National Alliance for Caregiving

NOVEMBER 2021

Caring For The Caregiver:
Incentivizing Medical Providers to Include Caregivers as Part of the Treatment Team

About the National Alliance for Caregiving

NAC's mission is to build partnerships in research, advocacy, and innovation to make life better for family caregivers. Our work aims to support a society which values, supports, and empowers family caregivers to thrive at home, work, and life. As a 501(c)(3) charitable non-profit organization based in Washington, D.C., we represent a coalition of more than 60 non-profit, corporate, and academic organizations; nearly 40 family support researchers with expertise in pediatric to adult care to geriatric care; and more than 50 advocates who work on national, state and local platforms to support caregivers across the United States. In addition to our national work, NAC leads and participates in a number of global meetings on caregiving and long-term care, working closely with peer organizations from more than a dozen nations. Learn more at www.caregiving.org.

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National Alliance For Caregiving

Leadership
C. Grace Whiting, JD
President/CEO
National Alliance for Caregiving

Project Direction
Lauren Rachel St. Pierre, MSW
Innovation Director
National Alliance for Caregiving

Contributing Editor
Lauren Rachel St. Pierre, MSW
Innovation Director
National Alliance for Caregiving

White Paper Authors
Dolores Gallagher-Thompson, PhD, ABPP
Professor of Research (Emeritus)
Department of Psychiatry, Public Health & Population Sciences
Standford University
Founder and Co-Director
Optimal Aging Center

Ann Choryan Bilbrey, PhD
Director of Training
Optimal Aging Center

Contributing Subject Matter Experts
Allison J. Applebaum, Ph.D.
Associate Attending Psychologist
Director-Caregivers Clinic,
Dept of Psychiatry & Behavioral Sciences
Memorial Sloan Kettering Cancer Center

Jennifer Birdsall, PhD
Chief Clinical Officer
CHE Behavioral Health Services

Barbara Bricoli
Principal and Owner
B2 Advisory Group

Molly Carpenter
Gerontologist
Home Instead

Rita B. Choula, MA
Director, Caregiving
AARP Public Policy Institute

Jennie Clark
Gerontologist, Board Certified in Alzheimer Education,
Certified Geriatric Care Manager, Certified Dementia Practitioner
Stanford Healthcare

Barbara Cohoon, Ph.D., MSN, RN
President
Clinical Policy Strategies LLC

Sue Coyle, COTA, BA, CMC
Aging Life Care Manager
Coyle Care Management and Consulting, LLC

Jennifer Dexter
Director, Policy
National Health Council

Wen Dombrowski, MD, MBA
Chief Convergence Officer
CATALAIZE

Brian M. Duke, MHA, MBE
System Director, Senior Services
Main Line Health

Robert Espinoza. MPA
Vice President of Policy
PHI: Quality Care Through Quality Jobs

Katelyn Fitzsimmons
Product Management Director Sr, LTSS Specialty Organization
Anthem, Inc

Rita Ghatak, Ph.D.
Principal & Owner, Aging 101
Founder & Former Director, Aging Adult Services, Stanford Healthcare

Elizabeth Gibboney
Chief Executive Officer
Partnership HealthPlan of California

Lisa M Gibbs, MD
Professor and Chief, Division of Geriatric Medicine and Gerontology
ACO Medical Director, UCI Health
Department of Family Medicine
University of California, Irvine

Robyn Golden, LCSW
Associate Vice President of Social Work and Community Health
Co-Director, Center for Excellence in Aging
CO-Director, Center for Health and Social Care Integration
Chair, Department of Social Work
Rush University Medical Center

Theresa (Terri) Harvath, PhD, RN, FAAN, FGSA
Professor & Senior Director for Strategic Initiatives
Director, Family Caregiving Institute
Betty Irene Moore School of Nursing at UC Davis

Amy Sander Herr, MHS, PMP
Director, Health Policy
West Health Policy Center

ACKNOWLEDGEMENTS CONTINUED

EXECUTIVE SUMMARY

Caregivers are not well integrated into U.S. healthcare systems. Across care settings, caregivers lack formal and consistent roles on the care receiver's care team and struggle to manage their care recipient's needs with their own. Only 29 percent of caregivers report being asked by a healthcare professional about their care-giving needs; this rate drops to 13 percent when the question referred to what the caregiver needed to be able to care for themselves (2020 Report of Caregiving in the U.S.; AARP and National Alliance for Caregiving).

There is no single solution that can address this complex area of need. Variations in payment models, insurance coverages, healthcare settings, and types of provider challenge innovators to generate flexible solutions and scale or adjust emerging models to fit caregivers' specific needs. Additional challenges to innovation persist: lack of standards of care, limited awareness of revenue opportunities, poor accessibility of billing code information, trouble identifying caregivers, and limited practice guidance.

Emerging intervention models demonstrate promising evidence that caring for caregivers is effective at reducing caregiver stress, but additional study is needed to demonstrate cost-effectiveness and relevant impacts on care recipients. Supportive infrastructure is needed to assist healthcare providers, payers, and others with the incentives and information required to expand existing initiatives and develop new solutions. There are opportunities for innovation in the development of caregiver engagement standards, practice flows, caregiver rapid assessment tools, and business practices to support caregiver engagement.

INTRODUCTION

More than 1 in 5 people in the United States care for a family member, friend, or neighbor with a health care need or functional disability. More family caregivers find themselves caring for multiple people (24 percent) and working while caregiving (61 percent). Family caregivers face increasing complexity meeting the medical and support needs of their care recipients; 7 in 10 do so with no paid help. Without adequate and affordable services and supports, the escalating demands on family caregivers contribute to their physical, emotional, financial strain, and decline in self-reported health.[1]

Caregivers require support to function in their caregiving role without negative impact to their health and financial well-being. Caregiver services that address unmet needs increase family caregivers' well-being and capacity to care, directly improving caregiver health and preparedness to provide care. They take the form of caregiver assessments, education and/or training, relief or respite, social support, and direct payment. Additional caregiver services may benefit caregivers indirectly, acknowledging their role as a valued member of the care team and improving their capacity to partner in care. These patient-targeted caregiver services commonly take the form of care coordination support, training, and information exchange. Caregiver supports have an additional benefit—better care and outcomes for the care recipients.

More than half of caregivers rely on providers such as doctors, nurses, or social workers to supply them with information on caregiving; however, few caregivers (29 percent) discuss their needs with their healthcare professionals. Providers have an opportunity to better support caregivers and those they care for by expanding their caregiver services and seeking reimbursement for the services they may already provide.

A better understanding of the incentives available to providers to identify and support caregivers can help address the gap between the need for these services and awareness and use of them by providers. This report is intended to serve as a tool to facilitate the engagement of providers, payers, and other public and private stakeholders in understanding and utilizing existing incentives for family caregiver services across multiple care settings and provider types.

BACKGROUND

The Centers for Medicare & Medicaid Services (CMS) define *caregivers* as "family members, friends or neighbors who provide unpaid assistance to a person with a chronic illness or disabling condition" (CMS.gov, 2021). Caregivers assist with multiple tasks for their care recipients depending on the nature and longevity of the illness involved. For example, 99 percent help with instrumental activities of daily living (IADLs) that allow the care recipient to live independently.

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[1]Compared with 2015, fewer caregivers report their health status as excellent or very good (41 percent, down from 48 percent in 2015) and a greater proportion report being in fair or poor health (21 percent, up from 17 percent in 2015). One in four find it difficult to take care of their own health (23 percent) and a similar proportion report caregiving has made their own health worse (23 percent). (2020 report of Caregiving in the U.S.; AARP and NAC)

These include managing finances, cooking, shopping, housekeeping, and the like. Approximately 60 percent assist with activities of daily living (ADLs), basic self-care tasks such as bathing, eating, toileting, and so on. (AARP and National Alliance for Caregiving, 2020). Caregivers also provide emotional and social support to improve a sense of well-being in the care recipients. As diseases progress, caregivers see an increase in the number of medical tasks they are asked to provide, the amount of care coordination required, and the possibility of becoming the care recipient's decision maker (both medical and financial).

