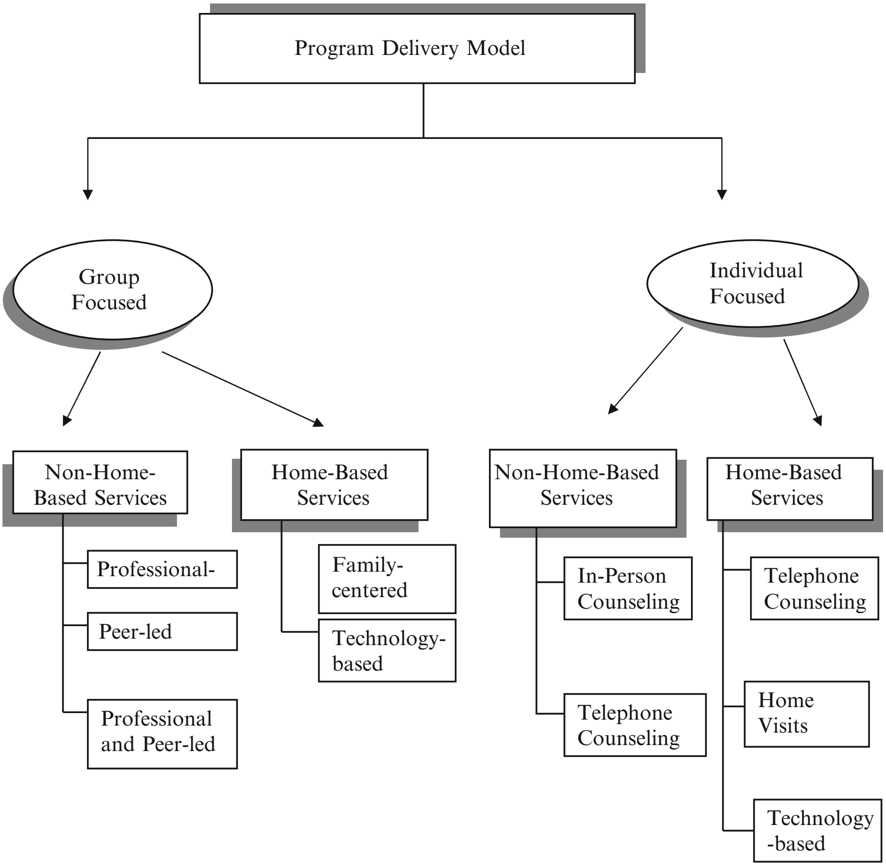

Fig. 2.2 Common models of service delivery among caregiver education and support programs

1999; Colantonio et al., 2001; Cox, 1999; Eaves, 1999; Gallagher-Thompson, 2003; Houde, 2001; Kramer, 2002; Laditka et al., 2001; National Alliance for Caregiving & Center for Productive Aging, 2003). A wide range of explanations have been suggested for why these characteristics would reduce the likelihood of caregivers engaging in education and support programs. Among racial/ethnic minorities, studies have found that race and ethnicity per se may not significantly contribute to service utilization upon adjusting for confounding factors. Rather, race and ethnicity act as proxies for other factors related to service use, including familial closeness and contribution as well as cultural norms (Scharlach, Giunta, Chow, & Lehning, 2008). Greater prevalence of mistrust towards the health system and formal care providers, fear and language barriers also affect decisions to participate in programs (Cox, 1999; Monahan, Greene, & Coleman, 1992). Among employed caregivers (most 55 years of age or younger), who account for over 15% of the workforce (Wagner, 1997), difficulties balancing caregiving responsibilities with employment obligations are often cited as a primary reason for not engaging in programs (National Alliance for Caregiving & Center for Productive Aging, 2003).

Men constitute nearly 30% of all caregivers and over 36% of all spouse caregivers (Kramer, 2002; Kramer & Lambert, 1999). They are far less likely than women to participate in caregiver support and education programs (Kaye & Appelgate, 1990; National Family Caregivers Association, 2000) while having a greater propensity to solicit the support of formal services (Brown, Chen, Mitchell, & Province, 2007). Thus, with regard to caregiver education and support programs, men caregivers are harder to reach and engage, as compared to their female counterparts. Although relatively few studies have examined gender differences in service utilization (National Family Caregiver Association & National Alliance for Caregiving, 2001; National Alliance for Caregiving & Center for Productive Aging, 2003; Navaie-Waliser, Spriggs, & Feldman, 2002), issues related to gender roles regarding masculinity (Brown, Chen, Mitchell, & Province, 2007), stigma associated with men as caregivers (National Family Caregivers Association & National Alliance for Caregiving, 2001; National Alliance for Caregiving & Center for Productive Aging, 2003), and negative self-image reduce the likelihood of men to self-identify as a caregiver (Hirsch, 1996). Thus, lower participation rates often are observed in caregiver programs among men (Houde, 2001). An observational study by Calasanti and King (2007) found that men approach caregiving work like a job often time separating their emotions from tasks. By contrast, women often see caregiving as a natural extension of their gender roles across the life course. Gender differences in caregiving styles may impede the help-seeking process for male caregivers because gender roles have instilled in them the values of independence and pride in skills. There are also logistical reasons that reduce the likelihood that men will participate in caregiver programs, including being a long-distance caregiver (National Alliance for Caregiving & Center for Productive Aging, 2003) and difficulties balancing caregiving responsibilities with employment (Carmichael & Charles, 2003).

Social and Environmental Contexts

Commonalties in the social and environmental contexts of hard-to-reach caregivers include the absence of secondary family caregivers, social isolation, rural residence, being a long-distance caregiver, not living in the same household as the care recipient, and lack of transportation (Anderson et al., 2000; Bruce & Paterson, 2000; Buckwalter, Davis, Wakefield, Kienzle, & Murray, 2002; Houde, 2001; Morgan et al., 2002; National Family Caregivers Association, 2000). In considering the social and environmental factors that affect access to family caregiver education and support programs, it is clear that caregivers often face the challenge of overcoming a multitude of barriers. For example, the absence of a secondary support system to rely on often leaves caregivers with little choice but not to engage in programs because they do not have someone else to help care for the care recipient. Similarly, being socially isolated is often correlated with living in a rural community which has also been linked with inadequate transportation.

Service Delivery System Factors

Several system factors have been identified consistently in the literature to be associated with family caregivers' access to education and support programs. These factors include caregivers' general lack of awareness about the range of available services, the longitudinal nature of caregiving support programs, lack of culturally appropriate services, and non-home-based modes of service delivery most often utilized by programs (Bruce & Paterson, 2000; Colantonio et al., 2001; Gallagher-Thompson et al., 2003; Laditka et al., 2001; Morgan et al., 2002; National Family Caregiver Association & National Alliance for Caregiving, 2001; Whittier et al., 2005).

Despite the relatively fast growing number of caregiver education and support programs nationwide, in general, many caregivers are not aware of these existing services as resources. Lack of sufficient or strategic marketing of these programs has resulted in inadequate outreach to all caregivers. Another system factor that affects caregiver access to education and support programs is their structural design, requiring caregivers to participate over a specified length of time with certain frequency. Studies have found that when longer and more frequent meetings are required by programs, especially in non-home-based settings, the likelihood of inconsistent participation and higher attrition increase significantly (Boothroyd et al., 1998; Botsford, 1994; Bruce & Paterson, 2000; Colantonio et al., 2001; Eaves, 1999; Gallagher-Thompson et al., 2003; Monahan et al., 1992; Morgan et al., 2002; National Family Caregiver Association & National Alliance for Caregiving, 2001).

Emotional and Physical Health Attributes

Several factors related to the emotional and physical disposition of family caregivers have been found to be common among hard-to-reach caregivers. Given that a typical family caregiver provides, on average, 20 or more hours of care per week (National Alliance for Caregiving and American Association of Retired Persons, 1997; Navaie-Waliser, Feldman, et al., 2002), many feel heavily burdened. These heavily burdened caregivers often experience high levels of stress and lack the time flexibility to participate in support or other types of programs (Barusch & Spaid, 1991; Colantonino et al., 2001; Laditka et al., 2001; National Family Caregiver Association & National Alliance for Caregiving, 2001). Another factor that is common among hard-to-reach caregivers is their inability or unwillingness to leave care recipients to partake in support programs (Farran & Keane-Hagerty, 1994). A third factor affecting family caregivers' access to education and support programs is their physical health. Studies have shown that caregivers in more frail health are more likely to attend support programs, perhaps because they have greater concern about their ability to provide care, and thus are more motivated to attend (Scharlach, Giunta, Chow, & Lehning, 1998).

Barriers to Accessing Caregiver Education and Support Programs

A useful model to draw on when examining barriers faced by caregivers in accessing education and support programs is the behavioral model of health services utilization proposed by Andersen and Newman (1973). The model examines service utilization according to three sets of factors, namely predisposing, enabling, and need.

Predisposing factors are characteristics of a caregiver that affect his/her propensity to access programs and services. Examples of predisposing factors found as barriers to accessing education and support programs among family caregivers include:

- Male gender
- Middle-aged and younger caregivers
- Racial/ethnic minority background
- Negative or mistrusting attitudes towards the health system and formal care providers, often rooted in a history of discrimination
- Cultural beliefs (traditional values and norms)
- Primary spoken language being non-English

Enabling factors are measures that affect a caregiver's ability to access education and support programs. Examples of enabling factors that have been found by past studies to serve as barriers to accessing caregiver education and support programs include:

- Disjointed care systems, which often do not provide caregivers referrals to education and support programs
- Rural communities as primary residents of caregivers
- High caregiving demands
- Part-time or full-time employment by caregivers
- Lack of secondary caregiver support systems
- Transportation difficulties
- Unavailability of obtaining alternative care for the care recipient during periods of attendance
- Caregiver and care recipient not living together
- Unawareness about availability of programs
- Characteristics of health-care system and individual staff members

Need factors are a caregiver's characteristics that indicate vulnerability for which education and support groups serve as an intervention. In essence, need factors are the "motivating force" behind a caregiver's decision to engage and maintain his/her participation in education and support programs. The most prominent need factors reported in the literature as barriers to accessing caregiver education and support programs include:

- High levels of subjective caregiving burden
- High levels of depression
- Poor physical health, particularly limited mobility
- Perceptions of low or inadequate knowledge and skill levels
- High level of functional dependence among care recipients

Future Directions: Implications for Practice, Research, Education/Training, and Policy

As practitioners, researchers, evaluators, program planners, policymakers, and advocates continue to realize the invaluable contributions of family caregivers, outreach and support efforts must become more tailored and better focused in order to be more inclusive of all caregivers, especially hard-to-reach caregivers who are likely to have many unmet needs. The summary findings highlighted in this chapter offer insights that can help ameliorate some of the challenges faced by family caregiver education and support programs as they strive to provide outreach to hard-to-reach caregivers. Although there are many future directions to consider for enhancing practice, research, education/training, and policy/advocacy, a selected set of recommendations that are feasible for more immediate implementation are provided in the following sections.

Implications for Practice

Based on existing evidence and knowledge as surmised from the literature, implementation of the following recommendations are encouraged, several of which have recently been implemented to enhance practice (Whittier et al., 2005):

1. There is a tremendous need for caregiver education and support programs to increase their visibility by using diverse marketing strategies. Lack of awareness of available programs remains one of the most frequently cited reasons among hard-to-reach caregivers for not participating in programs. Marketing strategies that have been shown to be most effective in reaching caregivers include sending media messages that focus on the concept of “ask for help” rather than “take care of yourself”; use of specific languages such as “family caring” or “family care” rather than “informal caregiver” which carries negative connotations, particularly along gender lines; avoidance of phrases such as “don’t” or “shouldn’t” which may be perceived as negative criticism; use of campaign tones that are comforting, reassuring, and empowering; and providing multiple means of contact including telephone, mail, fax, and website communication (Atlee, 2001).
2. Marketing and public relations efforts focused on caregiver education and support programs would benefit from targeted, culturally appropriate messaging

that aims to increase engagement by racial/ethnic minority caregivers. These messages also will need to be sensitive in providing recognition and inclusion of nonkin caregivers (i.e., friends) given their significant involvement in the broader network of caregivers among racial/ethnic minority care recipients.

3. The aggregate literature strongly suggests that caregiver support and education programs will function more effectively in serving caregivers if they are a part of a more coordinated system of intervention. Therefore, using an "added on" model of service delivery rather than a disjointed and fragmented service delivery approach would likely enhance a program's ability to increase participation among hard-to-reach caregivers. In addition, providing a wide range of services that include a home-based component, with flexible schedules within this model of service delivery is important because it recognizes that not all services and modes of service delivery will appeal to all caregivers.
4. Given that the residential location of family caregivers, in particular rural communities, affects their accessibility to education and support programs, establishing satellite programs within rural settings could offer an opportunity to engage hard-to-reach caregivers who would otherwise not be easily reachable.
5. Offering some form of transportation assistance, such as vouchers for taxi rides and program-sponsored van pick-ups, is another approach to improving accessibility of hard-to-reach caregivers to education and support programs.
6. Providing temporary respite care (e.g., adult day care or home care) for care recipients would offer short-term relief for family caregivers and enhance the likelihood that hard-to-reach caregivers could participate in education and support programs.
7. Programs should avoid using the term "caregiver" during outreach activities without providing an expressed definition of the term and activities that would qualify someone as a caregiver. This approach would likely increase the probability that "hidden" or unacknowledged caregivers would self-identify (Pickett-Schenk, 2003). The choice of an optimal term to identify caregivers is not straightforward. For example, internationally focused caregiver education and support programs have had success reaching caregivers by using the term carer (Loyd & Carson, 2005; Stoltz, Uden, & Willman, 2004), however whether adoption of such a term in the United States would be well received remains unclear.

Implications for Research

Future research on hard-to-reach caregivers can contribute to the current knowledge by investigating:

- The efficacy of employing different strategies to engage hard-to-reach caregivers based on the stage of service delivery (e.g., identification, recruitment, engagement) at which caregivers become classified as hard to reach.
- The degree to which caregiver self-identification affects caregiver actions: Do these caregivers perceive any benefits or risks in being identified as caregivers?

What is the best strategy for improving self-identification of caregivers to trigger self-help actions? Are there negative health and social consequences of not self-identifying oneself as a caregiver? What factors affect a person's decision or ability to self-identify as a caregiver?

- The effectiveness of large-scale, well-controlled gender-specific interventions on outcomes among men caregivers, including propensity to self-identify as a caregiver and participation level in education and support programs.
- The benefits of caregiver engagement level in education and support programs on the health and well-being of care recipients. Although such measures are more distal to caregiver education and support program outcomes, they would lend a more comprehensive picture of the potential impact of such initiatives. At present, rigorous longitudinal or controlled intervention studies have not been performed to adequately inform the literature on this research topic.

Implications for Education/Training

The two most prominent themes from an education/training perspective that would likely impact caregiver education and support programs' ability to reach hard-to-reach caregivers are the following:

1. Programs need to provide more clear messages to family caregivers about their purpose and how participation benefits caregivers.
2. More multilingual staff need to be hired so that culturally appropriate outreach is provided in various languages as an effort to reduce communication barriers among non-English speaking family caregiver populations.

Implications for Policy/Advocacy

The literature shows that family caregivers, formal care providers, and policymakers concerns and priorities often contrast (Chappell, Reid, & Dow, 2001). Understanding needs from a caregiver's perspective is critical to maximizing service use, particularly among hard-to-reach caregivers. From a policy/advocacy perspective, it is paramount that caregiver programs support campaigns that address the following issues:

- Studies have shown that employer costs related to employee's caregiving are significant, costing employers nearly 4.7 billion dollars in replacing employees who resign because of their caregiving responsibilities (Lilly, Laporte, & Coyte, 2007). Employer-sponsored support of caregiving activities would likely reduce the many challenges faced by hard-to-reach caregivers who experience difficulty balancing employment with caregiving responsibilities and program participation as well as potentially reduce financial loss to employers.

- The idea of family caregivers as political constituents is very foreign to most caregivers. However, the potential advantages of political mobilization are clear and powerful to some caregivers. Therefore, programs need to increase efforts in assembling and training groups of family caregivers in public policy advocacy techniques. The impact of the voices of empowered caregivers cannot be underestimated in setting policy agendas.
- Continued reliance on family caregivers without adequately engaging the diverse populations of caregivers can create a stressful and potentially unsafe environment for the caregiver and the care recipient. Thus, policies that support the development and implementation of a broader array of accessible, culturally diverse, and tailored caregiver education and support programs increase the likelihood of reaching as many caregivers as possible, especially hard-to-reach caregivers, many of whom have high levels of unmet needs.

Conclusions

This chapter summarizes the literature, presents an overview of the barriers to accessing family caregiver education and support programs, and offers recommendations for future directions. The chapter highlights what is known and unknown about hard-to-reach family caregivers and what is needed to improve outreach to, and engagement of, these caregivers. As education and support programs continue to strive to serve family caregivers, more creative and tailored avenues of service delivery are necessary to engage the many hard-to-reach caregivers who could benefit from participation but remain at-large unsupported.

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Chapter 3
Utilization Patterns of Caregiver Education and Support Programs

Deborah J. Monahan

This chapter analyzes the utilization patterns of caregiver education and support programs with an emphasis on psychoeducational support groups and respite. An overview of the issues, definitions, conceptual frameworks, and evidence from research and current practice is provided. The structure of utilization patterns reviewed in this chapter includes (1) who attends education and support group programs, (2) what specific interventions are used, (3) implications of attendance at these programs, and (4) their beneficial outcomes. Studies reviewed in this chapter include those that focus on utilization patterns as well as outcome studies that examine utilization. Some of the later include studies of service use such as health-care utilization and cost outcomes. This chapter also discusses the status of educational and supportive interventions for caregivers in the future along with their attendant research, practice, policy, and advocacy implications. Families increasingly are caring for frail older adults with the assistance of community-based education and supportive programs. As more baby boomers enter retirement and become chronically ill over the next several decades, the incidence and prevalence of frail older persons needing supportive educational services will increase (National Alliance for Caregiving-NAC, AARP, & Metlife, 2009; NAC & AARP, 2005).

Although future service needs of the baby boom generation will vary depending upon their socioeconomic and residential status, they will most likely include caregiver support, health services, information and referral, volunteer opportunities, employment and retirement counseling and health insurance counseling (Maloney, 1998). Service utilization research often focuses on a limited number of services and "caregiving research needs to accumulate evidence regarding determinants of caregivers' service utilization" (Hong, 2010, pp. 98). Given the likelihood of continuing constraints on the expansion of professionally provided services, much of the growing burden of care will have to be absorbed by family

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and other informal systems of caregiving. The well-being of aging boomers could become jeopardized if the costs of frailty are too high and there are shortages in eldercare services (Ervin, 2000). Because of concerns that this increased burden will seriously tax the capacity of informal care systems, it is important to examine how education and support programs are utilized and whether they provide the kinds services families need.

Growth in the number of persons providing care has led to the development of intervention programs in direct support of family caregivers. A particular focus of research inquiry has been on psychoeducational support group interventions. These programs have been designed to provide caregivers with emotional support, informative support, and enhancement of their coping skills (Monahan, 1994). Because education and support groups are a key intervention modality for caregivers, there is growing interest in factors that may influence their efficacy. This chapter focuses on those psychoeducational support group interventions.

When caregivers participate in intervention programs, they generally want to learn more about how to provide effective care to a family member, typically a spouse or a parent. They usually seek out information and sometimes they need acknowledgment that they are "doing the right thing." For caregivers, these interventions feel "safe" because of the presence of others who are also providing care to a relative. In communities across the United States, education and support groups are meeting in religious settings, nonprofit social service agencies, medical centers, and hospitals in order to help family members learn how to provide care to older adults. Many of these programs are free or have a nominal fee associated with their participation and caregivers attend these programs during the day, in the evening, and even on weekends.

What lessons have we learned from these programs over the past 20 years, and how can they be improved for the next generation of caregivers? In a recent review of evidence-based psychological treatments for family caregivers, Gallagher-Thompson and Coon (2007)) have suggested that the design and implementation of these intervention programs have improved over time. This chapter examines how these programs are utilized in order to design more effective interventions for those caring for chronically ill or frail older adults and their families.

Overview of the Issues: Why Study Utilization Patterns?

Studying utilization patterns of service programs helps us to understand service needs. Whether programs are underutilized or overutilized tells us something about the demand, quality, satisfaction, and ultimately the actual need for services. Findings from the National Alliance of Caregiving and AARP (2005) reveal that of caregivers already receiving an outside service, almost eight in ten (79%) say they need more help or information about at least one of the unmet needs listed (e.g., finding time for myself, keeping the person I care for safe, balancing work and family responsibilities, choosing an assisted living facility, etc.). A better understanding of service utilization also enables us to learn about the relationship between informal and formal care. Benefits accrue to both the recipients of support and those who provide support (King, 2006). Using data from the National Long-Term Care Survey, Spillman and Black (2005) reported that during 1994–1999, use of any formal care declined from 43 to 34%, and that nearly two-thirds of care recipients relied entirely on informal caregivers in 1999 compared with 57% in 1994. Utilization patterns, in particular, reveal aspects of the quality of the service. A program is considered to have value and to be successful if consumers use it. Program quality and reputation also affect our propensity to use services and may be viewed as efficiency measures in outcome research. In research, service utilization has been used as an outcome variable in evaluating the cost effectiveness of programs.

Despite the popularity of education and supportive interventions for caregivers, they are not for everyone. Indeed, some caregivers may *not* need services to enhance their own caregiving. They may consider professionals "outsiders" or intrusive, preferring to solve their own problems by learning about caregiving through reading books and talking to friends and relatives. Some may feel that they have all the requisite knowledge and do not wish to discuss sensitive issues of caregiving outside of the family. Others do not wish to participate in group intervention programs that require attendance at meetings at any distance from their homes or neighborhoods. Yet for many, the group experience provides a respite from the complexities of providing care and is a good place to acquire more information about family caregiving. As educators and researchers, we need to understand how these programs work and to offer strategies to help families use the services effectively. What if services are needed and not available, or if they are available but of insufficient quality? Practitioners and researchers would like to be able to pinpoint *why* services are either sufficient or insufficient so that caregivers have access to viable resources, if they are needed.

How Education/Support Groups Help Caregivers

Education and support programs have been defined in numerous ways. Sorensen, Pinquart, and Duberstein (2002, p. 357) define psychoeducational interventions as structured programs aimed at providing information about disease processes, resources, and services as well as training caregivers to respond effectively to the care needs of their relatives. They define supportive interventions as both professionally-led and peer-led unstructured support groups focused on building rapport among participants to discuss problems, successes, and feelings regarding caregiving. A critical role for educators is to communicate to stake holders *how* these programs can be developed to maximize program efficacy (Monahan, 1994). Components of supportive group programs that can be assessed include reviewing the education/support group purpose, understanding the program's boundaries, determining the adequacy of number of sessions, selecting the format and location, and assessing the organizational structure.

In their research on supportive interventions for frail elders, McCallion and Toseland (1995) identified several ways that psychoeducational groups help caregivers. Their findings include: increasing caregivers' understanding of their relative's condition, enabling them to make better use of formal and informal supports, improving their coping abilities, encouraging them to take better care of themselves, improving problematic relationships with their relative, and improving their home care and behavior management skills. These researchers also assert that mutual support and psychoeducational groups have the potential to help caregivers cope with their situation at relatively low cost to society. They conclude that supportive group interventions can strengthen the support network of socially isolated caregivers, educate caregivers about community resources, and provide alternative coping skills that will help caregivers meet their own needs. In a recent study of 1,247 caregivers in the United States by the National Alliance for Caregiving in collaboration with AARP (2005), 7% of the sample reported that they had participated in support groups. For all of these reasons, support groups have become a popular intervention to learn more about the roles and tasks associated with family care.

Conceptual and Theoretical Frameworks

Caregiver education and support groups have emerged, in part, because caregiving has become a normative phase of adulthood (Brody, 1985) and these groups help families learn about their new roles. Below are examples of the types of questions and issues caregivers often raise as they make the transition to their new roles.

> I'm a recent caregiver and I don't know what to do about my mother's condition. She had a hip replacement operation and lives alone. Should I be with her all the time? How can I manage her affairs and still take care of my own family?
>
> My husband continues to drive when he can't remember where he is half the time. I'm not certain that he even remembers who I am anymore, he won't eat, what should I do?
>
> I'm not good at taking care of someone else. This is difficult for me. I'm not sure that I can do it.

One consequence of this recent demographic shift to increased family caregiving is that caregiving has become both an activity and a status transition that can alter a caregiver's social network, social support, and psychological well-being (Pillemer, Suitor, & Wethington, 2003). When faced with a spouse's unexpected illness following a medical emergency such as a heart attack or stroke, caregivers may not know what to do and how to handle the caregiving tasks. Such sudden and dramatic changes, particularly, in the physical and cognitive condition of the older adult, make a caregiver more likely to use education and supportive group interventions to ease the transition into the caregiving role.

A major theoretical framework for understanding service utilization is Andersen and Newman's (1973) model of the determinants of medical care utilization. In their model, utilization is determined by *predisposing* factors such as the propensity to use services independent of personal circumstances that may cause the need for service use (e.g., sociodemographic variables such as gender or age), *enabling* factors that help to explain differences in the resources available to the individual who uses the services (e.g., transportation, health insurance, etc.), and *need* factors (e.g., level of perceived burden, comorbidity, etc.) that are chiefly influenced by serious health problems. In a subsequent article, Andersen (1995) explains that although health services' use originally focused on the family as the unit of analysis, he shifted to the individual because of the difficulty in developing measures at the family level. Andersen views utilization pragmatically and argues that effective access is established when utilization studies show that use improved health status or consumer satisfaction. The model was expanded to guide future investigations regarding long-term care use by racial/ethnic groups by including psychosocial determinants of service use such as attitudes and knowledge, social norms, and perceived control (Bradley et al., 2002). In the expanded model differences were found among African-American and white focus group members in their accessibility of information about long-term care, social norms concerning caregiving expectations, and concerns of privacy and self-determination.

Several researchers adapted the Andersen 1995 model in an innovative study of the use of health and human services by community-residing older adults with dementia (Toseland, McCallion, Gerber, & Banks, 2002; Toseland et al., 1999). The authors developed a comprehensive list of 33 health and human services (identified from previous studies) as being potentially useful to persons with dementia and their family caregivers. They measured service utilization comprehensively as current service use in the past year, future service use (likelihood), frequency of service use in the next year, and duration of service use. Their results suggest that the behavioral model was able to predict more variance in the use of human services than in the use of health services. Several other studies using this model will be reviewed later in this chapter.

Caution should be exercised, however, when applying this model to minority and rural caregivers. In their critique of the Andersen model, Radina and Barber (2004, page 17) urge policy makers and practitioners to be aware of within group differences among Hispanic caregivers when developing interventions aimed at increasing formal service utilization within this population. They also note that measures of race, gender, and the relationship between the caregiver and care recipient also affect caregiving and its outcomes. Several researchers have reported that African-American, Native American, and Hispanic caregivers underuse formal services to assist with caregiving tasks (Caserta, Lund, Wright, & Redburn, 1987; Logan & Spitze, 1994; Morano & Bravo, 2002). In a review of ethnicity in caregiving research, Dilworth-Anderson, Williams, and Gibson (2002) discuss how culture influences the meaning of seeking assistance outside of the family and how culture affects an individual's perception of the meaning of disease, illness, and disability. Studying 1,508 caregivers in California, Scharlach, Giunta, Chow, Lehning, and Del Santo (2008) found that in their logistic regression model with other predisposing, enabling, and needs variables, race, ethnicity, and immigrant status no longer were found to have a significant main effect on formal service use.

Studying respite service use among minorities and rural caregivers, Montoro-Rodriguez, Kosloski, and Montgomery (2003) selected a practice model of service utilization. Service characteristics were central to their analysis and unlike the behavioral model (e.g., Andersen & Newman, 1973; Andersen, 1995), factors in the practice model could be manipulated to encourage service use and could add more significantly to explanatory models of service use over other models. Another criticism of the behavioral model is that it gives insufficient attention to cultural values, contextual variables, and is inflexible (Wolinsky, 1994; Wolinsky & Johnson, 1991).

Farkas, Jette, Tennstedt, Haley, and Quinn (2003) provide an important conceptual link to understanding how utilization affects educational interventions. They analyze how to target the learning needs of specific user groups through the use of four strategies: *exposure* (increasing caregiver information), *experience* (increasing caregiver positive attitudes and knowledge), *expertise* (increasing caregiver competence), and *embedding* (increasing program utilization by caregivers over time). In their fourth strategy, "embedding," they describe how caregivers realize their own capacity for determining service needs and use. The concept of embedding is important because most caregivers are their own case managers, and they will ultimately make the decision about whether or not to use additional services.

Current Status of Education and Support Groups: Practice, Education, Research, and Policy/Advocacy

Several research studies have conceptualized "utilization" as an outcome variable. The primary question addressed by these research studies is, "What is the effect of psychoeducational and supportive interventions on service utilization?" These studies focus on caregiver groups from among the following users: adult children of persons with dementia, spouse caregivers of persons with dementia, adult children of frail elderly persons, and caregivers of older veterans. They are typically focused on educational and supportive interventions, and conducted in cities throughout the United States using a diverse sample of caregivers and formal research protocols.

In a study examining the utilization of community resources for dementia patients, Caserta et al. (1987) described the difficulties in studying utilization. Even in the presence of documented service needs, utilization can be low because of perceptions of lack of availability, difficulties in accessing services, limitations in caregivers' personal resources, and their own fatigue. In their national caregiver survey ($N=597$), 72% reported that they utilized support groups, the mean length of use was 18.5 months (SD=14.7), and approximately 82% of support group participants had belonged to a group for 2 years or less (page 211). They reported that respite use accounted for 62.5% of the service utilization in their study. The investigators concluded that although awareness and access were moderate indicators of service utilization, they did not necessarily lead to utilization. Instead they found that the care recipient's level of impairment and service needs were important factors in service utilization.

Long-term effects of support group utilization were studied with a group of daughters and daughters-in-law ($N=65$) caring for frail elderly persons who volunteered to participate in a study evaluating the effectiveness of psychoeducational groups (Toseland, 1990). Outcome measures such as changes in network size, level of satisfaction, and perception of social support were examined at post-test, 6-month, and 1-year follow-up. It was reported that treatment group participants increased their knowledge of community resources and had increases in their social network size. In a series of studies evaluating the efficacy of psychoeducational support groups, Toseland and colleagues found that the groups increased knowledge of services, but not use (Smith & Toseland, 2006; Toseland, Rossiter, Peak, & Smith, 1990; Toseland, Labrecque, Goebel, & Whitney, 1992; Toseland, Blanchard, & McCallion, 1995; Toseland et al., 2001). The role of support groups in fostering utilization of services was examined in a study of 301 caregivers attending Alzheimer's support groups (Gonyea & Silverstein, 1991). The researchers found that families attending support groups were more likely than control group families to use community resources. They also found that families who belonged to a support group for a longer period of time and attended more meetings in the past year reported more formal service use.

