



Hospice & Palliative Care Federation of Massachusetts

ACCESS TO HOSPICE CARE *A report on the Admitting Practices of Massachusetts Hospices*

**A report of
the Standards/Best Practices Committee
Hospice & Palliative Care Federation of MA
January 2004**

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ADMITTING PRACTICES AND ACCESS TO HOSPICE CARE

I. BACKGROUND

The Standards and Best Practices Committee was appointed by the Board in 2002 and charged with “providing opportunities for examining standards, competencies and making recommendations to members that will improve end of life care.”

The Committee surveyed hospices in Fall 2002 regarding their needs for “best practices” and current admitting practices. 21 out of 41 surveys were returned for a response rate of 51%.

II. EXECUTIVE SUMMARY

The Committee analyzed the survey data and has prepared the following information for each of the admitting practices:

- *Survey results*
- *Regulatory, accreditation standards and applicable voluntary standards* from:
 - Medicare Conditions of Participation
 - State Licensure regulations
 - Accreditation standards of Joint Commission on Accreditation of Health Care Organizations (JCAHO) and Community Health Accreditation Program (CHAP)
 - Voluntary Standards and Service Guidelines from the National Hospice and Palliative Care Organization
- *Discussion points* from Committee meetings
- *Recommendations* for hospices to consider as they expand their admission practices to allow for greater access to hospice services and more standardized clinical practice patterns across the state.
- *Suggested Supportive Strategies* are commonly used treatment modalities in hospice.

In its work, the Committee concluded that **there are several over-riding principles that could enhance access to hospice care for beneficiaries by recognizing:**

- Access to hospice is enhanced as hospices make available more treatment modalities.
- There are treatment methodologies, appropriate for hospice care today, that were inappropriate or unavailable in the past. They are necessary tools in the treatment of patients’ symptoms that prove not to be amenable to other types of interventions.
- Access to hospice care is enhanced by a one-on-one visit with the patient and family prior to a decision of whether to admit the patient whose treatment might preclude hospice admission. Often, after an honest discussion about the risks and benefits of the treatment, and by offering options for comfort and symptom relief, patients may decide to choose admission to hospice.

Results of the H&PCFM Hospice Survey, Fall 2002

Admitting Practices

HOSPICE	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	
Free Care Policy	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Sliding Scale Policy	X	X		X		X	X					X	X	X	X	X	X	NA	X	X		
Allow "outlier" services for non-Medicare patients	X	X	X	X	X	X		X	X		X	X	X	X	X	X	X	NA	X	X	X	
Capability for translation services	X	X	X	X	X	X	X	X	X	X	X	X		X	X	X	X			X	X	
Admit a patient seven days a week/24 hours a day	X	X	X		X	X	X		X		X	X		X	X	X	X	X	X	X		

N=21

Key: X = Yes

Summary of Admitting Practices

	<u>YES</u>	<u>NO</u>	<u>NA</u>
Free care policy	21	0	
Sliding scale policy	13	7	1
Allow "outlier" services	18	2	1
Capability for translation	18	3	
Admit 24/7	16	5	

Summary of Admitting Practices

	<u>YES</u>	<u>NO</u>	<u>NA</u>
Free care policy	21	0	
Sliding scale policy	13	7	1
Allow "outlier" services	18	2	1
Capability for translation	18	3	
Admit 24/7	16	5	

Results of H&PCFM Hospice Survey, Fall 2002

Hospice Access by Type of Intervention

HOSPICE	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Without a DNR	W	MA	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W
With no primary caregiver	W	MA	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	MA	W	W
On ventilator support	MA	WN	MA	WN	WN	W	MA	W	WN	MA	MA	MA	MA	MA	W	MA	W	MA	MA	W	W
On IV Hydration	W	W	W	W	W	W	W	W	W	W	W	W		W	MA	W	W	W	W	W	W
Receiving anti-viral medications for AIDS	W	W	MA	W	W	MA	W	MA	W	MA	MA	MA	WN	W	MA	W	MA	W	WN	W	W
Receiving blood products	WN	WN	WN	MA	MA	MA	MA	MA	MA	WN	W	MA	MA	W	MA	W	MA	W	W	W	W
Receiving enteral therapy	W		W	W	W	MA	MA	W	W	W	W	W		W	W	W	W	W	W	W	W
Receiving palliative chemotherapy	W	MA	W	MA	MA	MA	W	MA	MA	WN	W	W	WN	W	MA	W	W	W	WN	W	W
Receiving palliative IV therapy for symptom management	W	MA	W	W	W	W	W	W	MA	W	MA	W	MA	W	W	W	MA	W	W	W	W
Receiving palliative radiation	W	WN	W	W	MA	MA	W	MA	MA	W	W	W	WN	W	W	W	MA	W	WN	W	W
Receiving TPN	W	MA	MA	WN	W	MA	MA	WN	MA	MA	WN	W	MA	MA	MA	W	MA	W	WN	W	W