In 2017, the AARP Public Policy Institute reported the estimated economic value of 41 million unpaid family caregivers in the United States. These individuals provided an estimated 34 billion hours of care worth approximately $470 billion (Reinhard, Feinburg, and Houser, et. al, 2019). Today, the number of caregivers in the United States has increased to almost 48 million (AARP and National Alliance of Caregiving, 2020). Most caregivers care for one person (76 percent), but there are an increasing number of caregivers caring for multiple adults with chronic illnesses (24 percent). While there are currently no nationwide family caregiver statistics that show the economic value of caregivers performing specific tasks, there are several tasks that directly benefit the medical system. Delaying or preventing costly hospitalizations, assisting the system to provide care that culturally aligns with the care recipient's values, and increasing access to non-institutional services such as home-based community care all contribute to the medical structure (Kaye & Teshale, 2020).

CAREGIVER SERVICES

In this report, we define *caregiver services* as "any intervention intended to increase the well-being of **either the patient or the family caregiver**." Caregiver services are roughly divided into two types, depending on who receives the services. See Figure 1 below. Services designed to improve patient care provide the caregiver with either knowledge or additional skills that allow her/him to inform the medical treatment team, resulting in enhanced patient care. Services that target caregivers directly are intended to improve caregiver well-being; any benefit to the patient, even if expected, is incidental. It is our recommendation that **both** types of services are required and that the time has come to change national and local policies to implement this recommendation.

FIGURE 1.

Caregiver Services Provided to Caregiver by Medical Providers
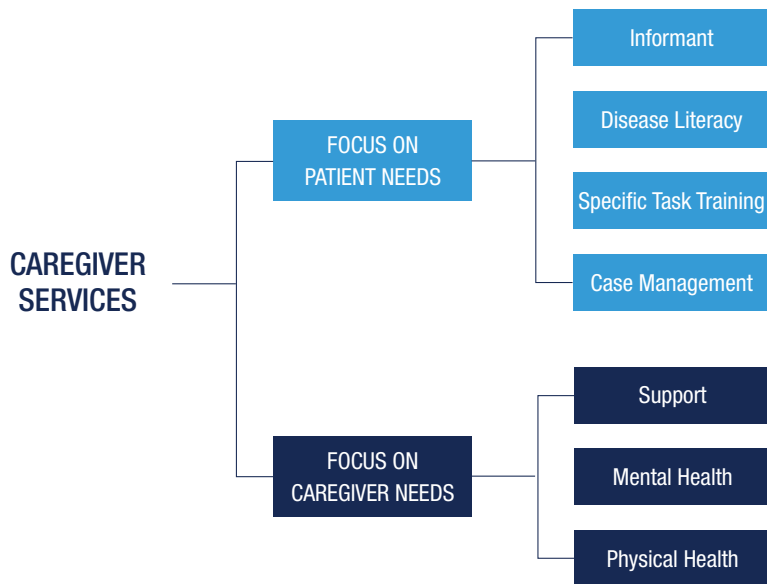
Patient-Targeted Caregiver Services

One patient-targeted caregiver service is time spent with the caregiver as an informant regarding patient symptoms and behavioral changes. Interacting with a family caregiver to obtain additional information can directly influence patient care. Provider observations are limited to the time of an office visit or based on reports from patients or patient contacts. These observations are typically brief and in a novel setting where the care recipient may not act as they do in daily life. In addition, patient self-reports may be unreliable, especially if the care recipient is cognitively impaired. Caregivers offer

a broader source of information about daily life patterns relevant to healthcare (e.g., eating, hygiene, falls). A caregiver who spends many hours with a patient is well-positioned to answer questions regarding medication or treatment compliance, note changes in behaviors, and identify disease progression indicators. In addition, a caregiver may be aware of information missing from patient records (for example, patient or family history) that may provide additional pertinent data. Noting the many benefits and the critical roles that caregivers provide, there has been an increasing push to more meaningfully integrate family caregivers into the medical care team (Friedman & Tong, 2020).

Patient-targeted caregiver services also address the need for more information about the patient's disease and management. Primary care physicians (PCPs) note that "how-to" questions dominate physician-caregiver conversations, with 83 percent of PCPs reporting discussions about managing medications; 80 percent discussing arranging services; 79 percent sharing information about the patient's condition; and 71 percent discussing medical or nursing tasks (Skufca, 2019). Case management services also fall under this category as resource needs become apparent, but case management is rarely done in the primary care setting due to staffing issues. When provided (for example, in specialty geriatric clinics), it typically includes patient/caregiver education and coordination of services with community-based health care providers.

Increased reliance of the healthcare system on family caregivers to deliver technical medical care in the home is well documented (AARP and National Alliance for Caregiving, 2020). The recent 2020 Caregiving in the U.S. report notes that 58 percent of caregivers report being responsible for such medical/nursing tasks as injections, tube feeding, catheter, and colostomy care, among many other complex tasks. Technical skills include operating equipment, engaging the care recipient in the use of the equipment, and reliable and valid reporting of services delivered along with any related health indicators related to use of that equipment. Preparation and training in these technical skills are critically needed, but who will provide it? When, where, and how?

As of this writing, caregivers report being inadequately trained for medical/nursing tasks; little to no implementation monitoring occurs over time. For example, fifty percent of male caregivers and one third of female caregivers report receiving no training on performing medical tasks when care recipients are discharged (Reinhard, 2019).

Some states have attempted to incorporate caregivers into recipients' care teams. The Caregiver Advise Record and Enable (CARE) Act requires hospitals or rehabilitation facilities allow patients to designate a family caregiver, note that person in the patient's medical record, notify the caregiver when plans for discharge or transfer occur, and provide education and demonstration of any procedures the caregiver is expected to do at home.

Unfortunately, this bare-bones approach has been signed into law in only forty states states (plus the District of Columbia, Puerto Rico, and the U.S. Virgin Islands (Rodakowski, Leighton, Martsolf, & James, 2021). In these states, the act is having a positive impact. In a 2017 survey of Pennsylvania hospital executives, most hospitals (90 percent) reported changes had been made, with 63 percent of patients having a caregiver noted in the medical records. Discharge notification was made in 45 percent of cases, with caregiver instruction and demonstration occurring in about 32 percent of inpatient stays (Rodakowski et. al, 2021). Even in these cases, caregivers report increased stress and anxiety caused by the possibility of causing harm to their care recipient due to lack of training.

Caregiver-Targeted Services

For optimal patient care, caregiver themselves may need services that address their social, physical, and/or mental health issues. Caring for someone with chronic illness is a demanding job; about 40 percent of caregivers report a high level of strain (AARP and National Alliance of Caregiving, 2020). Mental health services may be required. Recent reviews note a prevalence rate of 31 percent for depression and 32 percent for anxiety in caregivers of persons living with dementia (Collins & Kishita, 2019; Kaddour & Kishita, 2020). In addition, most caregivers report high levels of other negative emotions, including frustration, guilt, and a sense of hopelessness regarding the future (Schulz & Eden, 2016). Sixty-six percent of PCPs report discussing caregiver emotion management during patient office visit (Skufca, 2019). In a national survey, Wolff and colleagues (2020) found that, when health care workers asked caregivers patient-targeted questions, caregivers reported being listened to (88 percent always or usually) and asked about their understanding of the older adults' treatment (72 percent always or usually). However, caregiver-targeted questions regarding whether they needed help dropped to 28 percent. Thus, there appears to be a disconnect between what the physician believes is happening and what the caregiver is reporting.

In some settings (e.g., academic medical centers) caregiver support groups may be available at little or no cost as part of the services provided. However, referrals to community-based organizations for disease-specific groups are more common. Caregivers who require additional care for their own medical or mental health are usually referred to their own physician. Little is known about the efficacy of these referrals: do caregivers follow up? What are the results? How do we set up a system to determine if their needs are truly being met? These important questions remain unanswered but are key to solving the puzzle of how best to address caregiver needs.

CAREGIVER ROLE IN CARE PLANNING BY PROVIDER AND SETTING

OUTPATIENT SETTINGS

Many disciplines provide services to or interact with caregivers—not by treating them as patients but by serving as information providers to the caregiver. In outpatient medical settings, caregivers primarily interact with the primary care physician or internist of the care recipient; they may or may not have a PCP of their own in that same system (or at all). Many managed care organizations provide care coordination for the identified patient, as all referrals to specialty physicians need to come from them. Specialty physicians practice medicine within narrow fields.

The top seven are:

1. cardiologist (heart disease),

2. oncologist (cancer),

3. pulmonologist (lung disease),

4. neurologist (neurocognitive disease),

5. endocrinologist (diabetes),

6. nephrologist (kidney disease), and

7. geriatrician (specialist working with older adults).

