



VIA ELECTRONIC SUBMISSION AT REGULATIONS.GOV

September 9, 2024

The Honorable Xavier Becerra
Secretary, Centers for Medicare & Medicaid Services
U.S. Department of Health and Human Services
Attention: CMS-1807-P, P.O. Box 8016
Baltimore, MD 21244-8016

RE: CMS-1807-P – Medicare and Medicaid Programs: Calendar Year 2025 Payment Policies Under the Physician Fee Schedule and Other Changes to Part B Payment and Coverage Policies; etc.

Dear Secretary Becerra:

On behalf of the Cancer Caregiving Collaborative, thank you for the opportunity to provide comments on **Medicare and Medicaid Programs: Calendar Year 2025 Payment Policies Under the Physician Fee Schedule and Other Changes (“Proposed Rule”)**.

The Cancer Caregiving Collaborative is an initiative of the **National Alliance for Caregiving**, representing those who care for an estimated 18 million cancer survivors in the United States, a number that is projected to grow to 26 million by 2040.¹ The Collaborative is a multi-phase, cross-sector initiative working to address the unmet needs of cancer caregivers through two priorities: healthcare integration and financial health. We were greatly encouraged by CMS’s leadership in the CY 2024 Physician Fee Schedule to take steps to integrate family caregivers into models of healthcare delivery and are likewise encouraged by the expansion of caregiver supports in the Proposed Rule for the CY 2025 Physician Fee Schedule.

The undersigned organizations and subject matter experts respectfully submit the following comments and responses to the Proposed Rule on behalf of the Cancer Caregiving Collaborative:

- I. The Proposed Rule’s new provisions to expand Caregiver Training Services (CTS) to include direct care training will help support better treatment for cancer survivors who rely on family caregivers to conduct medical and nursing tasks.**
- II. The Proposed Rule’s telehealth and health information technology provisions support better care for cancer survivors and other Medicare beneficiaries who may be immunocompromised, and their family caregivers.**
- III. We respectfully ask that CMS clarify that providers may conduct a caregiver assessment and may offer subsequent CTS when reasonable and necessary regardless of the underlying diagnoses of the Medicare beneficiary who needs care.**

From the perspective of the Cancer Caregiving Collaborative, the proposed updates to Caregiver Training Services (CTS) and related supports in the CY 2025 Physician Fee Schedule provide new opportunities to support cancer survivors¹ who are enrolled in the Medicare program. Nationally representative data have shown that cancer caregivers are more likely to help with medical and nursing tasks than caregivers helping with other conditions. These tasks include work such as administering injections, tube feedings, catheter and colostomy care, and other at-home nursing needs (72% vs. 56%).ⁱⁱ

Despite relying on the unpaid care provided by cancer caregivers, health systems inconsistently support cancer caregivers. A 2023 survey of cancer centers found that one in four had no programs to support family caregivers, and only one in five had training on helping with medical nursing tasks (22%) or on caregiver self-care.ⁱⁱⁱ Research from the National Cancer Institute Clinical Oncology Research Program revealed similar lack of support for cancer caregivers.^{iv} In surveying 204 practice groups, less than half (40%) had a process to identify and document caregivers. Only 20% of practices offered caregiver training or education classes, on topics such as assistance with activities of daily living, and medical/nursing tasks. Likewise, in research published this year in the *Journal of the National Cancer Institute*, only 16% of community oncology clinics screen caregivers for distress.^v

The Proposed Rule would encourage health systems to better support cancer caregivers. Caregiver assessment and CTS can improve patient outcomes and the quality of life of Medicare beneficiaries who are living with cancer. The Proposed Rule's expansion of these benefits for family caregivers offers health providers and researchers new tools to understand this clinical benefit and to examine how to equip caregivers with the knowledge and skills needed to support those in their care.

I. We support the Proposed Rule's new provisions to expand CTS to include direct care training focused on specific clinical skills that will help support better treatment for cancer survivors who rely on family caregivers to conduct medical and nursing tasks.