Key: W = would admit
 WN = would not admit
 MA = may admit

N=21

Summary of Access to Hospice Care

	<u>YES</u>	<u>NO</u>	<u>MAY</u>	<u>NR</u>
Without a DNR	20	0	1	
With a primary caregiver	19	0	2	
On ventilator support	6	4	11	
On IV Hydration	19	0	1	1
Receiving anti-viral meds for AIDS	11	2	8	
Receiving blood products	7	4	10	
Receiving enteral therapy	17	0	2	2
Receiving palliative chemo	11	3	7	
Receiving palliative IV therapy (sx managment)	16	0	5	
Receiving palliative radiation	13	3	5	
Receiving TPN	7	5	9	

Results of H&PCFM Hospice Survey, Fall 2002

Hospice Access by Type of Intervention

HOSPICE	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Without a DNR	X		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
With no primary caregiver	X		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X		X	X
On ventilator support						X		X							X		X			X	X
On IV Hydration	X	X	X	X	X	X	X	X	X	X	X	X		X		X	X	X	X	X	X
Receiving anti-viral medications for AIDS	X	X		X	X		X		X					X		X		X		X	X
Receiving blood products											X			X		X		X	X	X	X
Receiving enteral therapy	X		X	X	X			X	X	X	X	X		X	X	X	X	X	X	X	X
Receiving palliative chemotherapy	X		X				X				X	X		X		X	X	X		X	X
Receiving palliative IV therapy for symptom management	X		X	X	X	X	X	X		X		X		X	X	X		X	X	X	X
Receiving palliative radiation	X		X	X			X			X	X	X		X	X	X		X		X	X
Receiving TPN	X				X							X				X		X		X	X

N=21
 Key: X = Would admit
 ■ = Would not or may admit

III. ADMITTING PRACTICES

There was considerable variability among hospices with regard to their admitting practices. A summary of that variability is included below:

Variability Among Programs Regarding Admitting Practices

	<u>Have Policy</u>
Free care policy	100%
Allows for outlier services on non-Medicare patients	86%
Capability for 24-hr admitting	76%
Sliding scale policy	62 %

NOTE: Translation capabilities varied widely depending on the language. (See Section D, Page 6)

A. Has a Free Care Policy

Survey Data N=21

Yes 21 No 0

Applicable Requirements/Standards

DHHS Corporate Compliance Guidelines: “the hospice does not offer or provide...free services.. to patients...for the purpose of inducing referrals...”

NHPCO Service Guidelines: “Core services...should not be restricted due to an uninsured situation, an inability to pay for the full or adjusted cost of services...”

“Admit all patients for whom care is appropriate regardless of their ability to pay. ”

Recommendation

-Free care is not only allowed by hospices but is expected in cases where the patient is eligible for hospice services by the program’s admitting criteria, elects hospice, and has no ability to pay. Agencies should not provide free services to patients who are not eligible or not electing hospice care. Hospices should have a free care policy, combined with its sliding scale policy, as part of its voluntary corporate compliance effort to screen patients for need and protect against allegations of inducing patients by providing free services.

B. Has a Sliding Scale Policy

Survey Data N=21

Yes 13 No 7 Not applicable 1

Applicable Requirement/Standards

NHPCO Service Guidelines: "Policies and procedures should be in place to address billing and collection for services that are the patient's/family's responsibility."

MA Licensure: 141.205(A)(1): Patient Rights and Responsibilities: Each hospice shall have written policies and procedures that protect the rights of all patients and families. Rights shall include but need not be limited to: (1) right to be informed of...any sliding scale fee associated with services provided.

Applicable Requirement/Standards

CHAP: CI.6, "Patients and families must be advised before care is initiated of the extent to which payment for services may be expected and the extent of payment that may be expected from the patient."