Medical offices (whether for general medicine or specialty medicine) may have a support staff of professionals who interact with the caregiver on behalf of the patient. For example, nurses, nurse practitioners (NP), physician assistants (PA), social workers, and case managers may be part of the "core" team (if there is one), with ancillary services such as pharmacy, nutrition, physical therapy, occupational therapy, and psychology "on deck" as needed. These providers may also choose to engage the caregiver in treatment planning and implementation.

In a 2019 survey of medical offices, providers most in contact with caregivers were medical doctors (84 percent), nurses (74 percent), nurse practitioners (44 percent) and physician assistants (30 percent). The average length of contact was eleven minutes for the physician and 15 minutes for the NP/PA (Skufca, 2019). These interactions focused on goal setting and treatment planning for the care-recipient, not for the caregiver him- or herself. It is notable that most physicians (97 percent) and NP/PA (95 percent) reported interest in working with caregivers but cited challenges such as the caregiver not being part of the same health care system as the care recipient and thus unable to be treated as a "patient" in their own right. At best, most practices (even those that are "resource-rich") do a cursory assessment of caregivers' needs but focus their time and energy on the identified patient due to current service reimbursement fee structures.

MENTAL HEALTH SERVICES

Mental health services (for either or both care recipient and caregiver) can be provided by several disciplines including: psychiatrists (medical doctors who specialize in mental health); behavioral health and /or clinical psychologists who are licensed doctorate level providers; master's level providers (e.g., counselors, therapists, or licensed clinical social workers), and others (e.g., certified peer specialists, pastoral counselors). The ability of these professionals to seek reimbursement for their services depends on the insurance rules and regulations that govern their specialty. Caregivers without appropriate mental health coverage included in their health insurance have the option to pay out-of-pocket. However, this limits provider access only to those with the financial means to pay privately. This can be particularly challenging for many ethnically and linguistically diverse caregivers for whom culturally appropriate services (delivered in the caregivers' preferred language) may not be available, thereby discouraging them from seeking needed mental health care. The American Psychiatric Association offers best practices for delivering culturally competent mental health care for information https://www.psychiatry.org/psychiatrists/cultural-competency/education/best-practice-highlights. They emphasize the need for cultural humility to successfully provide needed services (Stubbe, 2020).

INPATIENT SETTINGS

In the inpatient setting, a multidisciplinary team approach may be used. Depending on the facility, this team can consist of the primary doctor, consulting doctors, registered nurses, nurse practitioners, physician assistants, occupational therapists, dieticians, technicians, therapists, social workers, patient care coordinator, spiritual care services, support staff, and others. Many of these practitioners use unique CMS billing codes, with the added complexity that reimbursement depends on who and how many are attending to the patient. In these settings, caregiver interactions are patient-focused, with the staff assisting the caregiver in performing the role of emotional support companion, as assistant by providing instrumental support for the patient, as representative by being the patient advocate, as navigator helping the patient to understand their disease and make care decisions, and lastly, as planner helping the patient to execute any recommended discharge plans (Miller et. al, 2016). Caregivers may be considered a "member" of the care team and contribute to treatment planning as well as implementation, depending on the practices of the medical facility. Rarely are they asked about their health care needs or informed of specific programs that will address those needs.

PAYMENT

NOTE: Information provided here and in the Payer Section is intended to provide only a general overview of existing systems. In practice, these systems are increasingly complex and difficult to navigate for providers, patients, and caregivers.

There are currently six payment models in the United States used to reimburse medical providers for their services:

1. fee for service;

2. capitation;

3. relative value units;

4. bundled payment;

5. comprehensive primary care plus; and

6. concierge care (Healthcare in America, 2017).

The most traditional form of reimbursement is *fee for service*, in which the medical provider submits a claim for each service performed. It is a volume-based model. *Discounted fee for service*, usually occurs with managed care organizations in which a medical provider agrees to a prearranged discount on the regular fee for service fees.

Capitation is the structure by which a medical provider agrees to a flat fee per month for each person enrolled in a managed health care plan, no matter the actual cost of providing that medical care.

In the *relative value unit* (RVU) model, compensation is dependent on the value of service provided; the RVU is part of the formula used to determine the reimbursement amount. An RVU is assigned to each service provided and is used to compute compensation. For Physician Work RVU, Medicare assigns each service a value based on level of time, skill, training, and intensity required to provide a given service. The costs of maintaining a practice such as rent, nonphysician staff cost are known as the Practice Expense RVU, and a Malpractice RVU covers professional liability services. These RVUs are then modified by the Geographic Practice Cost Indices, which takes into account the cost of providing services based on location of the practice.

The *bundled payments* model occurs when hospital and medical provider expenses are combined into a single payment. There are different models within this model dependent on setting.

The *comprehensive primary care plus* model contains two pathways: *comprehensive care* which include patient access, care management and coordination, and patient engagement; and *financial support* which contains care management payment, incentive payments for quality and utilization and alternative to fee for service payment structures. This model is not tied to an office visit but is paid per person per month. In this model the medical provider is paid prospectively yearly and then retrospectively reconciles with a performance-based incentive based on how well a practice performs on patient experience measures, clinical quality measures, and utilization measures.

Concierge care is the alternative to the more traditional payment models. There are two main types of concierge medical practices: concierge or retainer-based and direct primary care. Neither of these models typically have co-pays, deductibles, or co-insurance fees, but instead, work by charging patients a retainer. Many medical providers practice a hybrid version of this model by also accepting insurances.

PAYERS

In 2019, almost 89 percent of Americans were covered by some form of health insurance (Cohen, Cha, Martinez, & Terlizzi, 2020), of which 18 percent had Medicare (Elflein, 2020). The 2014 CMS National Health Expenditures Report for 2014 indicated the following for physician revenue: private medical insurance averages 34 percent, Medicare 22 percent, Medicaid 17 percent, self-pay 12 percent, other health insurance programs 11 percent and third-party payers and programs 4 percent.

Private Medical Insurance

Private health insurance refers to any health insurance offered by a private company rather than the federal or a state government. In a field of over 900 health insurance providers, the top ten companies control almost half of the market (JC Lewis Insurance Services, 2020). In 2019, the top five private medical insurance companies by covered lives were: UnitedHealthcare, 70 million members; Anthem/Blue Cross Blue Shield, 39.9 million members; Aetna, 22.1 million members; Cigna, 20.4 million members; and Humana, 16.6 million members.

Most insurance companies reimburse medical providers through the use of Current Procedural Terminology or (CPT®) codes. CPT® codes are submitted by medical providers to describe the services they provide. Medical providers note several issues while trying to be compensated for services provided. David Belk, MD noted that most physicians are unaware of how much they will get paid for each claim as the "methods are varied, convoluted and rather opaque" (Belk, 2012). In his experience with billing, it was difficult to know how much he would receive for any CPT® code he submitted as it was highly dependent on the insurance company and the patient's policy type. He noted an additional difficulty in that approval was heavily dependent on the insurance company; not all companies approve the same services.

Recognizing the need to support caregivers, insurance companies may offer resources or programs targeted specifically to caregivers. Blue Cross Blue Shield Association's 2020 Health of America reported on the impact of caregiving on mental and physical health and noted the critical need for caregiver support (Blue Cross Blue Shield Association, 2020). UnitedHealthcare, like many medical insurance companies, offers a caregiving resource webpage under their health and wellness sections. UnitedHealthcare also offers an innovative employer-based caregiving program called *Solutions for Caregivers*. It encourages "a more supportive company culture for caregiving" (UnitedHealthcare, 2019). Other insurance companies are recognizing the health consequences of caregiving on caregivers. Anthem is partnering with *ianacare* for a new app that enables caregivers to create a team from their personal social circles of friends, family, coworkers, and neighbors who can assist them when needed (Think Anthem, 2020). Many private medical insurance companies recognize the stress and burden being experienced by caregivers and are reaching out to both private and public organizations and businesses to seek out ways to alleviate caregiver distress.

