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Caregiving Families Within the Long-Term Services and Support System for Older Adults

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Long-term care services and supports are primarily a family industry that warrants psychologists' involvement through practice, research, and policy advocacy. Families are poorly integrated into service systems despite the dominance of family caregiving work within health care and long-term care. This article positions family caregiving work within the context of family life across the life span, noting overlaps and distinctions between normal family life and caregiving work for older adults whose physical or cognitive challenges require assistance. The prevalence, work, and consequences of family caregiving for older adults are described. Families are identified as key partners in long-term care, despite substantial policy and practice barriers to integrating them into care structures and systems. Policy options for reducing or eliminating barriers are suggested, as are professional practice opportunities for psychologists to support caregiving families. Approaches to assessment and interventions for caregivers across a variety of settings are described. Gaps in research are highlighted, with a focus on how to understand caregiving as embedded within context of family, long-term care services and supports, and health care. Caregiving work presents an imperative for expanding psychologists' engagement in integrating and supporting the families whose caregiving is so critical to a rapidly aging society.

Keywords: aging families, caregiving, long-term care, public policy

Long-term care for older adults is primarily a family industry. Families provide over 75% of all long-term care provided to older adults (Thomas & Applebaum, 2015) and 90% of long-term care for all adults (Kaye, Harrington, & LaPlante, 2010). This article sheds light on a key issue within the 2015 White House Conference on Aging's (2015) focal area of long-term services and supports, namely, the work provided by families that is referred to as *caregiving*. Family caregiving is viewed within the context of normal family care across the life span, with associated costs and benefits. Assessment of family members' well-being and the contexts of caregiving should be integrated into various settings in which families interface with service delivery systems. Interventions that benefit caregivers are reviewed, and the gaps in knowledge and services that would benefit caregivers are outlined as key policy issues. Psychologists' opportunities to support caregivers through research, advocacy, and services are highlighted.

Definitions of caregiving clearly overlap with services provided for persons in formal long-term care systems, as well as with work that is considered normal within family life.[1] Paid caregivers provide services in many industries within the long-term care service system, including assisted living, home health, and nursing homes. Family members who provide care are typically unpaid caregivers (sometimes called informal caregivers). The 2015 report on the most recent national survey by the AARP and National Alliance for Caregiving (NAC) defined caregiving for adults as "unpaid care to a relative or friend 18 years of age or older to help them take care of themselves," identified with including "helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing" (AARP & NAC, 2015, p. 3). The inclusion rules of this definition reference four characteristics: (a) work is unpaid, (b) care recipient is adult (age 18+), (c) caregiver had prior relationship with care recipient as family or friend, and (d) services are provided that help with personal needs

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[1] In this article, the term *family* is defined broadly to include nuclear, extended, chosen, fictive kin, and close-friend relationships that function as family.



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or household chores. Note that these definitions are broad, encompassing a heterogeneous population that inevitably includes quite diverse subpopulations and is thus likely to reflect wide variability in experience. Although the breadth of the definition suits the purpose of the survey conducted by AARP and NAC, that same breadth presents challenges to researchers, practitioners, and policymakers who seek precision. Specific policies, agency operating rules, or research projects use definitions that vary according to characteristics of the caregiver, care recipient, or the caregiving tasks.

By definition, adult family caregivers have a history in which the person receiving care has other, longer term titles such as husband, wife, partner, daughter, son, niece, or friend. Although the caregiver may perform new tasks for the care recipient, the caregiving tasks also may have a history, having been accomplished in the same or a different way during their historical relationship. Indeed, assistance with instrumental activities of daily living (IADL) are commonly shared or divided among members of households of healthy adults (e.g., spouses) to add efficiency to household function. Giving and receiving care is considered a fundamental aspect of family life and friendships rather than an inherently extraordinary task. What is implicit in the definition is that the presence of illness or disability positions one person to *need* assistance, shifting the task functions from a simple family or friend task to a caregiving task, and thus shifting the roles into what is defined as caregiving.

Who Are the Caregivers and Care Recipients?

The AARP/NAC survey released in 2015 is the most recent in a series of surveys of unpaid family caregivers in the United States conducted since 1997, and is used extensively by policymakers (AARP & NAC, 2015). Using the definition above, they estimate that 34.2 million adults in the United States provided care to an adult age 50 or older in the previous 12 months, representing approximately 14.3% of the entire American adult population. The vast majority are relatives (85%) caring for one adult (82%), but 18% take care of more than one adult. Caregivers are more likely to be female (60%) than male (40%). The caregivers' average age is 49.2, a mean that includes adult children as well as spousal caregivers who tend to be considerably older (average age of 62.3 years old). Variations by race and ethnicity show the oldest average age among White caregivers (52.5), which is greater than the average age of African Americans (44.2), Hispanics (42.7), or Asian Americans (46.6).

