

Workgroup Report on Hospice Care, Palliative Care and End of Life Counseling

Executive Summary of Workgroup's Conclusions and Recommendations

Hospice care and palliative care programs provide valuable services to our dying patients and their families in Maryland to maximize their quality of life in their final days and to support their families before and after a patient's death. Hospice care is available in patients' homes, in hospice facilities, and in nursing homes. Palliative care programs exist in some hospitals.

There are financial and administrative disincentives that prevent many patients from taking advantage of hospice care while in nursing homes and from taking advantage of palliative care programs in hospitals. Hospice care use has been increasing over the years but its general use and length of stays are still far short of what one might reasonably expect were terminally ill patients being routinely referred for hospice care.

The reluctance of physicians to give up on curative treatments for terminally ill patients, the difficulties of discussing death with patients, the challenges of making accurate prognoses of survival times, the lack of reimbursement for providing end of life care counseling, and insufficient training in end of life care are all factors contributing to fewer referrals to hospice and palliative care and shorter lengths of stays in hospice. Patients and families are also reluctant to discuss death and are often not aware of hospice and palliative care options.

The workgroup believes that education of practitioners and the public is essential to move towards a health care system that provides quality end of life counseling and care to patients and families. Thus, the workgroup is recommending that a consortium of State agencies and health care organizations create an educational campaign aimed at health care practitioners, terminally ill patients, their families, and the general public to increase public awareness of hospice and palliative care services and to improve the quality of end of life counseling and care provided by practitioners. This would include distributing an End of Life Bill of Rights and accompanying educational materials to educate practitioners and the public about quality care at the end of life.

The workgroup recommends that quality indicators for end of life care be established by the Centers for Medicare and Medicaid Services working with the Maryland Health Care Commission. Also, to encourage the use of hospice care in nursing homes and simplify payment Congress should eliminate the Medicaid requirement that hospices pay nursing homes for their patients' room and board and instead reimburse the hospice and the nursing home separately. Finally, the workgroup recommends that the Centers for Medicare and Medicaid Services establish a pilot program to reimburse end of life care counseling and to assess whether such counseling improves family satisfaction with end of life care and compliance with the patient's wishes for care at the end of life.

INTRODUCTION

The workgroup was asked to examine the following questions:

1. What are the types of care available in the state for individuals at the end of life for palliative and hospice care?
2. What is the degree to which these options are utilized within a home setting, long-term care setting, hospital setting, and hospice setting?
3. What is the average length of time spent in various types of palliative and hospice care settings?
4. What are the types and degrees of barriers that exist regarding awareness of and access to hospice and palliative programs?
5. What are recommendations to improve awareness and access to hospice and palliative care programs?

1. What are the types of care available in the state for individuals at the end of life for palliative and hospice care?

Types of Hospice Care

- A general hospice care program is a coordinated interdisciplinary program of hospice care services for meeting the special physical, psychological, spiritual, and social needs of dying individuals and their families, by providing palliative and supportive medical, nursing, and other health services through home or inpatient care during the illness and bereavement: (1) to individuals who have no reasonable prospect of cure as estimated by a physician; and (2) to the families of those individuals.¹
- The Medicare Hospice benefit defines four levels of care²
 - Routine Home Care: Can be received at home or in an institutional setting i.e. nursing home.
 - Continuous Home Care focused on acuity of the patient can be up to 24 hours.
 - General Inpatient Care which is more intensive and for the patient.
 - Inpatient Respite Care which is more to address family needs.

Determination of Eligibility for Medicare Hospice Benefit

- Attending physician and hospice medical director must certify that to best of their judgment the patient is more likely than not to die within 6 months.
 - “The certification must specify that the individual’s prognosis is for a life expectancy of 6 months or less if the terminal illness runs its normal course.”³

¹ Md. Code Ann., Health-General Article, § 19-901(d).

² Stevenson, D, H. Huskamp, D. Grabowski, and N. Keating. 2007. Differences in Hospice Care between Home and Institutional Settings. *Journal of Palliative Medicine* 10(5): 1040-1047; 42 U.S.C.A. § 1395x(dd).

³ 42 CFR § 418.22

- The Centers for Medicare and Medicaid Services recognizes that medical prognostication is not always an exact science and that the prognosis can be extended beyond the initial six month certification should the initial prognosis regarding life expectancy be incorrect.⁴

Palliative Care

- The goals of palliative care are to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision making and providing opportunities for personal growth. It can be delivered concurrently with life-prolonging interventions or as the main focus of care.⁵
- Palliative care prevents and relieves suffering and enhances the person's quality of life. While hospice care is care for those with a life-limiting illness and care for their families for the last months of the patient's lives, palliative care can be received by anyone with a serious illness regardless of life expectancy.
- Palliative care is care for those with serious chronic illnesses and their families to get relief from serious symptoms, discuss their goals of care, and discuss advance planning (advance directives).⁶
- Palliative care can be provided by hospitals, hospices, nursing facilities, and health clinics.⁷
- Palliative care can also be provided in physician's offices, clinics, outpatient Palliative Care Clinics, and homes.⁸
- Ideally, it uses a team approach to address the needs of patients and their families, including bereavement counseling.
 - An appropriately resourced palliative care team may consist of a chaplain, social worker or psychologist, nurse, and a physician.
- Palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life.
 - Palliative medicine does not mean that curative care is being withdrawn.
- Medicare and Medicaid may cover some medications and treatments but not all.