Medicare

Instituted by the U.S. government in 1965, Medicare is health insurance for those aged 65 or older and younger individuals with a qualifying disability. Medical providers who choose to participate and agree to accept the rates set by Medicare are referred to as participating providers. In 2015, the Kaiser Family Foundation surveyed primary care physician and found the number of providers that accept Medicare was roughly the same as those that accepted private medical insurance (93 percent vs 94 percent). However, the number of providers accepting new Medicare beneficiaries were somewhat lower in comparison (72 percent vs 80 percent; Boccuti, Fields, Casillas, & Hamel, 2015). While most Medicare beneficiaries noted no difficulty accessing care, those with no supplemental insurance and those under age 65 with a qualifying disability reported some difficulties in finding a participating provider. Many primary care doctors have stated that Medicare doesn't reimburse them adequately and the paperwork is too complicated.

For the participating provider, the rules under which they receive reimbursement are complex. Payment is determined by a relative value scale. The panel that sets the scale meets three times a year and modifies the relative value unit (RVU) cost based on annual changes in a variety of criteria. The RVUs are adjusted by specific pay for performance programs. These pay-for-performance programs add a value-based payment that attaches financial incentives and disincentives to provider performance. While still using the fee-for-service model albeit with RVUs, it connects reimbursement to metric-driven outcomes, proven best practices, and patient satisfaction, with the intent of aligning payment with value and quality (Medicare Payment Advisory Commission, 2021).

Medicaid

Medicaid is the U.S. public health insurance program for low-income individuals . In 2017, Medicaid covered 20 percent of all Americans (75 million), and 62 percent of nursing home residents. One in five Medicare beneficiaries receive Medicaid assistance to cover premiums, cost-sharing, and other benefits such as long-term care that are not covered by Medicare. It is structured as a federal-state partnership, with the federal Centers for Medicare and Medicaid Services (CMS) responsible for implementation by setting core eligibility requirements and benefits and states having the flexibility to administer the program within federal guidelines. States can choose to cover optional services (e.g., prescription drugs, eyeglasses, dental care, and so on).

Over two-thirds of Medicaid beneficiaries are enrolled in private managed care plans that contract with states to provide comprehensive services; others receive their care in the fee-for-service system. Low payment rates have long been associated with lower physician participation in Medicaid, especially among specialists. The participation rate varies by state, and is largely tied to reimbursement rates. In Montana, for example, primary care doctors are reimbursed at the same rate for Medicaid and Medicare, and they have a doctor participation rate of 90 percent (Robertson, 2017). Physicians who take no or few Medicare patients cite the reasons for not participating in Medicaid as low payment (89 percent), delay in payment (76 percent), billing requirements (76 percent), and high clinical burden (60 percent), noting that Medicaid patients tend to have poorer health (Sommers, Paradise, & Miller, 2011).

At the same time, a 2015 report to Congress referencing the Patient Protection and Affordable Care Act's discontinued Medicaid primary care payment increase included that "there is not enough evidence to definitively determine whether the payment increase had an effect on provider participation or enrollee access to primary care in Medicaid" (MACPAC, 2017). More evidence is needed to better understand how Medicaid primary care payment incentives impact provider participation and ultimately enrollee access to primary care.

CURRENT PROCEDURAL TERMINOLOGY CODES

The Current Procedural Terminology (CPT®) system, developed by the American Medical Association (AMA), is used to track healthcare utilization, gather statistical healthcare information, and identify services for payment. Level I CPT® codes are the five-digit numerical codes used primarily to identify medical services and procedures. Level II CPT® Codes are performance measurement codes used to collect quality of care data. CPT® Codes are the preferred coding system for Medicare, Medicaid, and private medical insurers and are used by qualifying providers to identify provided services when the provider is seeking reimbursement. Appendix A, includes a list of CPT® Codes found in the American Medical Association's® 2021 Profession Edition that mention interactions with family, or caregivers. The authors have divided category Level I CPT® Codes into the sub-categories of Patient-Targeted Caregiver Services and Caregiver Targeted Services. A third category consists of Level II CPT® Codes that mention family or caregivers. Appendix A is intended for educational reference only. Refer to the American Medical Association's® CPT® 2021 Profession Edition for complete details.

BARRIERS TO INTEGRATING FAMILY CAREGIVERS INTO THE HEALTH CARE TEAM AND TO ASSESSING AND PROVIDING CARE TO CAREGIVERS DIRECTLY

Multiple barriers exist to prevent implementation of the dual aims of this report, not the least of which is the hodge-podge of payment options and financial limitations described above. Following are several key additional issues that need to be addressed in a thoughtful manner for progress to be made.

STANDARDS OF CARE

Standards for integrating caregivers into healthcare for their care recipient are lacking for most systems and providers, as are standards for evaluation and treatment of caregivers' own mental, physical, and social concerns that may interfere with their ability to adequately perform the caregiving role. The CARE Act established basic standards for hospitals, but comparable standards for incorporating caregivers into outpatient and long-term care settings do not exist. There are also no current guidelines for what to assess, and how to treat, the caregiver's medical and psychosocial problems. Without such standards and associated regulatory systems to monitor compliance, healthcare systems and providers lack motivation to prioritize caregiver integration and service provision.

AWARENESS OF REVENUE OPPORTUNITIES

Confusion on how to get paid for engaging caregivers is a substantial deterrent for providers and care systems. Even those who value and want to integrate caregivers into clinical care or to address the needs of both the patient and the caregiver find it daunting to establish business operations to fund this multi-layered work.

Three key barriers need to be addressed:

1. accessible information on billing codes and the rules for use,

2. simple mechanisms for identifying the appropriate caregiver(s) to engage for each patient, and

3. practice strategies for time-efficient engagement with caregivers.

ACCESSIBLE INFORMATION ON CODES AND CODING RULES

Although many billing codes exist (see Appendix A), there are no business practice guides that efficiently help health systems understand which are relevant to particular practices. Business offices typically lack an easy-to-understand summary of codes appropriate and useful for specific service settings. In the absence of such guidelines, billing managers must "reinvent the wheel" to figure out the best set of options for their practice. Although there are relevant CPT® codes for outpatient medical services (and related mental health care), a readily accessible set of model coding does not exist for specialty practices (e.g., cardiology, oncology), long-term care settings (e.g., skilled nursing facilities), primary care, and hospitals so that caregivers can be included in care planning and also assessed (and hopefully treated) for existing problems of their own that may interfere with providing optimal care. The risks of being pursued for fraud due to simple clerical errors also represent a substantial deterrent, especially for relatively low rates of reimbursement. Systems may avoid using available codes unless very specific, authoritative information is available.

EFFICIENCY OF IDENTIFICATION OF THE CAREGIVER(S)

Although identifying a single caregiver for the identified patient may seem an easy task, the size and complexity of today's families often require providers to assess the roles of various persons in order to figure out who is the primary caregiver. This is particularly true for culturally diverse families. For example, among African Americans and members of LGBTQ+ communities, "fictive kin" are often caregivers. Fictive kin refers to those care providers who may not be related to the care recipient by blood or marriage but function as if they are (Badana, Marino & Haley, 2019; Fredriksen-Goldsen & Kim, 2017). Failure to recognize and honor these relationships will further complicate treatment planning and implementation.

Existing approaches to defining a decision-making proxy reflect an inadequate conceptualization of caregiving within families that leads systems to falsely believe that they have addressed the issue of caregiver integration. Implementation of efforts to integrate caregivers into healthcare systems requires more sophisticated approaches to culturally diverse families. It is a major barrier to caregiver integration if each health practice setting must build its own standard of practice that has flexibility to honor cultural variabilities for caregiving roles.

EFFICIENT COMMUNICATION CHANNELS

Once identified, providers fear being drawn into time-inefficient communication that exceeds reimbursement. Time-efficient mechanisms for extracting key assessment and adherence information from caregivers are needed that align with the rate of reimbursement for communication with family members. The limited availability of standardized brief assessment tools for entry-level providers (e.g., medical technicians) to extract critical information about patients and about caregiver well-being is a barrier to efficient involvement of caregivers.

ORGANIZATIONAL PRACTICE GUIDANCE

A significant barrier to integrating caregivers into health systems is the shortage of guidance on processes and procedures for doing so. Currently, a limited set of model programs have demonstrated viable ways to integrate caregivers into some healthcare settings (including four described in Recommendations and Appendix B). Yet, providers and systems considering such an undertaking will almost inevitably be inventing the wheel yet again, a costly endeavor because efforts at innovation have not been packaged in practice guides related to workflow. A model program will be described later to illustrate that the dual aims of integrating caregivers into the care recipient's treatment team. Identifying and treating caregivers' own psychosocial needs, *can* be done.