Living arrangements vary based on the complexity of the care recipients' needs and the race and ethnicity of the caregivers. Almost half of care recipients live in their own homes (47%), although 35% live with the caregivers. The remaining 18% live in a long-term care or senior housing facility or others' homes. Caregivers' time investment varies by site of residence of the care recipient. Most of the caregivers (57%) who invest under 21 hr/week in caregiving are providing services for recipients living in their own homes, whereas most of the caregivers (62%) who provide 21 or more hours of care live with the care recipient. Caregivers who reside with care recipients have been in the role on average over 5 years, approximately 2 years longer than caregivers to persons living alone. Coresidence probability increases with the complexity of the care situations.

The care recipients addressed here are older persons with functional disabilities who have a prior relationship with the person now defined as caregiver. The reason for needing care may be physical disabilities, most commonly from arthritis, heart disease, and diabetes, or cognitive disabilities such as dementias and strokes (U.S. Senate Commission on Long-Term Care, 2013). The average age of care recipients is 69.4, with 47% of care recipients over age 74 (AARP & NAC, 2015). With advancing age, the care recipient population becomes increasingly female, with approximately 45% of care recipients under age 50 being male whereas those over age 50 include only 33% male care recipients.

The caregiving research literature seldom examines dyadic data on caregivers and care recipients, and rarely includes other family members. An example of a research program that examines caregivers within the context of the relationship with a care recipient with mild cognitive impairment (MCI) and broader network is the Virginia Tech MCI Family Study. In-depth interviews were analyzed to identify multiple trajectories of change in relationships and well-being over time as dyads adapt to illness (Roberto, McCann, & Blieszner, 2013). The views family members take toward the emerging deficits in memory correlated

with the coping strategies used (Roberto, Blieszner, McCann, & McPherson, 2011). Findings from this research program suggest that the relational context of caregiver, care recipient, and others is a critical factor in understanding risks and benefits of caregiving, and in designing interventions to assist them.

What Do Caregivers Do?

Emotional and Instrumental Support

The caregiving work provided by families for older persons is broad in scope, including activities as diverse as assistance with medical/nursing tasks, monitoring and advocacy related to health and services, daily life tasks, body care, and psychological support for coping with pain, functional disability, and/or life-threatening medical conditions (Fingerman, Miller, & Seidel, 2009). Mundane aspects of daily life typically continue within the relationship of caregiver and care recipient and their broader social system. For example, the same two people who are defined as caregiver and care recipient in a research or policy context are also two people in a historical relationship who celebrate holidays, prepare and share meals, care for pets, share entertainment, respond to financial challenges, argue, nurture, communicate, worry, and so forth.

Although definitions of caregiving often focus on instrumental tasks, emotional caregiving also is a normative activity that families perform intergenerationally across the life span (Fingerman et al., 2009). Personal victories and defeats, challenges and opportunities, successes and failures, and beginnings and endings are often shared with family members who support, console, equip, and comfort. In later life, emotional support from family and close friends is particularly valued and predictive of well-being (Carstensen, 2006). Persons who rely on family caregivers for assistance with the IADL often rely on those caregivers for emotional support as well. The difficulties that generated their reliance on family for assistance can isolate them socially from other members of the community, leaving family in the role of mediating access by providing transportation or brokering social engagements. The mutuality of the emotional support roles of caregivers and care recipients is profound in its importance, and often represents a substantial renegotiation of the existing relationship between caregiver and care recipient, as models of spousal dyadic adjustment to illness have elaborated (Berg & Upchurch, 2007). The relationship history almost certainly shapes the nature and challenges involved in emotional support reciprocity.

Partner With Formal Care Systems

When formal service systems are engaged to supplement or supplant the care provided by families, caregiving family members must learn skills to partner effectively with service organizations, residential facilities, and health services. Formal providers may be involved for a short period, such as during rehabilitation following a fall, surgery, or hospitalization. In chronic care, formal providers are often engaged for longer periods, either in a residential facility or at home, because care needs sometimes exceed the capacity of a single person to lift or transfer a frail person, or to provide 24-hr care. Day programs offer engaging services for older adults that supplement the stimulation and care available at home. These programs also allow families to maintain employment or to engage in self-care that sustains capacity to care for the person at home. Residential care may be the only option for meeting the medical or personal care needs of a person who requires heavy physical assistance or specialized care (e.g., when two persons are needed to assist the transfer from bed to wheelchair or toilet). In sum, long-term care services are used with increasing frequency during late stages of frailty or illness, often in partnership with family supports. Thus, the vast majority of family caregivers must advocate, monitor, and communicate with health care professionals (AARP & NAC, 2015).