In a 16-state study of factors associated with attendance at support groups, Burks, Lund, and Hill (1991) studied caregivers of persons with dementia ($N=490$). Results of their stepwise regression analysis showed a positive relationship between numbers of meetings attended, perceived helpfulness of those meetings, and length of time providing care. An unexpected finding was that those attending more support group meetings reported lower life satisfaction. The researchers concluded that in planning the agenda of support group meetings, a greater emphasis should be placed upon the broader life context of the caregivers such as their life stresses, personality, social relationships, and other issues related to aging, as well as the difficulties in caregiving.

In a study of the factors associated with support group use in a community in the Southwest, Monahan, Greene, and Coleman (1992) surveyed 289 caregivers attending educational support groups for the frail elderly using the Andersen model as the theoretical framework for the study. Among the predisposing variables studied were age and gender. Older caregivers and those in Spanish language groups were more likely to participate; however, gender was not a significant predictor.

Of the enabling factors, poorer health and having a secondary caregiver, but not the care recipient's impairment level, were the most significant predictors. Caserta et al. (1987), however, reported that impairment level of the care recipient was a significant predictor of service use. For the need predictors, those with greater emotional distress and those caring for someone with Alzheimer's disease were the most likely to attend support groups. In a longitudinal study of patterns of service use by race, Cox (1997, 1999) studied 309 caregivers to determine the best predictors of use and differences between users and nonusers, also using the Andersen model. Need factors were the only predictors contributing to the use of support groups. The author concluded that caregivers of the most cognitively impaired relatives turn to support groups for help; however, those who report the most burdens (e.g., caring for physically impaired relatives) were least likely to use support groups.

The volume of research studies on these topics has led to the publication of several meta-analyses. These meta-analyses have been conducted on the effectiveness of supportive interventions for caregivers (Brodaty, Green, & Koschera, 2003; Schulz et al., 2002; Sorensen et al., 2002) and analyzes of psychosocial interventions for caregivers to relatives with dementia (Cooke, McNally, Mulligan, Harrison, & Newman, 2001). These reviews have relevance to this discussion of utilization as an outcome measure in studies of program effectiveness. Brodaty et al. (2003) reviewed 30 studies of intervention programs involving 2,040 caregivers and found significant benefits in caregiver knowledge and in their satisfaction with the psychosocial interventions. Caregivers in their study appraised their coping skills as having improved, identified their training as helpful, and indicated that they would participate in future training programs. In the Sorenson, Pinquart, and Duberstein (2002) analysis of 28 studies involving 817 caregivers, the supportive intervention group had 6 studies and included 432 caregivers. They concluded that among all different types of treatments, psychotherapeutic and psychoeducational interventions showed the most consistent positive effects on all outcome variables.

Schulz et al. (2002) meta-analysis addressed several aspects of service utilization. They reported that several studies showed both increases and decreases in formal service use (e.g., adult day care and respite) and informal support (e.g., obtaining assistance from other family members). In their analysis of the effect of supportive interventions on nursing home use, they reported varying rates of institutionalization between treatment and control group members ranging from 12 to 50%. They also reported that caregivers in the treatment conditions were less likely to institutionalize their care recipient 12–18 months after enrollment than caregivers in control conditions, and several studies reported delays in placement from 166 to 300 days. The authors concluded that “positive effects were demonstrated; however, achieving such effects requires very intense, multidimensional interventions that include heavy doses of counseling, support and education.”

Other studies reporting delays in the utilization of expensive services such as nursing home care and other health-care expenses associated with use of caregiver programs have been reported. Delaying institutionalization of the care recipient was found in several studies of caregiver supportive interventions (Brodaty, McGilchrist, Harris, & Peters, 1993; Brodaty & Peters, 1991; Greene and Monahan, 1987; Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; Peak, Toseland, & Banks, 1995; Toseland & Smith, 2006). Using a randomized controlled trial in the Mittelman study, the researchers reported that caregivers were approximately two-thirds as likely to place their spouses in a nursing home, at any point in time, if they were in the treatment group rather than if they were in the control group. In a study of the outcomes of a health education program in a Health Maintenance Organization (HMO), the researchers found that the program had a significant impact on reducing total HMO costs for both caregivers and their spouses (Toseland & Smith, 2006). Using data from the Medicare Alzheimer’s Disease Demonstration Evaluation (MADDE) of 4,761 caregivers, Gaugler, Kane, Kane, and Newcomer (2005) found that individuals who utilized in home help services earlier in their caregiving careers were more likely to delay institutionalization. Recently, Wray et al. (2010) found significant short-term overall cost savings resulting from several health-care utilization sources (nursing home use included) in a study of telephone psychoeducational support groups for veterans and their caregivers with dementia.

Cooke et al. (2001) evaluated the effects of 40 intervention studies using an elaborate classification system that identified 15 components of interventions (such as general education, support group, social support, social skills training, cognitive problem solving, and respite). The researchers decided not to conduct a meta-analysis due to numerous methodological challenges including varying sample sizes, attrition rates, intervention duration, and limitations in research designs. The authors concluded that two-thirds of the interventions did not produce consistent positive benefits in terms of improved psychological well-being, perceived burden, or social outcomes. However, among the studies that demonstrated improvements, the inclusion of social components (social support) or a combination of social and cognitive (problem solving) components seemed to be relatively effective. These are often the components that can be targeted for inclusion in education and support group interventions.

Over the past two decades, findings from the intervention research literature have begun to yield the necessary data to examine program effectiveness. The earliest meta-analytical studies (Knight, Lutzky, & Macofsky-Urban, 1993; Toseland & Rossiter, 1989) called for greater methodological rigor. While gains have been made, wide variations in the implementation strategies of these programs will pose challenges for future evaluation initiatives. These include variations in program length, sample size, program purpose, group composition (e.g., spouse, adult-children, and other relatives), randomization methods, and choice of control/comparison groups, among others. Nonetheless, many of these programs are expanding and taking hold as vital components of community service systems. Nationwide there are education and support groups in every city providing services to frail older adults and their families. These programs are usually offered free of charge or have a nominal fee. Many are offered at convenient neighborhood locations such as churches, schools, nonprofit social service agencies and hospitals, and also at employment sites. Growth in the popularity of these programs suggests that consumers like them and that they gain useful knowledge from their participation in these programs. Evidence is also emerging that some of these programs are cost effective and have the capacity to delay costly institutional care.

Future Status of Education and Support Groups: Practice, Education, Research, and Policy/Advocacy

This section discusses utilization patterns of caregiver education and support programs in the context of future needs as well as their implications for practice, education/training, research, and policy/advocacy. Practitioners and researchers need to continue their inquiry into understanding how utilization affects caregiver outcomes. More attention will need to be given to the specific components of program design and implementation issues as these services are being developed and expanded. In many cases, longer-term interventions may be necessary. Such interventions should pay particularly close attention to the fidelity of the intervention and adherence to the program's purpose and goals. This can be challenging when interventions are longer term, particularly where there is staff turnover, with newer staff less familiar with the original program goals. This could account for some discrepancies in findings where some researchers argue that service utilization has increased while others claim that it has not, even with increases in knowledge of services and how to use them.

If program replication is indicated, then it will become essential to document exactly what was taught and learned, and whether the intervention had specific effects on care recipients, such as their utilization of other social or health services such as fewer days spent in a nursing home or hospital. This process will also require that programs pay closer attention to the targeting of the intervention to specific user groups. That is, if the goal is to make an impact on a particular illness group, it will be necessary to focus the educational content on the disease-specific problem and relevant coping strategy, rather than introducing unmeasured heterogeneity, combining several disease groups together as is commonly seen in the literature. This approach will require greater cooperation between health-care and social service agencies, between social workers and nurses, between caregivers and the professionals. There is a clear need for increased partnerships in training and service delivery among professionals and caregivers. This will require continued state and national funding of demonstration programs, with adequate funds set aside to specifically evaluate program effectiveness. Moreover, there are increasing roles for policy analysts and advocates alike, whose attention will be focused on the findings from these studies as well as the participation rates and outcomes of various user groups.

As future program evaluations are planned and attempts made to explain utilization patterns and participant outcomes, closer attention should be given to the demographic characteristics of the service population, including dimensions of race, ethnic, and cultural factors. The influence of their geographic locale, particularly rural area residence should also be considered. Although findings are mixed, a number of studies suggest that programs emphasizing access to services are likely to increase use among caregivers of individuals with dementia (Kosloski, Schaefer, Allwardt, Montgomery, & Karner, 2002). Several researchers have argued that effective strategies for recruiting minorities need to take into account their specific expectations. Barriers to service utilization such as unmet patient and caregiver need, attitudes toward support group affiliation, and bias in neuropsychological screening tests all must be considered in designing effective programs (Lampley-Dallas, 2002).

According to Toseland et al. (2002), future research should examine the appropriateness, quality, and impact of human service use by caregivers of persons with dementia. This suggests that studies go beyond numeric counts of service use alone even when it might be easier to obtain this type of data. Although it is generally more difficult to obtain data about the quality or impact of the services used by caregivers, this is the type of information that is most valuable to educators, researchers, policy analysts, as well as consumers. Toseland et al. (1999) also studied service use and included a comprehensive list of 33 health and human services (including support groups) that are potentially useful to individuals caring for older adults in a community setting. They measured current and future use, frequency and duration of service use, and found that 12% of their sample reported that they "currently used" support groups, while 33% said that they intended to use support groups "in the future." They also found that caregivers consistently reported that they would use more services in the next year and that removal of barriers to service use (access, cost, and transportation) would increase service utilization. They concluded that service utilization would increase in the future "if caregivers are empowered to negotiate the human service system and if research is conducted on innovative methods to deliver them." These are important roles for caregivers and their advocates in the future.

Future directions in research will require increased attention to randomization as a means of controlling for confounding effects, closer scrutiny to treatment contamination (such as when caregivers participate in multiple interventions), and a more careful analysis of dosage issues and specification of outcome measures. Increased attention to these methodological issues will be necessary to generate the data needed to plausibly assess the cost effectiveness of these interventions. Moreover, as Gallagher-Thompson and Coons (2007) have urged, future work would benefit from stronger theoretical grounding. Other challenges for researchers evaluating service utilization include unmeasured constraints on the caregivers' time, energy level and health, as well as the limited social diversity in most samples of caregivers. Measures that have often been used by researchers such as service knowledge, service use (e.g., long-term care, home care, respite, etc.), service cost, and network size will need to be conceptualized and measured more rigorously. Concerns have also been raised about the size of the groups, turnover, and leadership (peer-led vs. professional-led) of the educational groups. Heterogeneity of user types has been a concern because of differences in the range of caregiver needs that are frequently not addressed in the analysis or results.

One policy question raised by these interventions is how much government and other formal service providers should pay to support family caregiving. The conclusion of one policy analyst is that, "the family responds to its own dynamics which by and large are impervious or invulnerable to manipulations via public policies" (Doty, 1995, p. 120). Given the difficulties in the measurement of program effectiveness and other methodological challenges, the efficacy of these interventions is emerging. These programs offer a low-cost solution to helping family members cope with their caregiving challenges (Greene & Coleman, 1995; McCallion & Toseland, 1995). A controversial policy issue that has been raised in discussions of family caregiving and community-based long-term care is that of "substitution effects." That is, whether or not families will withdraw their caregiving efforts when free or low-cost service is available (Greene & Coleman, 1995; Kane & Penrod, 1995). This issue raises important questions for policy analysts in the future. What is the balance of responsibility between society and the family and does the provision of formal care reduce the amount of informal care that families provide (Weiner, 2003).

Although there are numerous challenges for educators and researchers in developing viable intervention programs that can be plausibly tested for program efficacy, it is important that these interventions continue to be developed and evaluated if we intend society to make a greater investment in them. A recent federal investment in caregiving education was made with the creation of the National Family Caregiver Support Program (NFCSP) funded by the Administration on Aging, through the Older American's Act of 2000 (Public Law 106–501). This program funded competitive research and demonstration projects that link special populations and communities by developing and testing new approaches to support caregivers. In 2003, the congressional appropriation for the NFCSP was 155.2 million dollars – these funds are available to provide direct services that meet the needs of caregivers, such as information and assistance, caregiver training, support groups, respite care, and supplemental services (www.aoa.gov).

Recent trends suggest a decline in formal care that may be associated with changes in Medicare home health payment after passage of the Balanced Budget Act of 1997, which reduced the availability of these benefits (Spillman & Black, 2005). It is encouraging, however, that the Administration on Aging has advocated for expanded resources for family caregivers by encouraging their use of technology and the internet to provide information on educational, outreach, and advocacy initiatives for caregivers. In their study of nonuse of community services, Brodaty, Thomson, Thompson, and Fine (2005, page 542) reported that in addition to respondents perceived lack of need, many caregivers "denied a need for services despite self-reported low levels of satisfaction with their caregiving role and high levels of resentment and overload." An impact of this outreach initiative on service utilization is captured in their report, "Compassion in Action" (2004). Their implementation findings reveal that in fiscal year 2002, states, tribes, and communities across the United States have provided information about caregiving to over four million individuals, provided assistance in accessing services to approximately 444,000 caregivers, and served almost 182,000 caregivers with counseling, support groups, and training services. Continued and increased funding of federal initiatives for family caregivers is critical to easing the burden of service demands that can be expected to emerge as the baby boomers begin to use services. One potential future outlet is greater use of the internet and telehealth. Use of the internet and telehealth can pave the way for a new generation of informed consumers who are knowledgeable and effective in utilizing community resources.

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Chapter 4
Education and Support Programs for Family Caregivers: Current Practices Across Health-Care Scenarios

Timothy R. Elliott

Family caregiving in the United States occurs within the context of several important societal changes that impinge directly upon the experience and adjustment of persons who live with a chronic and debilitating health condition. In their day-to-day routines, families have more influence on the personal health of each member than any other individual or any health service provider (Elliott & Shewchuk, 2004). Unfortunately, family members are typically viewed as informal, ancillary factors in health service delivery and most health-care delivery systems overlook their role as front-line service providers for many persons who live with chronic and debilitating health-conditions.

Although a family member may assume a caregiving role at any point in time, most contemporary conceptualizations of family caregiving address episodes associated with aging family members (and corresponding health-related problems that contribute to declines in functional and cognitive abilities), and with children that have severe physical and developmental disabilities. Indeed, the bulk of the extant literature and existing health and public policies address these caregiving scenarios (Shewchuk & Elliott, 2000).

But American health-care systems have been besieged by escalating health-care costs and an unprecedented rise in the number of chronic health conditions among people in general (accompanied by an increase in life expectancy among these individuals), and a shortage of nursing personnel (Donelan et al., 2002). Almost half of the American population has at least one chronic health condition, and almost one half of these people have more than one such condition (Partnerships for Solutions, 2004). Chronic health conditions are now the leading cause of disability and death in the United States (Institute of Medicine, 2001). On any given day in this country almost 70% of all health-care expenditures are associated

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with these conditions and their associated complications (Frank, 1997). Furthermore, the rates of disability associated with chronic health conditions have experienced the largest percentage increase among 18–51-year-old adults (Lakdawalla, Bhattacharya, & Goldman, 2004). Yet health-care institutions and their delivery systems have maintained their traditional focus on acute care and episodic illness while undercutting and ignoring programs of assistance to persons who live with chronic conditions (Shewchuk & Elliott, 2000).

Consequently, many family members are compelled to circumscribe or exit their normative life roles to provide in-home assistance to loved ones who may face an average life expectancy as they live with their condition (Lollar & Crews, 2003; Talley & Crews, 2007). These family caregivers often perform complex medical tasks (e.g., administering prescribed medications, wound care dressings) and supervise therapeutic regimens (physical therapy exercises, etc.) in addition to the emotional demands of support, physical demands of assistance in activities of daily living, and increased sense of daily burden in observing scheduled appointments, making arrangements for transportation, leisure pursuits, etc. (Donelan et al., 2002). Most family caregivers assume roles and perform these activities with little – if any – assistance from paid professionals or aides. Small wonder, then, that research has consistently documented that many caregivers experience declines in their personal health and well being over time (Vitaliano, Zhang, & Scanlan, 2003), as they experience a dearth of positive emotional experiences in their everyday lives (Quittner, Opipari, Regoli, Jacobsen, & Eigen, 1992), and neglect their personal health and encounter difficulties accessing health care for personal needs which may include being financially unable to refill their own prescribed medications (Donelan, Falik, & DesRoches, 2001). Family members who are in poor health when they assume a caregiver role are particularly vulnerable, and lower levels of education, older age, and unemployment are also risk factors (Donelan et al., 2001; Navaie-Waliser et al., 2002).

Family caregivers should receive as equitable a degree of training, skill development and ongoing support as observed in the training and preparation of other health-care professionals (Lengnick-Hall, 1995). This approach necessitates an explicit acknowledgement that family caregivers operate as formal extensions of health-care delivery, and the quality of their work is essential to the health and well being of the individual living with a chronic health condition. This approach also necessitates a collaborative – rather than a paternalistic – partnership with family caregivers that are sensitive and responsive to their opinions about needs and solutions in research and service-delivery programs and thus understandably require more community and home-based services (Israel, Schulz, Parker, & Becker, 1998).

In this chapter, various educational and support programs will be surveyed. The effectiveness of these programs will be noted. Issues that impinge on the study and implementation of these programs will be discussed, and recommendations for developing strategic services and informed health-care policy will be offered.

Clinical Practice: Educational, Training and Support Programs for Caregivers

For many years, the needs and concerns of caregivers of aging individuals experiencing cognitive and physical declines have received considerable attention from geriatric specialties. A variety of interventions have been developed and evaluated in this area. Similarly, intervention programs have been developed and studied among parents (mostly mothers) of children with severe disabilities and other chronic health conditions.

In contrast, the problems experienced by family caregivers of persons with disabilities and chronic disease acquired in the prime of life have only recently received substantive empirical scrutiny, and few intervention studies are available. To a great extent, this particular area has been guided by clinical lore and educational programs are typically limited to brief and sporadic on-site education provided by nurse, physical therapy, social work, or medical personnel as time and availability permit. Clinical programs for family caregivers are also constrained by the fact that most third-party payer systems do not reimburse clinicians for educating family members for caregiving activities. The absence of financial support signifies a lack of recognition for the essential role of family caregivers. It also places clear boundaries on the amount of time and effort clinical programs devote to caregiver education and preparation. Most clinicians are unable – or unwilling – to provide clinical services without financial compensation. Subsequently, most descriptions of caregiver training programs are either anecdotal (lacking in research documenting clinical efficacy) or research-oriented (supported by external funds to examine effectiveness and utility, but they are not representative of routine clinical practice).

In general, education and support programs can be categorized by the means and settings in which these are provided: in the institutional and clinical setting, and in community and home-based programs.

Clinic-Based Programs

Structured, psychoeducational programs that teach coping skills relevant to the tasks and demands of caregiving appear to be useful to family caregivers (Lovett & Gallagher, 1988; Toseland et al., 2001). There is some evidence that distressed caregivers may be more likely to benefit from these approaches than other caregivers (Toseland, Blanchard, & McCallum, 1995). A recent meta-analytic review of the literature confirms that psychoeducational programs are often effective in lowering distress and burden, and in increasing well being and satisfaction; however, the most pronounced and consistent effects appear to be the provision of knowledge and skills specific to a particular condition

(Sorensen, Pinquart, & Duberstein, 2002), although others find evidence that caregiver burden may be robust to most psychosocial interventions (see Acton & Kang, 2001).

Educational programs that are modified to meet the unique needs of individual caregivers may be effective because they have increased and immediate relevance to the caregiver (Brodaty, Green, & Koschera, 2003). This level of precision and ability to match content to the specific needs of the participant are hallmarks of psychoeducational programs (Burman & Margolin, 1992; Campbell & Patterson, 1995). Psychoeducational interventions can be conducted in inpatient, outpatient, community and home settings; they can be effectively adapted to serve culturally diverse populations (e.g., in Spanish; Gallagher-Thompson, Arean, Rivera, & Thompson, 2001). There is also evidence that caregivers benefit from programs that provide individual counseling sessions over a period of time that help them cope effectively with recurring stressors (and these benefits appear to be independent of care recipient problem behaviors; Mittelman, Roth, Haley, & Zarit, 2004).

Results from a large, multisite clinical trial indicate that psychoeducational programs can be substantially enriched by cognitive-behavioral theories of adjustment that offer clear directives for training (Sahler et al., 2005). In this work, individual sessions offered in outpatient clinics provided problem-solving training to mothers of children with cancer, and this intervention was superior to usual care in reducing maternal distress (and fostering increases in problem-solving abilities). Beneficial effects were observed for English-, Hebrew-, and Spanish-speaking mothers and positive effects were maintained 6 months after treatment. This research provides strong evidence for the effectiveness of psychological services for caregivers in the clinical setting.

Interventions that include caregivers as part of an inpatient treatment program for a loved one with an acquired condition do not seem to be particularly effective if there are no specific goals for the caregiver (Moore & Chaney, 1985). However, programs that educate the caregiver and the care recipient as a dyad about the condition and teach skills in self-care and coping, and that instill a greater understanding of the care recipient experience deserve greater scrutiny (Moore, 1989; Pakenham, Dadds, & Lennon, 2002). A recent meta-analysis of this literature suggests that interventions that involve family members and the individual with a chronic health condition have some positive effects in reducing care recipient and family member depression (although these effect sizes were relatively small; Martire, Lustig, Schulz, Miller, & Hegelson, 2004).

Yet it is illogical to assume that brief, inpatient-based educational programs are sufficient to meet the needs of family caregivers of persons who incur severe disabilities, as these needs, concerns, and the surrounding contexts are dynamic and evolving, subject to changes in their physical, psychological, social and financial resources, and in the resources and status of the care recipient (Shewchuk & Elliott, 2000). A limited and specific focus on the medical and functional needs of the care recipient is insensitive to the presence and consequences of contextual issues on caregiver health and well-being and, by extension, to the care recipient. Thus, services that are traditionally and understandably circumscribed to rehabilitation needs – as defined by the setting and the treatment team – will have little relevance to family caregivers over time, depending on the unique trajectory of their caregiving scenario and the resources that may be available (or depleted) over time.

Support groups for caregivers in the clinic setting have been used for some time but this format is contingent upon the composition and cohesion of its members and for many interested individuals mobility, transportation and logistical barriers prevent their participation (Elliott, Rivera, & Tucker, 2004). Few studies have demonstrated effects for informal, unstructured support groups, and when effects have been found, support groups were offered as a compliment to another and more structured psychosocial intervention (Gallagher-Thompson et al., 2003; Mittelman, Roth, Coon, & Haley, 2004).

Community and Home-Based Programs

Typically, most interventions are offered in a "top–down" fashion, as clinics and professional staff provide education and skill-building for problems they assume to be salient in the caregiving experience (Shewchuk & Elliott, 2000). It is preferable to regard families who have a member with health problem as experts on the "realities of their daily lives" (Mechanic, 1998, p. 284) and provide them with programs that assist them with the routines and tasks "…essential to maintaining family functioning" (Altman, Cooper, & Cunningham, 1999, p. 67).

Qualitative research clearly indicates that family caregivers experience a wide-range of problems that may not relate specifically to instrumental tasks associated with caregiving per se, but may reflect from issues in managing family life, resources and responsibilities and with role changes imposed by the health condition (Elliott & Shewchuk, 2002; Miller, Shewchuk, Elliott, & Richards, 2000; Willer, Allen, Liss, & Zicht, 1991). Community and home-based programs offer greater accessibility for caregivers, and they also offer an added advantage in addressing the problems and needs of immediate concern in the home environment. These features can increase the relevance and benefit of intervention programs. These interventions ideally help families become more active and expert in their self-management and operate competently as extensions of the formal health-care system (Wagner, Austin, & Von Korff, 1996).

Programs that emphasize "partnerships" with family caregivers recognize their needs for education, support, and counseling in the home environment (Grant, Elliott, Giger, & Bartolucci, 2001). Home-based assessment and training for caregivers of family members with recent-onset acquired disability has been offered as an extension of rehabilitation programs (Brown et al., 1999; Elliott & Berry, 2009) and caregiver education may be provided in community sites that offer additional programs and supports of value to participants, such as churches and community centers (Houts, Nezu, Nezu, & Bucher, 1996). These programs can circumvent problems with mobility and transportation restrictions, and work within the time constraints that many caregivers experience.

Family caregivers and care recipients benefit from problem-solving-based interventions provided in telephone interactions (Elliott, Berry, & Grant, 2009; Grant, Elliott, Weaver, Bartolucci, & Giger, 2002; Rivera, Elliott, Berry, & Grant, 2008). Telephone sessions can also supplement more traditional, clinic-based programs. One multisite, randomized trial of face-to-face problem-solving training sessions for mothers of children with cancer offered telephone sessions for participants unable to make the designated site and if they had attended at least one session with the trainer (Sahler et al., 2002). Telephone sessions have also been used to instruct family caregivers in moderate-intensity exercise training with measurable success (King et al., 2002).

Other long-distance technologies allow opportunities for novel interventions that can be scheduled at the convenience of the individual caregiver. Some programs have provided internet bulletin boards for caregivers to ask questions, request and download information, and post replies and comments to other participants (Bucher & Houts, 1999; Steiner & Pierce, 2002). More formal interventions have used web-based applications to conduct family counseling sessions, and these modalities have been used successfully with families that have teenagers (Hufford, Glueckauf, & Webb, 1999) and young children (Wade, Carey, & Wolfe, 2006) with disabilities. Home-based video counseling and speaker phone counseling, and face-to-face office-based counseling appear to be equally effective in reducing problem severity experienced by families and preadolescents with epilepsy; moreover, these respondents preferred the two home-based modalities over the traditional office visit (Glueckauf, et al., 2002). Inexpensive videophone conferencing can also be provided through existing land-based telephone services without computer reception, so that caregivers can have visual contact (from their television) with trainers to receive training at home (Elliott, Brossart, Berry, & Fine, 2008).

Although home-health services exist for some caregivers in the community, budget shortages have severely limited these programs for many families, particularly in rural and inner-city areas. These programs provide valuable services but vary tremendously in the degree to which they provide additional caregiver training and education. Evidence from the large-scale, multisite clinical trials of home-based interventions for caregivers of persons with Alzheimer's disease indicates that several services can be provided effectively in the home to benefit caregivers. Generally, reviews of the best caregiver intervention research to date conclude that "more is better" for these caregivers: programs that provide services, support, information, and skill building with a relative intensity (in terms of frequency and duration) have a greater positive effect than short-term, infrequent, and educationally-based programs (Bourgeois, Schulz, & Burgio, 1996; Sorensen et al., 2002). Psychoeducational and psychotherapeutic interventions that integrate diverse and multiple components of assistance specific to caregiver needs are recommended (Gallagher-Thompson & Coon, 2007). Caregiver distress may be significantly reduced by programs that focus on improving specific care recipient skills (Gitlin et al. 2003), or provide family counseling via computer-telephone integrated systems (Eisendorfer et al., 2003), or provide ongoing support in automated telephone contacts (Mahoney, Tarlow, & Jones, 2003).

Policy and Advocacy: Current Status and Future Directions

The needs of family caregivers in our society have progressed to the extent that their health and well-being is now considered a stated priority in public health (Talley & Crews, 2007) and mental health policy (Surgeon General's Workshop on Women's Mental Health, 2005). *Healthy People 2010* (2000) recommends the development of behavioral and social initiatives to promote the health and quality of family members who provide assistance in the home to a loved one with a disability. It is doubtful that any single service provider or institution can adequately and efficiently address caregiver needs, as these are dynamic and evolving, subject to changes in their physical, psychological, social and financial resources, and in the resources and status of the care recipient.

Unfortunately, family interventions to date have yet to demonstrate the sort of clinical efficacy and cost-effectiveness that would engender interest among most health policy makers (Thoits, 1995). Current health-care delivery systems have limited use for high-cost service providers who account for a significant amount of health-care expenditures; their utility in long-term and home-based prevention and health maintenance programs may have a lower payoff for families than behaviorally-based intervention programs (Zarit & Pearlin, 1993, p. 314). Regrettably, policy makers often view behavioral interventions – as typically described and prescribed by doctoral-level service providers, in particular – "as prohibitively labor intensive, because they equate it with one-to-one counseling by highly trained and expensive staff" (Leviton, 1996, p. 47). It is possible that delivery of interventions best suited for families will be provided by low-cost personnel who are able to conduct routine evaluations and provide guidance for self-management (Wagner et al., 1996). With the unabated and precipitous increase in chronic disease, most third-party payers (including disability insurers and pharmaceutical benefits programs) may be compelled to manage costs with low-cost service providers in chronic disease management programs. These programs may be well-suited to effectively monitor family caregiver training, support, and adjustment.

The bulk of the intervention research has understandably occurred among caregivers of persons with age-related cognitive declines, and this literature has often informed public policy concerning caregiving, generally (Mahoney, Burns, & Harrow, 2000). In fact, the most comprehensive randomized clinical trial (RCT) to date – Project REACH – has provided rich information to inform the next generation of research in this realm (Burgio et al., 2001). Yet this work, albeit comprehensive and enlightening, cannot generalize to the experience of caregiving for individuals who have incurred severe physical disabilities (e.g., spinal cord injuries, traumatic brain injuries) in young to middle-adulthood, and who may live a normal life expectancy. Unlike many conditions in which caregiving may be relatively time-limited (and ultimately determined by the course of the disease), young individuals with severe physical disabilities may face a normal life expectancy and require the ongoing, routine assistance of a family caregiver over their lifespan (Lollar & Crews, 2003). Families in these situations have many needs specific to the condition and effective caregiving may be essential in preventing secondary complications, ensuring quality of life, and in resuming meaningful social, personal, and vocational roles (Elliott & Shewchuk, 2004). Educational and training needs will ebb and flow over time, influenced by the dynamic processes that characterize the trajectories of adult and family life. Only a few states provide financial assistance to family members who assume a caregiver role, and in doing so, leave the labor force to assist loved ones who live with severe disabilities. Currently, the Veterans Administration health-care system provides some support to spouses who assume caregiver roles for permanently disabled veterans; the number of family caregivers in this system is increasing dramatically with the influx of military personnel physically disabled in international conflict (particularly from acquired brain injuries that can impair personal, social, and vocational roles).