Discussion

-A joint policy allows the hospice to charge for services at the patient's ability to pay so that the hospice may collect some reimbursement for services as well as show their effort to appropriately screen patients for free care.

Recommendation

-Hospices should develop a policy that jointly describes the hospice free care and sliding scale policy. The policy should set forth the process for determining ability to pay.

C. Allows Outlier Services for non-Medicare Patients Not in the Plan of Care

Survey Data N=21

Yes 18 No 2 Not applicable 1

Discussion

-Regulations do not prohibit hospice patients from receiving services outside of the Plan of Care such as chemotherapy, TPN and others.

-Some programs do not allow outliers, citing an ethical disparity between caring for those who have the ability to pay and not caring for those who can not.

-Whether a hospice provides outlier services to patients in private health plans is determined by a wide arrange of regulatory, ethical, reimbursement and philosophical concerns

-Services can not be left due to cost alone.

-Outlier services for Medicare patients: Medicare patients may elect to purchase palliative care services from a hospice program outside their regular Medicare benefits e.g, a patient may pay for palliative care services from a hospice program on a fee for service or per diem arrangement while on the 100 Day Skilled Nursing Facility (SNF) benefit.

C. Allows Outlier Services for non-Medicare Patients (continued)

Recommendations

- Develop clear policies, including an Ethics Policy, regarding how decisions are made in the Plan of Care, how treatment decisions are made, and how patients can have services outside of the plan of care, with the knowledge that if those services are not paid for by hospice, they would be paid for by the patient, or by their health plan.
- Hospice programs need to evaluate the types of treatment/interventions for pain and symptom relief that they provide as part of the plan of care. If there is concern about admitting patients with high-cost interventions, consider taking the financial risk and provide interdisciplinary services, assisting patients and families to make the appropriate treatment decision.
- Clarify with family and referral source physician before enrollment about what services the patient should expect from the hospice program.
- Complete non-coverage form whenever there are services the patient is receiving outside the plan of care.
- Insure that the Plan of Care does not include these items but include them in the medical record and state that they will be managed clinically.

D. Capability for Translation Services

Survey Data N=21

Hospices reported translation capability as follows:

- Portuguese (4) (The most common second language in MA)
- Chinese (2)
- Khmer (1)
- Russian (2)
- Spanish (5)
- German (1)
- French (4)
- Many (3)
- All of the above (5) (May be through use of AT&T Language Line)

Requirements/Standards

FEDERAL LAW requires that all recipients of federal funding, such as health care providers who serve Medicare, Medicaid and State Children's Health Insurance Program (CHIP) must provide meaningful access to services to individuals with limited English proficiency. The federal Department of Health and Human Services (DHHS) and the courts have applied this statute to protect national origin minorities who do not speak English well. Thus, recipients of federal funding must take reasonable steps to ensure that people with limited English proficiency have meaningful access to their programs and services.

NHPCO: "facilitate access to care..sensitive to the culturally diverse needs of the community it serves"

CHAP: CI.7a. Agency must provide "language-specific written materials as necessary

D. Capability for Translation Services (continued)

Applicable Requirements/Standards (continued)

and appropriate for distribution to patients and families ”

CI.7b “Interpretive services are provided as indicated and necessary, and ensure accurate communications between client and caregiver.”

JCAHO: RI2.100 (Elements of Performance): The organization facilitates provision of interpretation (including translation services) as necessary.

Discussion

- Translation services are not the same as interpreter services. Translators focus on individual words. Interpreters focus on context/intended message.
- As MA population grows more diverse, hospices may not be prepared to reach out to families from diverse cultures.
- There are risks in using family or friends for translation due to their lack of familiarity with medical terminology as well as the possibility that they will filter communication based on what they want the patient to know.
- Using children as translators may add a developmental burden.
- Per HIPAA regulations, a business associate contract is required for translators.
- Relatively few hospices reported having the capacity for in-house translation services in common foreign languages.
- Requirements include translation for the deaf.
- States can sometimes secure federal funds to help pay for language services in their Medicaid and CHIP program and offer other resources.

Recommendations

- Consider using any of the translation services below to accommodate patient needs. For more information call:
 - AT&T Language Line 1-800-752-6096 or www.LanguageLine.com
 - Hospital-based hospices can use the interpretive services of their hospitals.
- On admission, ask whether the patient would like to have a translator other than family or friends.