We support the proposed direct care CTS that “focus on specific clinical skills” including providing hands-on treatment, patient monitoring, and reducing complications as described in [HCPCS Code GCTD1](#), [HCPCS Code GCTD2](#), and [HCPCS Code GCTD3](#). These codes provide new support to caregivers who are assisting with direct care management, such as wound care and dressing, and infection control. In providing this care, family caregivers can often help protect the safety of a cancer survivor and support treatment goals.

These billing codes are particularly important for emerging research on medical and nursing skills training in cancer caregiving. Existing interventions focus on psychosocial wellness, but there are opportunities to better understand how to train cancer caregivers in practical skills that can assist a cancer survivor with activities of daily living.^{vi} In many ways, cancer caregivers are the ultimate care coordinators while also being tasks with conducting medical/nursing tasks in the home or community. Research consistently shows that cancer survivors who have family caregivers consistently fare better than those without a family caregiver. This is often because a cancer caregiver provides emotional and psychosocial support, physical help with activities of daily living, care coordination, and support for medical/nursing tasks. As a representative of the person with cancer, the caregiver can help communicate with physicians and other care providers, especially when a person with cancer downplays how they feel so that they can be a “good

¹ As defined by the National Cancer Institute, a “cancer survivor” is defined as, “one who remains alive and continues to function during and after overcoming a serious hardship or life-threatening disease. In cancer, a person is considered to be a survivor from the time of diagnosis until the end of life.” See NCI Dictionary of Cancer Terms at <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/survivor>, last accessed Aug. 23 2024.

patient.” Cancer survivors may also find that the toll of cancer results in fatigue or stress that makes it difficult for them to fully express their progress and needs, necessitating the support of a caregiver.

From diagnosis to treatment, and even during advanced illness, cancer caregivers tend to play a role in providing complex medical care to their loved ones. Providing care to someone with cancer is “an episodic and intense experience,” putting unique pressures on the family caregiver who spends, on average, nearly 33 hours a week helping the person with cancer, according to research from the National Alliance for Caregiving and Cancer Support Community, conducted in 2016.^{vii} Cancer caregivers are more likely to help with medical and nursing tasks than caregivers helping with other conditions, and these tasks include work such as administering injections, tube feedings, catheter and colostomy care, and other at-home nursing needs (72% vs. 56%). Cancer caregivers are more likely to help with managing finances (59% to 53%), putting them as one of the first points of contact for managing medical debt and related healthcare costs.^{viii}

The lack of training to conduct these activities can impact the confidence of the caregiver, and the outcomes of the cancer survivor. For example, the CanCORS study found that family caregivers play a foundational role in helping cancer survivors manage their treatment and disease. Most cancer caregivers help to manage the cancer survivor’s symptoms (76%), help with medication management (58%), or support wound management and dressing (26%). Yet, of the cancer caregivers who performed medical/nursing tasks, more than half reported that they did not receive training for all the care provided (57%). Without training and instruction on how to safely conduct medical/nursing tasks, caregivers had less confidence in their role and experienced a greater burden of care, as illustrated below in Figure 2, Adjusted burden summary scores with standard errors:^{ix}



Source: A CanCORS study, *Cancer*, 2017

Many cancer caregivers want additional training on the activities of care, and research has revealed that they are often concerned about the support available to help manage the treatment of the person with cancer. For example, in research published in 2023 in *Psycho-Oncology*, the CancerSupportSource™-Caregiver distress screening measure collected data on the experience of cancer caregivers.^x

Cancer caregivers had a broad range of concerns related to several different types of tasks, including providing physical or medical care, supporting treatment decision-making, and managing finances and medical bills. Almost half of cancer caregivers (41%) reported that they were seriously to very seriously concerned and more than half (62% were moderately to very seriously concerned about the cancer survivor’s pain and physical discomfort.

Aligned with the policies described in the Proposed Rule, research on screening for caregivers offers two distinct benefits. The first is potential improvement of patient outcomes, whereby reducing the distress of the caregiver allows them to better support the person in their care – and in turn, improve the outcomes of the cancer survivor.