It is also difficult to generalize from research conducted with older populations because family caregiving is construed differently in these other scenarios. For example, a spouse of a person with a spinal cord injury (SCI) may be intricately involved in daily "caregiving" activities as defined in strict clinical terms, but this couple may define their relationship in terms of their marriage and associated roles (Olkin, 1999). In sum, a spouse may identify as a "partner," "lover," or "wife" without ever identifying as a "caregiver" per se (Crewe, 1993). Similarly, many parents may perform instrumental and emotional tasks of caregiving, but disavow any association with the term "caregiver," choosing to identify as a mother or father. In these scenarios assistance and relevant training is still warranted, but the mechanisms of ongoing support should recognize and incorporate the ways in which these persons define their roles and the nature of assistance they deem necessary and useful.

Furthermore, the needs that currently face caregivers in our society demand immediate attention from health and public policy, and these needs may not be best served by a strict empirical reliance on randomized clinical trials, which can be inadvertently insensitive to the full spectrum of the caregiver experience. RCTs, as a logical extension of experimental methods, represent the "…the closest science has come to a means for demonstrating causality" (Haaga & Stiles, 2000, p. 14). But this model may not translate very well to the often-messy worlds in which applied delivery systems provide their services. Actual services conducted under "real world" conditions are replete with confounds, mediators, "outliers," and "covariates" that cannot ethically or practically be dismissed by the exclusionary criteria used in many RCT research protocols. As discussed previously, caregiver and care recipient adjustment is influenced by many behavioral, social, and contextual factors that are not within the practice domain of any specific health service delivery system, generally, or within any unique profession, specifically. The best RCT designs are reasonably focused on only one or two of these possible factors that influence adjustment; therefore, the effect sizes of RCTs (individually and cumulatively) with community-residing caregivers will likely range between "small" and "moderate." Consequently, the evidence from randomized clinical trials will lack a certain external validity for persons who live with chronic health conditions (Levant, 2004). The strict reliance of RCTs on untreated control groups and unmeasured characteristics that influence participation in research can obscure our appreciation of those who have limited access to services and limited access to participation in research (Tucker & Reed, 2008).

Furthermore, RCT designs typically and implicitly assume a linear response to treatment, such that decreases in distress should occur in response to “doses” of an effective psychosocial intervention. However, all changes in response to psychological interventions are not conveniently linear: We know that real-life setbacks and dramatic improvements can occur during the course of counseling (indicative of “discontinuous” changes; Hayes, Laurenceau, Feldman, Strauss, & Cardaciotto, 2007). There is evidence that community-residing caregivers may experience these kinds of responses to psychosocial interventions (Elliott et al., 2008; Rivera et al., 2008). Sophisticated designs and corresponding analytic strategies will help us determine mechanisms of change for both caregiver and care recipient, and the types of support they need at certain times.

It is important that researchers conduct program evaluations of existing services, and such research could benefit from examining existing clinic practices (Horn, 1997). Clinical practice research and program evaluations could provide additional and important information about the general effectiveness of caregiver interventions that may be otherwise obscured in clinical trials (which are understandably restricted to the study of specific variables or techniques).

Education and training programs should develop greater precision in identifying caregivers who are at risk and those who may be likely to fare well on their own recognizance. This level of assessment is necessary to avoid a “one size fits all” approach to service delivery. Many caregivers, for example, derive meaning in their role and adjust well, and many caregivers – care–recipient relationship flourish (Olkin, 1999). Unfortunately, very little research has examined personal growth and well-being among caregivers (Kramer, 1997). We do know that there is considerable variance among caregivers, and prospective research using sophisticated modeling techniques has identified characteristics of those likely to develop depression and ill health (Elliott, Shewchuk, & Richards, 2001) and those who are with care recipients at risk for secondary complications (Elliott et al., 1999) in the initial year of the caregiver role. Programs should identify and monitor families at risk, and provide appropriate support and assistance as needed. Program evaluation research and predictive models that take into account unique caregiver and family characteristics will help identify individuals who require more intensive therapeutic interventions from skilled staff and who are most likely to benefit from these high-cost services (Shewchuk & Elliott, 2000).

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Chapter 5
Ethnic, Cultural, and Gender Issues in Conducting Caregiver Educational and Support Groups

Carole Cox

Ethnicity, culture, and gender are variables that give meaning to the group experience as they provide a lens through which the group is perceived. Each can influence an individual's decision to join such a group as well determine the impact of the group. With the increasing diversity of society and the expansion of caregiver groups, it is critical to understand the roles that these factors can play in the group experience. This chapter discusses the ways in which ethnicity, culture, and gender can impact on caregiver education and support groups. In order to depict the role of these factors in groups, the author describes their impact and effects in empowerment groups for grandparent caregivers, a specific type of education and support group developed by the author for grandparents raising their grandchildren (Cox, 2000).

Culture and Ethnicity

Culture is a set of shared symbols, beliefs, and customs that shapes individual or group behavior (LeVine, 1974; Ogbu, 1993). According to Goodenough (1999), culture consists of the criteria or guidelines for speaking, doing, interpreting, and evaluating that people working and living together have acquired and continue to use in their interactions and activities. Consequently, culture gives meaning to the experience of caregiving and to interventions such as support groups that are designed to assist caregivers.

Separating ethnicity from culture is difficult as ethnic groups are in themselves bound by a shared culture that dictates values, beliefs, traditions, and norms for behavior. However, ethnicity, as distinct from culture, refers to a group's shared sense of people hood based on a distinctive social and cultural heritage passed on from generation to generation (Gordon, 1964). In the United States, this sense of people hood is primarily associated with race, religion, national origin, or some combination

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of these traits (Mindel, Habenstein, & Wright, 1988). Moreover, levels of ethnic identification can vary as persons vary in their commitment to it (Gans, 1979).

Ethnicity impacts on identity and behavior as it also may influence how one feels about his or herself (Pinderhughes, 1989). Thus, if an ethnic group is treated negatively, oppressed by society, individuals within the group may internalize these negative responses, experiencing themselves as less worthy and of lower status than others. Such feelings can affect their interactions with the greater society.

The importance of ethnicity in terms of identity also varies with the length of time since immigration and with the ease with which groups can assimilate into the greater society (Gelfand & Fandetti, 1986). On the other hand, factors such as language and physical characteristics that can impede assimilation may also cause persons to maintain an ethnic identity even though they would prefer to abandon it. It is also imperative not to assume that because a person belongs to a specific ethnic group that they necessarily adhere to cultural values, expectations, or behaviors. Such assumptions lead to stereotypes, which thwart any understanding and meaningful interactions with the individual.

Ethnicity and Culture in Groups

Ethnicity, culture, and gender are important factors to consider in groups as they can shape the ways in which individuals perceive and interact with them. Indeed, persons adhering to specific ethnic cultures may be reluctant to share problems and concerns within a group setting. Those who have experienced their own ethnicity negatively, who have internalized feelings of self-hatred and rejection, may be anxious about participating in a support group composed primarily of persons from the dominant culture. The group process can be further complicated if it includes both sexes in that this diversity can further affect the level of intimacy and comfort among participants (Cox & Ephross, 1998).

In working with ethnically diverse groups, it is essential that the worker is knowledgeable about values, traditions, and beliefs, which may govern the interactions of individuals within specific support groups. In the same way, working with male caregivers necessitates that the worker understands the factors that may inhibit their participation in a group as well as those that may attract them. Understanding the ways in which persons view authority, power, the sexes, levels of intimacy, persons outside of the group, as well as the function of the group itself are among the critical factors that can affect participation and responses. Practitioners must be familiar with the extent to which persons are comfortable with self-disclosure and expression and with trying out new behaviors in a group setting.

Critical to working with caregiver support groups is understanding how caregiving itself is interpreted. In certain cultures, there may be no word for caregiving and, consequently, persons will not perceive themselves as caregivers. Instead, they are enacting traditional roles of providing assistance to a family member, either young or old, who is in need. In some instances, as with Alzheimer's disease and other dementias, the illness may be viewed as a normal part of aging and for which the family is expected to give needed assistance (Henderson & Gutierrez-Mayka, 1992). Moreover, using formal supports and services may be perceived as a failure to adhere to expected roles and thus lead to increased stress among caregivers (Cox & Monk, 1993).

Studies of Asian caregivers of relatives with dementia reveal the ways in which culture can impact on both the perception of and responses to the illness. A study of Chinese, Japanese, Filipino, and Vietnamese families found that they all shared many common beliefs that affected their caregiving and help seeking. These include: dementia is a common part of aging, dementia cannot be cured, children are obligated to care for their parents, problems should remain within the family, and it is shameful to talk about senile problems in a family (Braun & Browne, 1998). Among most groups, it is looked as a stigma that reflects on the entire family. The stigma associated with cognitive impairment means that the illness is rarely discussed outside of the family and consequently, there is a strong reluctance to participate in any formal type of group.

Asian family caregivers are less likely than either African-American or white caregivers to report that the person they care for has AD or any mental confusion and are also less likely to report feeling any stress (National Alliance for Caregiving and AARP, 2004). Families are expected to play traditional roles of providing care to the elderly and tend to view dementia care as part of this process. As an example, among Korean families, daughters-in-law are expected to serve as caregivers to older parents (Youn, Knight, Jeong, & Bengston, 1999). Not fulfilling this role implies ignoring important familial and moral obligations. In addition, seeking outside support may also indicate an inability or reluctance to act as caregiver.

It is important to also recognize that many behaviors and attitudes toward formal groups may result from years of discrimination and racism rather than from cultural values or norms. Persons accustomed to feeling oppressed by others in society and excluded from many of its institutions and who have been accustomed to poor services and providers may be uneasy about joining a group sponsored by an agency from the dominant culture.

Gender in Caregiving Support and Educational Groups

Discussions of caregiver support groups generally do not examine the role of participants' gender. This may be at least partially explained by the fact that the majority of caregivers are women, that caregiving itself is perceived as a woman's role, and that male caregivers make less use of services, including support groups, than women.

Men make up approximately 30% of all caregivers but in some contexts, as in caregiving to young men with AIDS, compose between 41 and 53% of all primary caregivers (Turner & Catania, 1997; Turner, Catania, & Gagnon, 1994). One survey of caregivers over the age of 18 providing at least some care to a chronically ill spouse or older persons found that 44% of the sample was men (National Family Caregivers Association, 2000).

In comparison to women, much less is known about the caregiving experience of men. Comparisons of male noncaregivers to those caring for persons with dementia and AIDS finds the caregivers have higher levels of depression (Folkman, Chesney, & Christopher-Richards, 1994), more difficulty sleeping, use more over-the counter medicines, and have more respiratory problems (Fuller-Jonap & Haley, 1995). In comparison to female caregivers, the level of depression among male caregivers increases more over time (Schulz & Williamson, 1991). Moreover, grief is a more common response among male caregivers than among females (Rudd, Viney, & Preston, 1999).

However, even though caregiving can be stressful for men, they are largely underrepresented in caregiving services and support groups. Studies of men caring for persons with Alzheimer's disease find that they are significantly less interested in participating in support groups than women although they report the same challenges and burdens (Cox & Albisu, 2003; Cox & Monk, 1996). At the same time, men participating in support groups report that they greatly benefit from them (Kaye & Applegate, 1993).

A national survey of facilitators of support groups reported the most frequently mentioned deterrent to men joining a group was the belief that they should be able to manage on their own and that joining a group was an indicator of weakness, loss of control, and failure (Kaye & Applegate, 1993). Other factors deterring participation were a resistance to sharing personal problems in a group while health, a lack of awareness of groups, and misunderstanding of the group's purpose and function also constricted their involvement.

In working with male caregivers, just as in working with diverse ethnic populations, practitioners must be aware of their own stereotypes and biases with regards to the way in which the man perceives his role or that of support services. Many men may seek support and desire to strengthen their caregiving skills as they affirm the expressive nature of their roles. Consequently, workers themselves must be aware of their own perspectives of men's roles and their involvement in caregiving activities in order to be sure that their own biases and attitudes do not deter their active participation.

It has also been suggested that men, particularly older men, may do best in an all-male group feel less of a need to maintain a sense of self-sufficiency (Kaye & Applegate, 1990). It is difficult to have one male in a support group otherwise composed of all women since it makes the development of intimacy, trust, and communication, essential elements for an effective support group difficult to develop. Another suggestion that may make support groups more attractive to male caregivers is that they be described as places for obtaining information and developing skills rather that emphasizing the emotional support that they can offer.

McFarland and Sanders (2000) developed a psycho-educational group for male caregivers of Alzheimer's relatives that met for four sessions. Based on this experience they recommended several features that would make such groups attractive to men: groups should be small so that sharing of emotional experiences is easier; time should be allocated to discussing concrete caregiving skills; education as a part of the group; discussions of skills for managing stress.

Other recommendations for reaching male caregivers include advertising such groups as skill building classes rather than support groups; recruiting participants from a variety of sources; having flexible times for groups or combining groups with other services so as to meet the needs of working caregivers; teaching skills, providing information on how to access other services (Lauderdale & Gallagher-Thompson, 2002).

Educational and Support Groups for Grandparent Caregivers

In the last few years, there has been a proliferation of support groups for grandparents who are raising their grandchildren (Cohen & Pyle, 2000). Many of these groups originated as self-help groups founded by grandparents themselves with the purposes of eliminating isolation, gaining perspective, and developing a sense of empowerment (Kirkland, 1992). These groups have also become important sites for sharing information and learning new parenting skills and have been developed to work with diverse populations (AARP, 2003).

An early study of support groups among African-American grandparents (Minkler & Roe, 1993) found that participants felt that being among people with similar problems and life situations relieved stress as others understood what you were saying and feeling and you did not have to feel bad or embarrassed. The groups played a significant part in their lives and were places where they could both share and learn new modes of behavior.

As with other caregiving groups, workers with grandparents must be knowledgeable about the specific ethnic backgrounds, values, and traditions that can affect both group participation and child rearing. Moreover, workers must also be cognizant of familial relationships, the traditional roles of parents and grandparents, and how being directly responsible for a grandchild relates to such traditions.

Noticeably absent in the studies of grandparent caregivers and support groups are the discussion of grandfathers. Although data indicate that in almost half of grandparent headed households, a grandfather is present (Casper & Bryson, 1998), there is very little known about their experiences. However, a recent study (Bullock, 2005) suggests that these grandfathers may be experiencing a sense of powerlessness associated with their new roles and thus would benefit from interventions that could assist them to adjust. But, as with other support groups, it is difficult to attract male participants. The challenge remains to make groups attractive to these men and congruent with their specific needs.

Empowerment Groups

Empowerment groups are a specific type of support and educational group. The groups have specific goals of helping participants to achieve a sense of personal power, become aware of connections between individual and community problems, develop helping skills, and learn to work collaboratively toward social change

(Gutierrez, Glen Maye, & DeLois, 1995). According to Guiterrez and Ortega (1991), the personal level of empowerment is concerned with the individual's feelings of personal power and self-efficacy while the interpersonal level is concerned with an individual's ability to influence others. Consequently, empowerment must often involve changing attitudes that can be barriers to individual growth and change.

Groups focusing on empowerment provide settings in which participants are able to share concerns, learn from each other, and practice specific techniques aimed at fostering their growth and abilities. As participants become comfortable with these techniques, they are encouraged to use them outside of the group. The role of the group leader is that of a facilitator who recognizes that the participants are the experts and that they learn by sharing experiences and developing skills.

Consequently, empowerment can be a critical tool for grandparent caregivers as it assists them to cope with the parenting role by sharing information and learning how to deal effectively with the many challenges they face. At the same time, in order to be most effective, group facilitators must be sensitive to the ethnic backgrounds and culture of the participants as these factors can affect both the way the group and empowerment itself is perceived.

The empowerment group program described here was developed by the author to meet the needs of diverse groups of grandparents. It is composed of 14 classes, 3 h each. The classes cover a wide range of topics pertinent to these families ranging from loss and grief to self-esteem and behavior issues. Three of the classes deal with community services, legal issues, and advocacy. All of the topics are pertinent to the empowerment of the grandparents within the family and the community.

Participants for the grandparent empowerment groups were selected from grandparent support groups in a large Northeastern urban city. Each empowerment group had 15 participants with the only requirement for participation being that the grandparent was responsible for raising the grandchild. The goals of the groups were to develop the parenting skills of the grandparents and to empower them both within the family and in the community.

The findings discussed here come from several groups, a group for Hispanic grandparents who were not fluent in English, a group for African-American grandparents, and a group that was composed of both Hispanic and African-American grandparents. The Hispanics were all first-generation immigrants, primarily from Puerto Rico and the Dominican Republic. As a means of further understanding the ways in which these participants approach empowerment, it is essential to have some knowledge about their cultures and the ways in which it can impact on their roles as grandparents and within the group itself.

African-American Culture and Empowerment

The history of African-Americans in the United States has been a major influence on the role of the family and particularly the woman's role as caregiver. From the early nineteenth century until the mid-1960s, it was common for the black grandmother to accept and raise both her own grandchildren as well as more extended kin and orphans with no place else to live. Following the Civil War, grandmothers were frequently called upon to raise the grandchildren as the parents were searching for work (Jackson, 1986) or migrated to urban areas in the North and West (Burton & Dilworth-Anderson, 1991).

But, in addition to child rearing, the legacy of slavery also forced many African-American women to assume other roles working in households and in the fields. These conflicted with the more traditional ones, but simultaneously they often found themselves the pivotal figures in the slave household holding both the family and community together. This role did not end with emancipation, as it was often easier for black women than men to find work, further casting them into the role as provider for the family.

These experiences coupled with years of discrimination and oppression has encouraged self-sufficiency as a common trait among black women (Tate, 1983). According to Watson (1974), black women have tended to internalize the community's perceptions of them as strong, independent, and resourceful. Research indicates that difficulties in coping and feelings of lack of competence in the caregiving role can lead to greater stress and depression among African-American than white women acting as caregivers (Cox, 1995). Consequently, when grandparents assume the parenting role for their grandchildren, they may be vulnerable to feeling overwhelmed by its responsibilities and demands. Empowerment can thus play a major role in helping them to adapt and cope with the challenges they are likely to experience.

Latino Culture and Empowerment

Latino culture has been characterized as emphasizing a commitment to the value of familism, which places the needs of the family above those of the individual and a related sense of duty to offer emotional and material support to family members (Sabogal, Marin, & Otero-Sabogal, 1987). A strong emphasis is placed on the importance of children and the elderly and the obligation to help each as needed. Moreover, when such expectations are not met, there is an increased likelihood of intergenerational dissatisfaction (Cox & Gelfand, 1987).

Gender roles tend to remain strong among the first-generation Hispanic immigrants. Men are expected to be controlling, authoritarian, possessive, and a good provider to the family, demonstrating characteristics associated with machismo. Women are to be protected, submissive in relation to the male, and protective of their children (Carillo, 1982).

It is a common practice for older Hispanics to assist their children with childcare. When Hispanic families immigrate to the United States, their role as childcare providers becomes even more critical as it contributes to the family's ability to succeed although such involvement does not assure that conflicts will not ensue according to value differences (Gelfand, 1993). Consequently, grandparents assuming the parental role due to the absence or incapacity of their adult children may find themselves experiencing considerable role conflict and strain as they struggle to adjust their traditional role expectations to the reality of the new society (Burnette, 1999).

In her study of elderly Puerto Rican women, Sanchez-Ayendez (1994) found that child rearing was viewed as their primary responsibility and one that persists through adulthood. At the same time, although motherhood is a central role for women, other roles such as breadwinner and wife may also be enacted. Moreover, studies also show that with suitable mentors and encouragement, young Hispanic women can assume effective leadership positions in the community (Lazzari, Ford, & Haughey, 1996). Within the empowerment process, grandmothers are mentored to also feel comfortable in more assertive leadership positions.

The Impact of Culture in the Empowerment Groups

The African-American and Hispanic grandparents approached empowerment from different perspectives and roles. Whereas the African-Americans were accustomed to decision-making roles in the family, the Hispanic grandmothers were not. They saw their roles as primarily providing childcare for absent adult children but lacking any real authority or control. These roles were further complicated by the grandparents' status. Whereas the majority of the African-American group had legal custody of their grandchildren, very few of the Hispanic grandmothers had any formal relationship with their grandchildren.

As well as being more assertive within the family, the African-American grandmothers were also more accustomed to taking active roles in the community and in seeking services. Although both groups were familiar with community programs and willing to use them, the African-Americans were more demanding of their rights for benefits and accessible programs. Even though many agency staff was fluent in Spanish, the Hispanic grandparents still felt hampered by the language barrier. In some instances, they found themselves relying on their grandchildren to act as translators.

Overall, the African-American grandmothers were more accustomed to participating in varying types of groups. In contrast, although all of the Hispanic grandmothers were members of a grandparent support group, none had participated in any educational or training program in the United States. Consequently, the empowerment group was a very new and unique experience for them.

The two groups of grandparents shared many similar concerns. Both were eager to learn how to communicate with their grandchildren, to understand them, and to deal with behavior issues. Both groups felt that adolescents were the most difficult to raise and they equally worried about protecting their grandchildren and insuring their safety.

Behavior within the groups varied. Throughout the classes, the African-American group was willing to discuss, question, and challenge the material, each other, and the group leaders. In comparison, the Latina grandmothers, although comfortable in discussion, were unlikely to disagree with the readings or the facilitators. They also were reticent about sharing any concerns or problems they were having with their grandchildren or families. At the same time, they were eager to listen to others and to comment on their experiences.

The Hispanic grandparents, although interested in learning more about AIDS and substance abuse, were reluctant to talk about it themselves, even though it had impacted on many of their lives. In contrast, the African-American group was open in discussing AIDS and their own families' struggles with it and with drugs. It is interesting to note that within the mixed ethnic empowerment group, the openness of the African-Americans did impact on the Hispanics, who gradually became more comfortable in discussing more personal problems within the group.

The empowerment process for the Hispanic grandparents was a slow and gradual process but one which did lead to many formidable changes. At the end of the course, one grandmother explained how she had made her three grandchildren listen to her as she practiced her presentation on sex and AIDS. Her grandchildren were so stunned by her behavior that her teenage grandson began crossing himself! She felt that by being able to talk about these subjects she had reinforced her position within the family. Another gave her daughter advice about child rearing and the proper way to discipline children, reinforcing her talk with brochures she had received in the class. Her daughter's attention and interest strengthened her own sense of self-esteem and authority.

The Hispanic grandmothers also became more empowered within the community. Two of the grandmothers joined a group going to the state capital to lobby for more after school programs for children. As they discussed the event in the empowerment group, they acted as important role models for the other group members. Another grandmother became very active in the PTA informing the school about the specific needs of grandparent caregivers and working to obtain more support for them.

Role playing in class was an important learning tool as it compelled the grandmothers to try out the new ways of acting. In addition, it facilitated the understanding and relevance of the material as the grandmothers partnered with others assuming the roles of their grandchildren or agency personnel. It was particularly useful for those with difficulties in reading. It is important to note that this teaching strategy, although new to both groups, was enthusiastically accepted with both groups enjoying and learning from the experience.

At the completion of the course, all of the participants began giving presentations to other community groups, including schools, senior centers, churches, and support groups. By sharing their knowledge they strengthen their own roles and solidify feelings of empowerment. Following the example of the African-American grandmothers, the Hispanic group developed brochures describing their support group and its activities. A drawing of a tree with large branches and strong roots symbolizing the importance of grandmothers was framed by the words "Abuelas en Accion" (Grandmothers in Action).

Lesbian, Gay, Bisexual, and Transgender Caregivers

A distinct population of caregivers that remains underrepresented in research and in other studies as well in services are those identified as lesbian, gay, bisexual, or transgender (LGBT) caregivers. One of the largest studies of this population conducted by MetLife (2006) found that of the 1,000 LGBT persons aged 40–61 who participated in their national survey, 1 in 4 had been acting as a recent caregiver. More than a third, 36% were caring for parents while 18% were caring for their partners. The findings from the survey also revealed some conflicting responses. Almost 40% of the respondents felt that being a part of the LGBT community had strengthened their support networks while at the same time, almost 1 in 5 respondents were unsure who would be their caregiver if the need arose.

A survey of LGBT people in New York City (Cantor, Brennan, & Shippy, 2004) found that nearly half were acting as caregivers or had providing caregiving assistance within the past 5 years and that the difference in experiences between caring for a family of origin member or family of choice member were not minimal. In addition, the caregivers needed the same types of support as heterosexual caregivers, including respite, information and referral, back up services and support groups. Almost two-thirds stated that their sexual orientation made no difference in their family's expectations of them. Moreover, although this group of caregivers reported the same type of stress and strain experienced by other caregivers, they do not have equal access to the social, emotional of financial supports available to others.

Most family and caregiving policies and programs have yet to recognize the roles and needs of this increasing population of caregivers (Fredriksen-Goldsen & Hooyman, 2007). Further complicating their involvement with services are discrimination and caregiver anticipation of discrimination by providers (Brotman & Richard, 2007).

The need for and role of support and educational groups for caregivers can be expected to increase as the population continues to age. Distinct efforts are essential to engage these groups of caregivers, including those of the LGBT community, using strategies that are sensitive to their distinct experiences.

Summary and Future Directions

The discussion of empowerment groups for grandparent caregivers illustrates the ways in which culture and ethnicity can be incorporated into a group experience and how the group itself may be shaped by the culture of its participants. Understanding how these factors influence participation and the learning process in caregiver education and support groups is critical for the development of acceptable and meaningful programs. Reaching diverse caregivers necessitates understanding individuals' perceptions of the caregiving experience as well as their perceptions of the group itself.

Reaching male caregivers remains a formidable challenge. As noted earlier, they are more likely to participate in groups with an educational focus rather than a supportive one. Thus, framing groups as settings in which caregivers can learn new techniques and strategies that can facilitate the caregiving experience may be a more effective outreach tool than describing groups as sources for emotional support.

Although men may prefer all male groups, resources often limit their availability and therefore efforts must be made to encourage their participation in mixed groups. Further studies on ways to increase a group's attractiveness to both sexes can help to assure optimal participation.

As demonstrated in the empowerment model, caregiver groups can be more than support groups: they can be important contexts for strengthening the advocacy skills of participants. Learning how to work for policy and service changes that can better meet their needs, as caregivers is an important part of the educational process. Within the group, participants can learn lobbying strategies, the power of coalitions, and strategies for making legislators aware of their concerns. Advocacy is key to change and within the group caregivers can learn that they are critical to such efforts.

Group leaders must be sensitive to cultural differences that exist between themselves and the participants and among the members themselves (Davis, Galinsky, & Schopler, 1995). They must also be aware of their own biases and perceptions that may affect their own responses and beliefs. Through such sensitivity they can help to assure that the groups become positive and growth enhancing forums for the participants.

Ethnic diversity should not be a barrier to participating in support or empowerment groups. As found in the work with African-American and Hispanic grandparents, persons learn from each other regardless of diverse backgrounds and cultures. In fact, the ethnic diversity itself becomes an enjoyable learning tool for participants as they recognize that the issues and problems that they face are so widely experienced. Within the group and through the sharing that occurs, strong bonds can be formed that surmount ethnic differences. However, although diversity within groups should be encouraged, it is difficult to integrate into one person who speak different languages. Having interpreters and translators within the group can negatively impact on the flow of communication and actually interfere with the empowerment group process.

Recruitment efforts must be tailored to attract diverse participants and the groups themselves must reflect the culture of the group and its patterns of interactions. Understanding and building upon the factors that can make these groups most congruent with the interests and characteristics of ethnically and sexually diverse populations is imperative if they are to act as effective interventions to enhance caregiver well-being.

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Chapter 6
Caregiver Support Groups: Led by Peers, Professional, or Both

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Caregiver support groups are an intervention strategy that has been used extensively to relieve stress and to help caregivers learn and use methods of coping. Support groups offer family caregivers the opportunity to share experiences and issues, receive emotional support from persons who have similar experiences and problems, and learn caregiving strategies that have been successful for others (Toseland, Rossiter, Peak, & Hill, 1990). There are several types of caregiver support groups, however, and current research is inconclusive as to what types are most effective. As with other types of interventions, it is likely that the type of support group that is most helpful for a specific family caregiver depends upon the characteristics of the caregiver, the care recipient, and other characteristics of the social and physical environments (Zarit & Leitsch, 2001). This chapter discusses the types of caregiver support groups, emphasizing peer- vs. professional-led groups. Research, to date, that has evaluated support interventions for caregivers, including the effectiveness of support groups in general, and a few studies comparing peer- and professional-led support groups are reviewed. The characteristics of successful support group leaders and successful support groups suggested by the research are described. Finally, future education, practice, research, and policy needs to better assist family members who assume a large and increasing share of the care of ill and disabled persons in the United States and in other countries are discussed. Because the preponderance of caregiver support group research is with informal caregivers of persons with dementia, the chapter focuses mainly on the results of the studies of these groups.

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Types of Caregiver Support Groups

A common way of classifying caregiver support groups is by the type of leader: peer- vs. professional-led. A number of factors, however, distinguish different types of caregiver support groups. The type of leader is one means of classifying support groups, but other classifications reveal support group variations that may influence the effectiveness of peer and professional leaders (US Department of Health and Human Services [USDHHS], 2001).

Some caregiver support groups are led by peers, often called self-help groups, some by professionals, and some are co-led by a peer and a professional. Peers are family caregivers who typically have attended a support group and have learned how to lead a group through observation as a participant or by completing formal training. Professional leaders are usually social workers, nurses, or psychologists who may or may not have formal training in support group leadership. Shepherd et al. (1999) argue that professional- vs. peer-led support groups are an artificial dichotomy and that most support groups have variable combinations of peer and professional leaders, representing a continuum from peer-led to professionally led.

A second classification is determined by whether the group is open-ended or closed (not time-limited vs. time-limited) and a third by face-to-face vs. non-face-to-face interaction (telephone, internet, etc.). A fourth classification is by the focus or purpose of the group, including mutual support, education, psychotherapy/counseling, social/recreation, skill enhancement, or discussion, and a fifth is whether the support group interactions are synchronous or asynchronous. Asynchronous interactions among members of a support group may be by telephone, web-based electronic mail, or chat rooms, and are most often also self-help groups with no formal leader. Finally, caregiver support groups are often combinations of one or more of these types. No consistent typology of caregiver support groups exists, however, and clear definitions of types are lacking. Most of the studies of caregiver support groups have not focused on the comparison of peer- vs. professional-led groups. Rather, the outcomes of a single caregiver support group, peer-, or professional-led are evaluated. Thus, prior to reviewing the limited number of studies that have compared peer- and professional-led caregiver support groups, the results of three meta-analyses of caregiver support interventions in general are presented as background.