Resource

Language Service Action Kit. National Health Law Program/Access Project. 617-654-9911/www.accessproject.org. \$25.

E. Admitting Capability 24/7

Survey Data N=21

Yes 16 No 5

Three hospices said they could admit seven days/week during business hours with some limited capacity for evenings. Two said capability varied or was done case by case.

Requirements/Applicable Standards

MA Licensure 141.204 (d) and CoPs: RN care must be available 24/7.

NHPCO Service Guideline: “Hospices should have the ability to evaluate and admit patients 24 hours a day, seven days a week.”

E. Admitting Capability 24/7 (continued)

Requirements/Applicable Standards (continued)

CHAP: HII.21 and HII.2b - An agency must provide “necessary hospice care that is available 24 hours a day, seven days a week.”

JCAHO: CC.3.1 “provide patient access to staff when care and services are needed.”

Discussion

-Demand is low for nights but likely for evenings and weekends.

-Doctors on-call sometimes will not write narcotic orders or DNR orders and have limited information about the patient’s prognosis and plan of care.

Recommendations

-Since they are required to have registered nurses available 24 hours a day, hospices should provide 24/7 admitting capability using on-call nurses. Doctors should prescribe medications upon admission.

-Work with the Hospice Medical Director to have medication protocols or standing orders on hand so that if the on-call physician will not prescribe narcotics or other drugs, the Hospice Medical Director can order emergency medications.

IV. ACCESS TO HOSPICE CARE: Would you admit a patient...?

There was considerable variability among hospices with regard to their willingness to admit patients with certain high tech or high cost interventions. A summary of the responses is included below:

Variability Among Programs Regarding Access	N=21 % Providing Access
Without a DNR	95%
On IV hydration	91
With no primary caregiver	91
Receiving enteral therapy	81
Receiving palliative IV therapy	81
Receiving palliative radiation	62
Receiving palliative chemotherapy	52
Receiving anti-retrovirals	48
Receiving TPN	33
Receiving blood products	33
On ventilator support	29

IV. ACCESS TO HOSPICE CARE... (continued)

Introduction

In the best of circumstances, no procedure or treatment should be initiated on patients with a palliative care diagnosis without providing those patients or their surrogates with detailed information about the procedure, its short and long-term advantages and disadvantages and the consequences of its initiation or discontinuation. Education, reassurance and support about the considered procedure would automatically provide the contextual backdrop for any chosen treatment option.

In many cases, however, a patient's goals and values regarding the terminal phase of the illness are not honestly addressed, thought through, or apparent. This may make the patient, the health care proxy or surrogate ill-prepared to identify or implement the "what's next" decisions. As it often happens, what seemed like a life-saving procedure at the time of its implementation, begins to severely burden the patient's quality of life, causing increasing anxiety for both the patients and their loved ones.

Many hospices have specific written protocols for the initiation, admission and provision of care for patients opting to receive the more high-tech interventions included in the above list. Depending on the stage of the disease process, these interventions can be viewed as either life-sustaining, comfort and symptom control measures, or measures that can further contribute to pain and suffering by causing unintended results, side-effects or the hastening of death. In addition, for a palliative care interdisciplinary team, these procedures can sometimes be seen as interfering with and/or inhibiting the expression of psychosocial, spiritual needs, adding to the further discomfort of the patient and family.

In order to provide patients and their families with the education, reassurance, and support to make more informed choices, the Committee offers **Suggested Supportive Protocols** that are basic, easy to use and already available that integrate both drug and non-drug interventions for patients having access to care issues. These **Suggested Supportive Protocols** demonstrate that the team has other options for care, thus diffusing the "there's nothing else we can do" myth.

General Access Issues

Applicable Requirements/Standards

NHPCO: ACCESS - Promote universal access to comprehensive hospice and palliative care services

JCAHO:

-PT 1-5 2.1 "Performance expectations are established for new/modified processes."

-CC1 "organization admits only those patients whose identified care needs it can meet."

-CC2 "organization...responsible for providing care/services within its financial and service capabilities, mission and law..."

-HR4 "organization assesses, maintains and improves competence of all staff."