⁴ CMS-Pub 60AB, Transmittal AB-03040 (March 28, 2003), Program Memorandum, Provider Education Article: "Hospice Care Enhances Dignity and Peace as Life Nears Its End."

⁵ National Consensus Project, *Clinical Practice Guidelines for Quality Palliative Care*.

⁶ Barbara Supanich, RSM, MD, FAAHPM

⁷ Caring Connections. Palliative Care Questions and Answers. Available at http://www.caringinfo.org/LivingWithAnIllness/PalliativeCare/palliative_care_questions_answers.htm.

⁸ Barbara Supanich, RSM, MD, FAAHPM

2. What is the degree to which these options are utilized within a home setting, long-term care setting, hospital setting, and hospice setting?

National Hospice Trends

- The number of people using hospice has increased since it was first introduced over 30 years ago.
 - In 2005 more than 1.2 million people received hospice care and between 2000 and 2004 the percentage of Medicaid decedents that had been enrolled in hospice programs increased by almost 50%.⁹
 - In 2007 the number of patients receiving hospice services grew to an estimated 1.4 million patients.¹⁰
- In 2007 70.3% of hospice patients died at their place of residence. Of these patients 42% died at a private residence, 22.8% in a nursing facility and 5.5% in a residential facility. 19.2% of hospice patients died at a hospice inpatient facility and 10.5% died at an acute care hospital.¹¹
- Hospice use by nursing homes varies greatly across states.
 - One study estimated that the proportion of nursing home decedents who received hospice and palliative care was 10-30%.¹²

Medicare Hospice Statistics¹³

- In 2008 Medicare spending on hospice was 12 billion.
 - It is estimated that Medicare spending on hospice will nearly double in ten years.
- There has been a large increase in the number of for-profit hospices participating in Medicare.
 - For-profit hospices have made up over 90% of hospices that began participating in Medicare since 2000.
 - But in Maryland only 17% of hospices are for-profit.
- In 2006 the most common terminal diagnosis among Medicare hospice patients was cancer (roughly 33% of patients). The next most common diagnoses were heart failure and circulatory conditions (20%), followed by Alzheimer's disease and dementia (11%).
- Length of stay varies by diagnosis. At least a quarter of the Medicare hospice beneficiaries who had Alzheimer's disease, neurological conditions, or dementia had a stay of 180 days or longer. Such long hospice stays were least common among those beneficiaries with cancer, digestive diseases, or genitourinary diseases.

⁹ Gazelle, G. 2007. Understanding Hospice – An Underutilized Option for Life's Final Chapter. *The New England Journal of Medicine* 357(4): 321-324.

¹⁰ NHPCO. 2008. NHPCO Facts and Figures: Hospice Care in America. Available at http://www.nhpc.org/files/public/Statistics_Research/NHPCO_facts-and-figures_2008.pdf.

¹¹ *Id.*

¹² Bercovitz A., F. Decker, A. Jones, and R. Remsburg. 2008. End-of-Life Care in Nursing Homes: 2004 National Nursing Home Survey. *National Health Statistics Report* no. 9 (October 8, 2008).

¹³ Medpac. 2009. A Data Book: Healthcare Spending and the Medicare Program.

Hospice Use in Maryland¹⁴

- Hospice use in Maryland has been increasing; in 2004 13,291 people were admitted into hospice. This number grew to 15,878 in 2007.
 - Patient days have increased 42% from 2005-2008.
- The majority of people admitted into hospice in 2008 had cancer (46%) followed by debility unspecified (12%), dementia (12%), heart disease (10%), and lung disease (7%).
 - The remaining admissions were for kidney, liver, HIV, stroke/coma, ALS, Other/Motorneuron, and other diagnosis.
 - However the percentage of hospice enrollees with cancer has been declining in recent years.
 - The change in the percentage of cancer admissions to hospice simply represents a growth in other terminal diagnoses among hospice patients as the number of cancer patients who are in hospice is increasing, not declining.

Palliative Care in Hospitals

- 53 percent of hospitals with fifty or more beds have a palliative program¹⁵
 - In the last five years alone, access to palliative care in our nation's hospitals has more than doubled.
- Nationally 75% of large hospitals (more than 300 beds) have a palliative program.
 - 45% of mid-size hospitals (more than 50 beds) have a program
 - 20% of small hospitals have a program.
- In Maryland 80% of large hospitals have a palliative program
 - 63% of mid-size hospitals have a program.
 - No small hospitals have a program.

3. What is the average length of time spent in various types of palliative and hospice care settings?

National Length of Stay

- The median length of hospice service use declined from 1994 to 2000.¹⁶
 - In 2007 the median length of service was 20 days.¹⁷
 - The average length of service in 2007 was 67.4 days.
 - Approximately 30.8% of those served by hospice died or were discharged in seven days or less and 13.1% died or were discharged in 180 days or more.

¹⁴ Maryland Health Care Commission. 2007. 2004-2007 Hospice Survey Results. Available at <http://mhcc.maryland.gov/longtermcare/trendrpt.pdf>.

¹⁵ Center to Advance Palliative Care. 2008. America's Care of Serious Illness: A State by State Report Card on Access to Palliative Care in Our Nation's Hospitals. Available at <http://www.capc.org/reportcard/>.

