Expanding Screening for Unmet Palliative Needs

Position from the Center to Advance Palliative Care (CAPC)

Serious illness comes with heavy burdens, many of which can be feasibly mitigated by the health care system. CAPC recommends expanding existing screening requirements and processes to ensure early identification of avoidable suffering in patients with serious illness and their caregivers.

Serious Illness Presents Significant Burdens for Patients and Families

→ Physical symptoms can be a hardship for patients facing serious illness. The prevalence of burdensome symptoms and side effects—particularly pain, dyspnea, anxiety, depression, and fatigue – vary by diagnosis, but impact more than 50% of patients in some disease populations.[1-6]

  o Racial disparities have also been found related to how patients' symptoms are assessed and treated.[7-10]

→ Caregivers also face high burdens—a recent report found that more than one-third (38%) of caregivers report high emotional stress.[11]

→ The financial burdens that can accompany serious illness often create an additional layer of complexity. Also known as financial toxicity, these financial hardships can manifest in multiple ways, such as debt or unemployment, and can lead to anxiety, depression, and reduced quality of life.[12]

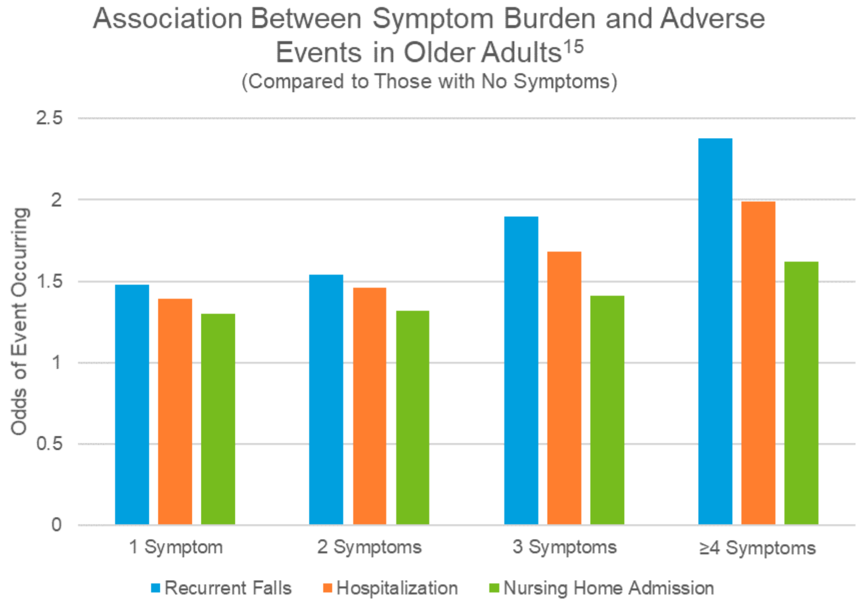
Many of the burdens that accompany serious illness can be mitigated through both clinician and health system intervention. However, screening for these burdens is not routinely conducted. There are opportunities to standardize identification of unmet needs among patients with serious illness and their caregivers, in order to improve both quality of life and health care delivery.

Symptom and Caregiver Burden Drive Avoidable Health Care Spending

When left unaddressed, the symptoms and stresses of serious illness not only affect patient quality of life but also result in avoidable health care utilization and spending.

In one large study of emergency department (ED) visits made by adult patients with cancer, 52% were identified as potentially preventable. Visits for uncontrolled pain account for 37% of the potentially preventable ED visits in this population, and the number of pain visits more than doubled in the eight-year period included in the study. Nausea (5.8%) and fatigue (1.4%) accounted for another significant proportion of the potentially preventable visits.[13]

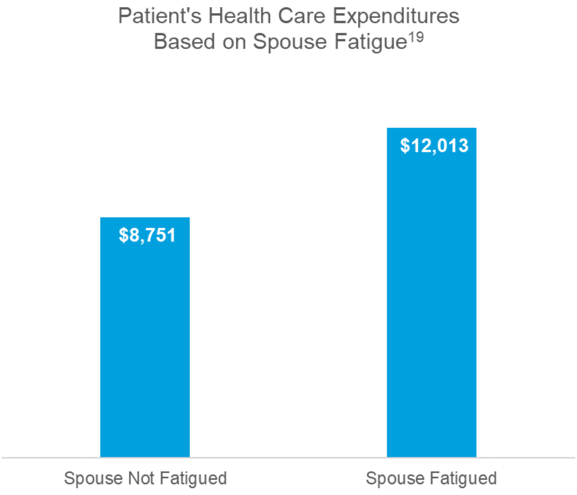
Other studies reveal the correlation between measured symptom burden and health care utilization, with higher total scores on a symptom screening associated with higher odds of hospitalization, 30-day readmissions, and increased lengths of stay.[14] The correlation between symptom burden scores and health care utilization is even stronger among older adults, with at least one reported symptom increasing the odds of hospitalization by 39% and nursing home admission by 30%, independent of other risk factors.[15]