A. Without a Do Not Resuscitate Order (DNR)

Survey Data N=21

Yes 20 No 0 Maybe 1

Applicable Requirements/Standards

FEDERAL LAW requires in the Patient Self-Determination Act that a patient may not be discriminated against based on his/her advance directive. CMS currently requires direct care staff to be trained in CPR.

NHPCO Service Guideline: “Hospice should provide access for those experiencing patient/family indecision regarding advance directives and requesting resuscitative measures.”

DHHS Memo 4/2/00: “Medicare certified hospice providers are bound by these requirements and may not refuse to have staff skilled in resuscitation or refuse to revive a patient

who desires to be resuscitated. However, hospice providers may counsel patients at election as to the hospice philosophy, including its philosophy on this issue, and a patient whose views are at odds with the hospice’s philosophy may elect to receive care from another source.”

Discussion

-Hospice licensed professional staff must be capable of providing CPR

-Regulations do not specify what “capable of providing CPR” means - does that mean that they are CPR certified or that they have knowledge of CPR?

-Costs associated with the initiation of CPR and life saving measures is not described in the DHHS memo of 4/2/00, “*Advance Directives and Do Not Resuscitate (DNR) in Medicare Hospice - Clarification.*” CMS has been reviewing this question since 2000 but has not yet released its expected clarification of its CPR requirements for direct care hospice staff, originally due April 2003.

-The request from the patient to be resuscitated must be part of the patient’s record and communicated within the team. The resuscitation itself would generally be outside of the hospice plan of care as it is life-prolonging and thus not appropriate within the hospice philosophy. Should 911 be called, the patient transported to an Emergency Department, and then hospitalized, the costs of those interventions would be outside of the hospice plan of care and thus not covered by hospice. Unless the patient had other insurance for coverage or revoked hospice prior to calling 911, the patient would be financially responsible for the cost of the care. Medicare would not pay for the resuscitation if it were related to the terminal diagnosis and the patient is on hospice at the time. This ambiguity of hospice honoring a patient’s wishes about resuscitation, yet not paying for the costs, is at issue.

-Referring physicians still lack information/education about the MA Comfort Care Protocol concerning resuscitation.

A. Without a DNR (continued)

Recommendations

- All hospices should admit patients without regard to their advance directives, including DNRs. It should be a clinical priority for the social worker to work with the patient to foster understanding of the consequences of CPR and his or her wish to be resuscitated in order to support a transition to a Plan of Care more reflective of the patient's condition.
- During admission, discussion with the patient about the Plan of Care will occur. If a patient requests resuscitation, a discussion must occur and a non-coverage form should be completed to notify the patient that the resuscitation service and any subsequent care related to the resuscitation would not be in the hospice Plan of Care. The financial implications would also be discussed so that the patient would understand his or her option to revoke the hospice benefit or payout of pocket.
- Once the patient has decided to sign a DNR, make sure that the Plan of Care is changed.
- Insure that the Comfort Care protocol forms are signed by a physician and kept in the home.

B. With no primary caregiver

Survey Data N=21

Yes 19 Maybe 2 No 0

One hospice said it would admit these patients only if the patient were safe at the time of admission and they could develop a clear plan on how to care for the patient when no longer safe.

Applicable requirements/standards

NHPCO Standard and Service Guideline -“Hospice should establish protocols ... that provide access for patients “regardless of....availability of a primary caregiver...”

CHAP: Requires agency to have a policy.

in HII.4a: “The agency must inform patients regarding its policy both verbally and writing. Patients and caregivers must be informed of their rights and responsibilities in the event there is an absent caregiver.”

Discussion

- Involve the social workers immediately. Have a strong social work team who knows community resources. Social workers can assist in determining competency, obtaining a power of attorney and health care proxy once the patient is admitted.
- At the time of admission, begin discussion with the patient as to options if the situation were to become unsafe.
- Private pay for home health aide services is a possibility. Arrange for family to move-in at a later date should there be a crisis.
- Patients can be placed on continuous care in lieu of hospitalization if a medical crisis occurs.

B. With no primary caregiver (continued)

Discussion (continued)

- Hospices have the ability to discharge the patient if the situation becomes unsafe for the patient at home alone. Protective Services can be called if the patient is older than 62 and is deemed at risk. The Veterans Administration may be a resource if the person is veteran or the Department of Mental Retardation if the patient is mentally disabled
- Competent patients have a right to choose to remain in an unsafe situation. The hospice would then have to decide if they can continue to provide adequate care.