¹⁶ Han, B., R. Remsburg, W. McAuley, T. Keay, and S. Travis. 2007. Length of Hospice Care among US Adults: 1992-2000. *Inquiry* 44: 104-113.

¹⁷ NHPCO. 2008. NHPCO Facts and Figures: Hospice Care in America. Available at http://www.nhpc.org/files/public/Statistics_Research/NHPCO_facts-and-figures_2008.pdf.

Length of Stay in Maryland

- In 2007 the average length of stay was 51.25 days which was a slight increase from 49.70 days in 2004.¹⁸
 - The median length of stay in 2007 was 26.01 days.
- In 2008 the average length of stay was 51.70 days and the median length of stay was 26.28 days.¹⁹
- The average daily census in MD has increased from 39.55 patients in 2004 to 50.28 patients in 2007.²⁰
 - In 2008 the average daily census increased to 52.10 patients.²¹
- In 2007, 39% of patients died in less than 7 days and 15% died after more than 180 days in hospice. In 2008, 42% died in less than 7 days and 13% died after more than 180 days in hospice.

Short Stays

- Short stays (less than 30 days before death) in hospice care do not enable patients to receive the maximum benefit of hospice services.²²
 - Symptom management is often difficult to maintain over a short term.
 - Families may not fully benefit from the support and bereavement services that are available from hospice providers.
 - Short stays can affect hospice agencies' financial viability.
- Previous research has indicated that hospice is most beneficial when provided for at least 3 months. However NHPCO reports that the median length of service was 26 days with 30% served dying within 7 days.²³
 - The longer the stay in hospice the greater opportunity to receive the full benefit of hospice and its wide range of services. However even a short stay will provide some benefit.
- In 2007 approximately 30.8% of those served by hospice died or were discharged in 7 days or less.²⁴

¹⁸ Maryland Health Care Commission. 2007. 2004-2007 Hospice Survey Results. Available at <http://mhcc.maryland.gov/longtermcare/trendrpt.pdf>.

¹⁹ Maryland Health Care Commission. 2009. Section C2_C4. Hospice 2008. Available at http://mhcc.maryland.gov/public_use_files/hospicedownload.html.

²⁰ Maryland Health Care Commission. 2007. 2004-2007 Hospice Survey Results. Available at <http://mhcc.maryland.gov/longtermcare/trendrpt.pdf>.

²¹ Maryland Health Care Commission. 2009. Section C2_C4. Hospice 2008. Available at http://mhcc.maryland.gov/public_use_files/hospicedownload.html.

²² Han, B., R. Remsburg, W. McAuley, T. Keay, and S. Travis. 2007. Length of Hospice Care among US Adults: 1992-2000. *Inquiry* 44: 104-113.

²³ National Hospice and Palliative Care Organization. 2007. Families and Patients Referred Too Late to Hospice Experience More Unmet Needs Montgomery Hospice. Available at www.nhpcp.org/i4a/pages/ondex.cfm?pageid=5235.

²⁴ NHPCO. 2008. NHPCO Facts and Figures: Hospice Care in America. Available at http://www.nhpcp.org/files/public/Statistics_Research/NHPCO_facts-and-figures_2008.pdf.

Families Perception of Short Stays

- One study in which family members of hospice patients were surveyed found that 87% reported that the patient was referred at the right time and 11.4 % thought they were referred too late.²⁵
 - Those who believed their relative was referred too late reported more unmet needs, a higher number of concerns and lower satisfaction with the quality of end-of-life care.
 - Only 20% of family members whose relative had a hospice stay of less than a month reported that they believed the referral was too late.
 1. Indicates need to educate families on benefit of longer stays.
 2. There also may be cases where earlier referral was not possible because patient refused or it was a late diagnosis.
- Another study found that families of patients with longer lengths of stay reported receiving more services and that those services were more helpful. But even with short stays most families said that services were helpful.²⁶

Factors Contributing to Late Referrals and Short Stays

- Patients and clinicians may not realize that hospice care at home may be covered by Medicare, Medicaid, or private insurance.²⁷
 - Patients and families may not realize that hospice includes coverage of medication and durable medical equipment.
- Patients and families may not be aware of the broad range of social and medical services available through hospice.
- Patients and clinicians may not want or feel that earlier intervention is appropriate
- Physicians may not always discuss the prognosis with patients.
- Application of curative model to end-stage incurable illnesses.
- Hospice is seen as giving up hope.

4. What are the types and degrees of barriers that exist regarding awareness of and access to hospice and palliative programs?

Physician Barriers

- Most important factor appears to be physicians' attitudes.²⁸
 - See patient death as professional failure.
 - Fear that they will destroy patient's hope.
 - Reluctant to discuss patient prognosis.

²⁵ Teno, J., J. Shu, D. Casarett and et al. 2007. Timing of Referral to Hospice and Quality of Care: Length of Stay and Bereaved Family Members' Perception of the Timing of Hospice Referral. *Journal of Pain and Symptom Management* 34(2): 120-125.

²⁶ Rickerson E. and et al. 2005. Timing of Hospice Referral and Families' Perception of Services: Are Earlier Hospice Referrals Better? *Journal of the American Geriatrics Society* 53(5): 819-823.

²⁷ Gazelle, G. 2007. Understanding Hospice – An Underutilized Option for Life's Final Chapter. *The New England Journal of Medicine* 357(4): 321-324.