Background and Relevant Research

Family members care for persons with many chronic illnesses and disabilities, such as cancer, stroke, diabetes, arthritis, injury, and dementia. Although caregiver support groups are a strategy used to relieve the burden and stress of family members who are caring for persons with many illnesses and disabilities, the preponderance of research assessing their outcomes and effectiveness has been conducted with support groups for caregivers of elders with dementia. The results of studies of support groups for caregivers of persons with dementia to date are mixed (Zarit & Leitsch, 2001).

Three meta-analyses are reported evaluating interventions for family caregivers of persons with dementia (Acton & Kang, 2001; Brodaty, Green, & Koschera, 2003; Sorensen, Pinquart, & Duberstein, 2002). An issue, however, is that a limited number of studies were located for the meta-analyses, making it difficult if not impossible to examine the separate effects of many specific types of interventions.

Sorensen et al. (2002) collapsed all caregiver support interventions from seven studies for analysis and found that, taken together, caregiver support interventions reduced caregiver burden and increased caregiver abilities and knowledge. Most of the studies of support groups that were included in the meta-analyses evaluated groups led by a professional.

The work by Brodaty et al. (2003), a meta-analysis of psychosocial interventions for caregivers of persons with dementia, included 30 studies and 34 interventions. Significant positive effects on caregiver psychological distress, caregiver knowledge, patient mood, but not caregiver burden, were identified. Positive effects were more likely if caregivers and care recipients were participants in the intervention. Four of seven studies indicated delayed nursing home admission resulted from psychosocial interventions. The separate effects of caregiver support groups, however, were not reported.

Acton and Kang (2001) evaluated the effects of interventions to reduce the burden of caregiving for an adult with dementia with a meta-analysis of 24 studies and 27 treatments. The effects of support groups, education, psycho-education, counseling, respite, and multicomponent interventions on caregiver burden were assessed. Support groups that were studied were usually led by laypersons with caregiving experiences. No collective effect of the interventions on burden was found and the separate effects of caregiver support groups were not analyzed. Only the multicomponent intervention category of support interventions had a statistically significant positive effect on caregiver burden. The investigators noted that burden may not be the best outcome to use to evaluate the effects of caregiver interventions.

Overall, the literature indicates that both professional- and peer-led caregiver support groups can be successful (Toseland et al., 1990). Support groups led by professionals are usually time-limited and more often include an education component than the peer-led groups. Caregiver burden is the most frequent outcome studied, but some question that burden is the best outcome to measure. Zarit and Leitsch (2001), however, recommend a two-step evaluation, first looking at support group process and second, goals, rather than just outcomes such as burden. They suggest that by assessing process and goals, the evaluation will more accurately determine whether or not the intervention is implemented and the goals of the intervention are achieved, thereby enhancing the interpretation of results and the identification of positive effects on outcomes such as caregiver burden.

Although the meta-analyses of caregiver support interventions do not specifically assist with comparing the effectiveness of peer- and professional-led support groups, some of the results, as well as results of single studies, suggest recommendations for leaders. Most caregiver participants perceived that mutual support and increased knowledge are benefits of support groups (Acton & Kang, 2001; Brodaty et al., 2003; Sorensen et al., 2002). Mutual support was rated highest, and the information about the care recipient's disease and behavior was the second most highly rated benefits of support groups by participants. There is evidence that caregiver attendance of support groups is better when the caregiver is accompanied by the care recipient (Brodaty et al., 2003), when the caregiver has fewer competing demands, more available time, and the support group location is convenient (van den Heuvel, de Witte, Sanderman, Schure, & Jong, 2002). Likewise, support groups that employ more than one strategy (e.g., mutual support, education) have been shown to be most effective (Acton & Kang, 2001), as well as those groups that are designed to address specific caregiver problems, such as depression (Mittelman, Roth, Coon, & Haley, 2004), and those that are not time-limited (Glosser & Wexler, 1985). Some researches indicate that the training and skill of the leader are most important for caregiver support groups' success (Toseland, Rossiter, & Labrecque, 1989; Toseland et al., 1990), although other researches have shown that the content of the groups, rather than the training or type of leader, may have more influence and lead to different outcomes (Lieberman & Bliwise, 1985; Toseland & Rossiter, 1989). Finally, Zarit and Leitsch (2001) argue that the goals and needs of the caregiver–care recipient dyad and the social context of the goals and needs must be considered in the design of all caregiver interventions. In a recent randomized, controlled study of 406 caregivers who were spouses of persons with Alzheimer disease, however, depression, burden, well-being, and delay in institutionalization of the care recipient outcomes were significantly improved for caregivers who received structured counseling along with participation in a caregiver support group compared with caregivers who received usual care of participation in a support group and information about additional resources (Gaugler, Roth, Haley, & Mittelman, 2008; Mittelman, Haley, Clay, & Roth, 2006). While this finding does not lessen the importance of caregiver support groups, it suggests that supports are more effective if combined with structured counseling.

Caregiver Support Group Leadership

Whether or not groups are led by a peer, a professional, or co-led by a peer and a professional, research suggests that some of the keys to effective caregiver support group leadership and success of caregiver support groups are training of the leader, caregiver member participation, and a focus on the member needs (Gonyea, 1989; Molinari, Nelson, Shekelle, & Crothers, 1994). Important functions of the leader are to bring the group together; plan the focus and activities of the group with the caregiver members; prepare a long-term plan for the group; make the necessary arrangements for the group, such as meeting announcements, location, speakers, refreshments, etc.; facilitate mutual support among the members; and summarize as well as reinforce the support and information shared among the members

(Molinari et al., 1994). To facilitate mutual support, it is important that the leader assists members understand current situations, promote an accepting atmosphere and open expression among members, assist members identify and meet their needs, provide and reinforce member coping mechanisms, facilitate member problem solving, and maintain focus on support among members and member learning (Toseland & Rivas, 2012).

Peer leaders are more apt to focus on group needs and are more often motivated by member mutual support (Stewart & Reutter, 2001). They are more likely to need training in group dynamics to prepare for group leadership. There is also more risk that leading a group as a peer will add to their own burden. Peer leaders more often supplement support groups with guest speakers than do professionals (Stewart & Reutter, 2001). On the other hand, professional support group leaders are more apt to be focused on the leader and the leader's goals and more frequently include education and other caregiver interventions in support group activities (Stewart & Reutter, 2001). Although professional support group leaders usually have more resources to assist with planning and conducting caregiver support groups, the groups led by professionals are also more often time-limited rather than those led by peers. Training is important for both peer and professional support group leaders (Toseland et al., 1990). Although it is encouraging that in one survey of 47 support group leaders, Gonyea (1989) found more than one-half (55%) of the leaders, whether peers or professionals, had some amount of training, almost one-half had no training.

Professional and peer co-led support groups have clear advantages over groups led by only a peer or a professional. Research suggests that co-led groups are most effective because the main benefits of each type of leader are enabled for caregiver participants (Chesler, 1991; Miller, 1998; Stewart & Reutter, 2001; Weiss, 1992). In other words, the complementary advantages of both types of leaders are exploited with co-led groups (Stewart & Reutter, 2001). For example, in a study of 21 peer and professional co-led support groups, including groups for caregivers of chronically ill children, elders with cardiac conditions, and a telephone support group for seniors; participants reported that professional leaders "set the tone, monitored group process, and insured that all members were heard; while peer leaders encouraged participation, provided reassurance, and offered information on coping strategies" (Stewart & Reutter, 2001, p. 109). Co-led groups combine the professional leader's motivation to help with the peer leader's mutual support motivation. Co-leadership also blends the peer leader's focus on the group's goals with the professional leader's focus on leader goals. The combined leader motivations and foci emphasize mutual support but also other caregiver support interventions. Although group leadership may vary along a continuum from peer- to professional-led, systematically documented positive relationships between support groups and desired caregiver outcomes are those that involve shared leadership and are supportive, respectful, helpful, egalitarian, and trusting (Banks, Crossman, Poel, & Stewart, 1997; Shepherd et al., 1999; Weiss, 1992).

Future Needs

Education

There is need to train professional and peer support group leaders; however, there are no data available to identify the difference in the needs of the two types of leaders (Price, Butow, & Kirsten, 2006). Peer leaders are most apt to have no specific training and lead groups mostly based on their own experiences as a caregiver and as a prior participant in a caregiver support group. Sharpe, Koerber, Macera, and Euster (1996) tested a training program for peer group leaders and found improvements in knowledge, communication skills, their conceptualization, and satisfaction with the group leader's role. Likewise, professional caregiver support group leaders may not have specific leader training despite a more likely foundation in group dynamics and leadership theory. Programs are needed that offer training for both types of support group leaders and to prepare leaders for support groups that have different purposes. There is also a need to train leaders for different types of support delivery, including how technology (telephone, internet) can be used to expand or enhance access to support and support groups for caregivers. In addition, nurse, social work, psychology, and gerontology educators should be sure to include the most current research evidence regarding the efficacy and effectiveness of caregiver support interventions in their curricula, as well as an emphasis on peer–professional partnership roles (Hughes, 2000), mutual support principles (Simpson, 1996), and collaborative problem solving (Stewart & Reutter, 2001). For all types of caregiver support group delivery (traditional face-to-face, technology-assisted face-to-face, or technology-assisted non-face-to-face), training of leaders must prepare them to clarify the purpose and objectives of support groups, the responsibilities of participants, and the selection and sequencing of discussion topics. Leaders should also be trained in strategies for handling issues that arise during group process, documentation of the support process, and in assisting participants who require more support than is offered by the group. Training in how to optimize the complementary roles of peer and professional leaders is also important to realize the added participant benefits of co-led groups. Finally, training that includes detailed acquaintance with common caregiver stressors, stress responses, and coping strategies; assistance with the preparation of topical session outlines, case studies for discussion, resource manuals, and administrative tasks; and the operation of technologies are recommended (Stewart & Reutter, 2001). Clearly, there is need for an evidence base for group leader training (Price et al., 2006).

How and by whom training of support group leaders can be funded and offered is an important question. In addition to the Alzheimer Association that provides some training, Area Agencies on Aging might also offer support group leadership training. Offering training through community colleges and vocational area schools could also be explored. Many universities with health science schools have externally funded centers for geriatric education of professionals that could offer training programs for support group leaders. In addition to including such training in the formal preparatory programs of nurses, social workers, and psychologists, these programs might as well offer support group leadership training for continuing education credit.

Practice

Current research, though limited, indicates that professional–peer co-led support groups may be preferred by family caregiver participants and have advantages over groups led by either a professional or a peer alone (Toseland & Rivas, 2012). In view of these advantages and the increasing emphasis on professional and client partnerships, providers are encouraged to adopt the co-led caregiver support group model when possible; augment their support group leadership and collaboration skills training, if needed for successful implementation of co-led support groups; prepare peers for long-term support group leadership; and document the outcomes (Courtney, Ballard, Fauver, Gariota, & Holland, 1996; Stewart & Reutter, 2001; Tse, Doughty, & Bristol, 2004).

Use of technology by providers and professionals to extend caregiver support is promising. Current technology can enable social support with face-to-face contact for family caregivers separated by any distance (Czaja & Robert, 2002; Hanson, Tetley, & Clarke, 1999; Morrow-Howell, Mahoney, Tennstedt, Friedman, & Heeren, 1999; Wright, Bennet, & Gramling, 1998). Caregiver support groups can also be organized so that persons in any number of locations can participate through the use of web-based or telecommunication technology that is now available (Czaja & Robert, 2002; Galegher, Sproull, & Kiesler, 1998; Mahoney, Tarlow, & Jones, 2003; Smith & Toseland, 2006; Wright et al., 1998). There is also recent evidence of positive outcomes when caregivers communicate and offer support via e-mail or internet chat rooms, even though the caregivers' communications are asynchronous and there is no formal leader (Brennan, Moore, & Smyth, 1995; Galegher et al., 1998; White & Dorman, 2000). Advantages perceived by caregivers and reported by Colvin, Chenoweth, Bold, and Harding (2004) are anonymity, asynchrony, and the ability to personalize use. Perceived disadvantages reported by the caregivers were limitations and frustrations of computer use.

Specialized support groups, e.g., depression, behavior strategies, etc., are recommended and are assumed to have greater benefits than when groups are composed of caregivers of individuals with diverse diagnoses (Wilson, Flanagan, & Rynders, 1999). Most research has examined the benefits of caregiver support groups that are specialized, such as support groups for caregivers of persons with dementia, with both female and male caregivers participating. Support groups for men are increasing, but there is minimal systematic research that has documented their effects compared with the effects of groups composed of males and females (Tsey, Patterson, Whiteside, Baird, & Baird, 2002). Caregiver support research that includes larger numbers of males and analysis by gender is needed (Houde, 2002). The caregiving experience of men needs further description, including their use or lack of use of support group interventions (Pierce & Steiner, 2004). Several advantages of specialized support groups are usually noted. The greater amount of support among participants due to increased common focus is most often documented. In addition, the ability of leaders to facilitate support and educate participants in more depth about issues and challenges associated with caring for persons with the same diagnoses, more shared understanding among participants of the need for support, and more willingness to give support to others are reported. In specialized support groups, positive benefits of information, affirmation, emotional, and instrumental support are mediated by social comparison, social exchange, and social learning (Stewart, Davidson, Meade, Hirth, & Weld-Viscount, 2001).

Whatever strategy is chosen to optimize caregiver support and interventions, it is important that providers (e.g., physicians, nurses, social workers, psychologists and so on) adopt caregivers as clients (Buckwalter & Hall, 1987; Stewart et al., 2001). Too often the emotional, physical, and social needs of the family caregiver are overlooked as attention is focused on the needs of the care recipient. It seems reasonable that professionals assess the needs of the family caregiver and prescribe interventions to promote health and prevent or treat illnesses. The focus of more providers on the caregiver–care recipient dyad will be increasingly needed if family caregivers are to assume optimal caregiving responsibility and prevent or forestall institutionalization of care recipients.

Research

Caregiver support research to date has been mostly with participants who are caregivers of persons with dementia, although studies of support for caregivers of persons with other chronic conditions have increased in recent years. In the review of literature, only three meta-analyses of caregiver support intervention studies were located and each included a small number of studies (Acton & Kang, 2001; Brodaty et al., 2003; Sorensen et al., 2002). The results of reported studies tend to be mixed and indicate a need for more systematic studies that test the effects of caregiver support interventions, including support groups that are led by a peer or a professional. Several issues are apparent from the review of current research regarding peer- vs. professional-led support groups.

A fundamental issue is taxonomic. Clarification of concepts and terms, their definitions, and measures would facilitate future research and advantage the accumulation of evidence to support practice. More attention to describing the process and goals of interventions in the design and methods of studies, such as suggested by Zarit and Leitsch (2001), is recommended.

The comparative outcome effects of different types of support interventions (mutual support, education, support group, and their combinations); delivery of support groups (traditional and technology-assisted face-to-face), leaders (professional-, peer-, and co-led), and leadership strategies (directive, delegated, participative, and laissez-faire) are mostly not known. Future research should emphasize the comparison of outcome benefits of the variety of support intervention approaches and describe the circumstances that motivate caregivers to seek and participate in support groups and other support interventions.

If caregiver support groups, peer- or professional-led, are to serve optimally, the diversity of caregivers must be taken into account, including those of persons with early dementia. Regardless of who is leading the groups, there are concerns about the lack of diversity and the lack of depth of emotional support for individuals (Gonyea, 1989). Participants of dementia caregiver groups are primarily Caucasian and middle class (Monahan, Greene, & Coleman, 1992). Although participants in one study felt they received support, they reported not receiving emotional support for difficult personal problems even when there was a trained profession leader of their group (Gonyea, 1989; Toseland et al., 1990). Thus, there is need to emphasize the inclusion of more men and minorities and the recruitment of more caregivers of persons in the beginning stages of dementia in support group and other support intervention studies. Support group leaders may need to attend more to the identification of caregivers who have severe emotional difficulties in order to obtain the support that is needed to prevent further stress and potentially serious illness.

Caregiver and societal outcomes also merit further research. Studies are needed that explore and document the caregiver outcomes that are most sensitive to specific interventions, including types of caregiver support groups. Examples of outcomes that are of interest are caregiver coping, depression, physical health, the type and amount of support gained by the caregiver, physician and hospital visits by the caregiver and care recipient, and relocation of the care recipient to a long-term care facility. Care recipient's emotional, physical, and functional outcomes and delay in institutionalization are also significant outcomes to assess. Costs of delivering interventions also need to be measured and evaluated in conjunction with their effectiveness, as well as the costs of care for the care recipient in an institution (Peak, Toseland, & Banks, 1995). The potential differential effects of support strategies for caregivers in varying age, gender, ethnicity, and other demographic groups, such as those caring for their own children vs. those with no childcare responsibility, also are important to evaluate outcomes and accurately inform practice and policy.

Policy/Advocacy

A critical policy need is to increase funding of caregiver support intervention research. Collaboration among state voluntary, advocacy organizations (e.g., American Association of Retired Persons (AARP), Alzheimer's Association (AA), National Caregiver Alliance (NCA) to promote funding of caregiver support programs, support group leader training, and research is recommended (Wolf, 2001). Eighty percent of care is now provided by families and will increase during the next several decades as the proportion of elders and persons with chronic illnesses in the population enlarges (Feinberg et al., 2003). Additional funds for caregiver support programs (e.g., support groups, support group leader training, respite) and for the reimbursement of caregiving by diverse populations of family members are deserving. Forestalling institutionalization is a worthy outcome for the care recipient, family, caregiver, and the public.

Summary

Research testing the outcomes of peer- vs. professional-led caregiver support groups is limited, and the results are mixed. The results of reported research, however, suggest that professional- or peer-led support groups are successful if the leader is well trained. Current research also suggests that professional–peer co-led support groups have advantages over groups led by either a professional or a peer alone. Combined with the increasing emphasis on professional provider–client partnerships, these additional advantages encourage the adoption of a co-led support group model. Further research is needed to evaluate the outcome advantages compared to those of professional- or peer-led groups. Future research to compare the outcomes of different types of support interventions and types of delivery for age, gender, ethnic, and other subgroups of caregivers and care recipients is also required to adequately inform practice and policy. Ultimately, advocacy for funding to enable more caregiver support research and funding of family caregiver services and support programs is the most pressing need.

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Chapter 7
Telehealth and Family Caregiving: Developments in Research, Education, Policy, and Practice

Robert L. Glueckauf and La Tonya Noël

One of the most exciting developments in the field of telehealth has been the use of telecommunication technologies to provide health information, education, and support to family caregivers of individuals with chronic illnesses. Telehealth has been defined as the use of telecommunications and information technologies to provide access to health information and services across a geographical distance, including (but not limited to) consultation, assessment, intervention, and follow-up programs to ensure maintenance of treatment effects. Internet, point-to-point videoconferencing, e-mail, telephone, biosensor, and virtual reality interactions between providers and family caregivers are all subsumed under the definition of telehealth (Glueckauf & Ketterson, 2004; Glueckauf, Pickett, Ketterson, Loomis, & Rozensky, 2003).

Recent epidemiological studies have estimated that between 22 and 27 million persons provide caregiving assistance to family members, a number expected to increase to 39 million by 2010 (Alzheimer's Association/NAC, 1999). Caregiving requirements may vary depending on the age of the care recipient and the severity of the disability, as well as the resources available to the caregiver. These tasks typically include monitoring and providing assistance in hygiene and self-care activities, managing complex medication and dietary regimens, organizing transportation, and managing care recipient problem behavior (i.e., problems with treatment adherence and aggressive responding). Unfortunately, such intensive home care activities are performed at high cost to caregivers in terms of their physical, financial, and psychological resources. Caregivers of children and adults with disabling illnesses may experience significant restrictions of social activities, disrupted family relationships, as well as deterioration in physical and mental health (e.g., Haley, Levine, Brown, & Bartolucci, 1987; Schulz & Quittner, 1998).

In an effort to address these significant psychosocial and health concerns, government agencies, private health-care facilities, as well as community and faith-based organizations have developed a wide range of respite, assisted living, day

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care, and support programs for persons with disabling chronic illnesses and their caregivers. Several states have established outreach programs that provide training materials to family caregivers and help to mobilize volunteer networks offering respite care and emotional support (The Older Americans National Family Caregiver Support Program, 2004). The State of Florida, for example, funds 15 memory disorder clinics that provide diagnostic services and family caregiver education, four model day care programs, and respite services (Department of Elder Affairs, 2011). Private health-care organizations, such as the national Alzheimer's Association, provide family caregivers basic information about dementia care, wandering ID programs, and support groups through their local chapters across the country (Alzheimer's Association, 2011). Churches and service clubs in a number of communities across the country also have created day care programs, educational forums, and informal telephone buddy networks for adults with chronic illnesses and their family caregivers (e.g., Project ShareCare, 2010).

Although these organizations have offered a variety of assistive care and residential services for individuals with chronic disabilities and their families, the gap between caregiver needs and available services continues to grow, particularly in the areas of health promotion, stress management, and lifestyle enhancement. Most agencies serving persons with chronic illnesses have only limited financial resources, small professional staffs, and cover broad geographical regions. By necessity, the majority of their services have focused on providing medical diagnostic exams, home care assistance, adult day care, and respite. As a consequence, expert consultation on stress management, caregiving techniques, and lifestyle enhancement for caregivers continues to be difficult to obtain, expensive, and in certain portions of rural America, nonexistent (Glueckauf & Loomis, 2003; Stamm, 2003; Wade & Wolfe, 2005).

Fortunately, recent advances in telehealth may provide an alternative vehicle for meeting the needs of family caregivers for information, education, and support not readily available in their local communities. Family caregivers are increasingly turning to the Internet and other computer-based resources (e.g., DVDs, automated telephone systems, and computerized kiosks) for information about their loved ones' medical condition and for strategies to enhance their coping skills and emotional well-being (Glueckauf, Ketterson, Loomis, & Dages, 2004). The potential role of telehealth in supporting family caregivers has also permeated the thinking and, in certain cases, the strategic planning, of policy makers in the federal government and national health organizations. Although the Centers for Medicare & Medicaid (CMS) has been slow to reimburse for home-based telehealth services to individuals with chronic illness and their family caregivers, several organizations (e.g., Alzheimer's Association) currently offer Internet- and telephone-based education and support to a variety of caregiver populations (Glueckauf, Pickett, Ketterson, Nickelson, & Loomis, 2003). Furthermore, federal and state cost-containment policies over the past decade have favored the development of home-based alternatives (e.g., use of the Health Buddy for VA patients with chronic illnesses) for long-term care (Huddelston & Kobb, 2004; Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000), thus setting the stage for future subsidized caregiver programs to ensure the sustainability of such initiatives.

The primary objectives of the present chapter are to (a) summarize research findings on the outcomes of telehealth interventions for family caregivers of persons with chronic illnesses, (b) describe the need for, and current barriers in, obtaining technology education and training for family caregivers, and (c) outline recent developments in telehealth policy and practice, particularly legislation to expand federal and state reimbursement for telehealth services. Future directions for telehealth and family caregiving are addressed in each of the three major sections of the chapter.

Current Research on Telehealth and Caregiver Intervention

Review methodology: Procedures and inclusionary criteria. First, a PubMed electronic database search was performed to assemble a pool of outcome studies on telehealth interventions for caregivers of individuals with chronic illnesses. The specific descriptors used in the literature search were as follows: caregiver, family caregiver, caregiving, family training, parent training, telehealth, telemedicine, teleconferencing, technology, Internet, online, telephone, and videoconferencing. This search yielded 150 citations. Next, a second electronic database search was performed using CSA Illumina which combined two smaller search engines (PsycINFO and Medline). The same search terms were used for both searches. The second search yielded 331 citations (see Fig. 7.1).

Studies included in the review were required to meet two major criteria: (1) evaluation of the effects of telecommunication-mediated intervention on the emotional, physical, and psychosocial functioning of family caregivers, and (2) incorporation of at least one comparison condition. The time frame for both database searches was 1997–2008. After careful review of all the citations, a total of 25 outcome studies met the final inclusion criteria (see Table 7.1).

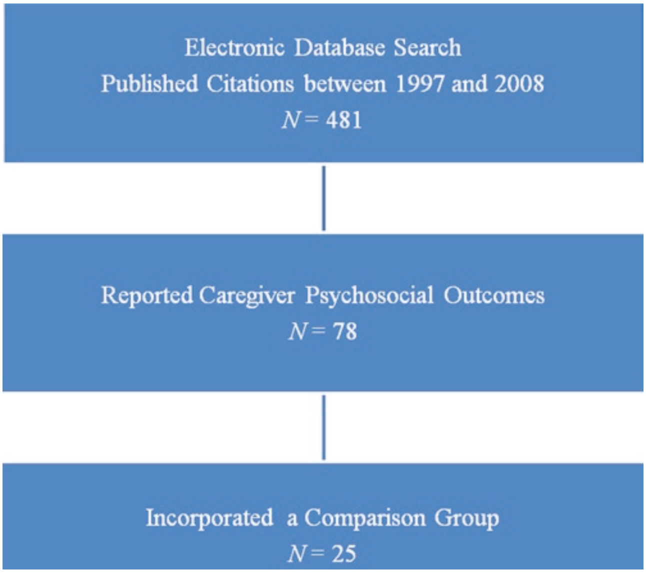

Fig. 7.1 Flowchart of electronic database search on telehealth and family caregiver interventions, 1997–2008

Table 7.1 Summary of telehealth interventions for family caregivers of persons with chronic illnesses

Authors	Modalities	Caregiver group	Design	Main findings
Beauchamp, Irvine, Seeley, and Johnson (2005)	Worksite-based Internet vs. waitlist control	Family CGs of older adults with dementia	RCT	Participants ($N=299$) were family caregivers of older adults with dementia. Study used an innovative distance work-site based intervention to evaluate its effectiveness on reducing dementia CGs' stress, strain, depressive symptomatology, and state anxiety, as well as self-efficacy and intention to gain support. The intervention group ($n=150$) reported significantly lower levels of stress, strain, depressive symptoms, and state anxiety than those of the control group ($n=149$). In addition, intervention participants showed statistically significant improvements in CG self-efficacy, and intention to gain support than their waitlist counterparts
Brown et al. (1999)	Telephone vs. f-to-f groups	CGs of patients with ABI	Quasi-experiment	ABI CGs participated in 1 of 10 telephone groups (TG; $n=52$) or 1 of 10 on-site groups (OG; $n=39$). Similar improvement was found across all outcome measures for OG and TG groups. Rural CGs reported fewer difficulties on all measures at each measurement interval than urban CGs. Both groups showed statistically significant improvement in emotional well-being and a trend toward improvement in family functioning. Participants from both groups rated their experience within the highly positive range, although rural CGs were somewhat more satisfied than urban CGs
Campbell et al. (2007)	Telephone-based couples skills training (CST) vs. usual care	Prostate cancer survivors and CGs	RCT	Couples were randomized to either telephone-based CST or usual care coordination services. Partners in the CST study arm reported less CG strain, depression, and fatigue as compared to the control participants
Connell, Sanders, and Markie-Dadds (1997)	Self-directed, behavioral parent training program plus telephone consults (SD) vs. waitlist group (WL)	Rural preschool children with clinically significant behavior problems and parents	RCT	Twenty four parents and their children participated in this behavioral intervention. The SD group ($n=12$) reported significantly greater improvement on measures of child behavior problems than the WL group ($n=12$). In addition, SD mothers reported lower levels of anxiety, depression, and stress as compared to WL mothers

Davis, Burgio, Buckwalter, and Weaver (2004)	Telephone, in-home, or friendly call (comparison group)	Family CGs and dementia care recipients (CRs)	RCT	CG and CR dyads ($n=71$) were randomly assigned to one of three conditions: Telephone training (TT), in-home training (IT), or a friendly-call comparison group (FC). IT participants showed reduced burden and distress at the 12-week follow-up and maintained their gains at the second 12-week follow-up. TT participants showed significantly reduced burden and distress at the second follow-up only. FC participants showed reduced CG burden and distress at the first 12-week assessment, but the effects dissipated at final follow-up
Dew et al. (2004)	Web-based plus usual services vs. usual services only	CGs and CRs with heart transplants	Quasi-experiment	Treated participants ($n=20$ dyads) received 4 months of web-based psychosocial training plus usual care. Control participants ($n=20$ dyads) received usual services only. CRs in the web condition reported significantly greater improvement in depression and anxiety as compared to CRs in usual care. Web CGs reported significantly greater declines in anxiety and hostility than usual care controls. No differences were found in medical compliance between groups
Eisdorfer et al. (2003)	Computer-based telephone vs. minimal education and support	Alzheimer's CGs	RCT	CGs in the combined family therapy and computer-based telephone intervention ($n=52$) showed significantly greater reductions in depressive symptoms at 6 months compared to CGs in the minimal educational and support condition ($n=41$)
Finkel et al. (2007)	Computer based-telephone vs. information only control	Dementia CGs	RCT	Family CGs of older adults with dementia were randomly assigned to computer-based telephone (CT) ($n=23$) or to information only ($n=23$) for 6 months. CT CGs reported significantly greater improvements in depression, bother with CR and social support as compared to information-only control participants

(continued)

Table 7.1 (continued)

Authors	Modalities	Caregiver group	Design	Main findings
Gant, Steffen, and Lauderdale (2007)	Videotapes plus telephone coaching vs. routine education and check-in calls	Male family CGs of dementia	RCT	Thirty-two male CGs were randomly assigned to a combined videotaped caregiver skills training plus telephone coaching ($n=17$) or to a routine education and check-in control condition ($n=15$). Study outcomes included CG self-efficacy, negative and positive affect, as well as CG upset/annoyance ratings. Both conditions produced significant differences over time on all three outcome measures. However, no differential positive benefits were noted for the combined video plus coaching condition
Glueckauf et al. (2002)	Point-to-point videoconferencing, telephone, and f-to-f family therapy	Rural teenagers with uncontrolled epilepsy and their parents	RCT	Teenagers and parents reported significant reductions in both problem severity and frequency across all three conditions ($n=36$) from pre- to posttreatment to the 6-month follow-up. Parents reported significant increases in prosocial behaviors from pre- to posttreatment to follow-up. In contrast, both parents and teachers reported no change in problem behaviors over time. No differences in adherence were found across the three modalities
Glueckauf et al. (2007)	Telephone-based cognitive-behavior therapy (CBT) vs. minimal education and support (ES)	CGs of rural adults with dementia	RCT	Seventeen CGs were randomly assigned to either telephone-based CBT ($n=14$) or an ES control group ($n=3$). No differences were found between groups on CG subjective burden and depressive symptoms. In contrast, CBT CGs reported significant improvements in self-efficacy for respite care needs and in managing CR disruptive behaviors as compared to ES CGs
Grant (1999)	Telephone (T), in-home visits (IH) vs. control group	Family CGs of stroke survivors	Quasi-experiment	Thirty CGs were assigned to 1 of 3 conditions: IH, T, or a control group. The IH and T groups took place over seven sessions. Outcomes were compared at week 2 and 5 and 13 weeks postintervention. The telephone group reported significantly greater improvements in depression, problem-solving skills, and CG preparedness at week 5 as compared to the control group. However, these gains were not maintained at the 13-week follow-up