Transitions across care systems are managed by families as health interruptions occur. Health interruptions caused by acute illness (e.g., influenza) or temporary disability (e.g., mobility restriction following joint surgery) often reduce overall health and well-being in addition to the original cause of the interruption. Thus, health interruptions often require services from a series of providers. Consider the example of an older woman whose fall at home results in a fractured hip. Surgery for hip replacement is followed by pneumonia as a consequence of low mobility during recovery, lengthening her hospital stay and interrupting rehabilitation of her hip. During her hospitalization, she receives services from multiple departments with no overlapping staff: emergency, surgery, rehabilitation, pulmonary, and geriatric medicine. She is discharged from the hospital to a skilled nursing facility for a few additional weeks of rehabilitation, after which she is allocated a few additional sessions of physical therapy from a home health agency. When the Medicare funding for home health services ends, she has not yet regained her previous level of functioning, so the family is left to facilitate further recovery or support the reduced level of functioning she now shows. This case illustrates the common challenges faced during transitions in which family and older adult provide the only continuity across systems because there is essentially no continuity in staffing or electronic record systems across these different settings. Furthermore, the increased level of acuity in older persons at the time of discharge engages families in providing substantial care at home that in formal care settings would require care by a nurse rather than an aid, according to state regulations.

Navigation of complex care service delivery systems is a significant challenge for families. Families are expected to explore the range and specific options for service delivery for a person whose needs exceed the current setting, without the assistance of a professional care coordinator. Services are delivered in fragmented systems whose funding streams are even more confusing. Families are often surprised to find that professionals may know little about settings to which patients may be transferred. Physicians, nurses, and social workers in hospitals may not have been inside the long-term care residences or agencies to which they hand off care. Long-term-care staff members often do not understand the workflow or regulations governing primary care, so lack skills and strategies for effective interface. High rates of staff turnover in health care, and particularly in long-term care, enhance the likelihood that even the most frequently used referrals cannot sustain a working relationship over time. Lack of coordination adds to risk that services chosen by families are not ideally matched to the needs of the care recipient, leading to an overrestrictive environment or adding risk in an insufficiently supported service structure.

Care Coordination

Communication among care providers during transitions is primarily formal, with printouts of documents from one record-keeping system sent without modification or explanation to another, often lagging by days and thus missing the opportunity to influence initial care plans in the new setting. Typical information that is transferred includes lists of medications, diagnoses, interventions, and possibly a summary of the episode of care. Useful information about the patient's communication or coping styles, motivation, patterns of behavior, care preferences, or family dynamics are very rarely transmitted across settings by staff. Formal assessment tools focus on health and functional characteristics of the care recipient, with limited emphasis on psychosocial processes that are valued by the person or family. Almost inevitably, historical social partners, such as families, become the historians of many types of information that position them to be advocates for their loved ones.

Support Continuity of Self

Families offer the continuity of social context across life stages and settings at all points in the life span, a rudder for the discontinuous identities and capabilities that characterize chronic disease. Just as college students recognize that family knows them in ways their dormitory roommates do not (and vice versa!), so older adults with chronic disease recognize that family members hold a wider view of them that extends beyond their illness or disability that has now become a salient aspect of their social persona. Particularly for persons with memory or other cognitive difficulties, families often play a critical role in sustaining continuity in intervention planning over time and across care systems. As a health incident or disease process unfolds, the changes in care recipient, caregiver, and other family members require adaptations in the social relationship structures. Unfortunately, the scope of change and effective strategies to support transitions in care are poorly researched and understood by the care systems surrounding the social system.

In summary, caregiving work is a restructuring of roles within long-term relationships as at least one person's functioning declines (physically and/or cognitively), positioning him or her to receive assistance from another person with a particular relationship history. A substantial shift in roles occurs between parent and adult child, siblings, spouses, or other relationship dyads when tasks are reallocated based on need. When done by one or more family members, caregiving work is a long-term care service and support that typically operates outside of the long term services and support or primary care service delivery systems. Beyond the personal existential value of family to the subjective identity of older adults, families play critical roles in maintaining a comprehensive record of health and care, including health motivation, medical history, care preferences, sensitivities, and challenges in care systems. Families must perform these tasks without the benefits of access to knowledgeable care coordinators who can inform, educate, guide, or help to link services, funding, and families. Families lack access to electronic and paper records that form the basis for health and long-term care service systems activities, thus being negated as core members of the care team despite their complex roles in the biopsychosocial well-being of the care recipient. Figure 1 depicts the social location of caregiver and older care recipient within their social system as well as both long-term care and primary care. The caregiver and care recipient are in the intersection of disparate systems focused most often on the care recipient, without appreciation of the social context. Ironically, neither family nor care recipients are empowered as full participants in service delivery systems.

How Is Caregiving Different From Family Life?