TABLE 2 Item endorsement, item discrimination, item correlations (N = 400), and exploratory factor analysis factor loadings and communalities for the final CSS-Caregiver measure (n = 250)

Factors and items	Item characteristics (N = 400)					EFA (n = 250)					
	%≥3	%≥2	IDI	Item-total r	Item-factor r	F1	F2	F3	F4	F5	h ²
Emotional well-being											
Feeling nervous or afraid ^a	27.0	48.5	0.72	0.61	0.87	0.89					0.77
Feeling sad or depressed ^b	24.8	52.6	0.80	0.66	0.87	0.80					0.69
Feeling lonely or isolated ^b	23.1	44.9	0.81	0.62	0.83	0.69					0.61
Worrying about the future and what lies ahead ^a	46.8	71.0	0.64	0.65	0.84	0.68					0.66
Changes or disruptions in work, school, or home life	27.1	53.4	0.75	0.61	0.76	0.42					0.47
Patient well-being											
Changes in the patient's mood or behavior	33.5	61.3	0.73	0.64	0.88	0.89					0.80
Changes in the patient's memory or thinking	29.1	51.5	0.69	0.57	0.83	0.73					0.61
The patient's pain or physical discomfort	40.6	62.4	0.71	0.63	0.85	0.67					0.60
The patient's eating and nutrition	37.3	61.3	0.73	0.61	0.84	0.62					0.58
Caregiving tasks											
Coordinating medical care for the patient	22.6	42.4	0.89	0.73	0.93			0.84			0.88
Providing transportation to treatment and appointments	18.3	34.3	0.76	0.62	0.86			0.80			0.68
Providing physical or medical care to the patient	23.4	42.1	0.86	0.70	0.86			0.63			0.67
Making treatment decisions	22.3	41.8	0.84	0.71	0.87			0.52			0.69
Finances											
Managing health insurance and medical bills	26.3	43.9	0.75	0.62	0.94				0.93		0.86
Managing household finances	29.3	44.4	0.76	0.62	0.95				0.83		0.79
Healthy lifestyle											
Exercising and being physically active	18.5	52.0	0.36	0.32	0.87					0.78	0.60
Keeping up with your health care needs	18.3	50.3	0.39	0.36	0.86					0.76	0.59
Eating and nutrition	13.1	52.8	0.59	0.48	0.83					0.66	0.56
Tobacco, alcohol, or substance use											
Tobacco, alcohol, or other substance use	3.3	13.6	0.21	0.23	N/A						N/A

Note: %≥3 = seriously to very seriously concerned; %≥2 = moderately to very seriously concerned.
Abbreviations: h², communality; IDI, item discrimination index between upper and lower quartiles, based on total distress score; Item-total r, corrected item-total correlation.
^aItem is part of anxiety risk screening subscale.
^bItem is part of depression risk screening subscale.

Source: CancerSupportSource-Caregiver: Distress Screening Measure, Psycho-Oncology, 2023

II. The Proposed Rule’s telehealth and health information technology provisions support better care for cancer survivors and other Medicare beneficiaries who may be immunocompromised, and their family caregivers.

The Proposed Rule expands reimbursement for Medicare Telehealth Services provided to family caregivers on a provisional basis to “allow additional time for the development of evidence of clinical benefit” when provided remotely. We agree that [CPT Code 97550](#)² and [CPT Code 97551](#) as proposed are similar to other services already available on the Medicare Telehealth Services List, and should be offered to providers as an additional tool to support family caregivers. We also support the inclusion of other CTS codes in the Medicare Telehealth Services List, including CPT codes 97552, 96202, and 96203.

CMS’s stated goal of a provisional approval of these codes is to encourage research on the clinical benefit of such services. This would support ongoing work by clinical researchers to better understand and document the instrumental role of caregivers in supporting cancer patients at home and in their community. Fostering research is particularly important as practitioners continue to develop and scale interventions to improve their training and support family caregivers, especially among caregivers from racial/ethnic, cultural, economic, and linguistically diverse backgrounds. Most existing cancer support interventions focus on psychosocial outcomes for family caregivers and coping with care, providing opportunities for innovation into interventions that improve the caregiver’s skills in providing direct care.^{xi}