WORKFLOW MODELS

Providers and systems are deterred by having to invent workflow systems for their specific settings, an effort that is costly in both time and money. Substantial variation exists across health settings, so integration of caregivers into systems requires investment in innovative approaches for each unique system. Models or prototypes of workflow models for engaging caregivers in health systems are not readily available for the range of settings (e.g., specialty clinic, primary care, hospital, home health, long term care) or around workforce characteristics (e.g., models for when a case manager is and is not available in each setting). Variations in characteristics of populations served and the structures of their families (e.g., multi- versus solo-caregiving families) add complexities that systems struggle to understand and address at a practical level.

RISK MITIGATION

Leaders recognize that innovation introduces risk. Barriers to this type of innovation include risks of fraudulent billing, risks to privacy, risks to time inefficiency, among many others. A lack of clear guidance about how to deliver services safely and effectively and bill appropriately is a substantive barrier to innovation.

ELECTRONIC RECORD ADAPTATION

Efforts to engage caregivers as part of the patient's care team or identify caregivers' needs immediately raise significant legal, ethical, and practical issues about how the information gathered will be documented and made available to others. Ethical issues related to privacy are as important to consider as issues related to access. Unused documentation does little to improve patient care. Yet documentation of caregiver distress in a chart that the care recipient "owns" adds complexities. Standards for handling family-level data are not developed or integrated into the commonly used electronic record systems.

COST DATA ARE INADEQUATE TO PROMOTE PRACTICE CHANGES

Defining and tracking the costs of engaging caregivers are major barriers to expansion of services to include caregivers. Research is needed to determine the conditions under which healthcare costs escalate when caregivers are excluded from the team versus conditions under which little cost is added when caregivers are omitted. Similarly, the costs of caregiver engagement needs to be more thoroughly understood and disseminated to reduce barriers created by the perception of out-of-control costs when families are more engaged in patient care.

PROVIDER TIME

Absence of information about the time invested in various types of engagement of caregivers in patient care poses a barrier to setting effective reimbursement rates or marketing them to providers. Reimbursement for provider coordination of patient care with caregivers requires data on time-use under various conditions of patient need, caregiver knowledge and skill, and availability of time-efficient assessment tools.

A related barrier is the need for validated tools that extract caregiver reports of patient behavior, care, and unmet needs. Tools also are needed that rapidly assess caregiver's own needs to sustain the service role. Furthermore, tools need to be available in multiple languages and cultural variability in assumptions about how families provide care.

REVENUE BUSINESS PRACTICES

Another barrier is the cost of billing for services that involve caregivers. The time cost of providers selecting codes and administrators processing codes, rejected billings, and debt collection is substantial, and thus may be perceived as a barrier to innovation.

METHODOLOGY: HOW DID WE ASSESS THE FIELD AND COME TO THESE CONCLUSIONS/ RECOMMENDATIONS?

A mixed methods approach was utilized, containing a literature review, survey of medical providers, and interviews with a broad range of professionals.

LITERATURE REVIEW

A literature search was conducted on the topics of services currently available to caregivers of adults with chronic illness by the medical field and how medical providers were reimbursed for providing these programs. The literature search provided many articles on various topics, including policy papers, ethical issues, barriers in treating caregivers of patients, programs designed address these barriers, and methods/success of reimbursement.

SURVEY

A brief, online survey of medical providers who worked directly with caregivers in their practice was conducted from January 2020 – December 2020. The survey was disseminated via email through various list-serves recommended by professional colleagues. The twenty-four-question survey asked for information regarding the integration of caregivers into the treatment team, services provided to the caregiver, and how the providers receive reimbursement for these services. Included were questions about the barriers medical providers may have experienced. Fifteen providers responded and, although the numbers were far below expected participation, the data provided was valuable. The limited participation was most likely due to the COVID-19 pandemic which began during the survey timeframe and was especially burdensome for medical providers during this time period.

INTERVIEWS

Twenty-five interviews were held online with forty-three individuals in the following categories: acute care and hospital care, long-term and post-acute care, health plans, home and community-based services, academic healthcare systems, and academia (see Appendix A). These informants were selected to allow for an inclusive view of the healthcare system, including the service provider, the administrator, the policy maker, and the payer, across the trajectory of services from home, primary care, hospital, rehabilitation, and residential. Interviewees were invited to participate via email. Interviews were semi-structured around the following topics: integration of family caregivers into models of healthcare, provision of caregivers' services, and reimbursement for caregivers' services.

THEMES

The information gathered from all three sources (literature review, surveys, and interviews) were analyzed. The following four themes emerged predominant:

1. Across all settings, the benefits for the patient of caregiver participation on the treatment team and the caregivers' own need for service was acknowledged.

2. Numerous barriers exist at all levels, from physician to administrator.

3. Lack of sufficient reimbursement for time invested, not only by the physician but other staff as well, is a significant barrier for use of existing CPT® codes.

4. There are some successful "model" programs that are trying to address these issues, but they are few and far between. They are discussed below.

RECOMMENDATIONS – OVERCOMING BARRIERS TO INCENTIVIZING MEDICAL PROVIDERS

1. CAREGIVER ENGAGEMENT STANDARDS IN ALL HEALTHCARE ENVIRONMENTS

Establish standards for caregiver engagement in all healthcare environments for which such standards are missing. This requires system-level buy-in which, as discussed previously, is difficult to obtain. Yet without administrative support, innovative programs that are not financially sustainable from the outset will not be created. On the national level, the CARE and RAISE Family Caregivers[2] Acts have set the stage for policy changes and for innovative approaches to these topics. However, although the CARE Act established standards for hospitals at the state level), comparable standards for integration of caregivers into practice need to be developed for primary care and specialty outpatient providers, home health, and long-term care. The activities initiated in response to the RAISE Act may provide foundational information to guide development of standards.

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[2]*The RAISE Family Caregivers Act requires the Secretary of Health and Human Services to develop, maintain and update an integrated national strategy to recognize and support family caregivers. (RAISE Family Caregivers Act of 2018 (P.L. No: 115-119), available at https://www.congress.gov/bill/115th-congress/house-bill/3759.*

Standards should include guidelines for handling information involving multiple family members. At a minimum, this should include creating a field in the patient's electronic medical record (EMR) to identify the primary caregiver by name and relationship and notating contact information (e.g., email, phone/ text numbers, preferred method of communication). This will, at least, identify the primary caregiver and potentially allow for "linking" of data in the patient's EMR with that of their primary caregiver.

Disseminate information. Once established, aggressive efforts are needed to disseminate the standards to healthcare systems and to the public so that both providers *and* caregivers can track whether these standards are, in fact, being met.

Adoption of standards needs to be associated with regulatory processes that result in consequences for non-compliance and incentives for compliance. For example, CMS is a very strong position to withhold funding from healthcare systems that do not actively involve caregivers in the ongoing health care of older adults with chronic medical issues.

2. CREATION OF PRACTICE FLOW GUIDES AND EFFICIENT ASSESSMENT TOOLS

Practice Flow Guides need to be created and disseminated, describing practice principles, models for application of principles in various settings, with detailed illustrations of exemplary innovation programs.

Efficient assessment tools to assess the patient (status and changes in functional health) and caregiver (status and changes in functional health that threaten sustainability of the caregiving role) need to be adopted. Screening models currently exist that can be adopted for use with caregivers themselves, patterned after what is done currently to assess depression. Medicare **requires** that all primary care patients be screened annually for depressive symptoms using the PHQ-2, a validated two-item questionnaire available in multiple languages. Persons screening positive are then automatically administered the full PHQ-9 questionnaire to assess depressive symptoms in more depth. This information is part of the EMR and therefore available to all providers. Depression is also noted on the problem list and the provider must indicate a treatment plan to address the situation. Standard cut-off scores may be established or adopted to help with decision-making regarding appropriate treatment.

A similar approach can be used to assess caregivers' mental health. The American Medical Association publishes a brief screen for caregiver stress that is available in multiple languages and can be self-scored. Depression and anxiety screens may also be included, bringing the total screening length to about twenty items. Caregivers scoring above accepted cut-offs would be given additional additional screening using full-length assessments. As with the PHQ, the results would be automatically recorded in the caregiver's medical record.