²⁸ McGorty K., and B. Bornstein. 2003. Barriers to Physicians' Decisions to Discuss Hospice: Insights Gained from the United States Hospice Model. *Journal of Evaluation in Clinical Pract* 9(3): 363-37;
Gazelle, G. 2007. Understanding Hospice – An Underutilized Option for Life's Final Chapter. *The New England Journal of Medicine* 357(4): 321-324.

- Little training in compassionate discussion of bad news.
 - Societal tendency to be reluctant to accept dying process.
- Difficult to accurately predict death.
- Research indicates that physicians generally over-predict patient survival.²⁹
- There may be a disconnect between physicians self-perceived and actual knowledge about hospice referral, meaning the physician doesn't know as much as he think he does.³⁰
- The hospice option may have been brought up earlier upon diagnosis and was not pursued by the patient, but the option is not revisited as disease progresses or health condition worsens.³¹
- Some physicians view hospice care as something reserved for patients who are immediately dying.
- Physicians' fear of losing control of their patients is a barrier to hospice utilization especially when a long-term relationship had developed.
- Physicians bring up hospice too late because the physician is reluctant to discuss the hospice option until curative treatment is clearly no longer effective.
- In a study on physicians in managed care it was found that 28% reported that they were concerned that patients would interpret hospice referral as a cost-containing method.³²
- Physicians may be uneasy about how to approach the issue with their families – feel they are letting them down by “giving up” and not continuing to pursue curative treatment.
- Life expectancy may be hard to predict for patients with non-cancer diagnoses.³³

Nursing Home Barriers

- Nursing home staff members' recognition of terminal decline, beliefs about hospice, and initiative significantly affect hospice referral and timing of referral.³⁴
 - Hospice referral depends on whether hospice is seen as complementing nursing home services or is seen as not adding value.
 - In one study no nursing homes had written protocols for assessing resident's terminal status or eligibility for hospice care and none had formal protocols for communicating with physicians on hospice eligibility

²⁹ Alexander, M. and N.A. Chistakis. 2008. Bias and Asymmetric Loss in Expert Forecasts: A Study of Physician Prognostic Behavior with Respect to Patient Survival. *Journal of Health Economics* 27 (2008) 1095-1108.

³⁰ Brickner, L. K. Scannell, S. Marquet, and L. Ackerson. 2004. Barriers to Hospice Care and Referrals: Survey of Physicians' Knowledge, Attitudes, and Perceptions in a Health Maintenance Organization. *Journal of Palliative Medicine* 7(3): 411-418.

³¹ Hospice Network

³² Brickner, L. K. Scannell, S. Marquet, and L. Ackerson. 2004. Barriers to Hospice Care and Referrals: Survey of Physicians' Knowledge, Attitudes, and Perceptions in a Health Maintenance Organization. *Journal of Palliative Medicine* 7(3): 411-418.

³³ Hospice Network

³⁴ Welch L., S. Miller, E. Martin, and A. Nanda. 2008. Referral and Timing of Referral to Hospice Care in Nursing Homes: The Significant Role of Staff Members. *The Gerontologist* 48: 477-484.

- Reimbursement rate shifts once hospice is elected.³⁵

Treatment System Barriers:

- Underutilization of treatment professionals such as clinical social workers who could assist physicians and patients with increasing awareness of hospice and palliative care options and facilitate referrals to such care as needed by applying their training and experience in:
 - Early identification of family needs and in dealing with complex family dynamics in time of crisis with an understanding of cultural diversity;
 - Relaying challenging information to the family, patient, or proxy, including knowledge about hospice services that are available to patients and family members; and
 - Facilitating collaboration among all interested parties, including physicians, care facility/hospice personnel, patient, and family members.³⁶

Observations from a Nursing Home Medical Director³⁷

In the nursing home setting, there are several barriers to referring patients to formal hospice organizations.

- If a patient is on the Medicare Part A Skilled Benefit in the nursing home, he or she cannot be referred to a formal hospice organization without signing OFF the Medicare Skilled Benefit in order to sign on to the Medicare Hospice benefit (since the hospice benefit is a substitute for the usual Medicare Part A). The patient will have to pay for the room and board portion of the nursing home bill (which is covered by the Medicare Skilled Benefit).
- For patients who are long term care residents in the nursing home, there is a disincentive for the nursing home to refer to formal hospice organizations, since the facility is paid a lower rate by hospice than the rate they would get without the hospice referral.³⁸
- So there are financial disincentives, either for the patients/families and or for the facilities to refer to hospice.
- In the nursing home setting, this nursing home medical director will often refer to hospice more for the benefit of the family than the patient per se.
- If the nursing home patient might benefit from the extra attention from the hospice team, this nursing home medical director believed it might make sense to refer the nursing home resident to hospice.
- But if the patient is cognitively not able to benefit from the team approach, she believed that as long as the physician is skilled in symptom management and palliative/hospice philosophy of care, there is probably no need to refer (unless the family issues need the hospice team). But the

³⁵ Hospice Network

³⁶ Maryland Legislative Council of Social Work Organizations

³⁷ Rebecca Elon MD MPH

³⁸ Hospice workgroup member Ann Mitchell stated that a nursing home is often paid a lower room and board rate because the hospice itself only gets paid 95% of the room and board fee by the State of Maryland., which the hospice then transfers to the nursing home.