Recommendations

- Hospices should develop a protocol to admit patients without a primary caregiver and work with discharge agencies and referral sources to come up with a plan. Hospices do have a right to discharge a patient when a situation becomes unsafe.
- Familiarize hospice staff with community resources that can be provided to support the patient at home such as an Area Agency on Aging for private care individuals.
- Contract with the patient at admission outlining the Plan of Care and the types of situations that would be considered unsafe, what the patient agrees to do if the situation becomes unsafe, and when the hospice would discharge the patient if hospice were unable to assure a safe situation.
- When safety is an issue, clear documentation is essential. Obtain an Ethics consult before discharging the patient from hospice.

C. On ventilator support

Survey Data N=21

Yes 6 Maybe 11 No 4

Some hospices said they would review each case on an individual basis including the location, diagnosis, and expectations of family and staff. Seven said they did not have staff competency (7). Reimbursement was an issue and factors about admission related to whether there were outlier payments available from the payer. One was planning to develop a policy to allow admission in 2003.

Discussion

- The goal of the Federation's vent patient project (2001-02) was to eliminate barriers to the admission of patients on ventilator support and to facilitate access to hospice care for these patients when appropriate. The need for ventilator support is most common among hospice ALS patients.
- Private health plans may contract for the vent support as an outlier.
- Durable Medical Equipment companies can usually do training in vent use and support the renewal of annual competencies at the time when the vent patient is admitted.
- Meet with families in advance to discuss why the patient wants to be at home, gain informed patient consent, address family concerns and plan for bereavement follow up.
- Some DME companies do an excellent job of training hospice staff when needed and assure that equipment is properly maintained.

C. On ventilator support (continued)

Discussion (continued)

-Home vent equipment is simple to use and is often well-understood by family members

Recommendations

-Hospices who are interested in admitting vent patients should make it known to the Federation so they can be on a list made available to health plans.

-Policies and staff training should be in place prior to admitting the patient.

-See *Appendix A* for “Vent Task Force Protocol” for procedures and practices to care for patients on ventilator support.

D. On IV hydration

Survey Data N=21

Yes 19 Maybe 1 No 0 No response 1

One hospice said it depends on the case but most likely, no. Another said they would admit the patient if the goals of hydration are palliative and short term.

Discussion

-Referral sources are tired of arguing about hospice’s philosophical issues and clinical rationale not to do IV hydration because of symptoms such as edema, urinary frequency, respirator distress and respiratory congestion.

-Hospices need to be able to explain why IV hydration is sometimes not helpful, and may even cause additional suffering and discomfort at the end of life.

-Staff report that sometimes that just seeing the IV bag gives emotional comfort to the family.

Recommendations

-Assess the patient for appropriateness of hydration versus an automatic “no” to a referral source

-Admit the patient and then work with the family to provide education about situations and symptoms where hydration benefits and when it can cause discomfort. Helpful publications include “Hard Choices for Loving People” (Hank Dunn, 2001) and “Gone From My Sight”(Barbara Karnes, RN)

-Use articles from medical journals to educate referral sources and families about benefits and risks.

E. Receiving anti-retro viral medications for AIDS

Survey Data N=21

Yes 11 Maybe 8 No 2

The availability of reimbursement for the medications seemed to be the principal concern and admission would be more likely if the insurer paid for the medications as outliers.

E. Receiving anti-retro viral medications for AIDS (continued)

Discussion

The number of AIDS patients in hospice care in MA is very small -- a major success story. The AIDS Care County Agencies still do make occasional referrals. Length of stay is very short. Sometimes AIDS patients have a difficult time tolerating anti-viral medications at the end of life.

Recommendation

-Patient pain and symptom management must be met. This may or may not include anti-retrovirals as they sometimes are used for active treatment. Assess the patient in person as potential lengthy use of the anti-retrovirals may not be in keeping with the patient's condition. Review lab results and educate the patient/family regarding the treatment indicators that would be observed that showed effectiveness.

