Unpaid Caregiving and Aging in Place in the United States: Advancing the Value of Occupational Therapy

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Unpaid caregivers are often expected to help family members or friends overcome activity limitations and participation restrictions to successfully age in place. Caregivers assume multiple responsibilities, such as managing their own physical and psychosocial needs and navigating a complex health care system, and many feel ill equipped to fulfill the necessary health care responsibilities for their care recipients. Underprepared caregivers may cause poor outcomes for care recipients. Federal and state policy proposals call attention to the need to better support caregivers, especially as their numbers increase. Occupational therapy practitioners are well positioned to effectively engage caregivers as they navigate the health care system. The occupational therapy process looks broadly at the functional abilities, environmental contexts, and occupational demands that play a pivotal role in successful aging in place for clients and better outcomes for their caregivers. Now is the time to define occupational therapy's distinct value to this area.

Nearly 90% of older adults in the United States want to remain in their homes and communities as long as possible (AARP, 2018), yet physical and cognitive declines and chronic health conditions associated with aging result in activity limitations and participation restrictions that affect their ability to safely age in place. With 9 million community-dwelling older adults facing increasing health complexities, unpaid caregivers must frequently provide essential support so those adults can maintain their desired living situations. As the U.S. population ages, approximately 18 million caregivers are being asked to do more than they ever have (Aufill et al., 2019). They help older adults not only with household chores and self-care activities but also with health care tasks. In 2017, unpaid caregivers provided an estimated 34 billion hours of care, worth approximately $470 billion (Reinhard et al., 2019).

In addition to the fact that caregivers are increasingly assuming more unpaid responsibilities, many feel unprepared to provide such care (Kaiser & Kaiser, 2017). This is unsurprising given that more than 90% of U.S. adults have never received caregiver training (Burgdorf et al., 2019). Untrained caregivers are at high risk of experiencing excess burden, chronic stress, and depression (National Academies of Sciences, Engineering, and Medicine, 2016; National Alliance for Caregiving, 2020), and their lack of training may also result in increased service utilization by the care recipient. For example, caregivers may experience a care-related injury (Shyu et al., 2010) if they have not received appropriate information, training, or referrals to meet care needs, and consequently their care recipients may require preventable hospital readmissions (Rodakowski et al., 2017). By understanding current policy initiatives, occupational therapy leaders can position the profession to play a key role in systematically including, assessing, and educating caregivers in regard to their critical role in supporting aging in place.

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U.S. Policy Initiatives Related to Unpaid Caregiving

Over the past 3 decades, several federal- and state-level policies have been mandated in response to the need to better support caregivers of community-dwelling older adults. These policies include the Older Americans Act (OAA) Reauthorization Act of 2016 (Pub. L. 114-144); the National Family Caregiver Support Program (NFCSP; Administration for Community Living, 2019); Medicare benefits; the Family Medical Leave Modernization Act (H.R. 2589 and S. 1185, 2021); the VA Maintaining Internal Systems and Strengthening Integrated Outside Networks (VA MISSION) Act of 2018 (Pub. L. 115-182); and the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act (2017; Pub. L. 115-119). Table 1 contains supplemental information on caregiving policies.

Originally enacted in 1965, the OAA was passed to support a range of community- and home-based services to help older adults age in place. This national policy provides infrastructure for state and local agencies to implement evidence-based programs to meet the needs of older adults and their families. When the OAA was reauthorized and expanded in 2000, the NFCSP was established to better support family caregivers as well as grandparent and older kin caregivers who have minor children. "States and tribes are allocated proportional grants to work in partnership with Area Agencies on Aging and local service providers in order to provide a flexible base of caregiver services" (Bangerter et al., 2019, p. 63), including respite care. In addition to the programs offered through the OAA, most older adults are eligible for Medicare, a federal health insurance program that covers hospital care, outpatient services, medical equipment, and prescription drugs. The Centers for Medicare & Medicaid Services (CMS; 2020) recently expanded reimbursement for home health and telehealth services to include caregivers of beneficiaries.