Alzheimer's Association workgroup representative pointed to research showing that a person with cognitive impairment, such as Alzheimer's disease, also receives benefits from palliative care during the course of the disease and hospice care at the end of life.³⁹

- The nursing home medical director further said she is repeatedly confronted in her nursing home medical director roles with attending physicians who are not comfortable with discussing end of life and palliative care issues with patients and families or just aren't willing to take the time to have these conversations.
- The failure of physicians to address these issues also is related to financial disincentives, as much or more than deficits of knowledge or attitude.
- It is very time consuming to address end of life issues with patients and families. There is no adequate reimbursement to do so.
- A key aspect of referral patterns to hospice in some communities is the relationship between the local physicians and the hospice organization.

Patient Barriers⁴⁰

- Misunderstanding about end-of-life care.
- Reluctance to discuss end-of-life issues with doctors.
- Patients may be overly optimistic in estimating prognosis leading to preferences for more aggressive treatment if they have a life expectancy of greater than 6 months.
- Patients may not be aware of the benefits and services provided by hospice and costs involved.⁴¹
- For patients with a developmental disability who have an agency providing support services there can be difficulty with delegating services and treatment to the support staff.

Information Given to Patients Regarding Prognosis and Options

- While medical oncologists report routinely telling terminally ill patients that they will die most say they do not routinely communicate an estimated survival time to their patients.⁴²
 - End of life discussions are associated with less aggressive medical care near death and earlier hospice referrals.
 - 87% of patients surveyed reported that they want as much information as possible regarding diagnosis and prognosis.
- Factors such as race and education level might play a role in patient-doctor communication.⁴³

³⁹ Smith, C. and Caine, S. 2007. Hospice Care for Alzheimer's Disease: Caring for the Patient, Family, and Caregivers. *The Internet Journal of Geriatrics and Gerontology* 3:2

⁴⁰ Welch L., S. Miller, E. Martin, and A. Nanda. 2008. Referral and Timing of Referral to Hospice Care in Nursing Homes: The Significant Role of Staff Members. *The Gerontologist* 48: 477-484.

⁴¹ Understanding Hospice – An Underutilized Option for Life's Final Chapter. *The New England Journal of Medicine* 357(4): 321-324.

⁴² A Review of Studies Relating to Patients' Desires to Know about their Diagnosis, Prognosis and Treatment Options

- Studies have shown that African-Americans tend to request more life-sustaining treatments than whites.⁴⁴
- Only 42% of patients in study reported physicians discussing hospice care.⁴⁵
 - Some physicians had a limited understanding of Medicare hospice benefits.
 - Some physicians believed available end-of-life options will be unacceptable to some of their patients.
 - Some physicians may feel there is no time for these discussions.
- Another study found that physicians favor over-predicting their patient's survival when making prognoses.⁴⁶
 - The most inaccurate prognosis is made when doctors are asked to communicate the prognosis to their patients.
 - Gender, race, availability of information and experience were identified as some of the drivers of this bias.
 - Predictions of patients' survival affects the choice of medical therapy, quality of patient care, and is especially important when it comes to end-of-life care such as referral to hospice care.

Maryland Study of Perceived Barriers

- Terminally ill nursing home patients have been less likely to receive hospice services than individuals residing in their homes.⁴⁷
 - Possible Reasons for lower utilization:
 - Institutional/cultural barriers: nursing homes are uncomfortable with certain palliative care practices, view hospice as intruder;
 - Lack of awareness of nursing home patients and families regarding hospice.
 - Physician attitudes toward hospice care.
 - Attitudes of nursing home administrators toward hospice care.
 - Belief that the nursing home is providing adequate end of life care.
 - Perception that nursing home regulations favor rehabilitation and restoration of functioning over palliative care.
 - Inability of nursing home staff to accurately identify patients with end of life care needs.
 - Perceived financial barriers: Medicare billing, delay for reimbursement from hospice for room and board of hospice patients.

⁴³ Desharnais S., R. Carter, E. Hennessy, J. Kurent, and C. Carter. 2007. Lack of Concordance between Physician and Patient: Reports on End-of-Life Discussions. *Journal of Palliative Medicine* 10(3): 728-740.

⁴⁴ Winston, C., P. Leshner, J. Kramer, G. Allen. 2005. Overcoming Barriers to Access and Utilization of Hospice and Palliative Care Services in African-American Communities. *OMEGA* 50(2): 151-163.

⁴⁵ Desharnais S., R. Carter, E. Hennessy, J. Kurent, and C. Carter. 2007. Lack of Concordance between Physician and Patient: Reports on End-of-Life Discussions. *Journal of Palliative Medicine* 10(3): 728-740.

⁴⁶ Alexander M., and N. Christakis. 2008. Bias and Asymmetric Loss in Expert Forecasts: A Study of Physicians Behavior with Respect to Patient Survival. *Journal of Health Economics* 27: 1095-1108.

⁴⁷ Tarzian A, and D Hoffman. 2006. A Statewide Survey Identifying Perceived Barriers to Hospice Use in Nursing Homes. *Journal of Hospice and Palliative Nursing* 8(6): 328-337.

- Administrative difficulties.