Grant, Elliott, Weaver, Bartolucci, and Giger (2002)	Telephone problem-solving (TPS) vs. sham control (SC) vs. routine care (RC) control group	Family CGs of stroke survivors	RCT	Seventy-four CGs participated in this three-arm study. Compared with the SC and RC groups, TPS CGs showed significantly greater problem-solving skills, caregiver preparedness, vitality, social, functioning, mental health, as well as concomitant significant declines in depression and role limitations related to emotional problems. There were no significant differences among groups on caregiver burden
Gray et al. (2000)	Internet (Baby CareLink) plus routine neonatal intensive care (NICU) vs. routine NICU	Very low birth weight children CGs	RCT	Baby CareLink families ($n=26$) reported higher overall quality of care than routine care families ($n=30$). They also reported significantly fewer problems with the overall quality of care received by their family versus routine care. In addition, Baby CareLink families also reported greater satisfaction with the NICU's physical environment and visitation policies. However, the duration of hospitalization was similar between the two groups
Hartke and King (2003)	Telephone psychoeducation vs. written materials plus usual support	Spousal CGs of stroke survivors	RCT	Eighty-eight participants were randomized to either eight-session telephone psychoeducation (TP) or usual care (UC). TP CGs were assessed after group assignment and at two follow-up points postintervention. UC CGs were assessed after group assignment at one follow-up point only. No group differences were found for changes in depression, loneliness, or stress. However, UC CGs showed significantly greater improvements on burden, whereas TPs showed significantly greater gains in competence
Hauber and Jones (2002)	Videophone vs. standard care	CGs of individuals with ABI with prolonged unconsciousness	Quasi-Experiment	Participant families ($n=5$) were followed for 4–8 weeks via videophone for support and training after rehabilitation. Follow-up telephone surveys were conducted with a family member 6–9 months after discharge and compared with a standard care group ($n=4$). More persons with ABI in the videophone group were living at home and had returned for rehabilitation at follow-up than standard care persons with ABI. In addition, families in the videophone group reported more of their needs being met than those in the comparison group

(continued)

Table 7.1 (continued)

Authors	Modalities	Caregiver group	Design	Main findings
King, Baumann, O'Sullivan, Wilcox, and Castro (2002)	Home-based telephone exercise (TE) vs. attention-control nutrition education (NU)	CGs of older adults with dementia	RCT	Compared with NU CGs ($n=49$), TE CGs ($n=51$) showed significantly greater improvements on total energy expenditure, stress-induced blood pressure reactivity, and systolic blood pressure reactivity. In contrast, NU CGs showed a greater decline in total calories from fats and saturated fats relative to TE. Both groups reported declines in psychological distress
Kozachik et al. (2001)	Nurse follow-up plus telephone (5 f-to-f and 4 telephone nurse visits) vs. usual cancer care	CGs of patients with cancer	RCT	No significant posttreatment differences were found for CG depressive affect between telephone plus nurse follow ($n=61$) and usual care ($n=59$)
Krishna et al. (2003)	Internet + routine asthma education vs. routine asthma education	Children with asthma and CGs	RCT	Interactive Multimedia Program for Asthma Control and Tracking (IMPACT) CGs ($n=119$) showed significantly increased asthma knowledge of children as compared to routine educational controls ($n=127$). IMPACT CGs also made significantly fewer emergency department visits than usual care CGs. In addition, IMPACT group children used significantly lower average daily doses of inhaled corticosteroids than the control group at the 12-month follow-up
Mahoney, Tarlow, & Jones, 2003	Computer-based, interactive voice response (IVR) telephone intervention vs. routine education and support	Alzheimer's CGs	RCT	Participants were randomly assigned to IVR skills training and support ($n=49$) or routine support ($n=51$). CGs with low mastery at initial assessment experienced a significantly greater decline in bother with CR, depressive symptoms, and anxious complaints than routine support CGs at the 18-month follow-up. There were no significant differences on changes in these outcomes between the telephone and usual support for CGs with high mastery at initial assessment
Marziali & Donahue, 2006	Internet videoconferencing vs. no intervention control	Family CGs of older adults with Alzheimer's disease, vascular dementia, and Parkinson's disease	RCT	Sixty-six CGs were randomly assigned to either an Internet-based psychosocial intervention ($n=33$) or a no-treatment control group ($n=33$). The intervention consisted of 10 Internet-based manualized group sessions followed by 12 additional online peer-led support groups. The Internet group reported a significant decline in perceived stress at posttreatment. In contrast, the control group endorsed an increasing pattern of perceived stress over time

Rivera, Elliott, Berry, & Grant, 2008	Home-based telephone problem-solving skills training vs. home-based telephone education only	Family CGs of persons with TBIs	RCT	TBI CGs were randomly assigned to a telephone problem-solving training group (PST; $n=33$) or telephone education only control group (EO; $n=34$). PST CGs received four in-home problem-solving training sessions and eight telephone follow-up training calls. EO CGs received telephone calls at preset intervals that were education-only calls. The PST group showed a significantly greater decrease in depression, health complaints, and dysfunction problem-solving styles as compared to the EO group. No group differences were observed on changes in CG overall well-being and burden
Smith & Toseland, 2006	Telephone support vs. usual care	Adult child and spouse CGs of frail older adults	RCT	Ninety-seven CGs of older frail adults were randomly assigned to either a telephone support or a usual care control group. Telephone support was significantly more effective than usual services in reducing burden, depression, and pressing problems as well as increasing social support and knowledge of community services for adult child CGs. In contrast, no significant posttreatment group differences were found on these variables for spouse CGs
Sneed, Finch, & Michel, 1997	Telephone counseling and support vs. routine care	Adults with implantable cardioverter defibrillators (ICDs) and CGs	RCT	Thirty-four adult ICD recipients and their significant other CGs were randomly assigned to a telephone counseling ($n=17$) or routine, postoperative care ($n=17$). The intervention consisted of weekly, telephone follow-up, evaluation, and counseling by a psychiatric liaison nurse, and participation in an ICD support group. There were no significant differences between treatment and control groups on target measures of adjustment
Winter & Gitlin, 2007	Telephone vs. usual care control group	Female dementia CGs	RCT	Female dementia CGs were randomly assigned to either telephone support ($n=58$) or a usual care control group ($n=45$). No statistically significant differences were found between groups on the main outcome variables. However, older caregivers (≥65 years of age) in telesupport reported significantly lower depression than older CGs in the control group

RCT randomized controlled trial; *CG* caregiver; *vs.* versus; *f-to-f* face to face; *ABI* acquired brain injury; *TBI* traumatic brain injury *WL* waiting list

As shown in Table 7.1, the large majority of telehealth outcome studies (21 of 25) used true experimental designs (i.e., random assignment to condition and the inclusion of at least one control group); the remaining four studies used a nonequivalent control group design (i.e., inclusion of at least one control group with nonrandom assignment to conditions). Fifteen telehealth interventions relied on standard telephone technology to deliver treatment services; the remaining 10 used computer-based telephone ($n=3$), Internet, or Web with standard desktop computers ($n=5$), videophone over standard telephone lines ($n=1$), and desktop videoconferencing over Integrated Service Digital Network lines ($n=1$).

Current Findings of Telephone-Based Caregiver Interventions

Evaluations of the efficacy of telephone-based interventions represent the majority of outcome studies performed with family caregivers (Glueckauf & Ketterson, 2004; Toseland & Rivas, 2005). Despite the limitations of this modality (e.g., unable to view body gestures), telephone continues to be the most widely available and least expensive technology for delivering health information and support to family caregivers (Smith, Toseland, Rizzo, & Zinoman, 2004). This is especially the case for telehealth applications in rural areas, where the Internet and other digital technologies (i.e., point-to-point videoconferencing) have been slow to penetrate (Glueckauf et al., 2005).

As shown in Table 7.1, the most common therapeutic approach used across the 18 telephone studies [i.e., those that used either standard ($n=15$) or computer-based telephone interventions in at least one intervention arm ($n=3$)] was psychoeducation ($n=15$). In the three remaining telephone studies, one intervention used a family systems approach, one focused on behavioral modification, and one used exercise and nutrition counseling.

The overall findings of the telephone-based interventions supported the efficacy of this alternative mode of health-care delivery in improving the emotional and physical well-being of family caregivers. Thirteen of eighteen telephone-based outcome studies (Campbell et al., 2007; Connell et al., 1997; Davis et al., 2004; Eisdorfer et al., 2003; Finkel et al., 2007; Glueckauf et al., 2007; Grant, 1999: Grant et al., 2002; King et al., 2002; Mahoney et al., 2003; Rivera et al., 2008; Smith & Toseland, 2006; Winter & Gitlin, 2007) reported significantly greater improvements on key caregiver health and psychosocial outcomes (e.g., improved sleep, decreased psychological distress and depression, or improved social functioning and caregiver confidence) from pre- to posttreatment and/or at follow-up as compared to routine care and education or a waiting-list control group. Satisfaction with both standard and computer-based telephone approaches was also found to be high across different caregiver populations (e.g., Alzheimer's disease, acquired brain injury, and epilepsy). In contrast, four studies (Gant et al., 2007; Hartke & King, 2003; Kozachik et al., 2001; Sneed et al., 1997) found no significant differential benefits for either telephone intervention over education or routine care for caregivers of adults with cancer, dementia, and cardiac disorders (i.e., patients with implantable cardiac defibrillators). In the one telephone study comparing telephone and face-to-face intervention, Brown et al. (1999) found significant positive and equivalent outcomes across both modalities, further reinforcing the efficacy of telephone-based psychoeducational intervention.

The primary limitations of the telephone-based intervention studies were the confounding of telehealth modality and type of treatment, and the use of small sample sizes. First, three studies (i.e., Connell et al., 1997; Grant et al., 2002; Mahoney et al., 2003) tested the effects of telephone-based treatment against control conditions that used different therapeutic intervention methods. For example, Grant et al. (2002) compared the effects of telephone-based problem-solving training against two treatment alternatives (i.e., telephone brief support only and standard face-to-face nursing care). A face-to-face problem-solving control group in which family caregivers received in-person, one-on-one, problem-solving training was not incorporated into Grant et al.'s (2002) research design. Thus, the effects of delivering problem-solving treatment over the telephone could not be directly compared to those obtained in traditional face-to-face problem-solving therapy. Although Grant et al. (2002) reported significantly greater posttreatment reductions in depressive symptoms for participants in telephone-based problem-solving training than for those who received face-to-face nursing care, causal conclusions about the efficacy of telephone-based problem-solving were substantially weakened. Posttreatment gains in the problem-solving condition may have been attributable either to the effect of transmission modality (telephone vs. face-to-face treatment) or to differences in the type of treatment (problem-solving training vs. standard nursing care). A similar confounding of delivery modality and type of treatment occurred in Connell et al. (1997) and Mahoney et al.'s (2003) studies.

Future Research on Telephone-Based Caregiver Intervention

To advance our knowledge about the therapeutic benefits of telehealth, future research should test the differential effects of telephone-based versus face-to-face intervention. Note that one study in the present review provided preliminary evidence supporting the equivalence of effects between these two delivery modes. In a head-to-head comparison between telephone-based and face-to-face caregiver interventions (i.e., those that varied only the mode of transmission across conditions), Brown et al. (1999) found positive and equivalent gains in psychosocial outcomes between telephone and face-to-face interventions for caregivers of family members with acquired brain injuries.

Turning to sample size considerations, the number of caregivers who participated in the previous telephone studies was small, thus reducing the strength and reliability of the overall results. Large, multisite randomized trials that target different caregiver populations are needed to ameliorate this limitation. It is essential that these studies are adequately powered to permit comparisons among different telehealth modalities across time, different participant populations, and different geographic locations.

Current Findings of Videoconferencing-Based Caregiver Interventions

Although a large number of web and telephone-based videoconferencing initiatives have been launched to address the educational and support needs of family caregivers of people with chronic illnesses, there are currently only a few controlled studies evaluating the efficacy and perceived utility of these modalities. As technology-savvy baby boomers become increasingly involved in caring for their parents, interactive video, particularly web-based videoconferencing, is likely to become the preferred medium for obtaining caregiver information and support. The overall pattern of results in this section of the review (Beauchamp et al., 2005; Dew et al., 2004; Glueckauf et al., 2002; Gray et al., 2000; Hauber & Jones, 2002; Krishna et al., 2003; Marziali & Donahue, 2006) suggested that videoconferencing holds considerable promise as an alternative to standard caregiver face-to-face intervention. The majority of these studies relied on web-based technology ($n = 5$), one used videophones with standard telephone lines, and the remaining study used Integrated Services Digital Network videoconferencing. All seven videoconference studies used some form of psychoeducational intervention to enhance caregiver functioning and quality of life. The findings of four representative web-based videoconferencing studies are highlighted below.

First, Beauchamp et al. (2005) employed a worksite-based clinical trial of a web-based program, known as “Caregiver’s Friend: Dealing with Dementia,” to enhance coping skills and to reduce negative caregiver psychosocial outcomes. Dementia caregivers were assigned randomly either to the web-based psychosocial intervention or to a waiting-list control group. Beauchamp and associates found that individuals in the intervention group reported significantly greater self-efficacy and intention to gain support for their caregiving efforts than waiting list control participants. In addition, web caregivers reported significantly greater reductions in depressive symptoms and anxiety than their control group counterparts.

Second, Gray et al. (2000) conducted a randomized study of the effects of an innovative Web-based neonatal care program, known as “Baby CareLink,” on the quality of care of high-risk infants at Beth Israel Deaconess Medical Center in Boston, Massachusetts. Within 10 days of birth, family caregivers (i.e., parents) of very low birth weight infants were randomly assigned to either Baby CareLink plus routine neonatal intensive (NICU) care ($n = 26$) versus routine NICU care ($n = 30$). The Baby CareLink intervention was carried out in two consecutive phases: (1) hospitalization and (2) post-discharge. During hospitalization Baby CareLink provided virtual baby visits (i.e., “See Your Infant” program), daily clinical reports, a confidential message center between parents and hospital staff, and distance education for family members. Following discharge from the NICU, the Baby CareLink program offered virtual “house calls” from hospital and community-based providers, remote monitoring of the infant’s health, a “family room” option that provided answers to common questions, and information about services and resources. Control group families received standard treatment at the NICU. Gray et al. found that the average rating of quality of care was significantly higher for the Baby CareLink families than that for routine treatment controls. CareLink families also endorsed significantly fewer problems with hospital care, the neonatal care physical environment, and visitation policies than did the control group. Furthermore, all infants in the CareLink program were discharged directly to home, whereas 6 of 30 control group infants were transferred to their referring Level II hospital facilities before they were finally discharged to their homes. Gray et al. (2000) asserted that discharge directly to home led to significant cost reductions in the BabyCare Link condition. However, insufficient evidence was provided to substantiate this conclusion.

Third, Marziali and Donahue (2006) randomly assigned 66 family caregivers of adults with neurodegenerative disease to one of two conditions: (1) web-based psychosocial intervention, or (2) a no intervention control. Web participants received computers and computer training. The Internet-based intervention was grounded in a lifespan approach for understanding variations in behavioral expressions in adult caregivers and consisted of 10, 1-hour web-based videoconferencing sessions. The intervention groups were subsequently divided into disease-specific smaller groups each of which included 4–6 participants. Outcome measures were taken at baseline and at 6 months follow-up. The intervention group showed a significant decline in overall psychosocial stress, whereas the control group data reported an increasing pattern of distress.

Last, using an innovative, web-based self-management approach, Krishna et al. (2003) randomly assigned 288 children with asthma and their family caregivers to either an Interactive Multimedia Program for Asthma Control and Tracking (IMPACT) plus standard care, or standard care only control group. The IMPACT intervention included 44 vignettes for enhancing asthma management, a symptom tracking module, and a program for recording medication use. The program was administered to children and their parents during regularly scheduled pulmonary clinic visits. The routine care control condition focused on family education based on the National Asthma Education and Prevention Program plus regular pulmonary clinic visits. Krishna et al. (2003) found that the IMPACT participants reported significantly greater decreases in days of asthma symptoms, annual emergency department visits, and average daily dosages of inhaled corticosteroids than those of the control group from pretreatment to the 12-month follow-up. In addition, caregivers in the IMPACT group displayed significantly higher levels of knowledge about asthma management than their counterparts in the routine care condition. Note, however, that no significant differences were found for perceived quality of life between IMPACT and control group caregivers.

Future Directions for Videoconferencing-Based Caregiver Intervention

The findings of this review suggested that web and telephone-based videoconferencing may be a promising vehicle for strengthening partnerships between caregivers and health providers and possibly, may improve psychosocial outcomes for caregivers as well as the effectiveness of caregivers in managing the health-care routines of family members with chronic illnesses. The Internet also may confer substantial economic advantages in providing education and support to family caregivers, as compared to standard face-to-face treatment. However, rigorous cost savings, cost-effectiveness, and cost-offset analyses are needed to demonstrate the economic benefits of this health-care delivery approach. Finally, caution should be exercised in interpreting the results of these early videoconferencing caregiver studies. The seven controlled trials reviewed in this section are seminal efforts, and thus require replication to substantiate the reliability the obtained effects.

Current Status of Telehealth Education and Training for Family Caregivers

Despite the growing recognition of the benefits of telehealth, a large proportion of family caregivers continue to face substantial barriers in obtaining basic instruction in the use of telecommunication technologies. This is especially the case for rural caregivers who may be required to travel long distances to attend technology training programs. Ironically, even those who reside in large metropolitan areas may encounter problems in attending technology education programs offered at local libraries and community centers. The high cost of respite care and the inadequacies of local transportation systems may preclude involvement in such activities (Glueckauf & Loomis, 2003; Glueckauf et al., 2005, 2007).

The reasons for these shortcomings can be located in three major areas: (1) overreliance on traditional hub-and-spoke, telehealth delivery models, (b) limited empirical evidence supporting the benefits of home-based telehealth, and (c) insufficient knowledge about how to best integrate e-health systems of care into the local community. First, the majority of federal- and state-sponsored telehealth initiatives have relied on hub-and-spoke models of care in delivering consultation and health services to patients and their family caregivers (Maheu, Whitten, & Allen, 2001). This health delivery approach links individuals with chronic illnesses in medically underserved communities to expert specialty practitioners at major medical centers. The spoke is typically a rural clinic, small hospital, or health department, and the hub is usually a university health science center, or a teaching hospital located in a large metropolitan area.

The technological knowledge and skills required of persons with chronic illnesses and caregivers to participate in hub-and-spoke transactions (e.g., clinical interviews) are minimal. Telehealth technicians or participating health providers usually assume full responsibility for ensuring that all telecommunication devices are operating effectively and that audiovisual communications are clear. Note, however, that the opposite is the case for telehealth services delivered in the home, where effective delivery is predicated on the caregivers' knowledge and skill in using computer-based technologies. Although family caregivers are increasingly seeking information and services from the Internet (e.g., Monnier, Laken, & Carter, 2002), telehealth programs sponsored by federal and state governmental agencies generally have not funded Internet-based caregiver and patient self-management programs. Such initiatives are likely to require additional expenditures in training consumers how to operate home-based computer technologies and in providing technical assistance when computer problems arise. Telehealth agencies (e.g., Office for the Advancement of Telehealth, State telemedicine programs) that historically have made large financial investments in supporting regional hub-and-spoke networks have been reluctant to invest in new models of care and in educational programs that are needed to sustain them (Schopp, Demiris, & Glueckauf, 2006).

A second explanation for the lack of technology education may lie in the recent emergence of research on the effects of telehealth for family caregivers of persons with chronic illnesses. As discussed in the review above, only a small number of randomized trials have been performed comparing the effects of telehealth-based versus traditional face-to-face intervention on caregiver health and psychosocial outcomes. Furthermore, the linkages between caregiver psychosocial functioning and care recipient health outcomes continue to be poorly understood (Glueckauf & Ketterson, 2004; Liss, Glueckauf, & Ecklund-Johnson, 2002; Schulz & Quittner, 1998). Thus, both public and private sector organizations (e.g., National Institutes of Health, U.S. Department of Education, and Robert Wood Johnson Foundation) may be reluctant to fund technology education initiatives until solid evidence has been garnered supporting the efficacy and cost-effectiveness of telehealth-based intervention programs for family caregivers.

Third, efforts in providing caregiver technology education have been thwarted by the failure to integrate e-health and traditional systems of medical care. Despite the popularity and widespread use of digital telecommunication technologies, there continues to be only limited knowledge about how to best integrate e-health into the larger framework of health-care delivery (Byrnes, Kulick, & Schwartz, 2004). At present, health promotion programs offered over the Internet and through other telecommunication modalities operate in parallel with general medical practice. These two systems of care need to be fully integrated not only to ensure fair and equitable allocation of health-care resources, but also to enhance the prospects of meeting the health promotion needs of patients with chronic illnesses and their family caregivers. Similar to other public health initiatives seeking to maximize medical efficiencies (e.g., preventive dental care, such as flossing; use of condoms), patients and caregivers will require new knowledge and skills in the use of cost-effective telehealth technologies.

Future Directions for Caregiver Telehealth Education and Training

The rapid growth of home-based computer technologies has radically changed the delivery of health-care information and services in the United States. It is essential that federal and state organizations, such as the National Institutes of Health, Office for the Advancement of Telehealth, National Institute on Disability and Rehabilitation Research, and State Departments of Health, recognize the shift in the landscape of telehealth and reorganize their funding priorities. The Internet and other computer-based technologies (e.g., automated telephone) are likely to become vehicles of choice for provision of health information and health promotion services to persons with chronic illnesses, particularly in light of spiraling costs of medical care. Education and training in the use of telehealth technologies are essential for enhancing the prospects of meeting the health promotion needs of family caregivers who increasingly will rely on the Internet for their main source of medical information and emotional support.

Current Policy and Practice Considerations in Caregiver Telehealth

Although government and lay caregiver organizations have argued that the use of distance technology has become a major determinant for effective coping with the stresses of everyday life, national policy on reimbursement for and the regulation of telehealth practice continues to preclude wide-scale adoption of this modality. Barriers to the development of telehealth networks have been discussed in detail in a number of publications (e.g., Council on Competitiveness, 1996; Glueckauf, Nickelson, et al., 2004; Nickelson, 2000). These barriers are longstanding and difficult to overcome, particularly in the context of complex and highly fractionated health-care systems. Although the wide range of issues surrounding telehealth policy and practice are beyond the scope of this chapter, one of the major challenges to the future growth of telehealth lies in the current limitations for provider reimbursement.

Several U.S. federal agencies have been involved in the development of telehealth policy and programs, including the Department of Defense, National Aeronautics and Space Administration, Department of Veterans Affairs, and the Department of Health and Human Services. Lobbying efforts by the American Telemedicine Association and the Association of Telehealth Service Providers, groups representing the industry and telehealth practitioners, have strongly influenced changes in U.S. federal telehealth reimbursement policy. The Balanced Budget Act (BBA, 1997) and the Medicare, Medicaid, and SCHIP Benefits Improvement and Protection Act of 2000 (H.R. 5661, 2000) are two such efforts that merit special consideration. The BBA of 1997 mandated that the U.S. Health Care Financing Administration [(HCFA); renamed Centers for Medicaid and Medicaid Services in July 2001] pay for telehealth services to eligible Medicare beneficiaries in rural health practice shortage areas (HPSAs). Although this legislation represented a significant breakthrough for patients and caregivers in underserved rural areas, it contained several restrictions that hampered its effectiveness (e.g., only a small set of providers were eligible for third party payments). Fortunately, these limitations were corrected with the passage of the Medicare, Medicaid, and SCHIP Benefits Improvement and Protection Act of 2000 (SCHIP; H.R. 5661, 2000). In addition to expanding the range of professionals eligible for reimbursement, this legislation nullified earlier HCFA regulations that require (a) telehealth providers to split fees with the referral source, and (b) the referring rural provider to be physically present during the teleconsultation interview.

Note that H.R. 5661 legislation (i.e., SCHIP Benefits Improvement and Protection Act of 2000) also included language about the use of "telehome care" visits. Although telehealth visits could not be substituted for standard in-home care nor reimbursed under the new Act, home care agencies were permitted to package telecommunication-based contacts with routine care as a valued-added option. Despite its limitations, this legislation has opened the door for the expansion of covered services to include home-based telehealth, especially if future research demonstrates that telehome visits for persons with chronic illnesses and their caregiver significantly reduce inpatient hospitalization and emergency room costs.

Perhaps, nowhere is there more interest and activity in home-based telehealth than in the health-care and telecommunications marketplaces. As discussed above, the Internet has drawn a great number of caregivers who are seeking health information about their loved ones and for themselves. For example, the Pew Internet & American Life Project survey (2003) reported that 50% of American adults have searched online for health-care information. Furthermore, more than half of individuals who recently conducted health searches did so for someone else, such as a spouse or a loved one with a medical problem. This trend is pulling many existing health-care organizations – including managed care organizations – toward business models that incorporate this growing consumer comfort with the Internet.

The convergence of marketplace and legislative interests in telehealth practice bodes particularly well for family caregivers. One helpful way to think about methods that caregivers can use to promote telehealth coverage is to use an integrated advocacy model – one that integrates marketplace and legislative activities (Glueckauf, Pickett, Ketterson, Nickelson, Loomis, 2003). The thrust of this model is that any advocacy activity – providing consultation to business or lobbying – must be accompanied by complementary activities in the other areas. For example, caregivers can sensitize telehealth equipment vendors to their unique needs (e.g., ease of use and need for robust, low cost technologies). At the state level, caregiver advocates can educate lawmakers about how telehealth technologies could be used to provide outreach services to target populations, such as caregivers of older adults with Alzheimer's disease or of children with severe cerebral palsy, faster, more efficiently, and for less cost.

One caveat to consider, however, is that state governments are often strapped for resources. A possible intermediate step may be for a consortium of caregivers, telehealth practitioners, and researchers to propose state demonstration programs across a wide range of caregiver populations traditionally served by the state, such as caregivers of individuals with developmental disabilities, and those requiring long-term state-sponsored rehabilitation services.

Future Policy and Practice Considerations in Caregiver Telehealth

The broad appeal of the hub-and-spoke model of telehealth practice derived from the assumption that the nexus of health care is the local community clinic or hospital, the site where most health-care services in underserved communities historically have been delivered. The hub-and-spoke approach also satisfied the logistical requirements of busy specialists who preferred to conduct telehealth consultations at locations in close proximity to their busy clinic practices.

However, the recent emergence of the Internet as the primary vehicle for health information and services for millions of patients and their family caregivers has changed the face of telehealth. It is essential that federal and state agencies sponsoring telehealth initiatives recognize this shift in the health-care delivery landscape and reorganize their funding priorities. In the future, Internet and other computer-based technologies are likely to become vehicles of choice for provision of health information and health promotion services to persons with chronic illnesses, particularly in light of the spiraling costs of specialty medical care. Family caregivers who have insufficient knowledge and skills may be unprepared to assist in telehealth-based care for their loved ones. Moreover, they may be unable to take full advantage of information and services available to enhance their own health and emotional well-being.

Final Note

The present research review suggested that telehealth holds considerable promise for meeting the educational and support needs of family caregivers. To avail themselves of the benefits of this health delivery modality, caregivers must have greater access to computer technology and technology education. Despite the recent increase in computer use among elder Americans (Pew Internet & American Life Project, 2004), many still cannot afford to purchase a computer or to gain access to the Internet. This is especially the case for those residing in underserved rural areas (Glueckauf et al., 2005). Although government and professional organizations have recognized the importance of technology and technology education for family caregivers, these agencies have been slow to make these needs a funding priority. As a result, caregivers must become more knowledgeable about legislative and marketplace forces driving telehealth and how to advocate for health promotion and technology needs.

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Chapter 8
Education and Support Outcome Sustainability: A Conceptual Framework

Kathryn B. McGrew

The sustainability of caregiver education and support program outcomes is arguably the most important and the least attended to of all program variables in education and support practice, research, education, policy and advocacy. Consumers, providers, and sponsors of programs want their investment in programs to pay off, in positive, enduring ways. Short-term outcomes are only beneficial if they can be sustained over time. How, over time, can caregivers sustain the immediate positive outcomes of education and support programs in order to achieve intermediate and long-term outcomes? This question is addressed in this chapter by presenting a framework for sustaining program outcomes and by describing six sustainability tests that should be addressed by all caregiver education and support programs. The chapter concludes with a discussion of current and future trends that affect the sustainability of caregiver education and support programs.

Caregiver support intervention studies come closest to examining sustainability when follow-up measures incorporated into program design and evaluation are reported as measures of "long-term effectiveness" (Labrecque, Peak, & Toseland, 1992; Mittelman, Haley, Clay, & Roth, 2006; Mittelman, Roth, Coon, & Haley, 2004; Pusey & Richards, 2001; Sorensen, Pinquart, & Duberstein, 2002). According to several reviews of the literature, the majority of outcomes of caregiver interventions are measured at pre-test/intervention and post-test/intervention, without follow-up (Cooke, McNally, Mulligan, Harrison, & Newman, 2001; Kennet, Burgio, & Schulz, 2000; Sorenson et al., 2002). One meta-analysis found that follow-ups were conducted in only 22% of the cases (Sorenson et al., 2002). Although Cooke et al. (2001) report that "where success in improving outcomes is reported immediately after the intervention, these are generally maintained over time" (p. 130), follow-up measures would seem the truest indicators of the sustainability of program outcomes.

There has been little discussion and consensus in the literature about when a short-term program outcome can be considered a long-term, sustained outcome.

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The longest measurement period discovered in the literature review for this study was an average 8-year follow-up period related to mortality and institutionalization (Brodaty, Gresham, & Luscombe, 1997). In a review of 30 studies (16 conducted in the US) of psychosocial interventions for dementia caregivers, Pusey and Richards (2001) found that the length of program follow-up ranged from "post-intervention only, to 2 years, with most less than 6 months" (p. 114). Sorensen et al. (2002) report an average follow-up of 7 months.

There are serious gaps and limitations in the research related to the sustainability of education and support program outcomes. In general, much of the research related to caregiver support is found in the gerontological literature, and that literature is dominated by dementia care. Another major limitation is the failure of research to reflect the heterogeneity of population, particularly racial and ethnic representations (Aranda, 2001). A third limitation is that we only know about program outcomes of controlled interventions, usually designed for the purposes of research. We know little about the long-term effects of community caregiver support programs that are now widespread, but that have not been the subject of evaluations.