Association Between Symptom Burden and Adverse Events in Older Adults[15]
(Compared to Those with No Symptoms)

Anxiety is a common—and treatable—symptom among people with serious illness, with studies showing a significant association between anxiety and increased health care utilization at the end of life, including increased odds of hospitalization (85%), ICU admissions (40%), and chemotherapy (42%) in the 30 days before death.[16] Patients with kidney disease are another population with significant symptom and caregiver burden, and are also frequent users of the ED, visiting an average of three times annually, most commonly for pain (55%), depression (33%), and constipation (12%).[17,18]

In addition to physical symptoms driving utilization and cost, caregiver burden also contributes to avoidable spending. An analysis of Medicare beneficiaries showed that costs were significantly higher for those whose spousal caregivers reported fatigue and sadness, adding $1,937 and $1,323 to Medicare spending over a six-month period, respectively.[19] Caregiver-reported strain/burden is also an independent risk factor for long-term nursing home placement of the care recipient, with caregiver depression also predictive of their own future physical decline and health spending.[20-22]

The evidence is clear: management of physical and caregiver burdens is needed to ensure effective management of population health and spending.


Patient's Health Care Expenditures Based on Spouse Fatigue[19]

Screening through Patient Reported Symptom Monitoring Improves Outcomes and Spending

Patient screening and symptom monitoring can positively impact those with serious illness. In a 2020 Canadian study, cancer patients who were assessed using the Edmonton Symptom Assessment Scale (ESAS) had a higher 5-year survival rate, as well as fewer emergency department and hospital visits.[23,24] Symptom monitoring, where the patient remotely reports current symptoms back to their clinician, has been found to improve health-related quality of life and decrease health care utilization.[25,26] There is evidence of a growing interest in utilizing symptom monitoring in non-cancer patient populations as well, with studies planned in both heart failure and kidney disease.[27,28]

The work in cancer and other illnesses builds on the success of telemonitoring heart failure patients. Evidence suggests that both hospitalization rates and mortality can be improved for high-risk heart failure patients; as a result, providers participating in value-based payment arrangements are encouraged to use telemonitoring in this population.[29,30]

While these findings highlight the promise of substantial improvement in person-centered care delivery with remote monitoring, some publications found no difference in outcomes with patient-reported symptoms.[31] These mixed findings suggest that for symptom monitoring to be most effective, the care team should be equipped to respond to any identified needs in a timely manner, with the requisite symptom management skills and/or referrals.

Systematic Screening Already Occurs in Some Health Care Programs

Despite the benefits of proactive screening for palliative care needs, little federal policy exists to require screening patients for specific symptoms or financial hardship, or caregivers for burden. In reviewing Conditions for Coverage (CfCs) and Conditions of Participation (COPs), quality reporting and value-based programs from the Centers for Medicare and Medicaid Services (CMS), and alternative payment models and demonstrations from the Center for Medicare and Medicaid Innovation (CMMI), we find only a small handful of distinct screening requirements or incentives for burden identification. This may be due in part to CMS's prioritization of outcome over structure or process measures.[32]

Fortunately, there are examples from federal policy that include patient screening, assessment, or monitoring. For instance, the Improving Medicare Post-Acute Care Transformation (IMPACT) Act of 2014 required standardized patient assessment data across long-term care hospitals, skilled nursing facilities, home health agencies and inpatient rehabilitation facilities.[33] Examples of federal programs in which screening for palliative needs is already required include:

CARE SETTING OR PROGRAM	ASSESSMENT INSTRUMENT	RELEVANT SCREENING OR MEASUREMENT AREAS FOR THE POPULATION WITH SERIOUS ILLNESS
Skilled Nursing Facilities	Minimum Data Set (MDS)	Pain, breathlessness, fatigue, anxiety, depression
Home Health Agencies	Outcome and Assessment Information Set (OASIS)	Pain, dyspnea/breathlessness, fatigue, depression, anxiety

