Do We Really Know How Long This Patient Will Live?

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Objectives

- To review the Medicare Hospice Benefit.
- To understand the certification/recertification process, including measurement of and recording of rate of decline in patients with non-cancer diagnoses, focusing on dementia.
- To explore strategies for prognosticating survival in hospice patients with non-cancer diagnoses, focusing on dementia.

Medicare Hospice Benefit

The Medicare Hospice Benefit

- Palliative care for individuals with a prognosis of living 6 months or less if the terminal illness runs its normal course.
- Implemented 11/1/1983
- Part of Medicare Part A
- Provides Federally funded dollars for EOL care
- Per diem reimbursement
  - Nursing, SW, HHA, counselor, physician
  - All therapies
  - Medications and DME

Development of the Benefit

- Dame Cicely Saunders: Developed modern hospice concept in UK.
- Elisabeth Kubler-Ross: *On Death and Dying* published in 1969 helped increase public awareness about dying in health care.
- Focus on "total person"
- Alternative service to those approaching EOL.
- Hospices accountable for all aspects of care, including quality.

National Hospice Study 1980-1983

- Demonstration Project funded by Robert Wood Johnson Foundation, John A. Hartford Foundation, and CMS.
- Principles
  - Patient and family know of terminal condition
  - Further treatment indicated on supportive basis
  - Interdisciplinary teamwork is essential
  - Family members should be actively involved
  - Trained volunteers should provide additional support

Differentiating Principles

1. Patient and family are unit of care.
2. Multidisciplinary team assesses the physical, psychological, and spiritual needs of patient and family to develop and provide a coordinated plan of care.
3. Pain and other symptoms associated with the terminal prognosis/previous treatments are controlled, but no heroic efforts are made to cure the patient.
4. Bereavement follow-up is provided to help the family cope with their emotional suffering.

CMS, 2014

Trends in Utilization

- Use of hospice for EOL care has grown steadily since 1982.
- Substantial growth: 513,000 served in 2000, to more than 1.3 million in 2013.
- In 2011, 44.6% of deaths received hospice care.
- Expenditures from $2.9 billion in 2000 to 15.1 billion in 2013.
- Expected to increase by 8% annually.

CMS, NHPCO, 2014

Trends in Utilization

- Overall, people are admitted late
  - 50% die w/in 3 weeks
  - 35% die in 1 week
- But there has been increased average lifetime LOS from 54 days in 2000 to 86 days in 2011.
- Significant minority of 12-15% live more than 6 months.
- 2013: Debility, AFTT, and dementia diagnoses comprised 30% of all hospice claims.

Evolution of Hospice Diagnoses

- At outset, cancer diagnoses accounted for largest percentage of beneficiaries.
- 1998 cancer diagnoses accounted for 53%, down to 31% in 2008 (CMS data).
- The increasing non-specific diagnoses and dementia diagnoses have longer LOS.
- More beneficiaries with longer LOS is concerning to CMS.
- Is benefit being used as intended?

Hospice Utilization

- Top 3 diagnoses:

Year	#1	#1	#3
2002	Lung ca 11%	CHF 7%	Debility 6%
2007	Debility 9%	Lung ca 8%	CHF 7%
2012	Debility 12%	Lung ca 7%	AFTT 7%
2013	Debility 9%	CHF 7%	Lung ca 6%

Federal Register, 8/22/2014

CMS Response

- Increased scrutiny
  - LOS
  - Live discharges/revocations
  - Use of GIP, continuous care
- F2F's, physician narratives
- Coding changes
  - Non-specific and dementia diagnoses
  - Multiple diagnoses on claims
- Increased hospice coverage of services
  - Medicare Part D
  - Related/Unrelated documentation

Non-Specific Diagnoses

- Not acceptable as primary diagnosis after 10/1/2014.
  - Debility
  - Adult Failure to Thrive
- "These diagnoses do not provide enough information to accurately describe Medicare hospice beneficiaries and the conditions that hospices are managing."
- They can be used as supporting diagnoses.

Federal Register 8/22/2014

Dementia Diagnoses

- Longer LOS and require less skilled care over longer disease trajectory.
- Does not mean that the symptom burden is less, but that different disease trajectories exist.
- These patients have complex needs that are often unmet and have poorer QOL.
- Need better prognostic tools to determine when hospice is most beneficial.