Caregiving work is ubiquitous in families across the life span, adding to the imperative to provide care in later life personally rather than institutionally (Walsh, 2011). In the broadest sense, caregiving fosters the development and survival of members (Brown & Brown, 2014). Child rearing includes training in basic activities of daily living. Later, during adolescence and young adulthood, parents prepare children to live independently by teaching or facilitating the learning of IADL, such as managing health care, transportation, appointments, personal finances, communication with service providers, schedules, shopping, and cooking. Older members support and assist younger members with

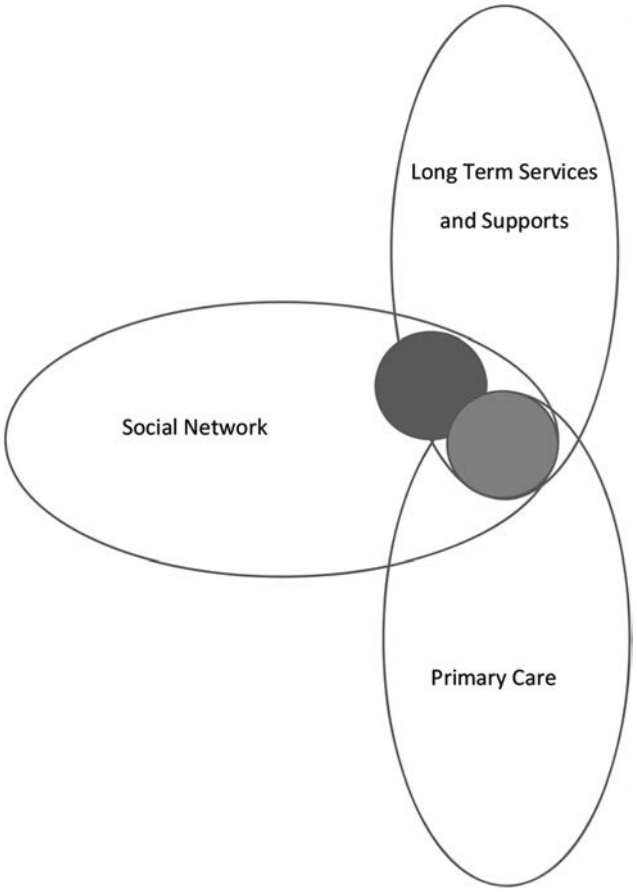


Figure 1. Caregivers and care recipients embedded in social and services networks.

instrumental as well as emotional support when purchasing a first home or rearing children, and with meals or house repair when the need arises. Similarly, younger members support and assist older members with new technologies, physically demanding tasks, or health care assistance. Young and old coparticipate in meaningful relationships that contribute to emotional well-being. Intrageneration care also is shared among siblings, cousins, and in-laws. Although considerable variation exists across cultures in the particular roles and rules for exchanges of care, the key point is that caregiving is ubiquitous in families, and thus often not identified by family members as distinctive in later life. Families develop new structures and processes to accommodate developmental transitions of members across the life span, from childhood to old age.

Norms of obligation to provide instrumental support within families generate expectations that members will step in to perform the tasks or provide support during periods of illness or disability (Bengtson & Roberts, 1991; Knight & Sayengh, 2010). Despite popular belief that adults are not caring for aging parents, over 80% of Americans say they feel obligated to care for parents (Pew Research Center, 2010) and involve themselves in care. Furthermore, over 80% of family caregivers report receiving positive benefits from caregiving (National Opinion Research Center, 2014), likely caused by biological pathways for the positive affect experienced from caregiving (Brown & Brown, 2014). Certainly, care strategies have changed substantially over the past century as society has aged and as formal care structures have emerged to offer older adults the options of choosing to "age in place" with support, move into the home of a relative (which few older adults desire to do), or move into congregate housing. Family caregiving tasks have shifted over the past century, but family engagement in caring for older adults has not declined.

What Are Key Caregiving Challenges and Opportunities in Later Life?

Caregiving for older family members is often a long-term commitment, with steady demands for care caused by chronic disease or condition. As chronic conditions reduce functional abilities, the demands of caregiving grow and change through periods sometimes referenced as stages. For example, dementia caregiving stages were defined by Aneshensel, Pearlin, Mullan, Zarit, and Whitlach (1995) as early, middle, and late caregiving, reflecting distinct types and amounts of instrumental and emotional support that

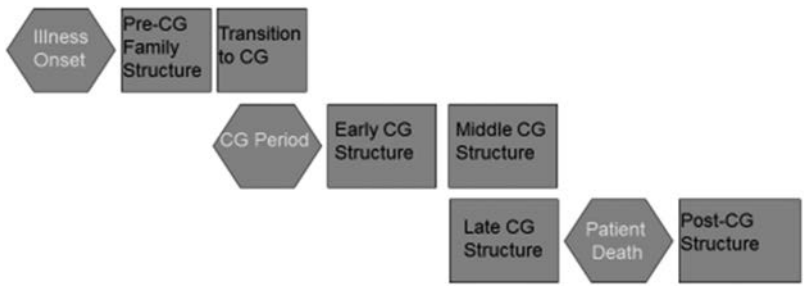


Figure 2. Stages of family caregiving for chronic disease. CG = caregiving. Reproduced from *Caregiver Family Therapy*, by S. H. Qualls & A. A. Williams, 2013, Washington, DC: American Psychological Association.

shape the caregiver's career (Figure 2). Other illness trajectories can be mapped similarly, defining phases or stages of transition in family roles and required adaptations to changing conditions over time.