HHS has currently recognized that telehealth, and specifically “tele-oncology” can offer benefits to people living with cancer in its Best Practice Guide for Telehealth and Cancer Care.^{xii} As described in the Guide, “Oncologists and other health care providers can use telehealth in a variety of ways to serve their patients and caregivers.” The Best Practice Guide recommends a hybrid model of care, or multi-modal care, that allows individuals with cancer to receive some services through telehealth while maintaining in-person visits that require high-touch treatment. Services suited to telehealth include routine cancer screenings, genetic counseling, consultations with specialists or second opinions for diagnoses, prescription management, remote patient monitoring, wellness services, psychosocial care, and palliative care.^{xiii}

Notably, the Best Practice Guide also includes Medicare billing guidance for providers of cancer care.^{xiv} Thus the provisional approval of [HCPCS Code 97550](#) and [CPT Code 97551](#) to provide caregiver training to support an individual’s functional status in the home and community aligns with existing provider guidance offered by HHS to improve the delivery of care. People living with cancer are often immunocompromised, and reducing unnecessary exposure to in-person healthcare facilities can protect them from the risk of infections and other complications.

For many families, the cost of cancer treatment coupled with the intensity and frequency of visits with medical providers creates a financial strain and make cancer care more difficult to access. Cancer survivors and their families may incur both initial diagnostic and treatment costs and long-term care costs due to cancer treatment.^{xv} Indirect costs, which drive financial toxicity for people living with cancer and their families, include loss of productivity or impaired quality of life. For example, one study of the Medical Expenditure Panel Survey found that cancer survivors undergoing treatment missed 22.3 more workdays per year than other types of patients. Other studies have found that low-income populations experienced

² Please note that the Proposed Rule refers to the CPT code 97550 as an HCPCS code. We support the provisional approval for these and all other relevant CTS services to be offered via telehealth. See <https://www.federalregister.gov/d/2024-14828/p-342>.

bigger impacts on their financial wellness. Like the stress on the patient, the time pressure of having to take time off work for cancer treatment can drive job loss, unemployment, and even loss of employment-based benefits such as health insurance for a family caregiver. This can also drive “personal stress and financial worry” experienced by both the person with cancer and their family caregivers, which can lead to increased psychological distress.^{xvi}

For these reasons, we believe the Proposed Rule would encourage health systems to better support cancer caregivers and support research to identify the clinical benefit of providing additional training to family caregivers on behalf of a cancer survivor. Remote services also allow for greater accessibility, particularly in areas of high need (such as rural communities) and for caregivers who may be balancing work, school, or other family responsibilities with caregiving.

Finally, the [additional infrastructure for health information technology \(health IT\)](#) will ensure that the Comprehensive Electronic Care Plan is made available to the patient and caregiver, in a “structured and standardized” format that allows for better care across settings. Managing care from acute-care settings such as a hospital and the transition to home or community-based settings requires “[the timely exchange of health IT](#)” as described in the Proposed Rule. Existing research on home-based care for cancer caregivers has identified health IT infrastructure as an essential tool for providing better care at home and in the community.^{xvii} The development of infrastructure to support the documentation and storing of family caregiver data is especially important in tracking the role of screening and interventions delivered.

One model of health IT integration that may be useful for regulators is the RUSH University Medical Center Caring for Caregivers (C4C) intervention that works to integrate family caregivers into age-friendly healthcare systems.^{xviii} The intervention, first established in January 2020, leverages the CARE Act^{xix}, a state law in effect in 44 jurisdictions that requires hospitals to identify the family caregiver in the medical record, provide training at discharge, and notify the caregivers of changes in settings. In implementing the CARE Act, RUSH has identified how to recognize the family caregiver within existing health IT infrastructure, such as within the Epic Electronic Health Record (EHR) tool. Telehealth, and expanded, interoperable health IT infrastructure, will continue to be important tools to keep cancer families safe and healthy at home and in the community.

III. We respectfully ask that CMS clarify that providers may conduct a caregiver assessment and may offer subsequent CTS when reasonable and necessary regardless of the underlying diagnoses of the Medicare beneficiary who needs care .