Hospice Billing⁴⁸

- To receive hospice, the patient must execute an election which effectively waives Medicare reimbursement for curative treatment.
 - Per regulation, the waiver must provide that: “an individual waives all rights to Medicare payments for the following services: (1) Hospice care provided by a hospice other than the hospice designated by the individual (unless provided under arrangements made by the designated hospice) (2) Any Medicare services that are related to the treatment of the terminal condition for which hospice care was elected”
 - The nature of the *per diem* reimbursement is not directly related to the cessation of curative or aggressive therapies.
- Federal law requires that for nursing home residents electing hospice who are dually eligible for the Medicare hospice benefit and Long-term Medical Assistance payments for nursing home room and board, the financial obligation for room and board is transferred from the nursing home to the hospice.
 - Thus the nursing home no longer bills Medicaid directly, but is required to bill the hospice which in turn is required to bill Medicaid for the patient’s room and board costs.
- Federal law prohibits Medicaid from paying more than 95% of the bill for room and board to the hospice.
 - Moreover, in Maryland, electronic billing for Medicaid room and board is generally available to nursing homes and hospices but smaller hospices have had difficulty affording the costs of availing themselves of the electronic billing option.⁴⁹ Thus, the amount of time it takes for hospices without electronic billing to obtain payment can be 3 or 4 times longer than if the nursing home were able to bill Medicaid directly. In addition, nursing homes generally are no longer able to bill Medicare for skilled care of the patient.
- A patient who is eligible for a skilled nursing benefit after a hospital stay but is not Medicaid eligible may forego the Medicare hospice benefit because to do so would force the patient to pay for room and board.⁵⁰
- Although all private insurers are required by Maryland law to offer hospice benefits, nationally in 2000 only about 10% of payments to hospices came from private insurance.⁵¹
- Private insurers typically define hospice in the same manner as Medicare and Medicaid and the hospice is required to follow all Medicare guidelines. The patient receives coverage for hospice care while in a nursing home but this

⁴⁸ Hospice Network

⁴⁹ Medicaid Program.

⁵⁰ Hoffman, D.E., and Tarzian, A.J. Summer 2005. Dying in America – An Examination of Policies that Deter Adequate End-of-Life Care in Nursing Homes. *The Journal of Law, Medicine & Ethics*. 294-309.

⁵¹ Hospice Association of America. *Hospice Facts and Statistics*. March 2008.

coverage does not include room and board except as provided under Medicare guidelines.⁵²

Perception of Palliative Care in Acute Care Hospitals⁵³

- This study interviewed providers, both physicians and non-physicians from 11 Pennsylvania hospitals.
- Most participants perceived palliative care as care that focuses on terminal pain and symptom management and on facilitating decisions to stop life sustaining treatment.
 - Some physicians worried that others viewed palliative care as a signal that providers had abandoned all hope for a patient.
 - Aside from nurses, few participants identified the need for palliative care earlier in the disease process.
 - Nurses tended to believe that palliative care should be available to all patients, not just as an option after disease orientated care had failed or was too burdensome, or when the patient reaches end-of-life.
- Conflation of the terms “palliative care,” “hospice care,” “end-of-life care,” and “terminal cancer care,” tended to be at the root of confusion related to who should receive palliative care, who should recommend and provide it, and when it should be started.
- Many physicians felt that symptom management for pain was part of their job and therefore palliative care consults for nonterminally ill patients were lateral consults and unnecessary.
 - However others recognized palliative care as a specialty whose practitioners can be called upon for various roles with actively dying patients.
- Typically participants felt palliative care consults should be arranged when aggressive care was futile, end-of-life preferences were not being met, there were disputes over the goals or course of care, or there were concerns about high-intensity treatment.
 - Consults are physician dependent, whether a consult occurs typically relies on the physician’s willingness to use palliative care.
 - However, nurses may be influential in getting a physician to order a consult.
- The biggest barrier to early use of palliative of care was identified as the narrow view about palliative care’s range of services and the physicians’ concerns about loss of autonomy.
- The biggest barriers to end-of-life care were the pervasiveness of a culture currently geared towards high-intensity treatment; the concerns of hospitals and providers about reputations and lawsuits; the beliefs and perceptions of patients;

⁵² Maryland Insurance Administration.

⁵³ Rodriguez, K. A. Barnato, and R. Arnold. 2007. Perceptions and Utilization of Palliative Care Services in Acute Care Hospitals. *Journal of Palliative Medicine* 10(1): 99-110.

the beliefs, experience, and medical specialty of individual physicians; and economic constraints that affect hospital practices and staffing.

Palliative Care Barriers

- Patients and providers may be reluctant to talk about death, and influenced by denial, including hope for a miracle or consideration of treatments unlikely to confer benefits.⁵⁴
- Cultural/religious differences between the provider and patient may be a barrier
- No insurance or incomplete coverage of palliative care services might impede the use of palliative care.
 - Providers may also be concerned about receiving reimbursement since many palliative care services are not billable.
- Patients and families may have many misperceptions and unclear definitions about palliative care.
 - Physicians who had referred patients to palliative care reported that patient's or family's unrealistic expectations regarding their prognosis was the biggest barrier.⁵⁵
 - Factors underlying this barrier could include patients'/families' incorrect understanding of the goals of palliative care, and physicians limited skills in communicating what palliative care represents.
- Physicians who had not referred patients stated that lack of familiarity with the palliative care team was the biggest barrier.⁵⁶
- Most physicians reported that they did not receive good training in palliative care during their residency/fellowship training.⁵⁷
 - However, most reported high levels of involvement in and comfort with pain and symptom management.
 - This suggests that a possible barrier to referral is the physician's perception that he/she is already doing a good job managing patient's symptoms so a palliative care consult is not needed.
- The study also found that there may be a possible disconnect between physicians' perceived abilities in addressing/discussing palliative care issues and the reality that physicians are not successfully engaging patients/families in these discussions.

