Literature synthesis on patient perspectives on learning disease prognosis

Overview

This summary is in response to a request to examine patient perspectives on learning disease prognosis, and the impact of prognosis on patient well-being. The overall findings suggest that preferences for learning about prognosis are highly individualized (1-5), but with a general theme of more qualitative awareness of their prognosis that are optimistic and not overly tied to probabilities (2, 3). Little is known about the impact of learning prognosis on patient well-being.

A search was conducted via Google Scholar, initially using the search term "communicating prognosis to patients." Systematic reviews were identified in the search results, and then a snowball sampling technique was applied based on examining articles that cited those reviews. Separate searches were also conducted for the terms "impact of prognosis on patients" and "patient-centered prognosis discussion." The analysis focused on articles published on or after the year 2000.

Summary and Conclusion

A brief review of the literature was conducted to understand patient perspectives and preferences on learning disease prognosis. While studies clearly indicated that the majority of patients would prefer to know their prognosis, a substantial minority of patients preferred not to be told this information. There was a high degree of variability in terms of how much patients want to know about their prognosis, how they want it communicated, and when they want this information. Thus, while there is not an abundance of evidence on this topic, there is a general theme of flexibility and highly individualized processes for communicating prognostic information to patients. A potential challenge for using prognosis as a key eligibility criterion, and the surprise question in particular, is that it may impose a more specific and structured framework that patients may view as providing too much information, too soon, and/or from someone with whom the patient does not have a trusted relationship.

Answers to Specific Questions

1. Do patients want to know their prognosis?

The general consensus is that most patients would like information on their prognosis as part of a broader discussion to include diagnosis, survivability, and their treatment options, but in most cases there is also a substantial minority who would prefer not to know (2-4, 6-8). However, a number of studies have found that preferences around prognosis are not uniform across diseases and disease states (3), and several studies recommend asking the patient in advance if they would like to know their prognosis (3, 6, 9, 10). There are studies that found that patients would prefer to know in broad terms at the time of diagnosis only (9).

2. How do patients want prognosis to be communicated?

While studies have consistently found in favor of communicating prognosis generally (3, 9), or at least offering the opportunity for this conversation, there is far less agreement on the specific approach to conveying this information. Patient preferences have been documented across a variety of contexts and approaches for having this conversation, including: who shares this information, who else is involved in the conversation, when this conversation occurs and how it is initiated, and how this information is conveyed.

There is a clear preference for the person who communicates prognosis to the patient to be a trusted provider with an existing relationship with the patient (9). Most studies have found that patients prefer to have family members involved in discussions of diagnosis and prognosis (3), but there is less consensus about what information should be shared with family and how to navigate those boundaries, especially as information needs between patients and families often diverge over time (3, 9).

Studies of how prognostic information should be communicated are limited. Patients indicated a strong preference for the treating physician to initiate this conversation in a direct manner (2), but again showed substantial variation in how they would like prognostic information presented and what other information they want in tandem with their prognosis (3). There is some evidence that patients would prefer more 'qualitative' information in this regard, such as whether they will live a 'long' time, as opposed to a more quantitative presentation (2, 5, 11). Similarly, a number of studies have documented patient preference for a positive framing that focuses more on survival than mortality (3).

Finally, timing of this conversation has been given some attention. Patients have expressed a preference to have this discussion at the time of diagnosis (9), while other studies have recommended that communicating prognosis should not be a single event, but rather an ongoing discussion between the provider and patient, with the idea that patients would like to be aware in an ongoing manner of their condition (3, 12).

3. How does knowing prognosis affect patient well-being?

The literature generally finds that patients who want prognostic information are better off after receiving it, in terms of satisfaction with treatment, anxiety, and depression (3). Patients receiving prognostic information, and generally honest and sympathetic discussion of their disease state, cited benefits such as empower decision-making and ability to prepare for death (6). Patients who do not desire prognostic information most commonly cited the emotional burden associated with that knowledge as the reason for not wanting to have that conversation (6).