CMS/ABT 5/1/2014

Dementia Diagnoses

- Dementia diagnoses which are manifestations of other disease processes:
  - Mental, Behavioral, and Neurodevelopmental Disorders
  - Diseases of the Nervous System and Sense Organs
- Manifestations of other disease processes
  - In diseases classified elsewhere
- Need to follow ICD-9 coding conventions
- There are certain conditions which have both an underlying cause and subsequent multiple body system manifestations
  - Etiology Code
  - Manifestation Code

Dementia Diagnoses

- OK to use as primary diagnoses
  - 331.0 Alzheimer's disease*
  - 331.82 Lewy body dementia*
  - 331.82 Frontotemporal dementia*
  - 046.1 Jacob-Creutzfeld disease*
  - 331.82 Parkinson's disease*
  - 331.11 Pick's disease*
  - 310.1 Senility with mental changes of nonpsychotic severity
  - 437.0 Cerebrovascular disease
    - 290.40 Uncomplicated vascular dementia
    - 290.41 Vascular dementia with delirium
    - 290.42 Vascular dementia with delusions
    - 290.43 Vascular dementia with depressed mood
- Need secondary diagnosis*
  - 294.10 dementia without behaviors
  - 294.11 dementia with behaviors

NHPCO, 2014

Diagnoses on Hospice Claims

- Need to report all diagnoses that are related to terminal prognosis, including those that can affect the care and management of the patient.
  - Specific diagnoses
  - Coexisting conditions
  - Symptoms
- Provides more accurate description of the patient's conditions.
- Through first quarter 2013: 72% of hospice claims reported a single principal diagnosis.
- FY 2013: 67% of hospice claims still reported only one diagnosis.
- Using Medicare Code Editor to flag problems with diagnoses.

Federal Register 8/22/2014

Initial Eligibility

- Determined by 2 physicians
  - Attending physician (if any)
  - Hospice physician
- Certification of terminal illness (prognosis)
  - Diagnosis of the terminal condition.
  - Other health conditions, whether related or unrelated to the terminal condition.
  - Current clinically relevant information supporting all diagnoses.

Certification

- Based on physician's clinical judgment regarding the normal course of the person's illness.
  - Specify that the person's prognosis is for a life expectancy of 6 months or less if the terminal illness runs its normal course.
  - Clinical information and other documentation that support the medical prognosis must accompany the certification.

Additional Considerations

- Primary terminal condition
- Related diagnoses
- Current subjective and objective medical findings
- Current medication and treatment orders
- Information about the medical management of any of the patient's conditions unrelated to the terminal illness.

Recertification

- Initial and second benefit periods
  - Physician narrative composed by certifying physician
- Third and subsequent benefit periods
  - Face to face encounter
    - Physician or employed NP
  - Physician narrative
    - Must be physician

Summary of Eligibility

- Expected that certifying physicians will use their best clinical judgment based on initial and updated comprehensive assessments and collaboration with IDG that individual has prognosis of 6 months or less with each cert and recert.
- Includes
  - Diagnosis of the terminal condition
  - Other health conditions, whether related of unrelated to the terminal condition
  - Current clinically relevant information supporting all diagnoses.

Prognostication

- prog·nos·ti·ca·tion
- prägˌnästəˈkāSHən/
- *noun*
- noun: **prognostication**
- the action of foretelling or prophesying future events."an unprecedented amount of soul-searching and prognostication"
- a prophecy.plural noun: **prognostications** "these gloomy prognostications proved to be unfounded"
- *synonyms:* prediction, forecast, prophecy, prognosis, divination, augury "their prognostications had proved remarkably accurate"

Prognostication

- Not an exact science!
- Based on clinical judgment regarding the normal course of an individual's illness.
- There still needs to be a basis for certification
  - Clinical information
  - Other documentation
- Decision can be reviewed if there is question whether the clinical documentation supports hospice eligibility.
- "The goal of any review for eligibility is to ensure that hospices are thoughtful in their eligibility determinations so that hospice beneficiaries are able to access their benefits appropriately."

Federal Register 8/22/2014

Terminal Prognosis

- Hospice provides services for all care related to terminal illness, related conditions, and management of pain and symptoms that result from the terminal illness and related conditions.