The proposed process contains: a) brief screens; b) full measures; c) develop treatment plan; d) implementation plan; and e) follow-up/re-assessment to determine whether intervention has been successful. A similar process could be followed to assess caregivers' medical conditions and other social problems (e.g., food insecurity, unemployment, and the like) that may negatively impact the caregiver's ability to do her/his job competently over time. This process can be done through embedded social work/nursing teams who review the data and provide the necessary follow-up care.

Principles, models, and exemplars are needed for specific settings, noting variations in implementation based on provider level of training and role, electronic medical record system idiosyncrasies, and other organizational characteristics. Two programs in particular illustrate how creativity, funding, and institutional support can come together to address caregiver-specific needs alongside those of the care recipient. Others are in development or are operational but do not have supporting data. This list can and will change over time as more innovative programs are implemented.

Program Spotlight: 4Ms Caregiving Initiative

The Caregiver Health and Well-Being Initiative (Caregiver Initiative, or CGI) was developed by the Department of Social Work and Community Health at Rush University Medical Center in Chicago, IL. The initial development of this visionary work was funded by the RRF Foundation for Aging, whose continuous championing led to funding from The John A. Hartford Foundation (JAHF) for refinement, scale, and spread across Age-Friendly Health Systems. Rush and the Institute for Healthcare Improvement (IHI) are working to integrate caregivers into the 4Ms of an Age-Friendly Health System (What Matters, Medication, Mentation, and Mobility) by prototyping the 4Ms CGI. The work is collaboratively led by Robyn Golden, LCSW, associate vice president, Population Health and Aging and Leslie Pelton, vice president, Institute for Healthcare Improvement. The partnership is the culmination of their years of experience related to supporting caregiver well-being and advancing age-friendly health systems.

The Rush Caregiver Initiative draws together evidence-based practices into a single framework to improve care for both the older adult care recipient with chronic medical illnesses by addressing the needs of their caregiver. It has two main components: system-level change and caregiver interventions. Caregivers are identified and documented in the patient's Electronic Medical Record (EMR). They also become patients themselves, with their own EMR, and their insurance coverage is documented in their chart. Services such as "Skill Building" (to address medication, mentation and mobility of the care recipient); "What Matters Family Sessions" (to discuss what matters to the dyad resulting in better informed care plans); and comprehensive assessment of caregiver status including depression (using PHQ-9), anxiety (using GAD-7), self-efficacy, caregiver burden, health literacy and social determinants of health, along with a biopsychosocial/spiritual assessment are provided. Staffing for these services is provided primarily by licensed clinical social workers who can bill using CPT® codes for family psychotherapy with or without the patient present or can bill for individual psychotherapy with Adjustment Disorder diagnoses. Billing may be done to the care recipient's insurance when consent is given, or to the caregiver's insurance when seeking consent is inappropriate. "Diagnostic assessments" of the caregiver may also be provided by the CGI staff and billed to the caregiver's insurance, and referrals are made for ongoing psychotherapy when needed, which is typically covered by the caregiver's insurance.

In sum, the 4Ms CGI program addresses the dual aims covered in this report: caregivers are documented in the patient's EMR, they are actively engaged in treatment planning, they are assessed for their own needs, and they are referred for mental health care or other services if indicated. This initiative provides a rich teaching and learning environment where detailed assessment of the 4Ms of the patient is done, with caregiver input, and then used to set measurable goals discussed at family care planning meetings. Referrals within the system and to community-based organizations are routinely made, and a closed-loop system is in place within the EMR to track follow-up.

Close to 150 families are served each year. Early results demonstrate reductions in symptoms of depression, anxiety, and caregiver burden that are statistically significant. The reductions are also clinically significant, moving caregivers from levels that indicate a need for treatment to levels below the threshold indicating a need for intervention.

In 2021, the 4Ms CGI program is being piloted in five healthcare systems, with scale and spread to Age-Friendly Healthcare Systems anticipated after June 2022. This comprehensive program recognizes that identifying, assessing, and supporting family caregivers is critical to age-friendly care of older adults.

Program Spotlight: Caregivers Clinic

Caregivers Clinic, Memorial Sloan Kettering Cancer Center (MSK). A second promising initiative is the Caregivers Clinic, housed in the Department of Psychiatry and Behavioral Sciences at MSK in New York City, led by psychologist Allison J. Applebaum, PhD. It is one of several programs to support caregivers of persons with any type or stage of cancer, at any point in the caregiving trajectory. The Caregivers Clinic provides psychosocial support by conducting assessments of caregivers' mental health needs and providing in-house psychotherapy, including cognitive-behavioral, existential, and supportive therapy, and bereavement counseling. Caregivers can self-refer to the clinic; they can also be referred by an oncologist or any other member of the healthcare team who is aware of caregiver distress. Care is typically delivered individually or in small groups, although both couples therapy and family counseling are available as needed. A peer mentoring program is also available that enables caregivers to learn from others facing similar challenges. Given the expense of this program, insurance is routinely billed; however, the developer shared that lack of adequate insurance coverage is one factor driving attrition—early termination of therapeutic services. This led the team to partner with the Cancer Support Community to pilot test their web-based and automated CancerSupportSource®-Caregiver (CSS-Caregiver) distress screening tool to better identify caregiver needs and triage caregivers to appropriate levels of care at MSK. A collaborative publication between the MSK and CSC teams describes these efforts in detail (Shaffer, Benvengo, Zaleta, et al., 2019). Data collection is an ongoing process; the group is attempting to show improved caregiver well-being as well as cost savings for the cancer patient among caregivers who received support for their unmet needs including mental health needs. It is included here because, by inclusion and integration of CSS-Caregiver online resources and continuity of care provided via reimbursable telepsychiatry billing codes, the MSK program's breadth was able to be expanded without insurance limitations.

Program Spotlight: Caring for Caregivers Care Model

While it has long been stated that caregiving interventions provide a cost savings for health care systems, few models illustrate the savings across a large healthcare system. One such model called the Caring for Caregivers care model,

developed by Venus Wong and associates at Stanford University's Clinical Excellence Research Center, provides a clinical and business case for the healthcare systems that serve the Medicare Advantage population (Wong et al., 2021). In looking to improve health outcomes, enhance patient experience, and decrease healthcare costs, this model identified and targeted three unmet caregiver needs: social isolation, care fragmentation, and unmet day-to-day care needs. The model estimates significant cost-savings for plans that adopt its three intervention components.

The social isolation component was represented by Health Education Program (HEP), peer group intervention for family caregivers of individuals with chronic illnesses. The care fragmentation component was addressed by the Healthy Aging Brain Center (HABC), a program providing medication management, care navigation, and brief family caregiver consultation. The final component, unmet day-to-day care needs was addressed through Care Angel, a virtual assistant that utilizes automatic reminders to the care recipients and can notify the caregiver and/or nurse that additional assistance is needed or there is a concern that needs addressing.

The cost-benefit analysis performed on the three evidence-based programs showed a significant potential savings for the healthcare system1. A randomized controlled trail (RCT) of the peer group intervention of HEP indicated a potential average net saving of $861 per caregiver per year and $1,461 per patient per year. In addressing the need for efficient caregiver and patient workflows, the HABC identified an estimated net saving of approximately $3,168 per patient per year using the HABC integrated care pathway. Targeting the unique daily unmet needs experienced by adults with chronic illnesses and their caregivers, the virtual assistant Care Angel showed a potential net saving of $492 per patient per year. The Caring for the Caregiver model has the potential to generate both better health-related outcomes as well as potential cost savings associated with lower healthcare utilization.

3. USER-FRIENDLY ACCESS TO CMS CODES TO FACILITATE USE

Billing codebooks and related rules need to be disseminated in user-friendly formats that protect providers from error and fraud while constraining the costs of processing billing. There is a pressing need for "pocket guides" and/or an "app" for mobile devices and/or a dedicated website that is regularly updated so that providers can find the information they need with confidence that it has been vetted by a reliable source. Currently, none of these options exist, so providers are on their own to figure out reimbursement codes.

REFERENCES

AARP and National Alliance for Caregiving. (2020). *Caregiving in the US 2020*. Washington, DC: AARP.

American Medical Association. (2020). *CPT 2021 Professional Edition*. American Medical Association.

Badana, A. N., Marino, V., & Haley, W. E. (2019). Racial Differences in Caregiving: Variation by Relationship Type and Dementia Care Status. *Journal of Aging and Health*, 31(6), 925–46.