4. What do we not know about prognosis and patient-centered serious illness care?

In general, there is limited evidence on the topic of patient-centered approaches to communicating prognosis, and the effect of learning prognosis on patients and their families. Existing evidence tends to be specific to diseases and disease states, and much of the evidence base comes from studies in other countries. While there are a number of guidelines for discussing

prognosis with patients, they are largely not from the patient's perspective, and more oriented to increasing provider comfort with initiating these discussions. Many of these guidelines recommend flexibility and tailoring the delivery of difficult news to the needs of the patient, which again may result in more nonspecific discussion around prognosis.

Little is known about the impact of learning prognosis on the patient. This is a challenging question to answer, given the high variability in patient preferences on this issue, and the timing difficulty in capturing patient responses to prognosis prior to death. Thus, while there is evidence that patients appreciate the delivery of prognostic information that is done in a sensitive and respectful manner, less is known about the adverse impacts of negative experiences of prognosis discussions.

The surprise question traditionally has been used as part of a provider's internal decision-making process. Little is known about how patients would respond to this specific framing, and whether they would want this information. To the extent that patients prefer a qualitative discussion of prognosis, this approach may be overly quantitative.

- 5. Other potential issues in terms of the role of prognosis in the proposal that arose during this review:
- Patients often have difficulty understanding their prognosis and overestimate their chances of survival (13), which may complicate the initial discussions around eligibility and enrollment.
- Providers often overestimate expected survival when communicating with patients, which may thwart timely enrollment of patients (14).
- Patients prefer to discuss prognosis with a provider with whom they already have an established relationship (9). This may not be consistent with the hand-off of the patient from the referring provider to an ACM physician. Similarly, given the individualized nature of the prognostic conversation between the patient and the referring provider, it may be important to have some coordination between the referring provider and the ACM physician before the ACM physician directly interacts with the patient.

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Physician-Focused Payment Model Technical Advisory Committee LOI: Environmental Scan & Relevant Literature

Coalition to Transform Advanced Care (C-TAC)
Letter Dated: <no date provided>
Letter Received: 11/8/2016

The Coalition to Transform Advanced Care (C-TAC) proposes a physician-focused payment model called the Advanced Care Model (ACM). The ACM is a population health alternative payment model intended to improve quality, care experience, and cost outcomes for beneficiaries with advanced illnesses.

The Advanced Care Model provides a population health management approach for the advanced illness population in the last year of life. The ACM integrates with existing APMs and contributes to their success. By creating an integrative model that is focused on a high-cost and high-need population, the ACM provides a mechanism to risk-stratify a broader Medicare population, specifies effective care interventions and creates additional financial incentives for existing APMs. In addition, the ACM will offer multiple pathways for organizations to incrementally add risk as existing or new APM entities. Primary care providers and specialists can participate in the ACM APM for physician-focused payment under the Quality Payment Program. Furthermore, the ACM meets the requirements for an advanced APM, with the potential to qualify participating palliative care providers and specialists.

The ACM APM is designed to support provider investment in infrastructure, create an ROI opportunity, and help providers migrate from FFS to risk. The three core components of the payment model are 1) a PMPM for up to 12 months post enrollment; 2) a population and value based payment through a phased-in two-sided risk arrangement; and 3) integration with existing value-based payments. The PMPM will cover care management and ambulatory palliative care provider E&M visits. The value-based payment will be adjusted based on meeting a minimum quality performance threshold. The proposed shared-risk model will encompass total cost of care in the last year of life (including PMPM fees) and include a 75-85% shared savings and shared loss rate, 30% total savings limit, 10% total loss limit, and 4% total risk and minimum loss rate.