Caregivers' careers are tracked through stages as the objective work of care assistance changes over the course of a chronic disease. Illnesses such as diabetes may limit vision or mobility (secondary to peripheral neuropathy) over time, creating additional work for caregivers. Earlier, diabetes caregiving by family members may be in the form of changes in food planning for family events, whereas later, insulin injections may need to be administered by a family member if the person with diabetes cannot accomplish them alone caused by functional limitations. Dementias that impair cognition place early care demands on support for IADL—the daily life tasks that are critical to independent life in the community. IADL functioning is compromised by deterioration in memory and executive functioning that characterizes early periods in the progression of a dementia. Difficulties with the more basic IADLs begin during the middle stages of caregiving for persons with dementia. In summary, the objective workload faced by family caregivers is determined by deterioration in functioning produced by diseases and conditions on their distinctive, and often idiosyncratic, trajectories. Psychologists working with caregiving families need to be familiar with the trajectories of chronic diseases and their functional implications (Gabriel, 2011).

Stress and Burden

The primary caregiver's subjective experience of caregiving work is predicted more strongly by the coping skills and strategies employed by the caregiver than by the amount or even type of objective work. Appraisals of the burdens of caregiving are powerful mediators of mental health outcomes (Pinquart & Sörensen, 2003), as are coping styles (Li, Seltzer, & Greenberg, 1999), perceived mastery (Boss, Caron, Horbal & Mortimer, 1990), and informal social support (Pinquart & Sörensen, 2003). However, little is known about the processes by which family caregivers select a coping style, develop mastery, and negotiate support. Models used in research often treat a response style as existing or not (e.g., problem-focused coping) without inquiry into the processes by which one strategy or another is selected, revised, or discarded. Positioning caregivers and care recipients within a broader social context with a personal history raises our immediate awareness that the caregiver's subjective awareness is likely to be influenced by the intersection of current demands with other aspects of life, including relationship history, other role demands (Stephens & Franks, 2009), and the amount of change in previous role structures needed to accommodate current care tasks (Roberto, Blieszner, McCann, & McPherson, 2011).

Family System Transitions

The family system in which family caregivers and care recipients are embedded also experiences stress from caregiving (Rolland, 1994). In addition to the individual level at which health changes in one person impact the well-being of another, the system itself is stressed as care responsibilities are increased, and care roles must be negotiated. Ambiguity about a person's ability to function in daily life, or in roles within the family, challenges the family to define care norms more specifically. Ambiguity as to the role the person maintains in the family also generates stress, as examined by Boss et al. (1990) in the case of persons missing in action in war, or related to dementia. Families of persons whose functional disability exceeds their capability (i.e., excess disability) experience frustration and confusion. When is assistance useful, and when does it undermine motivation to rehabilitate? The uncertainty about when and what type of help to provide is identified by family caregivers of older adults as a significant stressor.

Existing roles that can no longer be handled by the care recipient caused by the impact of the illness must be grieved and reallocated, or they go untended with some loss of functioning within the family. Two aspects of the timing of these role renegotiations add to the challenge: They often occur under time-sensitive conditions when members are anxious about the welfare of a loved one, and the new role configurations interrupt patterns that have often been established for decades. In many cases, families must act quickly to make important decisions about care despite the fact that they may never have worked together on a decision of any great consequence. If the care recipient's participation is constrained, other family members may be working around a gaping hole in the decision-making structure.

Caregiving often stresses the subsystems and processes of the family system. Tasks must be accomplished in new ways, often by new constellations of family members. Family structures often need to shift in order to create new ways of making decisions, establish new patterns of family communication, and negotiate just distributions of responsibility across family members who have never shared any similar type of responsibility previously. Whereas families' previous negotiations may have addressed nothing more serious than organizing a family holiday dinner, members of families now must interact about life and death situations about which they have little experience. Family care often invokes deeply held values and ethics about which there are often low levels of understanding of each other's views, making consensual decision-making quite difficult (Carpenter & Mulligan, 2009). Conversations that were too hard to initiate are now forced, and families often find those conversations difficult. No ideal family structure has been identified to accommodate caregiving. In some families, very old role structures emerge from childhood during conversations

among siblings who have lived hundreds of miles apart in adulthood. In other families, members have access to very different amounts or types of information about the care recipient's health or needs, leading to different conclusions about care strategies. Important care decisions are often made under adverse conditions, by families with little preparation for them, and without clear linkage to other care systems involved with the care recipient. What is clear is that a decision-making structure needs is needed for the well-being of family (Lieberman & Fisher, 1999) and clinicians (Quinn et al., 2012).