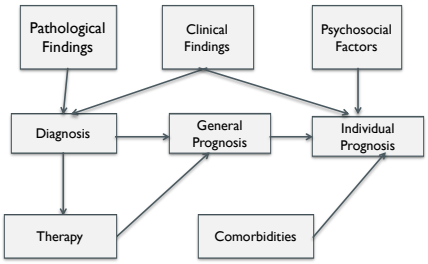
Prognosis

- Comorbid conditions
- Rate of decline
- Age and gender
- Nutritional status
- Functional status
- Number of hospitalizations
- Depression
- Social isolation

Prognostication

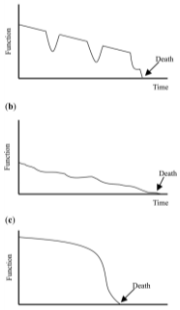
- Accuracy varies based on diagnosis
- More accurate when closer to death
- Population studies less helpful for the individual
- Multiple factors influence an individual's prognosis

Factors Influencing Individual Prognosis



Glare and Sinclair, JPM (11)1 11/2008

Prognosis Curves



- Prognosis of Organ Failure: COPD and CHF
- Prognosis of Dementia
- Prognosis of Cancer Diagnoses

CMS Expectations

- There are multiple public sources available to assist in determining hospice eligibility.
  - Industry-specific clinical and functional assessment tools
  - MAC websites
- Hospices are expected to use their expert clinical judgment in determining eligibility for hospice services.
- Documentation supporting a 6-month or less life expectancy is included in the beneficiary's medical record and is available to MAC's when requested.

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Stabilization while on Hospice Services

- If beneficiary improves/stabilizes and prognosis is no longer less than 6 months, then discharge should be considered.
  - Discharge when determination is made
  - They can be re-enrolled when they again appear to have prognosis of less than 6 months
  - Example: Acute infections
- If beneficiary in the terminal stages of illness stabilizes or improves, but still has reasonable expectation of continued decline and prognosis of less than 6 months, they still remain eligible for hospice services.
  - Example: Very end stage dementia

Federal Register 8/22/2014

Dementia

Dementia

- Types of Dementia
  - Alzheimer's disease is most common
  - Vascular dementia
  - Mixed dementia
  - Frontotemporal dementia
  - Lewy Body dementia
- Duration of illness 1-13 years
- Mean survival between 3-5.7 years

Dementia

- Last year of life is protracted disability
  - Infectious complications
  - Eating difficulties
- Slow declining trajectory is a challenge to determine prognosis and hospice eligibility.
- Individuals with advanced dementia can survive for long periods even when at risk for sudden life threatening events such as respiratory infections, urinary infections and pressure ulcers.
- Individuals who are thought to be not eligible and are denied hospice may decline and die within days or weeks.

Barriers to Quality Hospice Care in Dementia

- Dementia is often not thought of as terminal diagnosis.
- The LCD's are problematic in prognosticating survival.
- Accessibility of hospice services in nursing homes.
- Expertise of hospice staff in managing the unique clinical challenges of the dementia population.
  - Behavioral disturbances
  - Symptom control in cognitively impaired

Medicare Eligibility for Dementia

- Stage 7A or beyond according to FAST with all of the following:
  - Inability to ambulate without assist
  - Inability to dress or bathe without assist
  - Urinary and fecal incontinence
  - No consistent meaningful, reality-based verbal communication, or the ability to speak is limited to a few intelligible words

Medicare Eligibility for Dementia

- AND one of the following within the past 12 months:
  - Aspiration pneumonia
  - Pyelonephritis or other upper urinary tract infection
  - Septicemia
  - Multiple decubitus ulcers, stage 3 and 4
  - Fever, recurrent after antibiotics
  - Inability to maintain sufficient fluid and calorie intake
    - 10% weight loss in previous 6 months or
    - Albumin <2.5 g/dl

Prognostication

- LCD'S (Medicare Hospice Guidelines)
  - Created in 1996 as GUIDE to be used in conjunction with clinical judgment
  - Never intended to be used as public policy
  - Never validated
  - Ineffective at predicting prognosis
- Patients may not meet the LCD's and still have prognosis of less than 6 months
  - May be denied hospice admission

Hospice Guidelines (LCD's) and Survival

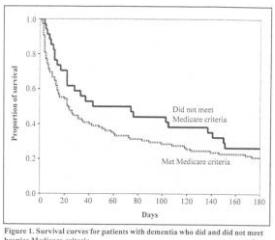


Figure 1. Survival curves for patients with dementia who did and did not meet hospice Medicare criteria.