We support the approach of recognizing the caregiver’s role as a partner in providing care and supporting the patient’s care goals, as described in the Proposed Rule, wherein reimbursement for CTS will “[allow treating practitioners to report the training furnished to a caregiver](#)” in strategies and specific activities to assist the patient in carrying out the treatment plan. We continue to support provisions in the CY 2024 PFS Final Rule that require the patient to identify the family caregiver and consent to the delivery of CTS, and the documentation of such in the patient’s medical record. Recognition of the patient’s voice, and ongoing consent to support a caregiver, is particularly important in cancer, where the intermittent nature of disease may mean that caregiver roles change over time.

Given the intense and changing role of the cancer caregiver, we request that CMS clarify that people living with cancer may be eligible for caregiver assessment and caregiver training services when “[reasonable and necessary](#)” as described in [CPT Code 96161](#). The current rule, as finalized in the CY 2017 PFS, allows for caregiver assessment as a depression inventory, when “reasonable and necessary” and the patient, due to a young age or cognitive disability, needs caregiver support.

[Examples](#) provided by the Rule are as follows:

- Assessment of maternal depression in the active care of infants
- Assessment of parental mental health as part of evaluating a child’s functioning
- Assessment of caregiver conditions as indicated where atypical parent/child interactions are observed during care
- Assessment of caregivers as part of care management for adults whose physical or cognitive status renders them “incapable of independent living and dependent on another adult caregiver,” such as: “intellectually disabled adults,” “seriously disabled military veterans,” and adults with “significant musculoskeletal or central nervous system impairments.”

It is not clear from the Proposed Rule whether the assessment and CTS support would apply in situations where “the patient cannot follow through with the treatment plan for themselves.” The Proposed Rule requires that direct care training for caregivers in particular should be [directly relevant](#) to the person-centered treatment plan to be considered reasonable and necessary. However, the Proposed Rule also suggests that receiving CTS would not be reimbursable in medical treatment scenarios where the patient can “follow through with the care plan for themselves,” essentially equating the ability to “ensure a successful treatment outcome” with the patient’s self-autonomy. Caregiver support is complementary to, and does not supplant, the patient’s own self-determination.

The guardrails in the proposed rule — that each training activity is “clearly identified and documented in the treatment plan” and the exclusion of reimbursement for services provided under home health, at-home therapy, or DME services — protect against fraud or abuse.

For these reasons, we request that CMS clarify that caregiver assessment and caregiver training services be offered regardless of the underlying disease state.

IV. Additional Considerations

Individual Training for Caregivers

We support the [HCPCS Code GCTB1 and HCPCS Code GCTB2](#) which expand CTS from instruction provided to multiple sets of family caregivers in a group setting to allow for CTS to be provided to individual family caregivers. allows for better caregiver education that is more accessible to family caregivers and can be tailored to address social determinants of health, such as language barriers or cultural barriers.

Assessment and Screener Tools

In practice, the provider’s ability to implement a caregiver assessment may be difficult, given scope of practice issues and the role of the caregiver as ancillary to the Medicare beneficiary. Many providers may not have the ability to record the outcome of a caregiver assessment within the Medicare beneficiary’s healthcare record. Furthermore, because the family caregiver is not the primary patient, assessment and subsequent CTS may not offer the support services and information needed to improve the patient’s treatment and care.

Because this is an emerging field of research and development, we encourage CMS to continue to allow for flexibility in the assessment process. Networks such as the Cancer Caregiving Collaborative can be helpful in encouraging providers to use evidence-based tools for assessment and screening. The Proposed Rule notes that the assessment should evaluate depression and anxiety in the family caregiver, with training to address these concerns. If possible, assessments for the direct care training interventions should more closely align with understanding how the caregiver is conducting direct care support and what gaps in knowledge are preventing support to the person living with cancer.

Examples of specific cancer caregiver assessments include the validated electronic distress screening (“Distress Screening for Family Caregivers”) which has been used by Memorial Sloan Kettering and other medical settings.^{xx} Other frequently used caregiver assessment tools include the Caregiver Reaction Assessment (CRA)^{xxi} for caregivers of people with chronic physical or mental impairments, and frequently used depression and anxiety screening tools such as the Patient Health Questionnaire-9 (PHQ-9) for depression, the corresponding briefer PHQ-4, and the General Anxiety Disorder-7 to assess anxiety.^{xxii} Providers may also be interested in caregiver-specific screening tools that are simple and easy to administer in a clinical setting, such as the Preparedness for Caregiving Scale^{xxiii} or the Caregiver Self-Assessment Questionnaire^{xxiv}.