Partnering With Service Systems

Long-term care services and support systems need to make explicit the role expectations for family participation as collaborators in the care team. Role definitions would address mechanisms and strategies for communication, responsibilities, rights, participation in the shared caregiving tasks, and the scope of information sharing that is appropriate to the tasks embedded in the role definitions. Role definition can range from extremely limited tasks or roles to expansive responsibilities that are critical to the well-being of the recipient of care. Training to conduct roles effectively should be made available. The identity and roles of family caregivers could be listed in the health and long-term care system permanent record. Financial compensation for the effort and time invested in caregiving are recommended. Tax credits or direct fee for service payments could address this issue.

Service systems for persons with long-term disability or chronic conditions need to regularly assess the functional care needs of each client, *and* the environmental and familial support structures in place to address those needs as a regular component of planning for continuity of care. A longitudinal tracking system for information on care recipient and caregiver is needed to assure continuity of care. Among the data to be tracked on care recipient and caregiver are levels and changes in functional capabilities, behavior problems, health conditions and wellness priorities, and limitations in time and capacity.

How Can Psychologists Assist Caregivers?

Assessment Services

Assessment of caregivers can focus narrowly on the distress of the caregiver, or broadly on the caregiving family as a system. Caregiver challenges are most frequently assessed from within a stress and coping model that evaluates the level of burden from caregiving, but a broader framework is often useful. Multiple frameworks are recommended in the Caregiver Briefcase that was developed by the American Psychological Association (APA) Presidential Task Force formed by former President Carol Goodheart, and is maintained with support from the APA Office on Aging.[2] Broader approaches include assessment of the situation, the context, and the meaning of caregiving to caregiver and care recipient. Multiple resources are available, including interview question suggestions as well as tools to assess specific aspects of the caregiving experience. Distress in dementia caregivers can be assessed by established scales such as the Zarit Burden Interview (Zarit, Reever, & Bach-Peterson, 1980) and the Revised Memory and Behavior Problem Checklist (Teri et al., 1992). Providers or researchers may want to supplement these with tools that assess positive aspects of caregiving or sources of resilience (Coon, 2012). Mental health tools that assess depression and anxiety have been used extensively with caregivers, as well as tools to assess grief. Interviews may be used to assess the family system by gathering historical information about the family structure and functioning, history of the illness and caregiving onset, roles and tasks accomplished, skills and strategies that are useful and needed, complications and successes in implementing the caregiving role, role overloads or conflicts, personal meaning and valuing of caregiving, resources available, and self-care skills and needs. In short, the dynamics of the caregiving experience and challenge require qualitative interview data in the absence of assessment tools to gather them. One model that guides providers through a systematic assessment of caregiving within a family systems framework is offered by Qualls and Williams (2013).

Assessment Research

Psychological research is needed to build tools that assess multiple dimensions of the caregiving experience and associated risks. Tools appropriate for various settings need to be developed because the setting shapes the amount of time the caregiver can invest and the skill of the person interpreting the tool. For example, in senior housing, brief assessments of caregiver distress may help identify families who would benefit from clearly communicated role prescriptions or self-care postplacement. Brief tools for use in senior service agencies or primary care may help identify families who are not yet self-identified as caregivers, and to identify the risks and needs of caregivers who have them. Certainly, integration of caregiving assessment into primary care is an emerging area of promise (Gillick, 2013), with potential for proactive case findings of caregivers in need. Similar efforts are emerging within hospitals, home health, neighborhoods and senior housing, attorney offices, and social service agencies.

[2] This information can be found at http://www.apa.org/pi/about/publications/caregivers/index.aspx.

A critical area for research is development of new tools that expand beyond the concerns of caregivers dealing with problem behaviors caused by dementia. Caregivers working with acute medical illnesses such as cancer, or whose care recipients' disabilities are primarily physical, likely need to be assessed for distinct sources of stress and strategies for coping with challenges. Tools are needed to assess caregivers' concerns about navigating across service systems, making decisions about what level or type of care is needed, and negotiating consensus among family members, all of which are issues that are not well addressed in current caregiver assessment tools. Certainly, assessment tools are needed to measure positive dimensions of caregiving that bring meaning and strength to caregivers.

Another area for psychological research is measurement of relational aspects of caregiving, including guilt and resentment of the care recipient or other family, family conflict about care, resource challenges, role challenges with implementing care, and historical aspects of relationships that are almost certain to influence the caregiving dyad (e.g., history of past abuse or trauma). As the field is questioning the simplistic views of caregiving as inevitably stressful, tools are needed to assess the dimensions that emerge as important predictors of positive as well as negative outcomes. Efficient approaches to assessing the needs of caregivers should be developed, validated, and embedded in primary care, social services, and long-term care services.