Key Terms

Palliative Care; End of Life Medicare; Advanced Illness Care; C-TAC; Advanced Care Model; Advanced Care APM; population health payment model

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Section 1. Environmental Scan

Environmental Scan

Key words: Palliative Care; End of Life Medicare; C-TAC Comment Response; Advanced Illness Care; C-TAC; Advanced Care Model; Advanced Care APM

| Organization | Title | Date |
|--|----------------------------------|----------------------------|
| Coalition to Transform Advanced Care (C-TAC) & AHIP Foundation | The Advanced Care Project Report | Accessed on: 11/11/2016 |

Purpose/Abstract

Background: The Advanced Care Project (ACP), co-sponsored by the Coalition to Transform Advanced Care and the AHIP Foundation, convened innovators from health systems and health plans to develop: a clinical model of care for patients and families living with advanced illness; a payment model framework that supports the transition from fee-for-service (FFS) toward performance- and risk-based reimbursement; and the identification of key considerations and issues related to operationalizing an advanced care program.

Summary: This report provides a summary of the clinical and payment model findings and outlines next steps for the ACP. This report provides a framework built on the best practices from leading programs across the country. The ultimate goal of the ACP is to disseminate this framework to encourage adoption and implementation of advanced care models that boost quality, support choice, and increase affordability of care for all Americans with advanced illness along with their families, caregivers and clinicians. Moving forward with such a model of care will help unify and strengthen our healthcare system and help make Medicare more sustainable for future generations.

Key words: Palliative Care; End of Life Medicare; C-TAC Comment Response; Advanced Illness Care; C-TAC; Advanced Care Model; Advanced Care APM

| Organization | Title | Date |
|---|---|----------------------------|
| Coalition to Transform Advanced Care (C-TAC) | Policy Agenda: Options to Transform Advanced Care | Accessed on: 11/11/2016 |

Purpose/Abstract

Background: The Coalition to Transform Advanced Care (C-TAC) was formed in 2011 by bringing together leaders, experts, policy makers, and stakeholders in the field of advanced illnesses. C-TAC is striving for change in the health care system and larger environment by disseminating best practices and proven solutions in advanced care delivery, promoting professional education, supporting policy and advocacy, and building public demand and empowerment for quality advanced care. Our mission is to transform advanced illness care by empowering consumers, changing the health delivery system, improving public and private policies, and enhancing provider capacity.

Summary: The policy agenda described in this document was developed in collaboration with C-TAC's membership. It reflects areas of consensus for federal and state policymakers and private stakeholders to act on to improve care for individuals with advanced illness and their families. The options are guided by four core principles: (1) transform advanced care to value-based payment and quality measure development; (2) align treatment and care objectives with patient goals and preferences; (3) engage patients, their families, and care givers with a full range of supports and services; and (4) strengthen professional education and engagement in collaborative, team-based models of person- and family- centered care delivery. This policy agenda provides wide ranging options that could help transform care for Americans with advanced illness and their caregivers and families.

Key words: Palliative Care; End of Life Medicare; C-TAC Comment Response; Advanced Illness Care; C-TAC: Advanced Care Model: Advanced Care APM

| Organization | Title | Date |
|---|--|-----------|
| Coalition to Transform Advanced Care (C-TAC) | C-TAC Public Comment Response: Medicare Program; Merit-Based Incentive Payment System (MIPS) and Alternative Payment Model (APM) Incentive Under the Physician Fee Schedule, and Criteria for Physician-Focused Payment Models | 6/27/2016 |

Purpose/Abstract

Background: C-TAC supports CMS's shift to a more value-based payment system for its beneficiaries. The unintended consequences of the previous fee-for-service payment system, that promoted more treatment rather than necessarily the right treatment, did not service people living with advanced illnesses. The opportunity now is to incentivize all providers to identify those patients approaching advanced illness and consider advance care planning, advanced illness care, palliative care, or hospice, as patient-and-family-centered options. The goal should be to foster identifying patients' goals and wishes and to share decision-making with them to deliver treatment tailored to meet their need, goals, and values.

Summary: C-TAC comments on the following: MIPS quality category, MIPS resource use category, Clinical Practice Improvement Activity (CPIA) category and APMs.