One area of consideration is whether CTS would eventually allow for psychological and behavioral therapy for family caregivers, similar to the interventions offered to military caregivers under the VA Caregiver Support Program. These include a Program of General Caregiver Support Services, which offers peer support mentoring, skills training, coaching, telephone support, online programs, and referrals to available resources to caregivers of Veterans.^{xxv} Likewise, the Program of Comprehensive Assistance for Family Caregivers offers mental health counsel to primary and secondary family caregivers, among other benefits.^{xxvi}

Providers should be encouraged, in addition to offering CTS as needed, to connect caregivers in distress with existing federal support programs, such as the National Family Caregiver Support Program^{xxvii} and the Lifespan Respite Care Program.^{xxviii} These existing federal programs may offer support to providers who would like to provide additional assistance to the caregiver, but are otherwise limited either by scope-of-practice issues, Medicare regulations, or other resources.

Reimbursement Rate and Alignment Across Government Agencies

Understanding that physicians and other providers may not yet be aware of the CTS first proposed in the CY 2024 rule, we would encourage CMS to evaluate whether existing reimbursement rates incentivize providers to include caregivers in their plan of care. Within the cancer and oncology community, the current rate of reimbursement may not be sufficient to engage physicians.

In delivering CTS and related caregiver assessments, it is important to look at the whole health system and how it might support this type of initiative. This may include reiterating that there are no restrictions in the application of this benefit – an oncologist or other specialty physicians may not be aware that they could use this program to help families who care for cancer survivors at home.

CMS should consider how patient advocacy organizations and federal advisory committees such as the RAISE Family Caregivers Act^{xxix} can help inform the use of assessments. For this fee to include additional health care providers as well as home- and community-based service providers, who offer evidence-based and evidence-informed training under other

Awareness and Access to Caregiving Training and Support

We would ask CMS to evaluate whether the existing co-pay requirements for CTS render the service inaccessible to family caregivers, particularly those in low-income communities. As an economic principle, cost-sharing initiatives such as co-pays are intended to help individuals make financial choices that reduce the cost of care while still achieving the desired health outcome. In this case, there is not a lower-cost alternative to CTS.

The cost barrier may prevent caregivers from receiving training at all — yet the caregiver may still be asked to provide support to the Medicare beneficiary. Caregivers could return home with the Medicare beneficiary without instruction on how to conduct medical and nursing tasks appropriately. In the long run, this puts the individual on Medicare at risk and could drive up health costs in other ways (such as unplanned or unnecessary hospital readmissions).

Further, we are encouraged that Medicare Learning Network® (“MLN”) has included some information about CTS for medical providers in its Health Equity Services Booklet on the CY 2024 Physician Fee Schedule Final Rule.^{xxx} We encourage CMS to continue to expand its educational efforts regarding the new caregiver training service reimbursement pathways in future MLN offerings. This would enable CMS to provide more comprehensive information that leverages multiple approaches to patient- and family-centered training and education. In particular, providers could benefit from information about CTS in online courses, fact sheets, webinars, and video tutorials through the MLN, as well as through email campaigns, social media outreach, provider conferences, and local workshops.

If possible, we would also ask that CMS consider consumer and beneficiary-facing educational materials that ensure that the public is also well-informed about these important policy changes. By implementing a multi-faceted educational strategy, CMS can ensure that healthcare providers, cancer survivors and their caregivers, and the public clearly understand of the new reimbursement pathways, ultimately leading to better utilization and outcomes.

V. Thank You and Contact Information

Thank you for your ongoing support and leadership. We stand at the ready to provide any additional information as you consider this Proposed Rule and other policies that impact those who care for someone with a healthcare need or disability.

If you need to reach us, please contact Yadira Montoya, M.S.P.H, Programs Director, at yadira@caregiving.org or (202) 918-1038.