Psychosocial Intervention Services

Interventions for caregivers produce small to moderate effect sizes overall (Pinquart & Sörensen, 2006), with some interventions showing significant and large effects on particular outcomes. Two interventions for caregivers of older adults have a sufficient body of evidence for their effectiveness to be recognized on the National Register of Evidence-Based Programs and Practices maintained by the Substance Abuse and Mental Health Services Administration (n.d.). Both focus on reducing the distress of family caregivers to persons with Alzheimer's disease or dementia and have several replications of clinical trials.

The New York University Caregiver Intervention provides spouse caregivers with a counseling and support intervention designed to improve the well-being of caregivers and delay institutional placement of care recipients (Mittelman et al., 1993). The four components of the program are (a) two individual counseling sessions tailored to the needs of the primary caregiver, (b) four family counseling sessions with the primary caregiver and selected family members, (c) encouragement to participate in local support groups after participation in the intervention, and (d) ad hoc counseling by telephone to help caregivers and families with crises and changing conditions. Outcomes for caregivers include improved perceived physical health, reduced depression, improved social support, improved appraisals of care recipient problem behavior, and delays in institutional placement (Mittelman, Roth, Coon, & Haley, 2004).

The Resources for Enhancing Alzheimer's Caregiver Health II (REACH II) program included psychosocial and behavioral training for adult caregivers (age 21 and over) of persons with Alzheimer's disease and dementia (Belle et al., 2006). Over a 6-month period, caregivers participated in 12 individual sessions (three on the telephone) and five structured support group sessions by telephone, and were given resource notebooks and telephones with visual display that supported conference calling. Outcomes for caregivers include improved quality of life and reduced prevalence of depression.

A large number of dementia caregivers have participated in clinical trials with each of these approaches with strong positive effects.

The establishment of these two approaches as nationally recognized evidence-based interventions demonstrates the viability, importance, and value of clinical research on interventions for caregivers of older adults. Translational research documents the viability and challenges of broad dissemination of these methods (Gitlin, Marx, Stanley, & Hodgson, 2015). Incentives are needed to increase the rate of dissemination of evidence-based interventions to alleviate the strain of family caregiving, and innovative models for integrating caregiver support services into existing service systems need to be developed.

Research on Interventions

Research priorities related to intervention include replications of the efficacy of existing interventions that have more modest quantity of empirical support, broadening the target population beyond caregivers of persons with dementia, generating and testing new interventions that address a wider range of caregiver concerns than patient problem behavior and caregiver well-being (e.g., providing nursing or medical services, partnering with services industries, family conflict), testing interventions across settings in which caregivers can be identified and receive services, and developing new measures to assess particular desired outcomes.

Today, practicing psychologists have a rather narrow set of evidence-based practices to guide their work with caregivers. The APA Caregiver Briefcase provides conceptual approaches, reviews of research on caregivers in varied circumstances, and introductions to the variety of interventions that have been developed to address varied populations. At this point, clinical judgment is needed to adapt the two evidence-based approaches detailed above to a wider range of populations, and to adapt other researched approaches for the particular setting in which the professional provides services, particular caregiver

and care recipient characteristics, and the particular populations served. Many interventions that lack a substantial body of evidence still show promise for benefitting caregivers to older adults (Coon, Keaveny, Valverde, Dadvar, & Gallagher-Thompson, 2012; Pinquart & Sörensen, 2006). In addition, psychologists have robust models for related work with families in family medicine clinics that can be repurposed for aging families (McDaniel, Campbell, Hepworth, & Lorenz, 2005). Obviously, new paradigms are needed to position caregiving within a broader understanding of the complex enterprise it represents, with positive meanings and benefits as well as negative stresses in some circumstances more than others.

Caution must be used in evaluating the evidence on the impact of interventions, as researchers have often used methods that undermined power to detect effectiveness or impact of the interventions (Zarit & Femia, 2008). Examples include assignment of nondistressed caregivers to interventions that could not improve their functioning or well-being, misalignment of caregiver problem with targeted intervention, measurement of outcomes different from the intended impact of the intervention, and absence of monitoring the fidelity of the implementation of the intervention. Findings may also be impacted by the selection of inequivalent control groups (Roth, Fredman, & Haley, 2015).

Psychologists need to build a stronger body of research by using research methods that effectively manage both internal and external validity. Tailored interventions, for example, require research designs that can handle assessment of outcomes of program components that are delivered in varying doses across caregivers and families. A wider range of measures is needed to capture more dimensions of the caregiving experience. Furthermore, the interface of families with other care systems needs to be investigated and interventions need to be designed and tested that help families navigate and partner with systems.

Federal agencies such as the National Institutes of Health and Administration on Community Living should fund research on efficient approaches to assessing the needs of caregivers, including the development, validation, and implementation of caregiver assessments in primary care, social services, and long-term care services.