Belk, D. (2012). *True Cost of Health-Care. Outpatient Charges*. https://truecostofhealthcare.org/outpatient_charges/

Blue Cross Blue Shield Association. (2020). *Impact of Caregiving on Mental and Physical Health*. The Health of America Report. https://www.bcbs.com/sites/default/files/file-attachments/health-of-america-report/HOA-Caregivers_3.pdf

Boccuti, C., Fields, C., Casillas, G., & Hamel, L. (2015). Primary Care Physicians Accepting Medicare: A Snapshot. *Kaiser Family Foundation*.

CMS.gov. (2021, February 1). Caregiver Partners. Outreach & Education: Partner Resource. https://www.cms.gov/Outreach-and-Education/Outreach/Partnerships/Caregiver

Collins, R. N., & Kishita, N. (2019). The Effectiveness of Mindfulness- and Acceptance-based Interventions for Informal Caregivers of People with Dementia: A Meta-analysis. *The Gerontologist*, 59(4), e363–e379.

Cohen, R. A., Cha, A. E., Martinez, M. E., & Terlizzi, E. P. (2020). *Health Insurance Coverage: Early Release of Estimates from the National Health Interview Survey, 2019*. National Center for Health Statistics. https://www.cdc.gov/nchs/data/nhis/earlyrelease/insur202009-508.pdf

Elflein, J. (2020, October 9). Percentage of U.S. Americans covered by Medicare 1990–2019. Statista: Health System. https://www-statista-com.org/statistics/200962/percentage-of-americans-covered-by-medicare/

Fredriksen-Goldsen, K. & Kim, H-J. (2017). The Science of Conducting Research with LGBT Older Adults — An introduction to Aging with Pride: National Health, Aging, and Sexuality/Gender Study (NHAS). *The Gerontologist*, 57 (suppl.1), S1–S14.

Friedman, E. M., & Tong, P. K. (2020). *A Framework for Integrating Family Caregivers into the Health Care Team*. RAND Corporation.

Goldyn, R. & Carbonell, E. (personal communications, March 10, 2021 and May 4, 2021). A model for caregiver health and wellness in age-friendly health systems.

Healthcare in America. (2017, March 7). *How Do Doctors Get Paid for Healthcare Treatment?* https://healthcareinamerica. us/how-do-doctors-get-paid-for-healthcare-treatment-f7538b9e50aa

JC Lewis Insurance Services, (2020, June 24). *Top 5 Health Insurance Companies in the U.S.* https://www.jclis.com/ health-insurance/top-5-health-insurance-companies/

Kaddour, L., & Kishita, N. (2020). Anxiety in Informal Dementia Carers: A Meta-analysis of Prevalence. *Journal of Geriatric Psychiatry and Neurology*, 33(3), 161–72.

Kaye, N., & Teshale, S. (2020). *Medicaid Supports for Family Caregivers*. Washington, DC: National Academy for State Health Policy.

Longacre, M., Appelbaum, A. J., Buzagio, J., Miller, M. F., Golant, M., Rowland, J. H., Given, B., Dockham, B. & Northouse, L. (2018). Reducing Informal Caregiver Burden in Cancer: Evidence-based Programs in Practice. DOI: 10.1093/tbm/bx028.

Matson, M., Song, L., & Mayer, D. K. (2014). Putting Together the Pieces of the Puzzle: Identifying Existing Evidence-based Resources to Support the Cancer Caregiver. *Clinical Journal of Oncology Nursing*, 18(6), 619–36. DOI: 10.1188/14. CJON.619–21.

Medicaid and CHIP Payment and Access Commission (MACPAC). (2015). March 2015 Report to Congress on Medicaid and CHIP. https://www.macpac.gov/publication/march-2015-report-to-congress-on-medicaid-and-chip/

Medicare Payment Advisory Commission. (2021). *March 2021 Report to the Congress: Medicare Payment Policy*. Washington, DC: Medicare Payment Advisory Commission

Miller, A. D., Mishra, S. R., Kendall, L., Haldar, S., Pollack, A. H., & Pratt, W. (2016, February). Partners in Care: Design Considerations for Caregivers and Patients during a Hospital Stay. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing* (pp. 756–69).

Reinhard, S. (2019). Home Alone Revisited: Family Caregivers Providing Complex Care. *Innovation in Aging*, 3(Suppl 1), S747.

Reinhard, S. C., Feinberg, L. F., Houser, A., Choula, R., & Evans, M. (2019). Valuing the Invaluable: 2019 Update Charting a Path Forward. *AARP Public Policy Institute*.

Robertson, L. (2017). *Fact Check: Medicaid's Doctor Participation Rates*. USA Today: FactCheck.org https://www. usatoday.com/story/news/politics/2017/03/29/fact-check-medicaids-doctor-participation-rates/99793460/

Rodakowski, J., Leighton, C., Martsolf, G. R., & James, A. E. (2021). Caring for Family Caregivers: Perceptions of CARE Act Compliance and Implementation. *Quality Management in Healthcare*, 30(1), 1–5.

Schulz, R., & Eden, J. (Eds.). (2016). *Families Caring for an Aging America* (pp. 2-6). Washington, DC: National Academies Press.

Shaffer, K. M., Benvengo, S., Zaleta, A. K., Levine, M., Bellantoni, C., Dannaoui A., Buzaglo, J. S., & Applebaum, A. J. (2019). Feasibility and acceptability of distress screening for family caregivers at a cancer surgery center. *Oncology Nursing Forum*, 46(2), 159-169, doi: 10.1188/19.ONF.159-169

Skufca, L. 2019. *Primary Care Providers' Experience with Family Caregivers*. AARP Research. https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2019/primary-care-provider-on-family-caregiver-role.doi.10.26419-2Fres.00273.001.pdf

Sommers, A. S., Paradise, J., & Miller, C. (2011). Physician Willingness and Resources to Serve More Medicaid Patients: Perspectives from Primary Care Physicians. *Medicare & Medicaid Research Review*, 1(2).

Think Anthem. (2020, October 2). Caring for Our Caregivers. https://www.thinkanthem.com/uncategorized/caring-for-our-caregivers/

Wolff, J. L., Freedman, V. A., Mulcahy, J. F., & Kasper, J. D. (2020). Family Caregivers' Experiences with Health Care Workers in the Care of Older Adults with Activity Limitations. *JAMA Network Open*, 3(1), e1919866-e1919866.

Wong, V., Rosenbaum, S., Sung, W., Kaplan, R. M., Bott, N., Platchek, T. & Shah, N. R. (2021). Caring for Caregivers: Bridging the Gap Between Family Caregiving Policy and Practice. *NEJM Catalyst Innovations in Care Delivery*, 2(4).

UnitedHealthcare. (2019, June 25). The Burden of Caregiving: A Growing Workforce Challenge. https://www.uhc.com/employer/news/client/the-burden-of-caregiving--a-growing-workforce-challenge

APPENDIX A – AMERICAN MEDICAL ASSOCIATION'S® CPT® THAT REIMBURSE FOR INTERACTING WITH FAMILY/CAREGIVER

This Appendix is intended for educational reference only. Refer to American Medical Association's® CPT® 2021 Profession Edition for complete details.

Patient-Targeted Caregiver Services

Codes	Definition	Criteria for Caregiver/Family Members
99241-99245	Face-to-face time outpatient consultations	Counseling provided consistent with the patient's and/or family's needs.
99324-99328	Domiciliary or rest home—new patient	Counseling provided consistent with the patient's and/or family's needs.
99334-99337	Domiciliary or rest home—established patient	Counseling provided consistent with the patient's and/or family's needs.
99341-99345	Home visit for the evaluation and management—new patient	Counseling provided consistent with the patient's and/or family's needs.
99347-99350	Home visit for the evaluation and management—established patient	Counseling provided consistent with the patient's and/or family's needs.
99490-99439	Chronic care management services	Educating the patient or caregiver about the patient's condition, care plan, and prognosis.
99491, 99487, 99489	Chronic care management services	Educating the patient or caregiver about the patient's condition, care plan, and prognosis.
99218-99220	Initial observation care	Counseling provided consistent with the patient's and/or family's needs.
99224-99226	Subsequent observation care	Counseling provided consistent with the patient's and/or family's needs.
99234-99236	Observation or inpatient hospital care	Counseling provided consistent with the patient's and/or family's needs.
99221-99223	Initial hospital care	Counseling provided consistent with the patient's and/or family's needs.
99231-99233	Subsequent hospital care	Counseling provided consistent with the patient's and/or family's needs.
99238-99239	Hospital discharge services	Instructions for continuing care to all relevant caregivers.
99251-99255	Inpatient consultation for a new or established patient	Counseling provided consistent with the patient's and/or family's needs.
99304-99306	Initial nursing facility care	Counseling provided consistent with the patient's and/or family's needs.
99307-99310	Subsequent nursing facility care	Counseling provided consistent with the patient's and/or family's needs.
99315-99316	Nursing facility discharge services	Instructions are given for continuing care to all relevant caregivers.
99318	Other nursing facility services	Counseling provided consistent with the patient's and/or family's needs.
99339-99340	Domiciliary, est. home (e.g., assisted living facility), or home care plan oversight services	Communication (including telephone calls) with family member(s), surrogate decision maker(s) and/or key caregiver(s) involved in patient's care.
99291-99292	Critical care services	Time spent on the floor or unit with family members or surrogate decision makers.