Suggested Supportive Protocols

Drug Therapies

- Non-steroidal anti-inflammatories/steroids
- Opioids (consider different routes of administration with vomiting, diarrhea, and dehydration)
- Treatment of neuropathic-type pains with anticonvulsants and/or antidepressants
- Treatment of aphthous ulcers with steroids
- Treatment of fatigue with stimulant (Ritalin)

F. Receiving blood products

Survey Data N=21

Yes 7 Maybe 10 No 4

Considerations on whether to admit the patient included: 1) the goal in using blood products is palliative in nature; 2) the symptoms could be controlled in another way; 3) the intervention is time-limited and/or; 4) whether the blood products would be paid for as an outlier by the payer.

Discussion

- Blood products cannot be excluded because of reimbursement but because of lack of medical utility
- Medicare regulations limit access to the Medicare Hospice Benefit if the patient is receiving blood products that will extend the prognosis beyond six months. Some hospices have a policy that states that care will be provided in the "least aggressive" way or "only if it can not be managed in another way" or is "not life-prolonging."
- One hospice had a contract with a hospital allowing an inpatient admission for blood products as it was less expensive to stay overnight in the hospital than provide them at home. The hospice pays the rate for the inpatient admission and the hospital pays for the blood products.

F. Receiving blood products *(continued)*

Discussion *(continued)*

-Another hospice arranged for blood products to be given in an oncology suite. First the Medical Director would make a house call to speak with the patient and re-evaluate the goal of care. Sometimes it is a quality of life issue. However, regular transfusions every other day may be futile care and the hospice could ask for the patient to sign a non-coverage statement form (See *Appendix B*).

Recommendations

-Blood products may be appropriate based on the pain/symptom needs of the patient. Assess the patient in person to determine rationale and probable length of use. Establish clear criteria for when blood products should be discontinued. Begin conversations early with the patient and family so they understand when blood products will no longer be effective and should be discontinued.

Suggested Supportive Protocols

- Oxygen
- Education regarding energy conservation approaches
- Provide nutritional/dietary counseling, possibly adding iron supplements
- High protein, high calorie diet with small, frequent feedings as needed
- Epoetin Alpha (Procrit) may be substituted for blood products when the patient has a functional bone marrow

G. Receiving enteral therapy

Survey Data N=21

Yes 17 Maybe 2 No Response 2

One said the admission would be reviewed on an individual basis. Nutritional needs of the dying patient should be discussed with the family.

Discussion

- There is variation as to whether a hospice program would pay for the insertion of a gastric (G) tube
- Depending upon the type of feeding tube used, an RN may be able to change the tube or the patient may need to have a physician insert in an outpatient setting.

Recommendations

-Admit the patient. Evaluate the patient for appropriateness of the feeding tube and feedings based on terminal status and any side effects. Inform referral sources and families about the declining nutritional needs of the dying patient and the potential for further discomfort should feeding continue. Have the social worker and nurse work with

the family to transition the patient off the G tube as appropriate. Address what would happen if the feeding tube were inadvertently removed or no longer was functioning -- under what circumstances would the hospice reinsert the tube?
-Pay for the feeding solution as part of the plan of care.

H. Receiving palliative chemotherapy

Survey Data N=21

Yes 11 Maybe 7 No 3

Hospices said considerations would be based on individual considerations including the goal of treatment and whether the treatment, particularly cytotoxic treatment, would be considered outside the plan of care and thus not paid for by the hospice program.

Applicable standards/requirements

JCAHO: "patient is monitored for medication effectiveness."

Discussion

- Many oncologists feel chemotherapy is palliative and that it maintains hope even in patients with far-advanced disease.
- Physicians may be ordering chemotherapy to avoid "the conversation."
- Palliative chemotherapy sometimes creates more symptoms that need to be managed.
- The cost of chemotherapy varies from inexpensive to extraordinarily expensive.
- Some palliative medications, like tamoxifen, create fewer symptoms to be managed and thus may be helpful.

Recommendations

- Palliative chemotherapy has a place in pain/symptom management and thus is appropriate in hospice. Assess the patient in person. Involve the Hospice Medical Director in discussion with the attending physician as to whether there is another way to palliate symptoms and improve or maintain quality of life other than with palliative chemotherapy. If palliative chemotherapy is included, be clear with the patient/family what treatment indicators would be present to show effectiveness and need for continued use.
- Corticosteroids can be used to manage symptoms related to inflammation.

I. Receiving palliative IV therapy

Survey Data

Yes 16 Maybe 5 No 0

Considerations included the individual needs of the patient and family and whether outlier reimbursement was available.