Additional Notes/Comments

Proposed Rule: https://www.federalregister.gov/documents/2016/11/04/2016-25240/medicare-program-merit-based-incentive-payment-system-mips-and-alternative-payment-model-apm

Key words: Palliative Care; End of Life Medicare; C-TAC Comment Response; Advanced Illness Care; C-TAC; Advanced Care Model; Advanced Care APM

| Organization | Title | Date |
|--|---|------------|
| Altarum Institute & Signatories: Center to Advance Palliative Care (CAPC), Center to Transform Advanced Care (C- TAC), Rush University Medical Center | Request for Information (RFI) - Implementation of Merit-Based Incentive Payment System, Promotion of Alternative Payment Models and Incentive Payments for Participation in Eligible Payment Models | 11/17/2015 |

Purpose/Abstract

Background: This document is a response to a request for information from CMS entitled "Implementation of Merit-Based Incentive Payment System, Promotion of Alternative Payment Models and Incentive Payments for Participation in Eligible Payment Models." This response was prepared by Altarum along with signatories that include Center to Advance Palliative Care (CAPC), Center to Transform Advanced Care (C-TAC), Rush University Medical Center, Silberman School of Social Work and supported by the American Geriatrics Society, and the Society for Post-Acute and Long-Term Care Medicine.

Summary: Altarum and signatories welcome the opportunity to create a new and scalable APM that focuses on the frail elderly population and that prioritizes delivery of long term support services. The letter lists the CMMI criteria for models and offers comments with regard to their usefulness, interpretation, and priority. Altarum and others have also added five criteria that would support the development of APMs generally and for our target population.

Additional Notes/Comments

Request for Information: https://s3.amazonaws.com/public-inspection.federalregister.gov/2015-24906.pdf

Key words: Palliative Care; End of Life Medicare; C-TAC Comment Response; Advanced Illness Care; C-TAC; Advanced Care Model; Advanced Care APM

| Organization | Title | Date |
|---|---------------------------------------|------------|
| Coalition to Transform Advanced Care | Advanced Illness Care: Key Statistics | 12/10/2012 |

Purpose/Abstract

Background: The Coalition to Transform Advanced Care (C-TAC) is a nonprofit nonpartisan organization dedicated to transforming advanced illness care empowering consumers. This report provided by C-TAC highlights key statistics that are relevant to improve a fee-for-service payment schedule. The statistics contained in this report provide an insight at facts that are sometimes unreported in medical reports.

Summary: This report also provides information on models that address advanced illnesses providing better outcomes. Notable models mentioned include the Sutter Health's Advanced Illness Management (AIM) program, which reduced hospitalization rates by over 60% and direct inpatient costs by \$2,000 per enrollee per month on average; the Aetna Compassionate Care program where inpatient days/1000 patients decreased by 82% and ICU days/1000 were reduced by 86%; and the Home-Based Primary Care (HBPC) model which has shown to reduce hospital days by 63%, nursing home days by 83% and total costs of care by 24%.

Key words: Palliative Care; End of Life Medicare; C-TAC Comment Response; Advanced Illness Care; C-TAC; Advanced Care Model; Advanced Care APM

| Organization | Title | Date |
|-------------------------------|--|----------|
| American Hospital Association | Advanced Illness Management Strategies | 8/1/2012 |

Purpose/Abstract

Background: The American Hospital Association (AHA) Board Committee on Performance Improvement (CPI) was created in 2010 to support performance improvement strategies across the AHA membership to align with the AHA's strategic platform. In 2012, CPI focused on advanced illness management (AIM). This report examines in depth how hospitals can increase access to AIM program. Additionally, it outlines AIM goals and highlights strategies on how to meet those goals.