Schonwetter, et.al, Am J Hospice and Palliative Care, 20(2) 2003

Tools

National hospice Study (1988)

- Early prognostic index developed by NHO (NHPCO) from data collected by cancer patients in hospice.
- KPS + Select symptoms
  - Anorexia
  - Weight loss
  - Dysphagia
  - Dry mouth
  - Dyspnea
- If no symptoms, prognosis is 6 months
- If all symptoms, prognosis is 6 weeks

?

Palliative Performance Scale (PPS)

- Modification of the Karnofsky Performance Scale, developed in 1999 and revised in 2001, 2006.
- Uses objective structured rating framework originally intended to measure performance status, but has recently been found to have prognostic value.
- Multiple studies have demonstrated correlation between PPS scores and survival.

Palliative Performance Scale (2007)

%	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
100	Full	Normal Activity No Evidence of Disease	Full	Normal	Full
90	Full	Normal Activity Some Evidence of Disease	Full	Normal	Full
80	Full	Normal Activity with Effort Some Evidence of Disease	Full	Normal or Reduced	Full
70	Reduced	Unable Normal Job / Work Some Evidence of Disease	Full	Normal or Reduced	Full
60	Reduced	Unable Hobby / House Work Significant Disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
50	Mainly Sit/Lie	Unable to Do Any Work Extensive Disease	Considerable Assistance Necessary	Normal or Reduced	Full or Confusion
40	Mainly in Bed	As Above	Mainly Assistance	Norma or Reduced	Full or Drowsy or Confusion
30	Totally Bed Bound	As Above	Total Care	Reduced	Full or Drowsy or Confusion
20	As Above	As Above	Total Care	Minimal Sips	Full or Drowsy or Confusion
10	As Above	As Above	Total Care	Mouth Care Only	Drowsy or Coma
0	Death	-	-	-	-

Palliative Performance Scale (2007)

%	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
60	**Reduced**	Unable Hobby / House Work Significant Disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
50	**Mainly Sit/Lie**	Unable to Do Any Work Extensive Disease	Considerable Assistance Necessary	Normal or Reduced	Full or Confusion
40	**Mainly in Bed**	As Above	Mainly Assistance	Norma or Reduced	Full or Drowsy or Confusion
30	**Totally Bed Bound**	As Above	Total Care	Reduced	Full or Drowsy or Confusion
20	As Above	As Above	Total Care	**Minimal Sips**	Full or Drowsy or Confusion
10	As Above	As Above	Total Care	**Mouth Care Only**	**Drowsy or Coma**
0	Death	-	-	-	-

PPS Validity

- Harrold, et. al., 2005
- Validated PPS in heterogeneous hospice population (n=466)
- Better correlation in nursing home and non-cancer populations.
- PPS=10-20%: 6 month mortality 96%
- PPS=30-40%: 6 month mortality 89%
- PPS=50-70%: 6 month mortality 81%

Harrold, et.al. JPM 8(3), 2005

FAST Scale

- Reisberg, 1996
- Initially developed for staging of Alzheimer's disease throughout the illness.
- Part of the LCD's for hospice eligibility (7a).
- Most commonly used tool for hospice eligibility.

FAST Scale

1. No difficulty
2. Forgetting objects, subjective work difficulties
3. Decreased job function, difficulty traveling to new locations, decreased organizational capacity
4. Difficulty with complex tasks
5. Requires assist in choosing proper clothing

6a. Unable to dress
6b. Unable to bathe
6c. Unable to toilet self
6d. Urinary incontinence
6e. Fecal incontinence
7a. Speaks less than 6 words per day
7b. Speaks one word per day
7c. Cannot walk w/o assist
7d. Cannot sit up w/o assist
7e. Loss of ability to smile
7f. Loss of ability to hold head up

Reisberg, Psychopharm Bull. 1988

Limitations of FAST Scale

- Assumes ordinal disease progression.
  - Excludes those with comorbidities
  - Skip stages due to other illnesses
- May not be valid for non-Alzheimer's dementia.
- Studies have not shown correlation between 7a/7c on FAST scale and 6 month prognosis.
- Alzheimer's disease progresses at different rates in different patients.

Mortality Risk Index (2004)

- Mitchell, et. al.
- Based on Minimum Data Set (MDS) collected on all SNF patients
- Suggested as alternative to the FAST scale
- Greater predictive value of 6 month mortality
- Only validated in newly admitted SNF patient.