⁵⁴ Goepp, J. et al. 2008. Provider Insights About Palliative Care Barriers and Facilitators: Results of a Rapid Ethnographic Assessment. *American Journal of Hospice and Palliative Medicine* 25(4): 309-314.

⁵⁵ Snow, C. and et al. 2009. Identifying Factors Affecting Utilization of an Inpatient Palliative Care Service: a Physician Survey. *Journal of Palliative Care* 12(3): 231-237. This study compared the barriers perceived by physicians who had referred patients to palliative care and those who had not made any referrals.

⁵⁶ *Id.*

⁵⁷ *Id.*

5. What are recommendations to improve awareness and access to hospice and palliative care programs?

There have been attempts to improve awareness and access to hospice and palliative care in Maryland and other states as discussed below.

Community Physician Outreach in St. Mary's County

- This study examined the use of community physician outreach to improve the referral of patients to hospice in St. Mary's County.⁵⁸
 - A survey given to families after the death of their loved one showed that St. Mary's County had the highest proportion of families responding that their relative had been referred too late compared to other counties participating in the survey.
 - 35% of families in St. Mary's compared to a mean percentage of 14% of families at other agencies.
 - The length of stay (25.3 days) was also less than the national average.
 - Results of the survey and length of stay data were presented at the annual meeting of physicians in St. Mary's Hospital as well at the Department of Family Medicine, the cancer Committees, and the Department of Medicine at the hospital.
 - A letter regarding the length of stay compared to the national average was sent to all physicians in the county.
 - During the three months following this intervention the average census at Hospice of St. Mary's increased from 21 patients to 31 patients.
 - The length of stay also increased by 7.4 days.
- It may not be possible to generalize the results of this study to the broader health care system because the study concerned a self-contained rural setting in which the hospice was owned by the hospital.

Michigan's Continuing Education Requirement

- Michigan passed legislation which requires physicians renewing their license to complete an appropriate number of hours or courses in pain and symptom management as determined by their respective board.⁵⁹

West Virginia's Continuing Education Requirement

- West Virginia passed legislation requiring licensed physician assistants, pharmacists, registered nurses, nurse practitioners, practical nurses, and osteopathic physicians and surgeons to complete two hours of continuing education coursework in the subject of end-of-life care including pain management.⁶⁰

⁵⁸ Taylor, C. 2004. Improving Referral of Patients to Hospice Through Community Physician Outreach. *Journal of Pain and Symptom Management* 28(3):294-295.

⁵⁹ M.C.L.A. 333.16204.

⁶⁰ W. Va. Code, § 30-1-7a.

One Method to Improve Hospice Referrals in Nursing Homes

- In one study researchers performed interventions in which a structured interview was used to identify residents whose goals for care, treatment preferences, and palliative care needs made them appropriate for hospice care. These residents' physicians were then notified and asked to authorize a hospice informational visit.⁶¹
 - Intervention was simple and relatively quick so could feasibly be implemented in most long term care settings.
 - Intervention was efficient resulting in hospice referral for approximately 20% of residents within 30 days.
 - Increasing access to hospice care improved families' rating of the care that residents received at end-of-life.
 - This suggests the benefits of hospice care for those patients who are referred earlier.
 - Intervention residents were admitted to the hospital less frequently and spent fewer days in acute care settings.

Thoughts on Recommendations

- There is a general dislike of a physician mandate that would require physicians to provide information on hospice and palliative programs.
 - Provide incentives to encourage physicians to discuss hospice and palliative care options.
- Better incentives are needed for nursing homes to refer to hospice.
- Education is needed for physicians and all who may be involved in making decisions about care of terminally ill patients (patient, family, physician).
- Continuing education, e.g., Michigan's program that requires physicians take continuing education course on palliative care or West Virginia's program that requires physicians and certain other health care providers to take continuing education in end-of-life care and pain management.
 - One important consideration in education is that many learners do not take a subject seriously unless they know that it will be covered in the final exam. Physicians in many fields may be involved in the care of the terminally ill. However, specialty certification exams seldom contain any questions about the topic.⁶²
 - The member boards of the American Board of Medical Specialties should be encouraged to correct this.
- There should be greater utilization of clinical social workers to facilitate earlier referrals to hospice and palliative care.

⁶¹ Casarett, D., J. Karlawish, K. Morales and et al. 2005. Improving the Use of Hospice Services in Nursing Homes. *Journal of the American Medical Association* 294(2): 211-217.

⁶² Comment from J. M. Zimmerman, MD, FACS

- It was noted that individuals diagnosed or suspected of having a brain disease that causes or can result in progressive cognitive impairment, including individuals with dementia, should be brought into end of life care planning early while the patient is still able to make decisions. Understanding that at the point of diagnosis of a progressive brain disease the individual may not want to immediately embark on an end-of-life discussion, it was therefore suggested that end-of-life counseling be offered to the individual at various times as appropriate and necessary during the course of the disease to ensure the individual has the ability to make their wishes known while they are able. Currently, the physician often does not revisit these discussions as the disease progresses. For individuals with more advanced cognitive impairment, the caregiver should be brought into those discussions.
- It was agreed that living with a disability is not a reason to trigger disclosures about hospice and end-of-life care. However, people with disabilities need to have the same access to information and options to make their own decisions when there is a need to discuss end of life planning. This includes the need for doctors and other medical professionals to encourage discussions, information sharing and provide options about end-of-life care to people with disabilities the same way they would to people without disabilities. However, there must also be appropriate safeguards so that people with disabilities receive the necessary information but are not encouraged or led to any particular decision.
- All hospitals should be encouraged to establish palliative care programs.