CARE SETTING OR PROGRAM	ASSESSMENT INSTRUMENT	RELEVANT SCREENING OR MEASUREMENT AREAS FOR THE POPULATION WITH SERIOUS ILLNESS
Guiding an Improved Dementia Experience (GUIDE) Model	Zarit Burden Interview (ZBI) Accountable Health Communities (AHC HRSN) or Protocol for Responding to and Assessing Patient Risk (PREPARE) tool recommended	Caregiver burden Health related social needs (HRSNs)
Enhancing Oncology Model (EOM)	No specified instrument; however, electronic patient-reported outcomes (ePROs) are required in later years	Pain, dyspnea, fatigue, depression, anxiety HRSNs, including financial distress
Medicare Advantage	Star Ratings	Care of Older Adults – Pain Assessment

Existing Case and Care Management Structures Also Offer Ready Opportunities to Identify Patient and Caregiver Burdens

There are case/care management teams and processes already in place in many areas of U.S. health care, and their responsibilities can be adjusted to accommodate screening for symptom burden, caregiver burden, and financial hardship, alerting the care team when action is needed.

Screening for symptoms and other burdens is fully aligned with the American Case Management Association's standards of practice and scope of services; specifically, "*Case Management will screen all patients for clinical, psychosocial, financial, and other factors that may affect the progression of care*".[34] Leaders from the Commission for Case Manager Certification (CCMC) state that professional case managers should play a "central role" in pain management, while some care management leaders in Medicare Advantage plans and ACOs have already integrated symptom assessment screenings into their processes.[35,36]

Case/care management teams and processes already exist in many areas of U.S. health care. Their responsibilities can be adjusted to accommodate standardized screening for symptom burden, caregiver burden, and financial toxicity, alerting the care team when action is needed. Specifically, these required care management programs could be easily adapted to include screening for unmet palliative needs:

- **Medicare Advantage (MA)**. MA plans are required to conduct health risk assessments (HRAs) for each enrollee within 90 days of initial enrollment and are encouraged to conduct follow-up assessments annually. Currently, there is CDC guidance recommending that these HRAs include screening for pain, fatigue, and depression.[37] Many plans include screening for additional unmet needs, so that symptoms and caregiver burden screenings may be feasibly added.
- **Medicare Advantage Special Needs Plans (SNPs)**. These plans must have a model of care including processes to identify enrollees' physical, psychosocial, functional, and social needs and follow-up on findings. Because the National Committee for Quality Assurance (NCQA) must approve the model of care, there is a specific opportunity for CMS guidance or even scoring adjustments to include symptoms and caregiver burden.
- **Center for Medicare and Medicaid Innovation's "ACO Reach."** Health care organizations participating in the Medicare ACO Reach model are required to screen each beneficiary for social needs using a standardized assessment tool, and financial toxicity would likely be identified through that process. Here too, CMS guidance on screening for symptoms and caregiver burden may be feasible, not only in the ACO Reach model, but in other alternative payment models, such as Kidney Care Choices or the upcoming Ambulatory Specialty Model.

Available Billing for Screening

Certain existing Medicare billing codes help compensate for the effort of screening and addressing identified needs, particularly:

- Administration of patient-focused health risk assessments, CPT 96160 (national average $2.91 non-facility only).
- Brief emotional/behavioral assessments, CPT 96127 (national average $4.53 non-facility only).
- Administration of caregiver-focused assessments, performed for the benefit of the patient, CPT 96161 (national average $2.91 non-facility only).

Recommended Actions

Screening people living with serious illness for symptom, caregiver, and financial burden will improve patient quality of life and drive value in the U.S. health care system. Since it is infeasible to establish universal screening requirements in every health care program, the focus should be on mechanisms that serve a high proportion of people living with serious illness. The following recommendations are informed by several existing programs that have processes to conduct screenings and act on their findings:

- CMS should require caregiver burden and symptom burden screenings in the mandatory Medicare Advantage Health Risk Assessment.

- → CMMI should require symptom reporting, similar to what is required in the Enhancing Oncology Model (EOM), in other Medicare alternative payment models for beneficiaries with serious illness, especially advanced kidney disease or heart failure.
- → CMS should expand the Medicare home health and skilled nursing intake assessments (i.e., OASIS, MDS) to include caregiver burden, and other key issues.
- → ACOs should be encouraged to incorporate screening for palliative needs in their care management processes.
- → CMS should expand the Hospital Quality Reporting Program (HQRP) to measure how often each hospital screens patients with serious illness diagnoses (including cancer, heart disease, kidney disease, and dementia) for financial toxicity using a simple screening tool, preferably validated, to facilitate identification and referral to financial assistance.

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