The Proximal–Intermediate–Distal Outcome Continuum

A useful heuristic device for thinking about the challenge of sustainability is to consider outcomes on a proximal–intermediate–distal continuum (see Table 8.1 and Fig. 8.1). This three-point continuum differs from the two-point (proximal–distal)

Table 8.1 Outcome examples

Proximal outcomes (intervention goals)
Acquired knowledge
Learned/mastered skills
Perceived social/emotional support
Personal insight
Intermediate outcomes (intended intervention effects)
Reduced perceived stress/burden
Improved or eased facilitation of care tasks
Reduced objective burden
Improved mood
Increased satisfaction
Maintained/improved relationships
Maintained/improved health
Maintained/improved financial security
Sustained or renewed social roles
Accessed services or other supports
Changes in care receiver health/needs/behaviors/mood
Distal outcomes (ideal outcomes)
Caregiver (and care receiver) well-being
Delayed institutionalization; care maintained

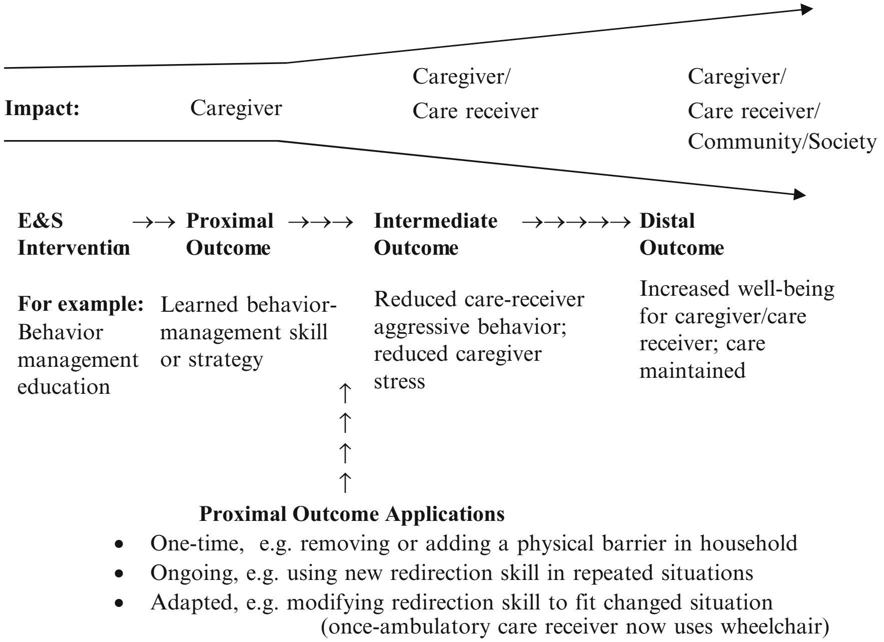

Fig. 8.1 Outcome continuum

conceptions of others (Schulz, 2000, 2001; Sorensen et al., 2002; Zarit & Leitsch, 2001). Schulz (2001) argues that better discrimination is needed between proximal and distal outcomes in caregiver intervention research. The three points on this continuum help to distinguish types of outcomes while bridging proximal and distal outcomes; it includes intermediate level outcomes as well as categories of outcome applications on the continuum.

In this continuum, proximal outcomes reflect the most immediate objectives of education and support programs, e.g., mastered knowledge, learned skills, or experienced support. Proximal outcomes are the tools used to achieve intermediate outcomes. Intermediate outcomes are the intended, though less directly related, effects of interventions, e.g., improved caregiver–care receiver communication, more effective behavior management, or improved caregiver mood. Intermediate outcomes contribute with other factors to distal outcomes.

Distal outcomes represent the loftier and more global objectives of education and support programs, such as overall well-being and maintained care at home. Distal outcomes lie farthest in time, breadth and complexity on the continuum. Although distal outcomes are farthest removed in time from the program intervention, they are not the same as long-term effects. In fact, proximal and intermediate outcomes may last a long time but still not achieve distal outcomes; and, distal outcomes may last only a short time. Distal outcomes simply take more time to achieve, in part because they are contingent upon first achieving proximal and intermediate effects. The characteristics that truly distinguish distal outcomes are their increased breadth and complexity. Distal outcomes may impact more people, may be impacted by more people, and are more likely to be confounded by changes in condition or resources than are proximal and intermediate outcomes. In this conception, distal outcomes are ideal outcomes that derive from multiple factors, including education and support.

Proximal Outcome Applications

It is possible for proximal outcomes to be sustained over the entire caregiving experience without changing that experience at all. For example, a mother caring for a child with severe autism and a husband caring for a wife with Alzheimer's disease may each master and retain knowledge from their respective programs about nutritional needs or toileting routines yet have little success in applying that information at home. They have achieved the proximal objectives of the programs but have not translated them into action or feeling. The first step in the sustainability of outcomes over the care experience is the effective "take-home"[1] application of proximal outcomes to achieve intermediate outcomes, e.g., improved nutrition in the household, improved care routine, or reduced perceived stress.

Proximal outcome applications may be divided into three categories: one-time, ongoing, and adapted. A *one-time* application of a proximal outcome happens once but has the power to achieve or contribute to an intermediate outcome. Using a toileting education intervention as an example, a one-time application of new information (the proximal outcome) might be the addition of an assistive device, such as a grab bar or a custom toilet seat. Or, it might be a change of bedroom location related to the location of the bathroom. Such one-time applications may achieve and sustain an intermediate outcome of reduced caregiver stress or improved caregiver health over the full course of the caregiving experience. In a one-time application, although the application is not sustained, its effect may be.

The *ongoing* application of a proximal outcome may result in a sustained effect. An example of an ongoing application that results in a sustained outcome from a toileting education intervention is the maintenance of a new toileting schedule, or the repeated use of new behavior-management skills related to toileting. Such ongoing applications can achieve a sustained outcome over the time of its application. Although they may also have lingering effects even when the applications are stopped, the goal of on-going applications is to maintain them as long as they contribute to the desired intermediate outcome(s).

The goal of an *adapted* application of a proximal outcome is to transfer or modify the proximal outcome to respond to changing needs or circumstances. Information or awareness gained from a toileting education intervention may need to be adapted as the care receiver's and/or caregiver's capacities change. For example, when

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[1] Participants of internet education/support groups from their own homes face the "take-home" challenge once they leave their computers.

individuals with autism learn new toileting skills, or when those with Alzheimer's disease become increasingly incontinent, the role and tasks of caregivers in assisting with toileting necessarily change. Furthermore, caregivers may gain or lose physical strength or other capacity to assist over time. Therefore, caregivers must adapt what they have learned in the toileting education intervention to new situations in order to achieve and sustain intermediate outcomes such as improved toileting routines or the reduction of perceived stress. Thus, adapted applications may be one-time applications or ongoing applications, both with potential long-term effects.

It should be clear that the take-home application of proximal outcomes, whether one-time, ongoing, or adapted, is necessary to achieve intermediate outcomes. How then, do intermediate outcomes lead to distal outcomes? In other words, how are intermediate outcomes such as reduced stress and improved routine themselves "applied" to achieve a distal outcome of improved well-being and/or maintained care at home? To achieve sustainability, i.e., to make the application of intermediate outcomes and/or their effects last, the design and implementation of education and support programs should address three threats to sustainability: outcome limits, loss, and lag.

Outcome Limits, Loss, and Lag

Outcome limits are evident in program interventions that do not match the needs and circumstances of the caregiver, in content or intensity. In such cases, proximal outcomes are not applicable to the caregiving situation or are not powerful enough to achieve intended intermediate outcomes. For example, an education and support group for caregivers of adults with severe mental illness may emphasize content related to parent–child relationships and therefore be less applicable to the needs and experiences of siblings. For sibling participants, proximal outcomes are less likely to be applied toward intermediate outcomes such as improved relationships or reduced perceived stress. And even when the content is a good match, e.g., for caregiving parents in the program, if the felt support is tentative or the education cursory, the application of these outcomes may have little impact on intended intermediate outcomes. In addition, participants whose culturally specific needs and values are not reflected in program content will experience outcome limits. Proximal outcome limits are clearly the first challenge in the sustainability of education and support program outcomes. There is little incentive in sustaining outcomes that do not make a difference.

Outcome loss is the erosion over time of proximal outcomes such as support, skills, and knowledge. The problem of outcome loss is especially germane to ongoing or adapted-ongoing applications of proximal outcomes. A program for caregivers of individuals with brain injuries may achieve very good success in teaching participant's communication skills or advocacy skills, yet over time, without practice or encouragement and support, those skills may be lost. The opportunity for their ongoing application is lost with them. In another example, adult children caring for aging parents who attend a monthly support group may find that the sense of support fades within 1 or 2 weeks. The intended outcome of improved emotional health is short-lived each month and diminished overall. Infrequent and time-limited programs would seem especially vulnerable to outcome loss.

Outcome lag is the failure of program outcomes to keep pace with changing caregiver needs and circumstances. Even when outcomes are retained, changing circumstances can create an education and support outcome lag over time. The direction of these changes is not so much the issue as the fact that once-useful knowledge, skills, and level of support become less applicable, or even useless. Even in situations where care receiver needs are relatively stable, there are other variables that can render program outcomes useless over time. These may be "exacerbating" or "protective" factors (Brodaty, 1996) and reflect the significance of changing contextual variables in the caregiving experience.

Caregiver capacity, living arrangements, financial circumstances, competing employment, and family demands, even simple caregiver "wear and tear," are examples of changes in circumstances that can create outcome lag. The risk of outcome lag is especially high for caregivers of individuals with progressive diseases like Alzheimer's and Parkinson's. As the disease progresses, caregiver roles, tasks, and demands on emotional resources change.

Even as outcome limits, loss, and lag threaten the sustainability of education and support programs, positive processes in the caregiving experience may moderate or compensate for them. Over time, caregivers and their care receivers can discover and develop new information or knowledge, personal coping skills, new support resources, personal insight, and experience-based effective care strategies. Furthermore, success in achieving personal, educational, and support program objectives is inherently empowering; mastery experiences should increase self-efficacy for caregivers and care receivers (Bandura, 1997). Caregivers and their care receivers can also benefit from outcome practice effects over time. Caregiving discovery and development may be independent of or indirectly related to education and support interventions. As moderators, the processes of discovery and development in the caregiving experience have important implications for the sustainability of education and support program outcomes and its measurement.

Six Sustainability Tests

As caregiver education and support programs work to improve outcomes over time, outcome sustainability should underlie all planning, implementation, evaluation, and follow-up decisions and activities. An education and support program should meet six sustainability tests: (1) Are goals and expectations reasonable? (2) Does program content match the needs of participants? (3) Do program length and intensity match program goals? (4) Are participants helped to anticipate and prepare for changes in caregiving conditions? (5) Is the program part of a comprehensive support strategy that includes direct services? (6) Is the program itself sustainable? In examining each sustainability test, we will address its practice implications and, where relevant, its research, education and policy/advocacy implications. (Guidelines for practitioners, developed from these sustainability tests, are found in Table 8.2.)

Table 8.2 Sustaining outcomes of caregiver education and support programs guidelines for practitioners

Set reasonable goals and expectations
It may be unreasonable for a program, by itself, to achieve distal goals such as delayed institutionalization
Intermediate outcomes, such as improved toileting routines and reduced perceive stress (however transitory), are respectable outcomes by themselves
Identify clear proximal goals, such as learned information and perceived support; understand the "take-home" application of proximal goals and their contribution to intermediate goals
Have a plan for measuring goal achievement based on reasonable expectations
Match program content to participant needs
Recruitment and referral communications should clearly communicate the goals, scope, target population, and activities of the program
Once the program is established, program content should be modified as needed to the actual composition of participants and their expressed or assessed needs
Content that is not readily modified should be generalizable enough to apply to most participants' needs most of the time
Content should be culturally sensitive and relevant
Match program length and intensity to program goals
Program length and intensity are not necessarily the same thing
Longer is not always better (program participation has time and other costs to caregivers even while it has benefits)
Reasonable time should be allotted for program content; when time is limited, goals should be limited
Multiple approaches, e.g., that combine counseling and education, contribute to program intensity and effectiveness
Anticipate and prepare for changes in caregiving conditions
Both program facilitators and participants should anticipate and prepare for changes in caregiving conditions
Content should be generalizable enough to be applied outside the group and after the program ends; content should be generalizable to changes in caregiving conditions
Content should include strategies for building participant confidence
Booster or refresher materials should be provided as possible for use beyond the program
Follow-up sessions can be helpful
Promote a comprehensive support strategy
Professionals involved in caregiver education and support should promote and advocate for comprehensive supports for caregivers, such as respite care and access to long-term care services
Professionals should advocate for inclusion of caregiver assessment and services in traditional long-term care service programs and settings
Sustain the program itself
The existence of the program is a message of support by itself
Work to "be there" for both current and future participants
Seek research opportunities to measure and document the effectiveness of the program
Seek opportunities to obtain ongoing funding and support

Reasonable Goals and Expectations

Current practices in caregiver education and support programs reflect a wide range of program objectives across disability and illness groups. Some would argue that distal outcomes, as broad program objectives, may be too much to ask of most education and support interventions. Zarit and Leitsch (2001) argue that outcomes are sometimes conceptualized in "grandiose terms (e.g., reducing caregiver burden, improving well-being), with little consideration of whether or not the specific intervention might produce those results" (p. S90). We are cautioned to identify and plan for "reasonable" program outcomes and to evaluate their impact accordingly (Kennet et al., 2000; Sorensen et al., 2002; Zarit & Leitsch, 2001). Programs should set reasonable goals and expectations for proximal outcomes, their application, their intermediate outcomes or effects, the length and breadth of their effects, and their impact on distal outcomes. The problem of outcome limits, loss, and lag should be acknowledged as a reality of education and support programs even under optimal conditions.

How do we identify and plan for "reasonable" and sustainable program outcomes? Two assumptions are applied in response to this question. First, intermediate outcomes as identified here should be considered respectable objectives for most education and support programs. Intermediate outcomes have value by themselves (Cooke et al., 2001; Zarit & Leitsch, 2001), and the longer the intermediate outcomes are sustained, the greater their stand-alone value. Second, the longer the intermediate outcomes are sustained, the greater their potential to contribute to distal outcomes.

Several related research challenges are evident. First, there is a "disconnection between proximal and distal goals that results in inappropriate expectations of caregiving studies" (Schulz, 2001, p. S112). Until recently, reasonable and clear outcomes for measurement had not been identified (Kennet et al., 2000; Zarit & Leitsch, 2001) and it is difficult to disaggregate outcomes (Schulz, 2001; Sorensen et al., 2002). However, Montgomery and colleagues are currently conducting a national demonstration project to evaluate a new caregiver assessment and referral protocol that identifies a set of outcome measures, such as caregiver "uplifts" (Montgomery & Kwak, 2008). Second, once outcomes are identified, their measures must be carefully selected. The advantages and disadvantages of standardized measures, the sensitivity of measures to change, and the relative values of qualitative and quantitative methodologies should be considered in selecting outcome measures (Zarit & Leitsch, 2001). Furthermore, available outcome measurements are not always culturally sensitive and therefore may limit our understanding of outcomes among culturally diverse groups (Gallagher-Thompson, Arean, Rivera, & Thompson, 2001). Third, most intervention research relies on pre-test, post-test measurements. Long-term sustained effects of program outcomes can only be measured in long-term follow-up of interventions. Therefore, despite the fact that obstacles to their inclusion include increased expense and participant attrition, long-term follow-up measures should be incorporated into program evaluation designs (Kennet et al., 2000). Fourth, proximal outcomes are relatively easy to measure, e.g., in program pre- and post-tests. However, such measurement tools measure "states" and not dynamics and therefore do not capture the mechanisms of action along the outcome continuum.

Matching Program Content and Participant Needs

This sustainability test requires attention to the problem of outcome limits. As stated earlier, proximal outcomes cannot or will not be sustained if they are not applicable to caregiver needs. Programs must match these needs in both content and intensity. Needs of caregivers include capacities and circumstances, as well as “stages of readiness” (Schulz, 2000, p. 233) for levels of program participation and particular content. Temporality and stages of readiness are special issues for families caring for children with lifelong disabilities. Family caregiving is experienced in discernable stages that have implications for the timing of support interventions and their outcomes (Bowers, 1987; Grant, Nolan, & Keady, 2003; Nolan, Keady, & Grant, 1995; Seddon, 1999). Families of children with intellectual disabilities have stage-wise needs and coping strategies (Grant et al., 2003). The “timing of interventions” is also important in programs with dementia caregivers (Schulz, 2001). It is important to design programs that are in synch with “key transitions” in stages of the caregiving experience (Seddon, 1999).

The process of matching program content to participant needs begins with referral and recruitment, and requires individual assessment. Recruitment and referral practices must bring the right participants to the program, and interventions must be developed that are responsive to the needs of the particular participant group. There is evidence that individually tailored interventions are more likely to be “successful” (Brodaty, Roberts, & Peters, 1994). In some cases, program goals may allow for goal adjustment after an intervention begins. This requires assessment to identify individual needs, goals, and outcome limits. Clinical assessment is more likely to be used in psychotherapeutic interventions than in other interventions; pre-tests or baselines often serve as an assessment (or vice versa) in evaluated interventions (Kennet et al., 2000). When interventions cannot be individually tailored, they must be sufficiently generalizable to the diverse needs of the participants and “relevant to the majority” (Toseland, 1995, p. 126).

It is difficult to know what intervention strategies or intervention processes produce long-term effects (Kennet et al., 2000; Sorensen et al., 2002). Gitlin et al. (2000) have identified several theories to explain “mechanisms of action,” i.e., why interventions “do or do not work” (p. 225). Stress process models (Pearlin, Mullan, Semple, & Skaff, 1990); motivational theories (Prochaska, Redding, & Evers, 1997); and self-efficacy or personal control theories (Bandura, 1997), e.g., may suggest content and type of intervention to produce sustainable outcomes. Little research has been conducted to identify these mechanisms of action in caregiver intervention programs (Gitlin et al., 2000).

The cultural relevance of program goals and content is a critical outcome limits issue. Until recently, attention to the role of cultural competence in family support programs has been insignificant. Cultural beliefs about illness and values about caregiving vary across ethnic and cultural groups (Gallagher-Thompson, Arean et al., 2000) with implications for recruitment, referral, and assessment, as well as for content and methods of intervention.

Educational resources are growing in this area. Recent projects relating to the culturally competent design of family support programs include: the REACH project (Resources for Enhancing Alzheimer's Caregiver Health; Gallagher-Thompson et al., 2003, REACH I and Belle et al., 2006, REACH II); a "cultural competence" guidebook from the Administration on Aging (2001); guidelines from the National Center for Cultural Competence in the Georgetown University Center for Child and Human Development, University Center for Excellence in Developmental Disabilities (Georgetown University, 2004); and related work at Portland State University's Research and Training Center on Family Support and Children's Mental Health (Gomez, 2002). With guidance from such sources, work to increase the cultural sensitivity of program goals and content should contribute to a better match with caregiver needs and the consequent promotion of outcome application and sustainability.

Matching Length and Intensity to Program Goals

The length and intensity of programs are related to outcome limit and loss issues. Although some education and support programs are identified and conducted as "on-going," most are time limited. Even in on-going programs, education and training topics are varied and therefore time limited. In a 2002 meta-analysis of interventions with caregivers for older adults, Sorensen et al. report that "the number of sessions ranged from 1 to 180 with a median of eight sessions" (p. 360).

Length of program and number of sessions do not always correspond with each other, or with the intensity of the program. Frequency is only a "rough indicator of program intensity" (Monahan, 1994, p. 704). One program for dementia caregivers was conducted within a 10-day period but involved intensive residential training with multiple components. This is the same program that reported an average 8-year follow-up outcome of delayed institutionalization and decreased mortality (Brodaty et al., 1997).

The power of longer interventions to achieve effects has been reported by Mittelman et al. (1993, 1995), Mittelman, Ferris, Shulman, Steinberg, and Levin (1996) and Whitlach, Zarit, Goodwin, and von Eye (1995). In Mittelman et al., a 12-month spouse–caregiver intervention using individual counseling and support groups, care receiver institutionalization was delayed by nearly 1 year compared to a control group. Longer is not necessarily always better, however. There is an "optimal intensity and duration of interventions" (Monahan, 1994, p. 710), and "length of the intervention should be matched to the goal of the program" (Sorensen et al., 2002, p. 369).

Multi-component education and support programs suggest another form of intensity, and there is evidence that they support caregivers more effectively than single component programs (Bourgeois, Schulz, & Burgio, 1996; Peak, Toseland, & Banks, 1995; Toseland, Labrecque, Goebel, & Whitney, 1992). Examples of multi-component programs include combinations such as counseling and skills education (Ingersoll-Dayton, Chapman, & Neal, 1990) and the Mittelman et al. (1993, 1995) use of individual counseling and support groups.

It should be noted that program participation creates its own demands on caregiver resources; conceived as one more caregiving "task," program participation becomes a cost–benefit decision for the participant. Rational participation decisions are reflected in measures of program utilization such as attendance (Monahan, Greene, & Coleman, 1992). Program length and intensity should be evaluated from an explicit cost–benefit perspective.

Anticipating and Preparing for Changes in Caregiving Conditions

The essential test of outcome sustainability is what happens "beyond the boundaries" (Rose, 1998) of the program. Because not all caregiving contingencies can be accounted for in program interventions, and because caregiving conditions change over time, it is important that proximal outcomes be "generalizable" (Rose, 1998; Toseland, 1995; Toseland & Rivas, 2005). Interventions should be conducted with an eye toward their take-home generalization and modification; this will allow for adapted applications in situations of outcome loss and lag.

Toseland (1995) provides guidelines for "maintaining and generalizing" outcomes of group interventions. These include helping participants "anticipate changing conditions and plan for them" (p. 126). The processes of outcome loss and lag can be anticipated and prepared for, with explicit preparation strategies built into program agendas and methods. Participants should also be prepared to identify and exploit discovery and development processes in their caregiving experience. They should look forward to the possibilities of practice effects, mastery experiences, and increased self-efficacy over time (Gitlin et al., 2000). Along these lines, Toseland proposes techniques to "[help] members develop confidence in their abilities" and to "help members [solve] problems independently by providing a framework for organizing data and solving problems that can be used in many different situations" (2005, p. 425). Meanwhile, outcome loss can be addressed by such strategies as follow-up sessions (Toseland & Rivas, 2012); booster or refresher sessions (Gallagher-Thompson & DeVries, 1994; Rose, 1998; Toseland, 1990); booster or refresher audio and video materials (Toseland & McCallion, 1998), or printed materials, including "self-help" literature (Rose, 1998); and peer-to-peer networking and support (Toseland, Rossiter, & Labrecque, 1989a, 1989b).

Evaluation, follow-up, and on-going assessments identify changing caregiver needs. Linkages and referrals to other support programs and services should be part of education and support program outcome sustainability strategies. Importantly, Cooke et al. (2001) suggest evidence of a delay in effects of program interventions; this has implications for individual and provider expectations and referrals.

Helping program participants anticipate and prepare for changes in caregiving conditions can be very sensitive work, even in programs less focused on the emotional aspects of care. This has significant implications for the education of program planners and facilitators. Facilitators may be lay (peers) or professional (Toseland, 1990); with most professional training offered in social group work (Toseland, 1995; Toseland & Rivas, 2012). Train-the-trainer education is increasingly common in education and support groups as can be seen in some "best practice" caregiver support programs such as the *Powerful Tools for Caregiving* program offered by Mather LifeWays Institute on Aging, or the *Caring for You*, *Caring for Me* program offered by the Rosalynn Carter Institute for Caregiving (Toseland, 2004).

It is worth noting that education and support group training can only be as good as the research that informs it, and significant research challenges have been identified. Education, practice, and research collaborations appear vital to achieving program effectiveness.

Promoting a Comprehensive Support Strategy

It may be unreasonable from a practice or policy perspective to expect education and support programs to meet caregiver needs on their own. Sorensen et al. (2002) divide caregiver interventions into two groups: "(a) those aimed at reducing the objective amount of care provided by caregivers (respite, interventions to enhance the competence of the care receiver) and (b) those aimed at improving the care-giver's well-being and coping skills (e.g., psychoeducational interventions and support groups)" (p. 357). It must be acknowledged that the complex and dynamic nature of the caregiving experience both creates and reflects an interdependence of interventions; the multitude of services and programs used by caregivers and care receivers has a combined effect on whether care is successfully maintained at home.

There is evidence that "more is better" (Bourgeois & Schulz, 1996, p. 79; Kennet et al., 2000, p. 63), i.e., that caregivers are supported most effectively by comprehensive supports, to include direct care services (Hinchliffe, Hyman, Blizard, & Livingston, 1995; Kennet et al., 2000; Sorenson et al., 2002; Zarit, Gaugler, & Jarrott, 1999). These include home and community-based care and respite services. Caregivers are more likely to benefit from skills training *and* respite than they would from one or the other alone. Thus, theoretically, the sustainability of education and support program outcomes is enhanced by services that meet the objective needs of caregivers.

At the policy and advocacy level, a comprehensive support strategy requires systems integration and "seamless support services" (Feinberg, 2001, p. 8). Thus, caregiver support programs in general have been add-ons to direct services programs for care receivers, usually relying on separate funding streams (Feinberg, Newman, Gray, & Kolb, 2004). Alliances across populations and provider groups, such as the National Respite Coalition, ARCH, National Respite Network, and the Family Caregiver Alliance work to promote comprehensive services.

Sustaining the Program Itself

To this point the chapter has focused on sustaining outcomes for individual participants who attend education and support programs. It is also important to consider the sustainability of the program itself, i.e., its continuing availability in the community. Aside from the obvious appeal of keeping a successful program open to an inevitable stream of caregivers, a sustained program can also help sustain outcomes of past and current participants. The program needs to "be there" for its participants, as an ongoing education and support resource in situations of outcome loss and lag, as well as caregiving discovery and development.

Mancini and Marek (2004) identify seven "sustainability elements" (p. 339) in their conceptual model of community-based program sustainability: leadership competence, effective collaboration among stakeholders, understanding the needs and resources of the community, demonstrating program results, strategic funding, staff involvement and integration, and program responsivity to changing needs in the community. They argue that "developing a sustainability plan is an entry-level activity rather than an endpoint" (p. 346). Both the sustainability of program outcomes and of the program itself require careful application of what we know from practice-based research. As we look toward the future, several important practice, research, education and policy trends will impact the direction and success of education and support sustainability efforts.

Current Trends and Future Directions

Four broad trends will impact the sustainability of future caregiver supports. First, we are undergoing a "paradigm shift" in "providing explicit support" for caregivers (Feinberg, Newman, & Van Steenberg, 2002, p. 7). Increased policy and program attention to the needs of caregivers is likely to contribute to a "new issue": potential conflict "between helping the caregiver and helping the patient, and the debate over the clinical significance of intervention outcomes relative to these two groups" (Bourgeois & Schulz, 1996, p. 85). As Schulz puts it, "Outcomes for whom?" (2001, p. S112). This is not only a policy and advocacy issue, but also a practice, research, and education issue. This shift could take us in two directions: toward conflict and further fragmentation or toward meaningful integration of caregiver and care receiver needs and interventions. Efforts toward reasonable expectations, appropriate program content and intensity, generalizable outcomes, and comprehensive services can and should account for the needs of all involved. Furthermore, efforts toward sustaining caregiver support programs themselves will be facilitated by cooperative instead of competitive use of resources.

Second, demographic forces will continue to affect the outcomes we pursue, the way we pursue them, and the measures we use to evaluate their impact. In particular, increasing racial and ethnic diversities of the population compels continuing work toward cultural competence in providing sustainable supports. This requires efforts to identify appropriate outcome measures for interventions and to design and test interventions responsive to a "diverse set of needs" (Gallagher-Thompson, Lovett et al., 2000, p. 107).

In addition, population aging will continue to have an impact. Of particular concern are "double jeopardy" families: aging families with multiple care needs, such as frail older adults with children with intellectual disabilities, mental illness, or other disability (Kinney & McGrew, 2001). Such families require multiple interventions from multiple systems. Their sustainability pressures are intensified by compounded needs of multiple care receivers.

Related to population aging is the increased attention paid to supporting secondary and long-distance caregivers (Metlife Mature Market Institute and National Alliance for Caregiving, 2004); and multiple generation families. Sought outcomes for these groups are likely to be different at some levels, and research is needed to identify sustainability issues particular to these groups.

Third, advances in telemedicine and telecommunication technologies will change not only the way care is provided and received, but also the way caregivers and families are educated and supported (Brennan, Moore, & Smyth, 1991; Whitten & Gregg, 2001). Studies indicate a growing use of telephone and computer technology to achieve program goals (Kennet et al., 2000; Pusey & Richards, 2001; Glueckauf chapter in this book; Smith, Toseland, Rizzo, & Zinoman, 2004). The potential for sustaining program outcomes through technology is basically unexplored, but the increasing use of technology appears inevitable.

Fourth, a growing consumer-direction, person-centered movement is reflected in current policy trends and program innovations (Doty, 2004; Dunst, Trivette, Starnes, Hamby, & Gordon, 1993; Research and Training Center on Community Living, 2003). This movement will have implications for the identification of individual and program goals and expectations. In addition, program content and implementation will increasingly be set by consumer choice; consumers will have increasing voice about quality and effectiveness of support programs. In addition, in keeping with these movements, consumers will assume increased responsibility for sustaining program outcomes.

Conclusion

This chapter has provided a broad conceptual framework best used as a heuristic for understanding and addressing program outcome challenges imposed by time. Building on an outcome continuum, the framework identifies types of outcome applications; threats to outcome sustainability; moderators of those threats; and implications for practice, research, education, policy, and advocacy. As program participants confront outcome limits, loss, and lag over time, they will be better served by programs that meet the six sustainability tests examined here.