Applicable Requirement/Standard

NHPCO Service Guideline: "Hospice should provide access for those receiving palliative intravenous therapy for symptom management."

Discussion

-Education, reassurance, support specific to unwanted side effects and unintended results of intravenous therapy administration at the end of life. Side effects may include third-spacing into subcutaneous tissues and an increase in pulmonary edema.

I. Receiving palliative IV therapy (continued)

Recommendation

- Admit the patient and discuss criteria for when to discontinue with patient and family.
- If palliative IV therapy is used, be clear with the patient/family what treatment indicators would be present to show effectiveness and need for continued use.

J. Receiving palliative radiation

Survey Data N=21

Yes 13 Maybe 5 No 3

Considerations included the individual patient/family needs, length of treatment, if palliative and not life-prolonging, if it were done at a contracted facility or if paid as an outlier.

Discussion

- The use of palliative radiation is based on patient symptoms which cannot be managed in another way.
- Consideration might include length of treatment and intensity of treatment. Symptom relief can often be achieved in short term, high dose radiation.
- Cost considerations might show a trade off with the use of palliative radiation versus medications when symptoms are not managed well.
- A financial impact study may prove that palliative radiation is cost-effective.

Recommendations

-Palliative radiation has a place in pain/symptom management in Hospice. Assess the patient in person. Involve the Hospice Medical Director in discussions with the attending MD to understand the goal and plan for radiation therapy.

K. Receiving Total Parental Nutrition (TPN)

Survey Data N=21

Yes 7 Maybe 9 No 5

This proved to be one of the treatments that presented that greatest degree of variation among hospices although considerations continued to be reimbursement, the goals of care, patient/family needs as well as staff competency.

Discussion

- Families should be informed about what this treatment does. It may not be appropriate as death approaches and nutritional needs taper off. As death approaches, patients generally increase or decrease their food intake based on how they feel. TPN requires the intervention of a professional to titrate and the sensitivity to patient needs is not as accurate.
- TPN has potential side effects making it important to weigh the burdens and benefits.
- TPN is very expensive. Has to be a central line in place. Needs to be monitored with

labs once a week.

K. Receiving Total Parental Nutrition (TPN)

Recommendations (continued)

-Hospices should admit the patient and work with the patient and family toward withdrawal as is clinically appropriate.

V. References

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VI. APPENDIX

Appendix A Ventilator Patient Protocol

Appendix B Form: Notification of Non-Coverage for Medicare Services

Appendix C Access Report Membership Survey Instrument, Fall 2002



Hospice & Palliative Care Federation of Massachusetts

Membership Survey

In the spring of 2002, the Board of the Hospice & Palliative Care Federation set forth five goals in a strategic plan. One of the goals is to “*Provide opportunities for examining standards, competencies and make recommendation to members that will improve end of life care.*” Carla Braveman, past president of the Federation and Executive Director, VNA Hospice/Alliance will chair this important committee.

The Federation’s role will be to:

- review existing standards
- determine the variation among providers
- develop educational materials/training that would encourage consistency and uniformity

I. ACCESS to HOSPICE CARE (All responses will be confidential.)

Would your hospice admit a patient....

- Without a DNR
- On IV hydration
- On ventilator support
- With no primary caregiver
- Receiving anti-viral medications for AIDS
- Receiving blood products
- Receiving enteral therapy
- Receiving palliative chemotherapy
- Receiving palliative IV therapy for symptom management

Receiving palliative radiation

Receiving TPN

II. OTHER ADMITTING PRACTICES

Do you.....

Have a free care policy?

Have a sliding scale policy?

Allow "outlier" services for non-Medicare patients

Have the capability for translation services?

Which languages? _____

Can you admit a patient seven days a week/24 hours a day?
If no, what are your hours for admission?

III. BEST PRACTICES

The Committee is interested in developing best practice models for areas of interest to the members. Please check the ONE topic that would be of the most interest to your hospice.

Bridge programs

Criteria for general inpatient stay

Short length of stay models

Respiratory distress

Intractable pain

Anxiety and restlessness at end of life

Terminal sedation/palliative sedation therapy

Other:

IV. CONTACT INFORMATION

Name _____ Hospice _____

Telephone _____ Email _____

Please check if you would be interested in joining this committee

Please FAX your completed survey to H&PCFM at 781-255-7078