Implications of Family Caregiving for Long-Term Services and Supports Policy

Family caregiving work has remarkably low visibility in public policy related to the network of services referred to as long-term care supports and services despite its dominance of the support services for older adults. In contrast, high visibility and substantial funding is invested in institutional long-term care services such as nursing homes, or home and community based services (HCBS). Yet when those same services are provided by family members, only a limited number of demonstration projects in a few states allow care recipients to select family members as their paid care. More commonly, families and/or care recipients hire strangers to provide socially or physically intimate care within the home of the care recipient, or family members provide unpaid care.

The sum of all government-funded long-term care services, $119 million, represents about one fourth of the economic contributions of family caregivers which were estimated at $450 million per year in 2009 (Feinberg, Reinhard, Houser, & Choula, 2011). In short, society relies on families to provide services in later life that defer or eliminate the need for paid long-term care services and supports that are primarily funded by the government. With the projected rapid growth in the aging population, the number of Americans needing long-term care is projected to more than double between 2010 and 2050, from 12 million to 27 million (U.S. Senate Commission on Long-Term Care, 2013). Simultaneously, the ratio of available caregivers to care recipients within families is projected to decline rapidly, with projections for the ratio of caregivers to care recipients age 80+ dropping from a 7:1 to a 3:1 ratio between 2010 and 2050 (Redfoot, Feinberg, & Houser, 2013). Public policymakers will find it challenging to meet those demands, leaving families increasingly vulnerable to being the default care system.

Federal policy and funding to support families in giving care launched in 2000 with the authorization of the National Family Caregiver Support Program (NFCSP) within the Older Americans Act Amendments of 2000 (2000) that is administered by the Administration on Community Living. The NFCSP authorizes services that provide information, assistance, counseling and training, respite support, and some supplemental services for family caregivers to older adults as well as older caregivers of children under age 18. Funding is distributed through states to regional Area Agencies on Aging (AAA). Regional variation in the services provided is substantial, and funding is modest. Psychologists have had limited involvement and could be viable subcontractors or partners in service delivery models.

Primary care is another venue in which family caregivers need to be engaged more effectively, and psychologists can play an important role in creating effective service systems. As the first source of health care for older adults and their families, primary care needs to figure out how to interface with specialty health providers as well as with long-term care. As primary care shifts toward models such as the patient-centered medical home, it continues to be office-centric with poor linkage to the person's real home, where health behaviors that influence chronic disease occur. Model programs such as VA Home Based Primary Care http://www.va.gov/geriatrics/guide/longtermcare/home_based_primary_care.asp offer pro-

viders important information about the living context in which daily health decisions about food, activity, medication use, and other health behaviors occur. More commonly, the social contexts of health are very minimally known to primary care outpatient settings, in which the dynamics of the caregiver–care recipient relationship or broader social network are essentially invisible. The tenuous link of primary care to the home-based reality of health as it is lived day to day is exceptionally problematic for older adults whose compromised functional independence requires assistance from informal or formal care delivery systems. Health-related social support is likely to be important to effective health self-management, because of the impact of social ties on health lifestyle factors such as diet, exercise, and medication management.

A key policy impediment to psychological services for families of older adults is the restriction on billing for services to families without the patient present under Medicare regulation. As the critical roles of families are defined within the long-term services and the broader health care system, funding policies need to be aligned with the critical psychological services that support families and their care partners in maintaining their key role in long-term care. The Center for Medicare and Medicaid Services should eliminate limitations and exclusions in Medicare reimbursement for services that are necessary and effective when caring for older adults. Reimbursement is needed for medically necessary mental and behavioral health consultation and training delivered to staff in long-term care settings, non-face-to-face services and consultation delivered to families and professional caregivers (without patient present), and interdisciplinary team conferences. Many federal agencies will need to review and revise current policies if families are to be supported as key members of the long-term care services and support network.

Conclusion

As dominant members of the long-term services and support network, families need to be integrated into what has traditionally been termed long-term services (e.g., senior residential housing, skilled nursing facilities, home health, social services) as well as primary care. Psychologists, who are increasingly integrated into health care and social service settings, need to include in their roles the assessment of families, the development of strategies for integrating families into systems, and use of interventions that support family integration into the care network. Research psychologists have key roles to play in continuing to document the need for, and value of, family involvement in supporting older adults. Research that established the value of psychological intervention lays the foundation for development of assessment tools and interventions appropriate for a wide range of populations across the spectrum of services where families and older adults seek services. Psychologists working in public policy arenas have critical work to ensure that services and funding for services are allocated in ways that support and strengthen family involvement, and that family-friendly support services are available to supplement or take on caregiving tasks when families cannot handle the intensity or longevity of care demands. The ubiquity of caregiving in family life may undermine the visibility of family needs and resources that are key components of the long-term care services and support system for older adults in the United States.

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