Summary: This report starts by defining AIM as the process in which a person with an advanced illness goes through four phases from when the condition is reversible to the final where the patient is eligible for hospice care. The correct planning and management of an advanced illness can lead to better outcomes including better quality of life and longer life. Strategies to increase access to Advanced Illness Management highlighted in the report include: developing a multidisciplinary care team with leadership buy-in; identifying qualifying patients through evidence based protocols; thinking beyond the hospital to promote the program; and using a performance improvement framework to measure, monitor, evaluate and adapt program between disease states and throughout time.

Section 2. Relevant Literature

Relevant Literature

Key words: Palliative Care; End of Life Medicare; C-TAC Comment Response; Advanced Illness Care; C-TAC; Advanced Care Model; Advanced Care APM; population health payment model

| Journal | Title | Date |
|--------------------------------|--|-----------|
| Journal of Palliative Medicine | An Evaluation of the Advanced Illness Management (AIM) Program: Increasing Hospice Utilization in the San Francisco Bay Area | 12/1/2006 |

Purpose/Abstract

Background: In the Medicare population, end-of-life care is fragmented and hospice is underutilized. Evidence suggests that hospice care is associated with increased patient/family satisfaction and reductions in overall health care costs. Advanced Illness Management (AIM) is a home-based program established to ease the transition between curative and comfort care for seriously ill patients who lack coordinated hospital, home health, and hospice care.

Objective: Measure the impact of the AIM program on the discharge disposition of participating home health patients.

Design: Retrospective cohort study.

Setting/subjects: A total of 435 patients who received home health services through the Sutter Visiting Nurse Association and Hospice (SVNA&H) and who were discharged between 2003 and September 2005 were included in this study. Participants were selected based on a life expectancy of 6 months or less and additionally matched on prognosis of current episode of illness and symptom status. Intervention patients were compared to those receiving usual home health care at two SVNA&H branches.

Results: In the within-branch comparison, a 28% difference was observed in the number of hospice referrals between patients who received the AIM intervention and Usual Care I (47% AIM; 33% UCI, p = 0.003). When patients receiving the AIM intervention were compared to patients from another branch, Usual Care II, a 67% difference emerged (47% AIM; 16% UCII, p < 0.0001). Among African American patients, 60% and 73% more patients were referred to hospice when AIM patients were compared to Usual Care I and Usual Care II patients, respectively (p < 0.01). These differences persisted after controlling for symptom status, patient demographics and home health length of stay.

Conclusions: The AIM program was successful at increasing hospice utilization through a targeted intervention focused on palliative and end-of-life care, increased patient education and decision making, and a dynamic treatment approach. The finding of increased utilization by African Americans, a population traditionally reluctant to use hospice, was particularly noteworthy.

Section 3. Related Literature

Relevant Literature

Key words: Palliative Care; End of Life Medicare; C-TAC Comment Response; Advanced Illness Care; C-TAC; Advanced Care Model; Advanced Care APM; population health payment model

| Journal | Title | Date |
|------------|--|-----------|
| Healthcare | From healthcare to health: A proposed pathway to population health | 9/28/2016 |

Purpose/Abstract

Background: Innovations in payment are encouraging clinical-community partnerships that address health determinants. However, little is known about how healthcare systems transform and partner to improve population health.

Methods: The authors synthesized views of population health experts from nine organizations and illustrated the resulting model using examples from four health systems.

Conclusions: The transformation requires a foundation of primary care, connectors and integrators that span the boundaries, sharing of goals among participants, aligned funding and incentives, and a supporting infrastructure, all leading to a virtuous cycle of collaboration. Policies are needed that will provide funding and incentives to encourage spread beyond early adopter organizations.

Additional Notes/Comments

https://www.ncbi.nlm.nih.gov/pubmed/27693259

Amsterdam, Netherlands

Key words: Palliative Care; End of Life Medicare; C-TAC Comment Response; Advanced Illness Care; C-TAC; Advanced Care Model; Advanced Care APM; population health payment model

| Journal | Title | Date |
|--------------------------------|---|----------|
| Journal of Palliative Medicine | Interventions to Improve Hospice and Palliative Care Referral: A Systematic Review | 8/1/2014 |

Purpose/Abstract

Background: Hospice and palliative care are underutilized among patients at the end of their lives despite evidence that they improve patient satisfaction and reduce costs.