Sincerely,

ⁱ National Cancer Institute, Division of Cancer Control & Population Services, Office of Cancer Survivorship, *Statistics and Graphs* (NCI, 2024) <https://cancercontrol.cancer.gov/ocs/statistics>.

-
- ⁱⁱ Gail G. Hunt, Margaret L. Longacre, Erin E. Kent, Lisa Weber-Raley, *Cancer Caregiving in the U.S.* (National Alliance for Caregiving and Cancer Support Community, 2016), https://www.caregiving.org/wp-content/uploads/2020/05/CancerCaregivingReport_FINAL_June-17-2016.pdf.
- ⁱⁱⁱ N.J. Odom, A. Applebaum, M.A. Bakitas, T. Bryant, E. Currie, K. Curry, H. Donovan, M.E. Fernandez, B. Ferrell, A. Azuero, T.F. Gray, B.A. Hendricks, D. Meier, C. Nightingale, S. Reinhard, T.S. Sannes, K. Sterba, & H.M. Young, *Availability of Family Caregiver Programs in US Cancer Centers*, 6 JAMA Network Open 10:e2337250 (2023), <https://doi.org/10.1001/jamanetworkopen.2023.372502023>.
- ^{iv} Nightingale CL, Sterba KR, McLouth LE, Kent EE, Dressler EV, Dest A, Snavely AC, Adonizio CS, Wojtowicz M, Neuman HB, Kazak AE, Carlos RC, Hudson MF, Unger JM, Kamen CS, Weaver KE, *Caregiver engagement practices in National Cancer Institute Clinical Oncology Research Program settings: Implications for research to advance the field*, *Cancer*, 2021 Feb 15;127(4):639-647. doi: 10.1002/cncr.33296. Epub 2020 Nov 2. PMID: 33136296; PMCID: PMC7854890. <https://pubmed.ncbi.nlm.nih.gov/33136296/>.
- ^v Nightingale CL, Snavely AC, McLouth LE, Dressler EV, Kent EE, Adonizio CS, Danhauer SC, Cannady R, Hopkins JO, Kehn H, Weaver KE, Sterba KR, *Processes for identifying caregivers and screening for caregiver and patient distress in community oncology: results from WF-1803CD*, *J Natl Cancer Inst.*, 2024 Feb 8;116(2):324-333. doi: 10.1093/jnci/djad198. PMID: 37738445; PMCID: PMC10852602, <https://pubmed.ncbi.nlm.nih.gov/37738445/>.
- ^{vi} Mollica MA, Litzelman K, Rowland JH, Kent EE., *The role of medical/nursing skills training in caregiver confidence and burden: A CanCORS study*, *Cancer*, 2017 Nov 15;123(22):4481-4487. doi: 10.1002/cncr.30875. Epub 2017 Jul 20. PMID: 28727147; PMCID: PMC5673528, <https://pubmed.ncbi.nlm.nih.gov/28727147/>.
- ^{vii} See *supra* n. ii.
- ^{viii} *Id.* at p. 19, Figure 7.
- ^{ix} See *supra* n. vi.
- ^x Zaleta AK, Miller MF, Fortune EE, et al., *CancerSupportSource™-Caregiver: development of a distress screening measure for cancer caregivers*, *Psycho-oncology*, 2023; 32(3): 418-428. <https://doi.org/10.1002/pon.6092>, <https://onlinelibrary.wiley.com/doi/10.1002/pon.6092>.
- ^{xi} Soojung Ahn, Rafael D. Romo, Cathy L. Campbell, *A systematic review of interventions for family caregivers who care for patients with advanced cancer at home*, *Patient Education and Counseling* (2020), 103:8 pp. 1518-1530, ISSN 0738-3991, <https://doi.org/10.1016/j.pec.2020.03.012>, <https://www.sciencedirect.com/science/article/pii/S0738399120301464>.
- ^{xii} See Telehealth.HHS.gov, *Telehealth and cancer care*, Best Practice Guides for Providers, <https://telehealth.hhs.gov/providers/best-practice-guides/telehealth-and-cancer-care>, last accessed Aug 20, 2024.
- ^{xiii} See *id.*, *Getting started: telehealth and cancer care*, at <https://telehealth.hhs.gov/providers/best-practice-guides/telehealth-and-cancer-care/getting-started>.
- ^{xiv} See *id.*, *Billing for cancer care via telehealth*, at <https://telehealth.hhs.gov/providers/best-practice-guides/telehealth-and-cancer-care/billing-for-cancer-care>.
- ^{xv} Rebecca A. Snyder and George J. Chang, *Financial toxicity: A growing burden for cancer patients*, *American College of Surgeons* (Sep 1 2019), at <https://www.facs.org/for-medical-professionals/news-publications/news-and-articles/bulletin/2019/09/financial-toxicity-a-growing-burden-for-cancer-patients/>.
- ^{xvi} *Id.*
- ^{xvii} See, e.g., Applebaum AJ, et al., *Fit for Duty: Lessons Learned from Outpatient and Homebound Hematopoietic Cell Transplantation to Prepare Family Caregivers for Home-Based Care*, *Transplant Cell Ther.*, 2023 Mar;29(3):143-150. doi: 10.1016/j.jtct.2022.12.014, Epub 2022 Dec 23, PMID: 36572386; PMCID: PMC9780643, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9780643/>.
- ^{xviii} See RUSH Center for Excellence in Aging, *Caring for Caregivers (C4C) Model*, at <https://aging.rush.edu/professional-older-adult-family-care/c4c/>, last accessed Aug 20, 2024; and Emma Opthof, Center for Health Care Strategies, *RUSH Caregiver Intervention: Advancing Age-Friendly Health Systems by Prioritizing Family Caregivers*, *The Playbook: Better Care for People with Complex Needs* (Jan 13 2022), <https://bettercareplaybook.org/blog/2022/12/rush-caregiver-intervention-advancing-age-friendly-health-systems-prioritizing-family> (last accessed Aug 20 2024).