Mortality Risk Index (2004)

Points	Risk Factor
1.9	Complete dependence with ADL's
1.9	Male gender
1.7	Cancer
1.6	CHF
1.6	Oxygen within 14 days
1.5	Shortness of breath
1.5	<25% food eaten at most meals
1.5	Unstable medical condition
1.5	Bowel incontinence
1.5	Bedfast
1.4	Age >83 yrs
1.4	Not awake most of day

MRI

- Risk estimate within 6 months

Score	Risk %
0	8.9
1-2	10.8
3-5	23.2
6-8	40.4
9-11	57.0
>12	70

Advanced Dementia Prognostic Tool (ADEPT)

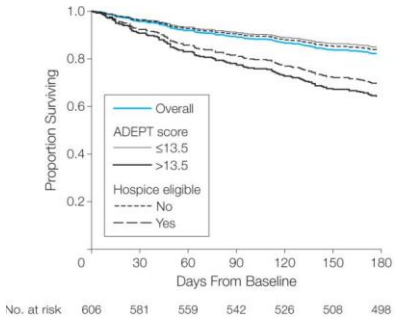
- Mitchell, et. al., 2010
- Revision of Mortality Risk Index (MRI)
- Based on minimum data set (MDS) collected for all SNF patients.
- Prospectively validated and compared with the Medicare hospice guidelines

ADEPT

- NH stay <90 days
- Age
- Male
- Dyspnea
- Pressure ulcer
- ADL's
- Bedfast
- Insuff oral intake
- Bowel incontinence
- BMI <18.5
- Weight loss
- CHF
- Score 1.0-32.5, higher score increased risk of death

Mitchell, et. al. JAMA 2010

ADEPT Score vs. LCD's



ADEPT

- Improvement over FAST scale/LCD's in predicting 6 month mortality
- High inter rater reliability
- High sensitivity (>90%)
- Low specificity (30%)
- Found to be better than the LCD's at prognosticating 6 month survival

Aminoff Mental Suffering Scale (2008)

- Suffering may impact prognosis
- Ten point scale:
  - Not calm
  - Screams
  - Pain
  - Decubitus ulcers
  - Malnutrition
  - Eating disorders
  - Invasive actions
  - Instable medical condition
  - Suffering according to medical opinion
  - Suffering according to family opinion

Aminoff MSSE (2008)

- Documentation of high suffering level on MSSE is associated with shorter mean survival
- Scoring 0-10 points
  - 0-3=Low 57.7 + 9.7 days
  - 4-6=Intermediate 44.7 + 5.9 days
  - 7-10=High 27.5 + 4.1 days

Looking for Other Predictors

- Harris, et al (2014) study in Journal of Pall Med.
- Looked for independent predictors of 6 month mortality after hospice admission
  - Age >65
  - Male patients
  - Admitted from hospital or to IPU
  - PPS interacting with diagnosis

PPS and Diagnosis

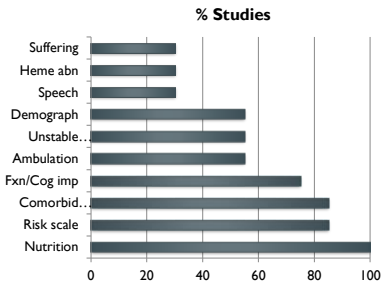
Diagnosis	<30	30	40	50	>50
Cancer	99.6	98.3	95.5	92.8	89.1
Debility	96.3	83.6	67.1	57.6	47.4
Cardiac	97.6	89.8	74.2	65.3	51.8
Dementia	93.2	73.6	54.9	51.4	36.6
Pulmonary	98.4	92.4	79.9	71.6	63.8
Stroke	92.8	67.4	48.4	39.4	32.6
Other	99.1	95.0	88.3	81.9	79.2

Meta analysis

- Brown, et. al., 2012
- Evaluated current tools
- Goal was to determine best prognosticators
- Variables supported by studies:
  - Nutritional status (anorexia)
  - Cognitive impairment
  - Functional impairment
  - Comorbidities
    - CHF
    - Cancer

Brown, et. al. Pall Med 2012

Identified Prognostic Indicators



Summary

- Prognostication is more difficult in non-cancer diagnoses, especially dementia.
- CMS expects us to use good clinical judgment, have thoughtful processes in place, use available tools, and document the rationale for eligibility.
- Need to consider individual prognosis:
  - Rate of decline
  - Comorbidities

Questions?

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