99366-99367	Medical team conference	With or without the presence of the patient, family member(s), community agencies, surrogate decision maker(s), and/or caregiver(s).
99457-99458	Remote physiologic monitoring treatment management services	Requiring interactive communication with the patient/ caregiver during the month.
99091	Digitally stored data service/ Remote physiologic monitoring	Including communication to patient and/or caregiver).
99457-99458	Remote physiologic monitoring treatment management services	Interactive communication with the patient/ caregiver.
99374-99375	Care plan oversight services— supervision of a patient under care of home health agency	Communication (including telephone calls) with family member(s), surrogate decision maker(s) and/or key caregiver(s) involved in patient's care.
99377-99378	Care plan oversight services— supervision of a hospice patient (patient not present)	Communication (including telephone calls) with family member(s), surrogate decision maker(s) and/or key caregiver(s) involved in patient's care.
99379-99380	Care plan oversight services— Supervision of a nursing facility (patient not present)	Communication (including telephone calls) with family member(s), surrogate decision maker(s) and/or key caregiver(s) involved in patient's care.
99495-99496	Transitional care management services	TCM requires an interactive contact with the patient or caregiver.
99497-99498	Advance care planning	Face-to-face service between a physician or other qualified health care professional and a patient, family member, or surrogate for counseling and discussion.
90887	Other psychotherapy	Interpretation or explanation of results of psychiatric, other medical examinations and procedures, or other accumulated data to family or other responsible persons, or advising them how to assist patient.
90989, 90993	Other dialysis procedures	Dialysis training, patient, including helper.
92626-92627	Auditory evaluative and therapeutic services	Use the face-to-face time with the patient or family.
96040	Medical genetics and genetic counseling services	Use the face-to-face time with the patient or family.
97156-97157	Family adaptive behavior treatment	Training guardian(s)/caregiver(s) of one or multiple patients.
96132-96133	Neuropsychological testing evaluation services	Interactive feedback to the patient, family member(s) or caregiver(s).
96130-96131	Psychological testing evaluation services	Interactive feedback to the patient, family member(s) or caregiver(s).
96167-96171	Health behavior assessment and intervention	These services emphasize active patient/family engagement and involvement.
96161	Caregiver-focused health risk assessment	Administration of caregiver-focused health risk assessment instrument for the benefit of the patient
97161-97163	Physical therapy evaluations	Time spent face-to-face with the patient and/or family.
97164	Reevaluation	Time spent face-to-face with the patient and/or family.
97165-97167	Occupational therapy evaluation	Time spent face-to-face with the patient and/or family.
97168	Reevaluation	Time spent face-to-face with the patient and/or family.

Caregiver Targeted Services		
99483	Assessment of and care planning for a patient with cognitive impairment	Identification of caregiver(s), caregiver knowledge, caregiver needs, social supports, and the willingness of caregiver to take on caregiving tasks
99490, 99491, 99439, 99487, 99489	Chronic care management services	Caregiver assessment
99492-99494	Psychiatric collaborative care management services	Included as direct care to caregiver as a patient as a result of caregiving burden and stress.
90785	Psychiatry	Caregiver emotions or behavior that interferes with the caregiver's understanding and ability to assist in the implementation of the treatment plan.
90832-90853	Psychotherapy	Include involvement of informants in the treatment process.
Category II Codes		
4174F	Counseling provided to patient and/or caregiver(s) (EC)	
4176F	Counseling provided to patient and/or caregiver(s) (NMA–No Measure Associated)	
4177F	Counseling provided to patient and/or caregiver(s) (EC)	
4322F	Caregiver provided with education and referred to additional resources for support (DEM)	
4324F	Patient (or caregiver) queried about Parkinson's disease medication related motor complications (Prkns)	
4325F	Medical and surgical treatment options reviewed with patient (or caregiver) (Prkns)	
4326F	Patient (or caregiver) queried about symptoms of autonomic dysfunction (Prkns)	
4328F	Patient (or caregiver) queried about sleep disturbances (Prkns)	
4330F	Counseling about epilepsy specific safety issues provided to patient (or caregiver(s)) (EPI) 8	
4400F	Rehabilitative therapy options discussed with patient (or caregiver) (Prkns)	
6080F	Patient (or caregiver) queried about falls (Prkns, DSP)	
6090F	Patient (or caregiver) counseled about safety issues appropriate to patient's stage of disease (Prkns)	

American Medical Association. (2020). *CPT 2021 Professional Edition*. American Medical Association.

APPENDIX B

VA Caregiver Support

The Veterans Administration health care system is a national resource that provides comprehensive health care (including mental health services) to eligible veterans and, more recently, to their family caregivers. Several programs currently exist to serve family caregivers of "wounded, ill, or injured veterans or service members," including the Program of General Caregiver Support Services (which provides resources, education, and support to caregivers of veterans regardless of service-connected disability or what era they served in) and the Program of Comprehensive Assistance for Family Caregivers (which provides monthly stipends to caregivers of veterans with at least 70 percent service-connected disability who served in certain periods of time—e.g., post 9/11). The VA Caregiver Support website is located at: www.caregiver.va.gov

It is easy to enroll in the general support services program: caregivers contact the VA caregiver support line to obtain a referral to their local caregiver support coordinator. This can be done online or by phone. The coordinator helps the caregiver access a variety of education and training programs such as "Building Better Caregivers" and the VA caregiver support line which gives access to licensed professionals over the phone to help deal with stress and burnout. There is also a peer mentoring program, a suicide prevention toolkit designed specifically for caregivers, and regular meetings of telephone-based support groups. All these services are free of charge, supported in part by the Elizabeth Dole Foundation which established a set of national "centers of excellence" for caregiver research and service provision.

In addition, the VA recently established the Respite Relief Program: hiddenheroes.org/respite which provides nonmedical support services at home to the veteran in order to give the caregiver a period of respite (or relief) from their usual caregiving tasks. Services include meal preparation, bathing assistance, grooming and toileting, and companionship; all are free of charge once eligibility is determined. Finally, in addition to the dedicated website noted earlier, there is a national toll-free number created for caregivers to learn about and access the many programs that currently exist; future programs are being developed.

While these programs provide excellent examples of what an array of educational and supportive services for caregivers can consist of, they lack certain key elements (such as standardized assessments and access to mental health providers for ongoing services) that have been called for in this policy brief. As well, few research studies have been conducted to demonstrate the efficacy of these programs, or their cost-saving potential in terms of healthcare costs for the veteran care recipient. One of the few studies published on this topic (Van Houtven et al., 2017) found an increase in veterans' engagement in outpatient primary and specialty care services in the short term (six months after enrollment) among veterans whose caregivers were enrolled in the comprehensive caregiver support program compared to the control condition. This difference did not persist at the time of follow up, about three years later, although use of mental health services was higher in the treatment group both initially and at follow up. It is unclear whether longer-term health outcomes improved to a significantly greater degree (or were about the same) for veterans whose caregivers participated in the support program. However, there are several ongoing research studies, supported by VA funds, to address these questions— both for participants in the caregiver comprehensive program and for those in the general support services program. Other studies to assess caregivers' quality of life, mental health, and/or physical health status before and after program participation are also in the planning stages. Therefore, greater clarity as to the impact of these programs will have to wait for these studies to be completed.