-
- ^{xix} AARP, *Supporting Family Caregivers Providing Complex Care, Policy & Research Initiatives*, <https://www.aarp.org/pri/initiatives/supporting-family-caregivers-providing-complex-care/> (last accessed Aug 20 2024).
- ^{xx} See *supra* n. x; and see also, Applebaum AJ, Schofield E, Kastrinos A, et al., *A randomized controlled trial of a distress screening, consultation, and targeted referral system for family caregivers in oncologic care*, *Psycho-oncology*, 2024; e6301. <https://doi.org/10.1002/pon.6301>, <https://onlinelibrary.wiley.com/doi/full/10.1002/pon.6301>.
- ^{xxi} Given CW, Given B, Stommel M, Collins C, King S, Franklin S, *The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments*, *Res Nurs Health*, 1992 Aug;15(4):271-83. doi: 10.1002/nur.4770150406. PMID: 1386680, <https://pubmed.ncbi.nlm.nih.gov/1386680/>.
- ^{xxii} Ellen L. Carbonell, RUSH University, Aging – *Caring for Caregivers Model Addresses Needs of Those Looking After Others*, *Journal of the Catholic Health Association of the United States* (2023), <https://www.chausa.org/publications/health-progress/archive/article/spring-2023/aging-caring-for-caregivers-model-addresses-needs-of-those-looking-after-others>.
- ^{xxiii} https://hign.org/sites/default/files/2020-06/Try_This_General_Assessment_28.pdf.
- ^{xxiv} <https://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/self-assessment>.
- ^{xxv} See VA Caregiver Support Program, https://www.caregiver.va.gov/Care_Caregivers.asp.
- ^{xxvi} See https://www.caregiver.va.gov/support/support_benefits.asp.
- ^{xxvii} See National Family Caregiver Support Program, <https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program>.
- ^{xxviii} See Lifespan Respite Care Program, <https://acl.gov/programs/support-caregivers/lifespan-respite-care-program>.
- ^{xxix} See <https://acl.gov/CaregiverStrategy> and <https://acl.gov/programs/support-caregivers> (last accessed Aug 19, 2024).
- ^{xxx} See <https://www.cms.gov/files/document/mln9201074-health-equity-services-2024-physician-fee-schedule-final-rule.pdf-0>.