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Chapter 9
Evaluating the Effectiveness of Caregiving Education and Support Programs

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The purpose of this chapter is to describe effective methods for conducting evaluation research about caregiver education and support programs. We considered a different focus, reviewing, and evaluating the existing literature. However, a large and growing body of literature already exists about the effectiveness of caregiver education and support programs and it seemed to us that another review would be redundant. The literature is summarized in numerous excellent reviews that have highlighted what is known about the effectiveness of caregiver education and support programs and what remains to be accomplished. In fact, so many review studies have been completed since the first review by Toseland and Rossiter (1989) two decades ago, here we list only some of the reviews since 2000 (see, for example, Acton & Kang, 2001; Brodaty, Green, & Koschera, 2003; Cooke, McNally, Mulligan, Harrison, & Newman, 2001; Coon, Gallagher-Thompson, & Thompson, 2003; Farran, 2001; Gallagher-Thompson & Coon, 2007; Gallagher-Thompson et al., 2000; Harding & Higginson, 2003; Kennet, Burgio, & Schulz, 2000; Pinquart & Sorensen, 2006; Pusey & Richards, 2001; Schulz, 2000; Schulz et al., 2002; Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007; Sorensen, Pinquart, & Duberstein, 2002; Thompson et al., 2007; Thompson, 2000; Toseland, Smith, & McCallion, 2001; Toseland, 2004; Yin, Zhou, & Bashford, 2002).[1]

Many different methods have been used by these review studies to evaluate the effectiveness of caregiver education and support programs. Meta-analytic and other review procedures differ with respect to the methodological rigor required of the studies included for review. Most of the previously cited reviews, however, emphasize the importance of rigorous evaluation methods and call for their use in future research (see, for example, Bourgeois, Schulz, & Burgio, 1996; Coon et al., 2003; Schulz, 2000).

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[1] For a list of additional reviews before 2000, contact the senior author of this chapter.

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This chapter, therefore, focuses on what it takes to conduct an effective and rigorous evaluation of a caregiver education or support program. It covers eight domains that should be addressed when evaluations are conducted: (1) aims, (2) background and theory, (3) selection of participants, (4) design, (5) specification of the caregiver program, (6) measurement and measures, (7) data analysis, and (8) human subjects. Although many of the topics covered appear in textbooks on evaluation research, it is our intent in this chapter to describe what special considerations and modifications may be needed when evaluating caregiver education, training, and support programs. While describing methods for addressing each of these domains, we also address implications for practice, research, education, training, policy, and advocacy.

It is recognized that practitioners and researchers reading this chapter may not be able to meet all the rigorous standards that are suggested. It is very difficult to conduct randomized field trials of innovative programs for caregivers of the frail elderly under any conditions, not to mention the exacting standards suggested here. Practitioners, researchers, and others currently conducting research about caregiver education and support programs must recognize that many large and rigorous studies have already been conducted, and much is already known. At the same time, great advancements have been made since the critical review of studies in the field by Toseland and Rossiter (1989) almost two decades ago. More studies are certainly needed, especially in specialized areas, and suggestions are made in this chapter for studies that could address these gaps in the literature.

Given the increasing sophistication and rigor in the field, small uncontrolled studies may no longer be publishable. Those pursuing new studies have to carefully examine the existing literature to see if what they are proposing will contribute to the large body of outcome literature that is now available. Still, areas that remain in need of study include long-distance caregiving, the relative merits of telephone and internet groups for caregivers, and internet websites and web-based tools for educating and helping caregivers manage their own expanded helping networks such as Share the Care (www.sharethecare.org) and Lotsa Helping Hands (www.lotsahelpinghands.com). Also, innovative programs for caregivers of persons with rare or understudied problems such as stroke and bypass surgery (which often causes memory loss), and studies of specific cultural and ethnic caregiver groups, all need more attention.

Aims

The first step in conducting an evaluation of caregiver education and support programs is to select and clearly define measurable aims of the evaluation. Aims should identify clear and explicit endpoints or outcomes that the program has a realistic chance to effect. At the same time, evaluators should have a good understanding of the policy implications of the aims that are selected, giving preference to defining aims that will help to inform future clinical practice, program development, and policies affecting the largest group of caregivers possible.

When developing aims, it is a good practice to try to achieve consensus about what is important and realistic to measure. In doing so, it is essential for evaluators to work closely with administrators and clinicians who are delivering caregiver programs in the community. At a minimum, administrators and clinicians should be consulted about their perceptions of the effective ingredients of the caregiver program, and the type of data that would capture an accurate picture of program effectiveness. It is important for evaluators to develop good working relationships with administrators and clinicians from the start of an evaluation so that the evaluation plan can be effectively implemented with a minimum of disruption. For example, in an Administration on Aging-funded study of the impact of a telephone caregiver support group intervention program, researchers teamed up with a senior service community agency serving the elderly that had a 16-county information and referral hotline (Smith, Toseland, Rizzo, & Zinoman, 2004). The agency invited callers to the hotline to participate in the study, and groups were led by a worker in the agency who received training and supervision from members of the research team. The program continued after the study ended and received a national award for excellence. Thus, when researchers partner with community agencies, dissemination of effective programs can occur more readily.

It is also important to carefully consider caregiver needs. If an evaluator does not have personal or professional experience working with caregivers, it is important for that individual to become familiar with caregivers' needs and what they hope to achieve by participating in a particular program. In this way, the aims of the evaluation are more likely to accurately reflect what is important to caregivers who are the consumers of the service.

The viewpoints of program planners, administrators, policy makers, and the sponsors of the evaluation of caregiver education and training programs are also critically important in the development of aims. These individuals often have a different perspective than clinicians and/or clients about what they would like the program to accomplish, and about what data are needed for decisions about practice and policy initiatives they may want to undertake in the future. They may also have a more global view of dissemination efforts, and the importance of translating research into practice in a wide array of communities and service programs.

The aims of an evaluation often overlap with stated program goals. For example, one goal of a caregiver program may be to educate caregivers about community resources and services. The evaluation may aim, therefore, to determine the impact of the program on caregiver knowledge of these resources and services. But evaluation aims may go further, for example, by examining the impact of the program on caregivers' actual use of community resources.

At other times, evaluation aims may have different purposes than program goals. For example, when a caregiver education and support program is developed, clinicians may view program goals as its ability to reduce caregiver depression. Administrators, however, may be more interested in the cost-effectiveness of the program, especially its impact on reducing caregiver and care recipient health use and care costs. Data from this latter type of evaluation may be used to help administrators develop contracts with Health Maintenance Organizations (HMOs) and Preferred Provider Organizations

(PPOs) to raise revenues, to deliver the program to a broader audience, and to lobby local and state policy makers for the expansion of new caregiver programs.

The aims of an evaluation may focus on the caregiver, the care recipient, the family, or the impact of the caregiver program on the larger society. Aims focused on caregivers may include changes in their psychological or social well-being, while aims focused on care recipients may also include evaluating changes in their physical health status. Aims focused on the larger society may include keeping frail older persons in the community for as long as possible. For example, one recent study on the effectiveness of a Health Education Program for caregivers found that the study had a positive impact on the standpoint of the health-care utilization and cost outcomes of the care recipients, as well as a positive impact on psychological and social variables (Toseland & Smith, 2006).

There have been relatively few studies about whether caregiver education and training programs save health-care costs. Mittleman, Ferris, Shulman, Steinberg, and Levin (1996) and Mittleman, Roth, Coon, and Haley (2004) found that a comprehensive caregiver support program for caregivers of persons with dementia delayed nursing home placement, but they did not conduct a comprehensive assessment of care recipients' health-care utilization and costs. Brodaty et al. found that a caregiving program can delay nursing home placement and death and reduce health-care costs overall (Brodaty & Gresham, 1989; Brodaty, Gresham, & Luscombe, 1997; Brodaty, McGilchrist, Harris, & Peters, 1993; Brodaty & Peters, 1991). Drummond et al. (1991) also found $20,000 of economic benefits for a caregiver education and training program conducted in Australia. In contrast, Peak, Toseland, and Banks (1995) found that a caregiver program for veterans only reduced costs for the frailest veterans. Brodaty et al. (2003) found that only 4 of 7 caregiver programs they reviewed delayed institutionalization, but Weinberger et al. (1993) found no cost savings. A more recent study by Wray et al. (2010) found significant short-term overall cost savings, but these cost savings were not sustained at 1 year follow-up. These mixed findings indicate a need for further economic evaluations of caregiver education and training programs in the future.

When developing explicit aims, it is also important to consider the number of objectives the program hopes to achieve and evaluate. Generally, the more aims one develops, the more outcomes need to be measured, and the more complex the evaluation becomes. The scope of an evaluation is determined to a large extent by the resources that are available to conduct it. It is also important to recognize that the more outcomes that are evaluated, the more likely it is for the evaluator to make a "type 1" error, that is, to conclude that the program has a significant impact on an outcome when, in fact, it does not. At the 0.05 probability level, for example, if one decides to measure ten outcomes, the error rate for the evaluation overall goes all the way up to 0.5, meaning that there is a 50% chance of at least one outcome appearing to be significant when in fact it is not. Although the tendency of many evaluators is to measure all outcomes that could possibly be affected by a caregiver education or support program, care should be taken not to inflate the type 1 error rate. This can be done by thinking carefully about primary and secondary aims, i.e., stating a priori what aims are most important and what aims are of secondary interest.

Whenever possible, it is important to develop hypotheses about each aim prior to beginning the evaluation. A priori hypotheses tend to sharpen the evaluation, making clear what effects are being evaluated, and the expected direction of those effects. For example, it might be hypothesized that a caregiver program will be significantly more effective ($p \leq 0.05$) than usual care in reducing depression among caregivers of dementia patients being seen at a primary care clinic. Stating a priori hypotheses avoids evaluation of all possible outcomes or the so-called "fishing expeditions," when all possible outcomes, even those that may not be related to the original intentions of the program, are examined. Although identifying serendipitous outcomes can be useful for future program development, causal inferences are best supported by hypotheses made prior to the implementation of the evaluation.

Background and Theory

When evaluating caregiver programs, it is important from both policy and practice perspectives to be aware of the existing caregiver literature as well as ongoing studies currently being funded by governmental and nongovernmental agencies. Literature reviews can help researchers to understand what is already known about caregiver education and support programs and where gaps in knowledge exist. They are helpful when thinking about the practice and policy relevance of the aims of the evaluation, and how these will further knowledge. Literature reviews can also identify important outcomes that might not have been considered by the evaluator, and they may yield information on specific measurement tools that have been shown to be effective when measuring particular outcomes.

A number of online resources now offer detailed information on evidence-based practice (EBP) in caregiving. For example, the Rosalyn Carter Institute (RCI) for Caregiving (2006) offers a web-based "toolkit" to assist in the choice and implementation of evidence-based caregiver programs. This toolkit includes articles and definitions for EBP in caregiving, guides for EBP implementation, and manuals, training materials, and other information on EBP caregiver programs (http://www.rosalynncarter.org/toolsresources/toolresources/). The RCI also maintains and updates an Evidence Based Caregiver Intervention Resource Center (http://www.rosalynncarter.org/grid/) that is the result of a comprehensive literature search and evaluation of caregiving scholars participating in the RCIs National Quality Care Network. A similar online service is provided by the National Center on Caregiving (NCC) maintained by the Family Caregiver Alliance (http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=368). The NCCs Research and Publication Unit publishes frequent updates on best practices and its Technical Assistance Unit provides telephone consultation and onsite assistance for program developers, with a special emphasis on identifying and replicating best practice model programs.

Ideally, evaluations of caregiver education and support programs should be framed within a theory explaining human behavior. Theories are useful in explaining the mechanisms by which caregiver programs affect caregivers, care recipients, or other support network members. For example, Lazarus and Folkman's (1984) stress, appraisal, and coping theory are frequently mentioned in the literature on caregiver outcomes. Using this theory, Morano (2003) and Oliver (2002) found that caregivers' appraisals of situations, and their coping skills had a significant impact on their psychological well-being. In fact, Oliver (2002) suggested that situational appraisals may be more significant determinants of well-being than actual stress.

Tsai and coworkers (Tsai, 2003; Tsai & Jirovec, 2005) have developed a Theory of Caregiver Stress (TCS) based on theoretical propositions from the Roy adaptation model (Roy, 1980). The TCS model suggests that depression acts as a mediator between perceived caregiver stress and self-esteem and marital satisfaction.

Theoretical models involving the interplay between caregiver stress, appraisal, and coping can be used by evaluators to explain how a support or education program helps caregivers adapt to the strains of caregiving. For example, if an evaluation confirms that the program had a positive impact on a particular outcome such as caregiver depression, then stress, appraisal, and coping theory could be used to explain the mechanisms underlying the impact. If a caregiver program teaches stress reduction strategies, the theory could be used to support the conclusion that the program worked by teaching caregivers new stress-reducing strategies. These strategies bolstered their coping skills, changed their appraisals, and reduced their stress which, in turn, contributed to reduced levels of depressive symptoms. An example of how the stress, appraisal, and coping theory has been used in the development of group intervention methods to support caregivers can be found in Toseland, McCallion, Smith, and Banks (2004) and Toseland et al. (2001).

Other theories such as the Progressively Lowered Stress Threshold model (PLST; Hall & Laloudakis, 1999; Richards & Beck, 2004; Stolley, Reed, & Buckwalter, 2002) and the Expressed Emotion (EE) model (Hinrichsen, Adelstein, & McMeniman, 2004; Magai, Cohen, & Gomberg, 2002; Nomura et al., 2005) have also been applied productively as theoretical frameworks underlying and directing the choice of interventions in caregiver education and training programs. Additional work is needed to determine how these and similar theoretical frameworks influence the impact of caregiver education and training programs, and what theoretical frameworks are most effective for different types of caregivers.

In addition to framing evaluations within an established theory of human behavior, it is also important to make explicit the theory underlying the interventions used in the caregiver program. Caregiver programs, for example, may use social support theory, cognitive behavioral theory, problem-solving theory, or other theories as the guiding framework for intervention components. When such theories are made explicit, they tend to sharpen the focus on the caregiver program, and enable the researcher to link particular program components to larger mechanisms for behavior change. Over the long-term, this fosters the development of new and better clinical programs and policies that are linked to a strong evidence base.

With respect to directions for the future, we need more and better theories about how to help caregivers. Most intervention programs are based on what researchers and clinicians think caregivers need, rather than on empirical evidence about caregivers' actual needs. One strategy for overcoming this tendency might be to examine what factors play into caregivers' decisions to institutionalize older adults, and then to develop individually tailored interventions to enable caregivers to keep their loved ones at home for as long as they want. Another strategy might be to ask caregivers about their needs and then to tailor interventions to directly address the expressed needs (Toseland, McCallion, Gerber, & Banks, 2002).

Participants

There are a number of factors to consider when selecting participants for evaluations of caregiver education and support programs. One is the size of the program's impact. In statistical terms this is referred to as the "effect size" that the evaluator would like to detect. The larger the effect size the evaluator expects to detect, the smaller the number of participants required for the evaluation. For example, if the evaluator believes a caregiver program will have a large impact on the outcomes measured, the evaluator may need to include only 40 participants in the evaluation to demonstrate this effect statistically. However, if the evaluator believes only a moderate impact will be achieved, 100 participants may be needed, and for a small impact hundreds of participants may be needed. Therefore, the size of the expected effect is critical in determining sample size. To calculate the number of participants needed to make sure a study is powered properly, the evaluator must have a prior estimate of the effect size that is expected. An estimate of expected effect size is usually based on prior research involving the same or a similar evaluation, preferably conducted with a similar population, or it can be based on a small pilot study of individuals who are likely to participate. The evaluator must also make decisions about the level of statistical power desired to detect a particular effect size (for example, 80 or 90% power to detect a given effect size), and whether the evaluator wants to detect positive and negative effects, or just positive effects. A complete but complex discussion of effect size, power, and the number of participants required for an effective evaluation can be found in Cohen (1988). Simpler explanations for those with less rigorous statistical backgrounds can be found in Dattalo (2007) and Kraemer and Thiemann (1987). Also, statistical programs such as NQuery Advisor are available to help simplify calculations of sample size easier. Powering studies correctly can help to avoid type 2 errors, i.e., concluding that there were no significant differences between a caregiver education or training program and a control group, when in fact there were significant differences but there were too few participants to detect these effects.

Few evaluations of caregiver training programs report how sample size was determined, or if the studies were sufficiently powered (especially after dropouts) to detect desired effect sizes. One important direction for the future is for evaluators to carefully consider effect size and power calculations when designing studies. When reporting outcomes and discussing conclusions, they should report both the a priori, expected effect size and the actual effect sizes observed, as well as the power of the study's actual sample size to detect significant differences. Taking this step will greatly enhance the rigor and usefulness of future studies.

Screening or targeting criteria are also important when deciding who will participate in an evaluation of a caregiver support program. Detailed exclusion and inclusion criteria can help sharpen the focus of an evaluation by specifying the intended target of the evaluation, and whether this particular group was served effectively by the program. For example, the target of an evaluation may be caregivers of persons with dementia, or caregivers with very high stress levels – groups which overlap, but are not identical. Similarly, the focus may be on adult children caregivers or spouses, male or female caregivers, or minority caregivers. Definitions of screening criteria have important policy and practice implications. For example, an evaluation that targets caregivers of persons with dementia may have important policy implications for keeping older persons with dementia in community settings, but few implications for caregivers of those with other diseases. For example, in a study of telephone support groups, Smith and Toseland (2006) found that the intervention had a much greater effect on adult children caregivers than on spouse caregivers. This differential effect was found because caregivers were carefully screened for their relationship to the care recipient, and were randomly assigned to groups composed solely of adult children or spouses. In general, evaluations with more restrictive exclusion and inclusion criteria can state with greater precision their impact on a particular subgroup of caregivers, whereas evaluations with less restrictive criteria derive less precise but more generalizable conclusions. For example, a study examining the effects of a training program for caregivers of persons with all types of disabilities could determine whether or not the program is effective for those who attended, but it is unlikely to reliably determine if the program was specifically effective for the few Latinas or the few African American caregivers who attended. For reliable conclusions about these populations, targeted studies of the training program for Latina and African American caregivers would be required.

One future direction for caregiver training and support programs, therefore, is to begin to identify subgroups of caregiver populations that could benefit from specialized interventions (grandparent caregivers, young adult caregivers, etc.), or subgroups that need special attention because interventions are either less effective for them or because they have received relatively little attention in the caregiving literature (ex. caregivers of persons who have experienced severe cardiovascular accidents/strokes, and caregivers of persons who have had bypass surgery and suffer from cognitive impairments).

When evaluating caregiver support programs, it is also necessary to consider strategies for recruiting and retaining participants in the evaluation. Collecting data from existing participants in a caregiver program is the easiest alternative, but it often has disadvantages, such as the inability to collect baseline data prior to participants' involvement in the program. There are many methods for recruiting new members, including (1) posting flyers about the program, (2) contacting social service agencies and civic organizations who may be aware of potential participants, (3) identifying participants through paper or computerized databases and then contacting them by mail, telephone, or during a face-to-face visit in clinic settings or at home, (4) publicizing the program through radio and television announcements or appearances, feature newspaper stories, or paid advertising.

We have found in many studies that identifying potential study participants through computerized medical records, and then contacting them by telephone or in-person when they come to clinic appointments, is an efficient means of recruitment. Feature newspaper stories and display ads in newspapers are also particularly effective recruitment tools. However, even using these methods, many evaluators report difficulty recruiting large numbers of caregivers for studies.

Another future direction, therefore, is to consider is how to make caregiver support programs more accessible and appealing. For example, we have been evaluating the effectiveness of telephone support groups for reaching out to caregivers who might not otherwise come to groups because of long travel distances or a lack of transportation. Internet groups may be another alternative for these caregivers. For a review of the literature about these "virtual" groups see Toseland & Rivas (2012), Toseland, Naccarato, & Wray (2007), or Glueckauf & Noel (2011).

Design

Many different types of research designs can be used to evaluate caregiver education and support programs, depending on the level of control the evaluator has over the assignment of participants to different study arms, and the type of data that is needed. A true experimental design, where caregivers can be randomly assigned to intervention and control arms, is the most effective design to control threats to the internal validity of the design, thereby enabling policy makers, practitioners, and scholars to place the greatest confidence in the findings comparing caregivers in different study arms. For information about threats to the internal and external validity of research designs see the classic text by Campbell and Stanley (1963). To randomize caregivers to conditions one can use a randomization program, such as the one that can be found at http://www.randomizer.org/.

It is important not to become confused between the notion of random assignment to intervention condition (i.e., caregiver education program vs. a caregiver support program) and random sampling from a population. Random assignment means randomly assigning caregivers to two or more intervention conditions for example, a caregiver education program and a wait-list control group. Random assignment helps us to rule out threats to the internal validity of the design. Because the internal validity of the design enables us to determine how confident we can be in the conclusions of the study findings, generally we are primarily concerned about random assignment and then, if possible, how closely the sample mirrors the general population of caregivers of interest (external validity of the design). Random sampling from a population has to do with the external validity of the study. It helps us to obtain a representative sample of caregivers from a specific geographic area or population of interest (ex. all long-distance caregivers, all adult children caregivers).

Most caregiver evaluation studies do not have the luxury of randomly sampling caregivers from a broad population of interest. Samples are often selected by soliciting volunteers or from an available group. For this reason, it is important to describe the sample in the study, and to compare it to any population figures for the local area, state or nation that may be available. This helps us to determine how generalizable the results of a study will be to a wider population (i.e., whether a caregiver education and training program that was found to be effective with one group of people in one community will be effective in another community with a different population of caregivers). For more information about the issue of random sampling and random assignment see Miller and Salkind (2002).

Sometimes, quasi-experimental designs are used because the evaluator is unable to form intervention and control groups through random assignment of participants to different arms of a study. More information on quasi-experimental designs and their effects on external and internal validity may be found in Shadish, Cook, and Campbell (2002). In cases where quasi-experimental designs are employed, it is important for the evaluator to specify the threats to the internal validity of the particular design chosen, and the implications for the findings and conclusions drawn from the evaluation.

Administrators, policy makers, and practitioners often do not realize that they may be able to employ a true experimental design in an evaluation without denying some caregivers the education or support program. A partial crossover or wait-list control group design, for example, enables all caregivers to receive the caregiver support program. In this type of design, some caregivers are randomly selected to get the intervention immediately, and others are placed on a waiting list. This type of design is particularly appropriate when recruitment efforts yield a large pool of participants who cannot all be served at once.

Administrators, policy makers, and practitioners sometimes raise ethical issues about placing caregivers in control groups. These concerns can often be allayed by making sure that caregivers in the control group are not denied any services that are routinely offered. In some cases, an augmented or alternative educational or support program can be put in place and evaluated to see if it is more effective than a current program. Administrators, policy makers, practitioners, and novice researchers can be counseled not to preempt the evaluation by assuming that the new program is more effective than usual care.

Another design issue that should be considered is whether persons collecting the data are kept blind to the intervention, and to what arms of the study participants are assigned. A single-blind design means that the data collector does not know to which arm of the study caregivers have been assigned. A double-blind study means that neither the data collector nor the participant knows to what arm of the study they have been assigned. Although single- and double-blind studies are recommended in the evaluation literature, they are often difficult to implement. Even when data collectors can be kept uninformed about whether a caregiver is in the intervention or control condition, caregivers often spontaneously mention their participation in the education or support group program to data collectors, or they mention that that they have not had any contact with the evaluation study since they took measures during a previous occasion. Double-blind studies are almost never possible, because caregivers need to be informed about their chances of receiving the intervention and control condition. Unlike placebo-controlled drug studies, where participants can be kept blinded to condition by taking pills that appear identical but contains either an active ingredient or a placebo, caregivers recognize whether or not they have been assigned to an intervention or control condition. Although blinding is not feasible in most studies, evaluators should take care to minimize bias by (1) not having access to responses from previous interviews (ex. baseline interviews), (2) cautioning data collectors and participants not to comment verbally on the caregiver programs being evaluated while taking the measures, and (3) reducing or eliminating the need for data collectors to interpret the data being collected. Although it may impose a strain on site resources, interventionists should never serve as data collectors because participants in the intervention arm of the study may not feel comfortable being candid about the impact of the intervention, particularly if their views are not positive.

Another potential source of bias is contamination between or among different intervention conditions or "arms" of a study. If caregivers from one arm of a study are likely to interact with caregivers from a different study arm, there may be some contamination of the purity of the intervention. The implications of this contamination may not be completely understood, but are likely to bias the study in favor of not finding outcomes, because those in the control group may have learned something about the training or education program by talking to or interacting with those in the intervention condition. This type of contamination is frequent in closed settings such as nursing homes or adult homes where residents interact frequently. If this is likely to be the case, efforts should be taken to reduce the possibility of contamination such as by asking caregivers not to talk with one another about the specifics of the intervention, and by making sure that caregivers do not interact when different intervention approaches are being offered at the same time. To make an assessment of the level of contamination, if any, caregivers can be asked periodically and at the end of the study the extent to which they knew about the specifics of alternative interventions offered in other arms of the study.

Still another design feature that should be considered is whether the evaluator wants to use intention-to-treat methodology, or a treatment received methodology. Intention-to-treat methodology retains participants assigned to a particular experimental condition (e.g., either intervention or usual care) in that condition for data analysis purposes, even if participants in the intervention arm refuse all or part of the intervention and return to usual care. Thus, using intent-to-treat methodology, if a caregiver crosses over from one arm of a study to another, they are treated in the analysis as if they remained in the original study arm to which they were assigned. This is a conservative way to approach data analysis and is the recommended procedure in the literature. In contrast, a treatment received analysis includes caregivers in the arm of the study in which they participated, even if it is not the one to which they were originally assigned.

Very few evaluations of caregiver support and training programs report whether an intent-to-treat approach was used. Most previous studies do not seem to use this methodology although it is highly recommended for rigorous field trials. One recommended future direction is that evaluations of caregiver support programs use this more conservative design approach to outcome analyses. For more information about intention-to-treat methodology, see Brown et al. (2008), Cuzick, Edwards, and Segnan (1997), or Kruse et al. (2002).

Specification of the Caregiver Program

It is important to carefully describe the components of the caregiver program before evaluations begin. Developing a manual that clearly describes the program, timing, intensity, and mode of delivery of each intervention component helps others to replicate it. This program description can also be used to publicize the program, and to disseminate it if it is found to be effective. Although manualized caregiver intervention programs are becoming more widely known, one important future direction is for additional manualized programs with good research support to be created. Toseland (2004) was commissioned by the Family Caregiver Alliance to review caregiver support programs and reports on how to obtain information on five of the most widely used caregiver support programs. The results of his review and analysis are posted on the Family Caregiver Alliance's website (http://www.caregiver.org/caregiver/jsp/content/pdfs/Education_Monograph_01-20-05.pdf).

It is also important to ensure that the intervention program is delivered as intended. When a caregiver education or support program is being evaluated it is helpful to systematically train the interventionists. It is also essential to put mechanisms in place to ensure that the program is being delivered with fidelity to the intervention manual or protocol that has been prepared. Experience in conducting evaluations of caregiver programs over the past 20 years suggests that interventionists sometimes have difficulty delivering the intervention as intended. Reviewing audiotapes or videotapes of the caregiver program being delivered is a good way to check on treatment fidelity and integrity. The tapes can also be used during consultation and supervision sessions with interventionists. While listening to a tape, the evaluator can rate, on a specially designed form, the extent to which the program is being delivered as intended. The evaluator can also take notes about what could be done to improve program delivery and to make it more closely reflect the intentions of the developers. One recommendation for the future is that more evaluators include treatment integrity/fidelity checks. Performing such checks has shown us that even some experienced workers do not know how to deliver the intervention as intended. Listening to tapes of groups and providing supervision can help workers deal with problems they encountered as they deliver caregiver training and education programs.

Measurement and Measures

To ensure the reliability and validity of the data that will be collected, it is important to standardize data collection processes. Several steps can be taken to ensure sound data collection. First, whenever possible, standardized measures with known reliability and validity should be used. Second, measures should be selected that are sensitive to change. Some measures are designed to measure traits that are unlikely to change as a result of a caregiver intervention. Unfortunately, many standardized measures do not include data about the sensitivity to change of the measure (i.e., any change that may be caused by the intervention program). Therefore, the evaluator often has to make a judgment about whether the wording of a particular measure is likely to be sensitive to changes that might be brought about by the caregiver education or support program. Third, the evaluator should be sure that all instructions are clear and appropriate to the level of reading or verbal comprehension of the caregivers participating in the evaluation. Fourth, those collecting the data should be carefully trained. Training should not be limited to verbal instruction. If personal or telephone interviews are planned, practice interviews are essential, first with research staff and then with caregivers who are similar to those who will actually participate in the evaluation. It is a good practice for the interviewer to solicit feedback from those who responded to practice interviews. At a minimum, this feedback should encompass the clarity, length, and substance of data collection processes and protocols.

Standardizing the measurement process also means being clear about who will be collecting data, when the data will be collected, and over what time period. In many evaluation projects there may be more than one data collector. In some situations, more than one person may be needed to collect interview or observational data. In other cases, data collectors may be collecting data from different data sources. For example, one data collector collects interview data while another abstracts data from medical records. Whenever multiple collectors are employed, the identity of the collector for each type of data should be recorded, so that it is statistically possible to test for differences in the data due to the variety of collecting styles. Also, each collector's data should be periodically checked to ensure adherence to standardized collection methods.

In addition to training data collectors, procedures should be developed about how data will be collected. For example, in one evaluation, pre- and post-test data may be collected during 1 h-long interview with caregivers within a week before and after the intervention. In contrast, in another evaluation a series of interviews may be needed to collect pre- and post-test data within a period of 1 month of the intervention.

Although it is not possible to identify all of the types of outcomes of caregiver education and support programs we may want to measure, frequently measured domains include: (1) emotional, such as perceived burden and stress, (2) psychological, such as depression and anxiety, (3) social, such as social support and social network, (4) physical, such as cognitive and functional abilities and survival, and (5) health-care utilization and costs. Commonly used measures of burden include the Zarit Burden Inventory, the Montgomery Borgotta Caregiving Burden Scale, the Caregiver Strain Index, the Caregiving Hassels Scale, and the Screen for Caregiving Burden. Montgomery and coworkers are also developing a Tailored Caregiver Assessment and Referral Tool that is currently being tested in field settings (Montgomery, 2007). Other measures can be found in books of measurement instruments such as those by Fischer and Corcoran (2007), Gallo (2006), Kane and Kane (2004), and McDowell and Newell (1987). There are, however, no minimum data sets or recommended measures for each domain although Montgomery (2007) is attempting to develop one and have it widely adopted, and similar efforts have been made within the Department of Veteran's Affairs. Therefore, one direction for the future is for consensus-building about a common core of measures. This would aid meta-analytic studies because researchers could more easily aggregate effect sizes from different studies using the same or similar measures.

Although standardized measures are available to measure aspects of some of the previously mentioned domains, there are times when nonstandard measures may be the only option available to capture the aims of the caregiver education or support program. For example, it may be appropriate to develop measures that collect data about participants' knowledge of local community services and resources. In these cases, evaluators should at least examine the internal reliability of any scaled measure that has been developed by calculating Cronbach's alpha on each measure collected during the evaluation. Preferably, an evaluator constructing a new scale should: (1) consult subject matter experts during initial item development, (2) include a reasonable number of items in the scale to increase reliability, and (3) perform a pilot test of the measure. For additional information on scale development see Loewenthal (2001) or DeVellis (2003).