The U.S. Department of Veterans Affairs enacted a program of comprehensive assistance for family caregivers of veterans injured in the line of duty after September 11, 2001, under the Caregivers and Veterans Omnibus Health Services Act of 2010 (Pub. L. 111-163). In 2018, the VA MISSION Act authorized a multiyear phase-in of an expansion of these services, which include monthly stipends, mental health counseling, and enhanced respite, to caregivers of eligible veterans from other eras (U.S. Department of Veterans Affairs, 2020).

Table 1. Supplemental Information on Caregiving Policies

Policy (Year Enacted)	Information
Federal	
National Family Caregiver Support Program (2000)	The five core services include information services, access assistance, respite care, counseling, and training.
Medicare (1982)	
Medicare Hospice Benefits (2019)	Families can qualify to receive medical equipment, homemaker services, short-term respite care, and grief and loss counseling.
Part A and Terminally Ill	Families can establish a care plan with a hospice provider who then delivers the needed assistance for individuals to remain at home with their families.
Coverage for Telehealth (2018)	CMS expanded Medicare reimbursement for some services to include patient- and caregiver-centered health risk assessments, advance care planning, and chronic care management to be delivered by telehealth.
Home Health Provisions (2018)	CMS implemented a new final rule for home health agencies to meet to be reimbursed by Medicare. The rule includes including, assessing, and educating caregivers of home health beneficiaries.
State	
Caregiver Advise, Record, Enable Act[a]	40 states
Family and Medical Leave Act expansions[b]	
Lower employer size	8 states
Definition expansion	14 states
Flexible sick leave	16 states
Caregiver tax credit	1 state, 10 other states considering a bill as of 2019

Note. Sources include National Academies of Sciences, Engineering, and Medicine (2016) and Aufill et al. (2019). CMS = Centers for Medicare & Medicaid Services. [a]Policy sponsored by AARP. [b]Policy drafted by national partnership.

The Family and Medical Leave Act of 1993 (FMLA; Pub. L. 103-3) supports family caregivers by permitting full-time employed Americans to receive 12 wk of job-protected, unpaid leave to care for a sick family member, bond with a new child, or manage a personal illness. The caveat of FMLA is that employees must work for a large company (50+ employees) for 12 mo or longer to qualify. One-third of states have bolstered provisions of FMLA through more inclusive definitions of family, lower employer size requirements, and enhanced flexibility of sick leave policies. Eight states (New York, California, New Jersey, Washington, Massachusetts, Rhode Island, Oregon, and Connecticut) have approved paid family medical leave. Another state-level initiative is the Caregiver Advise, Record, Enable (CARE) Act, model legislation that supports the integration of caregivers into hospital discharge planning to prepare them for performing care-related procedures at home (AARP, 2014, 2019). As of March 2019, the CARE Act had been adopted in 40 states (AARP, 2019).

Most recently, the RAISE Family Caregivers Act required the U.S. Secretary of Health and Human Services to convene an advisory council in 2019 to develop recommendations to systematically include, assess, and address family caregivers' needs, problems, and strengths in the care planning process. The Credit for Caring Act (S. 1443, introduced in 2019) would allow caregivers "a tax credit of up to $3,000 for 30% of the cost of long-term care expenses that exceed $2,000 in a taxable year" to support a spouse or other dependent relative with care needs. While the policy landscape evolves, the occupational therapy profession can show leadership in establishing standards for person- and family-centered care (PFCC) involving caregivers.

Occupational Therapy's Role in Enhancing Support for Unpaid Caregivers

Age-related physical, psychosocial, and functional changes often lead to encounters with multiple health care providers. This complexity of care demands that providers work collaboratively with both clients and their caregivers. Indeed, health care systems and providers are beginning to shift geriatric practice from a person-centered approach to a person- and family-centered orientation (Schulz & Czaja, 2018). PFCC is "an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families" (Institute for Patient- and Family-Centered Care, 2018, para. 1). Guiding principles of PFCC include dignity and respect, information sharing, and participation. Assessment of needs and experiences of care from the client and caregiver, promotion of communication and shared decision making, and coordination during care transitions are key elements of PFCC (Mroz et al., 2015).