Objective: To synthesize evidence regarding interventions to increase hospice referral/enrollment.

Design and Measurements: Researchers conducted a systematic review of the literature and selected studies that evaluated interventions aimed at increasing hospice use. We performed a MEDLINE search (1979 to April 2013) supplemented by manual searches of bibliographies of key articles. Study design, quality criteria, population, interventions, and outcomes for each study were extracted. The main outcome evaluated was hospice referral/enrollment.

Results: The search strategy yielded 419 studies, of which only 6 met our eligibility criteria. Three studies included nursing home populations; 1 included home care patients, 1 targeted care managers, and 1 reported on heart failure patients. Three studies had a cohort design, 2 were pre–post, and only 1 was randomized. Two studies evaluated a process to identify eligible subjects. Two evaluated the impact of advance care planning programs and 2 only provided education. Interventions that only provided education showed a median increase in referral of 5% (2.8%–17%) while interventions that identified hospice candidates showed a median increase in hospice referral of 19.5 % (19%–20%).

Conclusions: Interventions of different levels of complexity can improve the use of hospice services among subjects with high mortality risk. An approach that allows the medical team to assess patients' treatment goals and that engages the treating physician seems to be the most successful one.

Key words: Palliative Care; End of Life Medicare; C-TAC Comment Response; Advanced Illness Care; C-TAC; Advanced Care Model; Advanced Care APM; population health payment model

| Journal | Title | Date |
|------------------------------|--|-----------|
| BMC Health Services Research | Elements of Effective Palliative Care Models: A Rapid Review | 3/26/2014 |

Purpose/Abstract

Background: Population ageing, changes to the profiles of life-limiting illnesses and evolving societal attitudes prompt a critical evaluation of models of palliative care. We set out to identify evidence-based models of palliative care to inform policy reform in Australia.

Method: A rapid review of electronic databases and the grey literature was undertaken over an eight week period in April-June 2012. We included policy documents and comparative studies from countries within the Organization for Economic Co-operation and Development (OECD) published in English since 2001. Meta-analysis was planned where >1 study met criteria; otherwise, synthesis was narrative using methods described by Popay et al. (2006).

Results: Of 1,959 peer-reviewed articles, 23 reported systematic reviews, 9 additional RCTs and 34 non-randomized comparative studies. Variation in the content of models, contexts in which these were implemented and lack of detailed reporting meant that elements of models constituted a more meaningful unit of analysis than models themselves. Case management was the element most consistently reported in models for which comparative studies provided evidence for effectiveness. Essential attributes of population-based palliative care models identified by policy and addressed by more than one element were communication and coordination between providers (including primary care), skill enhancement, and capacity to respond rapidly to individuals' changing needs and preferences over time.

Conclusion: Models of palliative care should integrate specialist expertise with primary and community care services and enable transitions across settings, including residential aged care. The increasing complexity of care needs, services, interventions and contextual drivers warrants future research aimed at elucidating the interactions between different components and the roles played by patient, provider and health system factors. The findings of this review are limited by its rapid methodology and focus on model elements relevant to Australia's health system.

Key words: Palliative Care; End of Life Medicare; C-TAC Comment Response; Advanced Illness Care; C-TAC; Advanced Care Model; Advanced Care APM; population health payment model

| Journal | Title | Date |
|-----------------------------|--|-----------|
| Annals of Internal Medicine | Evidence for Improving Palliative Care at the End of Life: A Systematic Review | 1/15/2008 |

Purpose/Abstract

Background: Many persons and their families are burdened by serious chronic illness in late life. How to best support quality of life is an important consideration for care.