To conduct effective evaluations of caregiver education and support programs, evaluators should be aware of potential measurement problems. For example, everything possible should be done to reduce social desirability, that is, the tendency of responders to make socially desirable responses that may not represent their true feelings. Research on the impact of social desirability issues on the measurement of caregivers' opinions and emotions find that caregiver responses are often affected by the need to present and/or perceive themselves positively (Chou, Chu, Tseng, & Lu, 2003; Kaub-Wittemer, von Steinbuchel, Wasner, Laier-Groeneveld, & Borasio, 2003). Written instructions, the interviewer's demeanor, and the nature of the questions can all affect the tendency to make socially desirable responses.

Other common measurement problems include ceiling and floor effects. These problems happen when caregivers respond very positively or very negatively to all or most of the items in a particular scale at baseline, and have little room to change in a more positive or more negative direction at post-test (Cooke et al., 2001; Harding & Higginson, 2003). Measurement of caregiver satisfaction is particularly vulnerable to ceiling effects. Satisfaction ratings are routinely high in health-care measurement, even when corresponding quality-of-care measurements focus on specific problems rather than global satisfaction with care. For example, Meyers and Gray (2001) reported high ratings of hospice care by caregivers who simultaneously reported high levels of caregiving burden and a diminished quality of life.

Suggested reasons for consistently high satisfy satisfaction ratings include a possible inability of caregivers to perceive that their situation could be improved; social desirability issues, including a desire to propitiate powerful health-care provider figures or a reluctance to appear ungrateful for help received; and a focus on the positive aspects of the situation as a means of reducing dissatisfaction through cognitive dissonance (Fakhoury, McCarthy, & Addington-Hall, 1996). The issue of ceiling effects in satisfaction ratings can be resolved by utilizing a combination of

Table 9.1 Sample items for measuring caregiver satisfaction

1. In the last 3 months, has your disabled parent experienced any problems with home care services?

Yes No

2. Overall, how satisfied are you with the services provided by the home care agency?

1	2	3	4	5
Not at all Satisfied	Somewhat Satisfied	Fairly Satisfied	Very Satisfied	Extremely Satisfied

forced-choice items focused on specific problems frequently experienced by caregivers, followed by multi-choice items rating satisfaction with experiences in the problem domain (see Table 9.1 for sample items).

Data Analysis

Although a detailed discussion of how to analyze data from evaluations of caregiver education and support programs is beyond the scope of this chapter, some topics worth mentioning include: (1) baseline comparisons, (2) differential attrition, (3) outliers, (4) transformations, (5) approaches to longitudinal data analysis, and (6) analytic approaches for censored data. With respect to baseline comparisons, even if participants have been randomly assigned to intervention and control conditions, it is important to compare demographic and other baseline data, to assess whether randomization has successfully smoothed any differences between caregivers in the comparison groups. Ideally, the evaluator hopes that comparison groups do not differ on demographic and other relevant variables. If differences are found, these may be able to be controlled through statistical procedures such as analysis of covariance. It is also helpful to compare baseline data to any population data, or normative data, that may exist related to the measures that are selected for inclusion in the evaluation. In this way, it may be possible to say how participants in the evaluation appear to differ from representative groups of caregivers.

Before conducting outcome evaluations, it is important to check the data for uneven attrition from groups. Identification and scrutiny of any outliers is also important, in order to determine if transformations of the data are needed. Differential attrition from intervention or control conditions can present problems for accurate data analysis because those who drop out prematurely frequently differ in systematic ways from those who complete their participation in the study. Therefore, it is important to compare those who drop out from those who remain in the study. If differential attrition is found, propensity scoring and other statistical techniques may be used to equate the groups (Cochran, 1968; Rosenbaum & Rubin, 1984). Outliers are the data points of individuals that are very different from the data provided by other participants in the evaluation. Frequently, outliers are defined as data points that are at least two standard deviations from the mean scores of the other participants included in the data set. Outliers are particularly common when working with utilization and cost data. Long stays in inpatient settings can often make some participants' costs for health care much higher than the average of all participants. Square root or log transformations of the data often can help to normalize data when outliers exist and make it possible to analyze data that might not otherwise meet the assumptions underlying the statistical tests being used.

Data from evaluations of caregiver education and support programs often contain repeated measures. Repeated measurement may involve baseline data, data collected after intervention, and perhaps one or more follow-up data collections to examine the long-term effect of a program. There are several ways that these data can be analyzed. If only pre- and post-test mean scores are being compared, a simple correlated *t*-test can be used. If there is an intervention and a control condition, and data are collected at baseline and after intervention, three types of analyses can be used. One method is to calculate change scores, or the difference between pre- and post-test scores, and then to use an uncorrelated t-test to compare outcomes for the intervention and control group. This method can only be used if there is one intervention and one control condition. A second method that can be used with two or more comparison groups is to use baseline scores as covariates in an analysis of covariance. A third method that can be used is repeated measures analysis of variance. Repeated measures analysis of variance is more flexible than the other two methods because it can handle data from more than two measurement periods (for example data collected at baseline, immediately after a caregiver education or support group intervention, and then again during a follow-up period).

There are also newer methods for an analyzing data such as Random Effects Regression Models (RERMs) and Mixed Effects Regression models (MERMs). RERMs and MERMs offer several advantages over more traditional repeated measures data analysis approaches (Hedeker, 1995; Molenberghs & Verbeke, 2005; Singer & Willett, 2003). All participants can be included in data analyses, even subjects' data that are partly or completely missing. Random subject effects can be included in MERMs to control for subject-to-subject differences while outcome measures over time can be fixed effects. RERMs and MERMs also allow for adjustments of variance covariance matrix, such as adjustments for first-order autoregressive error terms, that is, the greater correlation often observed between data points that are closest in time. For example, health-care costs incurred in one 3-month period are likely to be more highly correlated with health-care costs during the next 3-month period than they are with health-care costs incurred in subsequent 3-month intervals. For more information about RERMs, MERMs and other methods to handle longitudinal data from evaluation of caregiver education and support programs see Singer and Willett (2003).

Another statistical technique that can be useful during evaluation of the impact of caregiver education and support programs is survival analysis. Survival analysis appropriately accounts for censored data, such as when the evaluator wants to examine if an education or support program has an impact on time to nursing home admission. Further guidance on survival analyses is available in Hosmer and Lemeshow (1999) and Kleinbaum and Klein (2005).

Human Subjects

The use of human subjects in behavioral science research requires attention to a number of issues, including legal and ethical treatment of subjects across a variety of research protocols. Prior to conducting an evaluation of a caregiver program, the study protocol is normally reviewed by an institutional review board (IRB) where the study will be conducted. In some cases, a community review board may conduct its own review. However, many community agencies frequently request a review by a locally prominent research institution, such as a university or hospital. Evaluations of caregiver education and support programs can present evaluators and the IRB with some particularly difficult issues. For example, if the evaluator wants to collect data from caregivers and care recipients who have dementia, special safeguards may have to be put in place to ensure the protection of the rights of persons with dementia who may not be able to understand consent forms.

Special issues are also encountered when evaluators wish to use data from medical records. The implementation of the Health Information Portability and Accountability Act of 1996 (HIPAA) in April 2003 has numerous implications for research involving health records and/or medical data in human subjects research. Specifically, HIPAA restricts certain types of transfers of personal health information (PHI) between institutions, which may create difficulties for many researchers. For example, research on caregiving often involves the use of data from the care recipient or caregiver's health records. In the past, this required only consent by the caregiver and/or recipient, and reasonable attempts to maintain confidentiality of the data. However, HIPAA requires more stringent safeguards.

Most institutions are able to comply fully with the complex requirements of HIPAA by creating what is called a limited data set. A Data Use Agreement specifying the contents of the transferred data is required between the covered entity (a health plan, health-care clearinghouse, or health-care providers) and the limited data set recipient (usually the researcher). The data use agreement also specifies safeguards used by the recipient to protect the privacy of the data, how the data will be used, and length of time a limited data set may be maintained by the researcher before being returned or destroyed.

A limited data set, as defined in HIPAA, is a PHI that can include specific identifiers and must exclude others. A limited data set may include dates (e.g., admission, discharge, and service dates, dates of birth and death), five-digit zip codes, and names of state, county, city, and precinct, but not any other postal address information. A limited data set must exclude the following direct identifiers of an individual and his or her relatives, employer(s), and household members: name; postal address information (except town or city, state and zip code which are permitted); telephone numbers; fax numbers; electronic mail addresses; social security numbers; medical record numbers; health plan beneficiary numbers; account numbers; certificate/license numbers; license plate numbers and other vehicle identifiers and serial numbers; device identifiers and serial numbers; URLs; Internet Protocol (IP) address numbers; biometric identifiers including finger and voice prints; and full-face photographic and any comparable images.

If the dataset can be stripped of all specific identifiers, including those allowed in a limited dataset, a data use agreement may not be required. However, many health care and research institutions have evolved their own requirements for complying with HIPAA. Health care organizations and researchers considering transfer of PHI for research purposes should check with their IRBs about the specific requirements at both sites. More information on HIPAA may be obtained on the U.S. Department of Health and Human Services Website at http://www.hhs.gov/ocr/hipaa/.

Conclusions

With respect to the current status of efforts to evaluate caregiver education and support programs, more and better evaluations have been conducted in recent years. Review studies that have summarized and analyzed the literature have concluded, for the most part, that caregiver programs are moderately effective in improving the emotional well-being and knowledge of caregivers (see, for example, Schulz et al., 2002). Although some evidence points to the greater effectiveness of individual as compared to group programs (see, for example, Knight, Lutzky, & Macofsky-Urban, 1993), these findings are from meta-analyses, not from comparison of individual and group education and training programs within the same study population. There is some evidence that group intervention is at least as effective as individual intervention in studies where the two modalities are compared directly (see, for example Toseland & Siporin, 1986). Therefore, additional studies directly comparing individual and group approaches to the same caregiver education and training programs are needed.

In addition to the recommendations for future directions made throughout this chapter, new evaluations of caregiver education and support programs may want to focus on programs for specific subgroups of caregivers. For example, although some caregiver education and support group programs have been adapted for working with different racial/ethnic groups, more work needs to be done in this area (Ramos, Jones, & Toseland, 2005; Toseland & Rivas, 2012). Similarly, some efforts have been made to develop caregiver education and support programs for caregivers of persons with specific illnesses, but most of this work has been limited to dementia caregivers (see, for example, Bourgeois et al., 1996; Schulz et al., 2002). Focusing educational and support efforts on specific diseases may allow interventionists to more carefully target educations and support strategies to better meet caregiver needs.

Implications

With respect to clinical practice, evaluations of caregiver education and support programs can help to identify effective and ineffective intervention strategies and to determine the magnitude of impact of different intervention strategies on different outcome variables. In some ways, we are just beginning to understand how to intervene effectively with caregivers. EBP is in its infancy in caregiver education and training programs. A careful examination of the standardized caregiver support programs most widely used in this country today show that they have a very limited rigorous evidence base supporting their use (Toseland, 2004). More evaluations of these studies used in actual field settings with a wide variety of populations are needed.

With respect to research, this chapter suggested that successful evaluations are best conceived as partnerships between evaluators, program administrators, and clinicians. Evaluators bring the research knowledge necessary to conduct rigorous evaluations, administrators bring their expertise about how to conduct evaluations within clinical settings, and clinicians bring their knowledge about effective intervention strategies. Although this chapter focused primarily on quantitative evaluation approaches, qualitative evaluations are also useful because they can provide rich descriptions of the impact of particular intervention strategies, and they can also help to elucidate effective coping processes that may be used in other education and support programs.

With respect to education and training, it is clear that rigorous evaluations of caregiver education and support programs require education and training in social science methodologies and statistics. Although program administrators and clinicians may not have technical evaluation skills, it is important for them to have a commitment in improving their practice and providing the highest quality services possible. Most undergraduate and graduate programs in the human services help students to appreciate the benefits of research, and many graduate programs teach students how to understand and properly interpret the results of evaluations and other research studies. Although administrators and clinicians may not have the time or the capacity to collect and analyze data, their support combined with the expertise of evaluators enables them to examine the programs that they deliver. Therefore, the support of evaluations by administrators and practitioners is critical and working in combination with researchers, can lead to more rigorous evaluations and a greater appreciation and understanding of the impact that caregiver education and support programs have on services to caregivers and care recipients.

With respect to policy and advocacy, evaluations of caregiver education and support programs provide data that policy makers and advocates can use to argue for caregiver programs in community and workplace settings. Most evaluations of caregiver programs are the type sometimes referred to as “efficacy” studies. These are single site studies used to evaluate a model program. Less attention has been paid to “effectiveness” evaluations that seek to determine if model programs that have been found to be effective in a single site are effective when they are disseminated widely and used in a variety of settings. As knowledge about caregiver education and support programs continues to increase in future years, more data will become available about the effectiveness of caregiver programs in a wide variety of community and institutional settings.

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Chapter 10
Current and Future Directions of Education and Support Programs for Caregivers

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This book is focused on the current and future directions of education and support programs in four areas: (1) professional practice, (2) education and training, (3) research, and (4) policy and advocacy. Caregiving and support for family caregivers have continued to take on increasing significance in the American society as baby boomers' age and life expectancy increase. As the debate rages about what to do to contain the increasing cost of health care, the central importance of family caregiving remains unquestioned. This concluding chapter will consider the current state of education and support groups for family caregivers and make recommendations that will help improve practice in the future.

Professional Practice

As the first decade of the twenty-first century comes to a close, one theme that emerges from the previous chapters is the tremendous increase in the last three decades in education and support programs to assist family caregivers. Programs to assist family caregivers are available in institutional and community settings in many areas of the country. They range from programs for young caregivers to grandparent caregivers. However, the great majority of caregiver education and support groups continue to be focused on adult children and spouses, and more programming is needed for young caregivers and grandparent caregivers.

Despite the increase in programs, we have several recommendations for professional practice with caregiver education and support programs of the future. First, most of the attention in the literature has been on support groups and educational programs for those with dementia. Even in this arena, however, there are significant gaps. There is a lack of support programs for those with early onset and early stage

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dementia and their family caregivers. There has also been little differentiation in programs regarding the needs of caregivers of people in the different stages of dementia. As the number of people with dementia increases in the twenty-first century, specialized education and support programs for caregivers of those with different stages of dementia will be needed.

Our first recommendation in the professional practice area also implies that there has not been enough attention in the literature to programs for caregivers of persons with other important health problems such as cerebrovascular accidents (CVAs or stroke), diabetes, chronic obstructive pulmonary disease, congestive heart failure, and end-stage renal disease. We know very little about caregiver needs in these areas and whether they would respond to education or support programs specifically focused on these diseases. Strokes, for example, can have a chronic effect on both mental and physical abilities, implying that caregivers may need the kind of support now being provided to caregivers of dementia patients. By contrast, the needs of caregivers of persons with other major diseases such as congestive heart failure may be more episodic and require different kinds of education and support programs. More research is needed in this area as we move further into the twenty-first century.

More attention should also be given to specialized populations, such as young caregivers of older adults and grandparent caregivers of children and teenagers. Young caregivers are a particularly difficult population to identify and to serve, yet one landmark study found that there are 1.4 million caregivers aged 8–18 (National Alliance for Caregiving in cooperation with the United Hospital Fund, 2005). Schools and hospitals may be one place to identify young caregivers. Identifying the appropriate services for them may be challenging because group programs for children spanning ages of 8–18 are not widely available, and forming age-appropriate groups could be difficult due to the lack of child caregivers within different age segments. More research is needed to determine how to identify and serve this group of caregivers. Grandparent caregivers have received more attention in recent years, but more research is needed to target services to them, especially those in poverty and those living in inner city and rural areas.

A second recommendation from several authors in the book is the need for much greater attention to minority caregivers. The American population has become increasingly diverse, and by 2042 white Americans are expected to be in the minority (U.S. Census Bureau, 2008). At the same time, we know that many minority family caregivers are much harder to reach than non-minority caregivers. Greater sensitivity to cultural norms of caregiving is necessary. While some cultural groups find it difficult to address these issues within a group context, others seek to validate their preferences by providing extended family care. We need new professional models, not only for understanding cultural differences and preferences, but also best practice models for reaching out to and sustaining engagement with minority caregivers in education and support groups. Although new models are emerging (see, for example, Cox, this book; Gallagher-Thompson et al., 2004, 2006; Knight & Sayegh, 2010; Nichols et al., 2004), more efforts in this area are urgently needed.

In the assessment of barriers to minorities receiving support and educational services, the Anderson behavioral model was used in this book to pinpoint predisposing, enabling, and need factors. Some barriers to the accessibility of caregiver educational and support programs by minority clients may be overcome by careful consideration of the most appropriate sponsors for such programs. Sponsors that are known and trusted by minority communities are in a much better position to recruit and retain caregivers from minority groups than community organizations that serve few minority clients. Similarly, matching the ethnic and racial backgrounds of recruiters and leaders of educational and support programs to the backgrounds of the caregivers who are to be served will help to increase caregivers' comfort with recruitment efforts. Program staff from similar backgrounds may also be able to decrease some of the barriers experienced by minority caregivers engaging in education and support programs, thus enabling such programs to meet their specific needs and sustain enrollment.

A third recommendation from the contributors to this book is to increase the use of technology to strategically reach those who cannot or prefer not to attend face-to-face groups. Glueckauf and Noël (this book) have shown that telephone technology can be effective in targeting services to hard-to-reach caregivers. In fact, when comparing groups for spouse and adult child caregivers, Smith and Toseland (2006) found that some adult children caregivers preferred teleconferencing to face-to-face groups because it fits better into their busy schedules. In recent years, telephone conferencing has become much cheaper with Skype and similar voice-over internet providers offering services at low cost. Therefore, teleconferencing education and support group may become more widely used in future years. Although video conferencing has also become more widely used, especially in medicine and nursing, most systems only allow for two-way interaction, making group video interaction from multiple individual sites impossible. With technological advances, this may change.

There has also been some exploration of the use of computer groups for education and support seminars. These allow a speaker to make a presentation over the telephone and to have slides or other digitized streaming computer media during the presentation. Such presentations can be followed by question and answer periods by caregivers who are on the telephone. There have also been online education and support groups that include synchronous (chat rooms) and asynchronous (bulletin boards) communication. Bandwidth can be a challenge with some of this technology, especially in areas not served by high-speed internet services. Additionally, some older adults do not have computers, do not intend to use them, or cannot afford high-speed connections. But this will certainly change in future years as older adults become more computer literate and access to high-speed internet becomes more accessible.

A fourth recommendation is to re-examine our conceptualization of the "caregiver" in emerging support and education programs. Although there have been a few studies of family treatment programs, there are very few of these reported in the gerontological literature. We need to include a better understanding of family systems of care including family friends and the so-called "fictive kin," not just caregivers in our education and support programs. Caregiving is a family affair, and often more than one family member is involved in caregiving. However, our education and support programs rarely address the issue of multiple caregivers, conflict among family caregivers, and the inclusion of caregivers who are fictive kin, or close family friends. Expanding caregiver education and support and programs to include family and friends, and family issues, would improve professional practice. Programs such as “Share the Care” and “Lotsa Helping Hands” are just two examples of resources that could be used by caregiver support and education programs to reach a wider array of family caregivers and close family friends.

As educators consider program development and expansion, they need to pay closer attention to the specific stage of the caregiving process. Most education and support programs focus on caregivers who are in the middle stage of caregiving. However, more effort should be focused on caregivers who are at the beginning of the caregiving trajectory to assist them earlier in the process to become engaged with caregiver support systems and to help them receive the services they need. This will also facilitate their understanding of the stages of caregiving and the services and community resources they may eventually need. We also need to ensure that caregivers in later stages of caregiving receive assistance from programs such as hospice, bereavement services, and other resources that are available to provide skills for coping during this difficult stage in the caregiving trajectory. Recent articles such as one by Blieszner & Roberto (2010) that focus on the responses of care partners to mild cognitive impairment may help to spur the development of stage-specific intervention programs for caregivers.

Education and Training

One recommendation for education and training in the twenty-first century is that we will need to improve how we disseminate caregiver education and support models, and provide more effective guidance and training about using the models. (Perhaps Area Agencies on Aging could facilitate this process.) Recently, a number of group manuals and training programs have been developed, several of which are described on the Family Caregiver Alliance’s National Center on Caregiving website, www.caregiver.org. There are also many other websites and organizations that offer advice and guidance to professionals and caregivers. Many of these organizations and resources are listed at United Hospital Fund’s website www.nextstepincare.org, the Rosalyn Carter Institute for Caregiving website www.rosalyncarter.org, and the National Alliance for Caregiving website www.caregiving.org. Despite this information, there have been a few systematic reviews of caregiver education and support model programs. Gallagher-Thompson & Coons (2007) provide one of the few reviews of evidence-based programs for caregivers, but this review includes psychotherapy and multicomponent intervention programs in addition to the pschoeducational and support programs that are the focus of this book. A state-of-the-art review of existing caregiver education and support programs, available training programs and costs, evidence bases, and how to access leader manuals and participant workbooks would be very helpful to both professional and lay leaders.

A second recommendation is that the training for group leaders of education and support programs should be intensified, updated, and relevant to the specific educational backgrounds of the leaders. In their chapter in this book, Maas and Specht mention the need for more training for professionals and paraprofessionals as to how to lead caregiver support groups. Yet, very little has been written about the leadership and co-leadership of caregiver education and support programs. In addition to leadership skills, there is a need for education about how to develop helpful group dynamics, and recognizing and working with the developmental stages education and support groups go through. Skills in the planning, beginning, middle, and ending stages of education and support groups are essential. However, few workers have received training in the leadership of groups and the empowerment of caregivers to take informal or formal leadership roles.

A third recommendation is that more education, training, and research are needed about the most effective formats for education and support programs. Anecdotal information suggests that many community support groups meet on a monthly basis for long durations. They are led in a fairly unstructured manner that emphasizes mutual aid and shared information. In contrast, most of the researches that have been carried out have focused on highly structured groups that met weekly for relatively short periods of 6–12 weeks. Similarly, some community groups have an open membership policy, while research studies almost always have closed groups with no new members entering after the start of the program. More systematic information is needed about why programs are effective or not, the specific ways in which the majority of community groups are led, and how rigorously controlled trials of time-limited structured groups can be best translated and implemented in community settings.

Even less is known about educational groups. Many community organizations offer half day or full day workshops for caregivers, but these are rarely evaluated. Zarit (2009) asserts that merely giving information and advice to overwhelmed caregivers is insufficient because it is often ignored, rejected, or not followed up for unknown reasons. He suggests that caregivers need to work with professionals over a period of time to unravel complicated family and individual issues. Thus, we need to know more about the effectiveness of educational seminars and workshops that last from a few hours to a day as compared to more intensive efforts that engage caregivers over a period of time. More attention should also be given to specialized populations such as young caregivers of older adults and grandparent caregivers of children and teenagers.

Research

Our first recommendation in the area of research is to screen caregivers for the type of problems the study is addressing. Not all caregivers are bothered by depression, anxiety, or caregiver burden. If we do not screen for the problems we hope the intervention will address, then there will be a number of people within the intervention group who cannot possibly benefit from the intervention, because they do not have the target problem(s). For example, if we are developing an intervention study to help caregivers cope with depression, then we should ensure that everyone entering the study has depressive symptoms or diagnoses of depression that can be ameliorated by the intervention. Most caregiver studies have not taken this approach and consequently effect sizes are weakened as many of those being treated are not able to benefit from the intervention.

Our second recommendation is to begin to tailor intervention studies to the needs of the caregivers in the study (Foster, Layton, Qualis, & Klebe, 2009). Caregivers often do not have a single problem such as depression or anxiety. One possibility is for caregivers to specify the goal or goals they want from the intervention and use goal attainment scaling to determine whether the caregivers have met their own goals (Kiresuk, Smith, & Cardillo, 1994; Marson & Dran, 2010). This would avoid researchers developing goals such as "reducing burden" that might not be salient for caregivers. For example, spousal caregivers of persons with dementia may indicate that they accept the burden of caregiving, and feel that it is their duty to take care of their loved one. What they might want instead of a reduction in subjective feelings of burden is a reduction in difficult behavioral symptoms of dementia of the care recipient. We recommend that caregivers should be asked at the beginning of education and support programs to identify what problems they want to address, and then tailor interventions within the programs to focus on specific individual goals. This also fits with current strengths-based movements to empower caregivers and give them as much freedom as possible to choose their own care plan for their loved one (McClive-Reed & Toseland, in press). Whenever possible this should also include inviting the care recipient and other family members to state their perception of needs and to foster a dialog between the primary caregiver, the care recipient and other family members about an appropriate and acceptable care plan.

Our third recommendation is to be careful about meta-analytic studies that have concluded that individual interventions may be more effective than group interventions. We know from the group work literature that when individual and group interventions are compared directly there does not appear to be any difference in outcomes, and in fact, group interventions may be superior in some cases (Toseland & Rivas, 2012). Meta-analytic studies may give false impressions because they often compare individually tailored interventions to group programs that do not individually tailor interventions. We need additional studies of individual and group studies on the same population using the same intervention approach to see if, indeed, individual interventions are more effective. Certainly, the popularity of educational and support group programs suggests that these programs may offer certain benefits to participants such as expanded support networks, mutual sharing and support that may not be duplicated in individual interventions. Thus, when comparing individual and group intervention programs, we should also carefully consider the measurement outcomes for the two types of approaches. Group education and support programs, for example, may increase social support and social networks, whereas individual programs may be better at training caregivers in specific skills or dealing with depression. Further research is needed that directly compares the efficacy and efficiency of individual versus group support and education programs.

A fourth recommendation is that treatment interventions should be carefully tailored to the outcomes they intend to produce, and there should be fidelity checks to ensure that interventions are delivered in the ways that they are specified (Zarit & Femia, 2008). Sometimes it is difficult to see the link between the intervention modules and the desired outcomes. The closer the link, the more likely the intervention will have an effect. Ensuring through treatment fidelity checks that the intervention is delivered in a standardized way is necessary to determine whether the intervention has been effective at changing the outcomes specified.

A fifth recommendation is that more studies of the effects of caregiver education and support programs on health care utilization and costs are needed. Although the chapter by Toseland, Smith and McClive-Reed in this book has identified a few of them, more studies are needed to examine the cost-effectiveness of caregiver support and education programs. Evidence of the specific attributes of cost effectiveness studies could lead to more successful policy and advocacy initiatives. Delays in nursing home placement, reductions in hospitalizations, and unnecessary outpatient use by caregivers who do not know where else to turn could potentially reduce expenditures on long-term care costs because the costs of education and support programs are relatively modest compared with outpatient, inpatient, or institutional care.

Policy and Advocacy

Our first policy recommendation is that a uniform assessment instrument be developed to determine the specific needs of caregivers. We are not alone in making this recommendation (Feinberg, 2004; Feinberg, Newman, Gray, Kolb, & Fox-Grage, 2004; Feinberg, Wolkwitz, & Goldstein, 2006). A uniform assessment would make comparisons across caregiver education and support programs possible. Although a complete assessment may not be possible for some community programs, even a partial use of some of the assessment tools recommended in a comprehensive uniform assessment would allow for comparisons across programs.

A second recommendation is that education and support programs should emphasize a single point of entry system created through the existing national system of Area Agencies on Aging with the assistance of the National Family Caregiver Support Program. A single point of entry system could foster the use of a standardized screening and assessment tool. We recognize that there are challenges to single point of entry systems. While agencies may be reluctant to give up their own intake procedures, duplication of services may arise as referral agencies put their own assessment and intake procedures in place in addition to single entry point system assessments. As a starting point, Feinberg et al. (2006) recommended greater collaboration between health care systems and the aging network.

Caregiver resource centers and 800 numbers that help caregivers gain access to existing education and support programs within a geographic area are other beginning efforts to implement single point of entry systems.

When considering the implementation of single point of entry systems, it is important to examine whether there are conflicts among different funders of care. For example, state Medicaid Home and Community-Based Waiver Programs and Medicare Programs may vie for single point of entry systems for long-term care and may undermine a single point of entry system supported by Area Agencies on Aging. Cross-governmental task forces and policy debates should be put in place to handle these conflicts so that one single point of entry system is developed that can serve the widest possible group of caregivers. During these policy debates it is important to act as advocates for the aging network and Area Agencies on Aging as being the best choice for a single point of entry system. This seems to be the best option because of their knowledge of the needs of family caregivers and their familiarity with a wide range of resources for both caregivers and care recipients in the local community.

A third recommendation is to continue to expand the Family and Medical Leave Act of 1993 in order to encourage more caregivers to participate. Paid leave, expanded coverage beyond public employees, and coverage for caregiving across the life-span are a few ways the program could be expanded in states that do not have these options. Program expansion would enable more caregivers to take advantage of education and support programs as well as many other services offered by the aging network. With the backing of the Olmstead Decision and the Americans with Disabilities Act, advocates can promote the expansion of state Olmstead plans to include caregiver education and support as one part of community-based service options to delay institutional care.

A fourth recommendation is to advocate for public long-term care insurance plans, or in lieu of public long-term care insurance, private insurance that includes coverage for caregiver education and support programs. Currently, most private long-term care insurance and public–private partnerships offer coverage for home health care aides and other in home services. There is little recognition of the important role that family caregivers play in the lives of those who are covered, or how to maintain and enhance the role of family and other caregivers in care plans.

A fifth and final recommendation in the policy and advocacy area is to promote increased collaboration among policy makers, practitioners, and consumers to improve the quality of caregiver programs in the twenty-first century. Collaboration is the most effective approach for sustaining the efforts of caregivers and for achieving optimal care for those in need of assistance (Haigler, Mims, & Nottingham, 1998). The Rosalynn Carter Institute for Caregiving has sought to find "common ground" among professional and family caregivers and care recipients with various illnesses and disabilities across the lifespan (Haigler, Bauer, & Travis, 2004). This approach is gaining interest among researchers and practitioners and will provide an important theoretical framework for collaboration in the future (Roberto & Jarrott, 2008).

Conclusions

Education and support programs to support caregivers and their families have emerged and grown dramatically in the last three decades. Despite this development, research indicates that there continues to be a need for additional services as well as research on their effectiveness and efficiency (Toseland, McCallion, Gerber, & Banks, 2002; Zarit, 2009). As we look to evidence-based approaches, three important questions for caregiver education and support programs emerge in the twenty-first century: what intervention has the best effect, what factors best predict desirable or undesirable outcomes, and what assessment and intervention tools should be used (Rubin, 2008). Although the future remains uncertain, we expect that if our recommendations are put in place and if we begin to answer these questions, an improvement in the outcomes of caregiver education and training programs will be seen in the twenty-first century.

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Index

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