Occupational therapy practitioners are uniquely situated to support PFCC. The profession's philosophy is rooted in the dynamic interplay among people, environments, and occupations (Law et al., 1996; Yerxa et al., 1989). To increase an understanding of this interplay so as to optimize client and caregiver health and wellness, occupational therapy practitioners turn to a fundamental method for practice: collaboration (Hooper & Wood, 2019). Occupational therapy practitioners establish rapport and develop collaborative relationships with clients and their families to explore environments and occupations during the care delivery process. This process requires practitioners to first recognize the value caregivers bring, namely, caregivers' perspectives about "how the client is doing, what the client needs, what the family needs, and what is most important and meaningful in everyday life have become part of the clinical dialogue" (Lawlor & Mattingly, 2019, p. 200).

In addition to gathering this subjective information during the evaluation, practitioners also observe clients and caregivers performing preferred activities (e.g., the caregiver assisting the client in getting dressed) to comprehensively understand challenges and engage in collaborative goal setting (Womack, 2012) that will guide intervention planning. Drawing on the large body of intervention research on improving client and caregiver outcomes and supporting aging in place (Rouch et al., 2020; Schulz & Czaja, 2018), occupational therapy practitioners can provide education and skills training for using health care and assistive technology, navigating the health care system and community, identifying resources, adopting mental health strategies, recognizing health condition symptoms, and adapting home environments.

As an exemplar, occupational therapy has been at the forefront of providing assistive technology and home modifications to support caregivers (Mann, 2001). Both high- and low-tech options are available to reduce care burden with activities of daily living (ADLs), instrumental activities of daily living (IADLs), and safety. A systematic review suggested that assistive technology contributes to the caregiver's quality of life by relieving not only time and effort spent on physical assistance but also anxiety and fears about safety (Madara Marasinghe, 2016). Calls have been made to develop innovative technology, such as smart homes and robotics, to support caregivers (Astell et al., 2019). It is critical that occupational therapy practitioners return to the evaluation phase of care delivery after such interventions have been implemented. Reevaluation allows the care team—practitioner, client, and caregiver—to determine whether interventions have positively addressed occupational performance challenges.

Interdisciplinary Care Team Role in Supporting Successful Aging in Place

In the context of current federal and state priorities, which are intended to support older adults and their caregivers residing in the community, the field of occupational therapy is well positioned to be part of an interdisciplinary wellness and prevention care team. Although payment for wellness and preventative care can be challenging (e.g., training of caregivers, as well as preventative occupational therapy services, are rarely included in reimbursement structures), occupational therapy practitioners can partner with home- and community-based organizations, such as local Area Agencies on Aging, to offer services through NFCSP (Bonder & Goodman, 2019).

One evidence-based, person-centered, interdisciplinary intervention that includes occupational therapy is the Community Aging in Place–Advancing Better Living for Elders (CAPABLE) program (https://nursing.jhu.edu/faculty_research/research/projects/capable/). Over 5 months, the team assesses, educates, and problem-solves to help clients achieve self-identified goals targeting limitations in ADLs and IADLs and associated environmental barriers. CAPABLE involves up to 10 home sessions of 60 to 90 min each (for details, see Szanton et al., 2014). CAPABLE is effective in reducing disability in older adults, lowering inpatient and long-term service use, and decreasing Medicaid spending for low-income older adults with one or more ADL impairments that affect their safety and ability to age in place (Szanton & Gitlin, 2016; Szanton et al., 2014, 2015). Given such compelling evidence, a National Institute on Disability, Independent Living, and Rehabilitation Research–funded project has been examining the adaptation of the original CAPABLE to include caregivers and promote aging in place through Area Agency on Aging programming (Toto & Fields, 2019). This study has the potential to create and demonstrate a CAPABLE model that is both person and family centered. Studying the implementation of programs like CAPABLE will help ensure that vital interdisciplinary services are available to support successful aging in place, especially in a reimbursement environment that controls what goals are covered in the care delivery process.

Conclusion and Next Steps for Occupational Therapy

Federal, state, and health care shifts are fostering opportunities to involve and educate clients and unpaid caregivers together. Occupational therapy practitioners can be valuable members of the interdisciplinary care team by showing support for mandated and anticipated health care policies related to caregiver involvement, embracing PFCC principles in everyday practice, and approaching the care delivery process to translate evidence-based interventions into broad-service programs. Moving toward these objectives will maximize successful aging in place for clients and improve outcomes for caregivers.

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