Purpose: To assess evidence about interventions to improve palliative and end-of-life care. **Data Sources:** English-language citations (January 1990 to November 2005) from MEDLINE, the Database of Abstracts of Reviews of Effects, the National Consensus Project for Quality Palliative Care bibliography, and November 2005 to January 2007 updates from expert reviews and literature surveillance.

Study Selection: Systematic reviews that addressed "end of life," including terminal illness (for example, advanced cancer) and chronic, eventually fatal illness with ambiguous prognosis (for example, advanced dementia), and intervention studies (randomized and nonrandomized designs) that addressed pain, dyspnea, depression, advance care planning, continuity, and caregiving.

Data Extraction: Single reviewers screened 24Â 423 titles to find 6381 relevant abstracts and reviewed 1274 articles in detail to identify 33 high-quality systematic reviews and 89 relevant intervention studies. They synthesized the evidence by using the Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) classification.

Data Synthesis: Strong evidence supports treating cancer pain with opioids, nonsteroidal, radionuclides, and radiotherapy; dyspnea from chronic lung disease with short-term opioids; and cancer-associated depression with psychotherapy, tricyclics, and selective serotonin reuptake inhibitors. Strong evidence supports multi component interventions to improve continuity in heart failure. Moderate evidence supports advance care planning led by skilled facilitators who engage key decision makers and interventions to alleviate caregiver burden. Weak evidence addresses cancer-related dyspnea management, and no evidence addresses non-cancer pain, symptomatic dyspnea management in advanced heart failure, or short-acting antidepressants in terminal illness. No direct evidence addresses improving continuity for patients with dementia. Evidence was weak for improving caregiver burdens in cancer and was absent for heart failure. Limitations: Variable literature indexing for advanced chronic illness and end of life limited the comprehensiveness of searches, and heterogeneity was too great to do meta-analysis.

Conclusion: Strong to moderate evidence supports interventions to improve important aspects of end-of-life care. Future research should quantify these effects and address the generalizability of insights across the conditions and settings of the last part of life. Many critical issues lack high-quality evidence.

Key words: Palliative Care; End of Life Medicare; C-TAC Comment Response; Advanced Illness Care; C-TAC; Advanced Care Model; Advanced Care APM; population health payment model

| Journal | Title | Date |
|--------------------------|--|-----------|
| Health Services Research | Identifying Older Adults with Serious Illness: A Critical Step toward Improving the Value of Health Care | 3/18/2012 |

Purpose/Abstract

Objective: To create and test three prospective, increasingly restrictive definitions of serious illness.

Data Sources: Health and Retirement Study, 2000–2012.

Study Design: We evaluated subjects' 1-year outcomes from the interview date when they first met each definition: (A) one or more severe medical conditions (Condition) and/or receiving assistance with activities of daily living (Functional Limitation); (B) Condition and/or Functional Limitation and hospital admission in the last 12 months and/or residing in a nursing home (Utilization); and (C) Condition and Functional Limitation and Utilization. Definitions are increasingly restrictive, but not mutually exclusive.

Data Collection: Of 11,577 eligible subjects, 5,297 met definition A; 3,151 definition B; and 1,447 definition C.

Principal Finding: One-year outcomes were as follows: hospitalization 33 percent (A), 44 percent (B), 47 percent (C); total average Medicare costs \$20,566 (A), \$26,349 (B), and \$30,828 (C); and mortality 13 percent (A), 19 percent (B), 28 percent (C). In comparison, among those meeting no definition, 12 percent had hospitalizations, total Medicare costs averaged \$7,789, and 2 percent died.

Conclusions: Prospective identification of older adults with serious illness is feasible using clinically accessible criteria and may be a critical step toward improving health care value. These definitions may aid clinicians and health systems in targeting patients who could benefit from additional services.

Additional Notes/Comments

The article was updated in 2017.

Section 4. References

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^{*} These sources were not included in the initial environmental scan and relevant literature review conducted based on C-TAC's Letter of Intent to submit its *initial* proposal; but were reviewed by the PRT as part the PRT's review of CTAC's revised proposal.