CONCLUSION

The health care system is currently structured to favor the provision of fragmented care oriented toward analyzing symptoms, making diagnoses, and administering therapeutic interventions. It does not encourage consideration of the entire patient in a holistic sense and it frequently fails to elicit the priorities of the patient to establish the goals of care. The latter requires a doctor-patient relationship, analysis of all options, and an open discussion about the options. But there frequently is little or no end of life care planning.

Medicaid pays the room and board charges for nursing home care if the person is Medicaid eligible. Private pay patients who reside in skilled nursing facilities, who qualify for and need the expertise offered by hospice, must absorb the financial burden for the room and board charges. Thus, patients in need of hospice services who are not Medicaid eligible may feel financial pressure to choose rehabilitative treatments to qualify for the skilled nursing home benefit so that nursing home room and board costs are covered under that benefit.

The current Medicaid structure and process for reimbursement to nursing homes provides a financial disincentive for facilities to refer patients to hospice. When a

Medicaid patient is in a nursing facility, and has elected hospice care, 95% of room and board costs are reimbursed to the facility. These costs would be otherwise directly reimbursed to the facility at 100%. In addition to a 5% reduction in reimbursement, the billing for the room and board must “pass through” the hospice who will, when reimbursed from Medicaid, reimburse the facility. Hospices are forced to decide if they will pay the facility the additional 5% from their reimbursement or pass on just the 95% reimbursement to the facility. It is clear that the reimbursement structure impacts the financial viability of either the hospice or the facility, creating little incentive for facilities to refer to hospice. To further complicate the issue, the vast majority of the processing for “pass through hospice billing” is done manually on paper bills, leading to extended delays in payment, further impacting the fiscal health of facilities. The Medicaid Program makes electronic billing available to all hospices but many smaller hospices find purchasing the equipment necessary to use electronic billing to be cost prohibitive. To overcome this barrier, smaller hospices could pool their resources to afford electronic billing or the legislature could consider making subsidies or grants available.

For patients needing and wanting the expert palliation skills of hospice staff while receiving symptom-relieving chemotherapy/radiation/transfusions/hydration, these treatments are not reimbursable because the hospice rates are not adjustable, placing the financial burden of paying for these expensive treatments on the hospice when they accept these patients. Insurance reimbursement often falls short in covering the full range of services that hospice provides at the end of life, thus requiring hospices to rely on donated funds to fill in the gaps in coverage. For example, Medicare requires bereavement care of family members, but does not reimburse for it. Medicare also requires an active volunteer program, but only recognizes a limited number of expenses as valid volunteer costs. Additionally, private insurance usually pays for hospice care but often will not increase reimbursement rates for long periods of time.

Urban and lower socioeconomic patients frequently utilize a variety of resources as their source of primary care. These include emergency departments and 24/7 urgent care centers. Here, the assigned doctor, nurse practitioner, or physician assistant may change monthly, quarterly or yearly. This creates a significant challenge in providing continuity of care. With limited continuity of providers and limited relationships, end of life care planning may not occur at all, resulting in frequent re-hospitalization. In the course of these hospitalizations, the patient often receives excessive diagnostic testing and is subject to aggressive medical treatments and interventions to prevent malpractice claims. Interventions such as CPR and intubation may be implemented, even when continued aggressive efforts would otherwise be deemed futile. Indeed, this can also occur with patients who have a primary care physician if there has been no end of life

care planning or if there has been no communication of that care planning to physicians temporarily in charge of the patient's care at the hospital.

Research concludes that physicians can be poor prognosticators, frequently overestimating the life expectancy of a patient resulting in patients dying without the support of hospice, or due to the late nature of the referral, not realizing the full services that hospice are committed to providing. Many physicians have not had adequate training in sharing difficult or disappointing news. The topic of end of life discussions is covered only superficially in medical school, without the benefit of role-play with patient actors. Young medical professionals learn on the job and are guided by the information they believe the patient/family wants. As a result, many practitioners are uncomfortable initiating the end of life discussion and engaging in a meaningful dialogue with patients and their families, failing to help them best understand what choices are available to them.

The physician's personal beliefs, values, comfort level with the end of life, and the patient's disease and the treatment options also impact the physician's ability and willingness to openly discuss goals of care at the end of life. Physicians are often reluctant to stop, or discuss stopping curative treatments, even when prognosis for improvement is poor and the burdens of treatment are likely to outweigh the benefits. Uninformed physicians believe that they will no longer be allowed to care for the patient if admitted to a hospice program.

Health care practitioners such as primary care physicians, specialists, nurse practitioners, and physician assistants have widely varying degrees of knowledge and understanding of what hospice provides to both the patient and the family. Health Care practitioners, patients and families often have misperceptions of what hospice is and when the services would be most effective. This includes the misperception that hospice equals death rather than the reality that hospice equals symptom relief and improved quality of life. Many believe that hospice care can only be used in the last days of life. This misperception can result in significant delays in referrals.

The public is partially educated by mass media (TV, movies) by the inaccurate portrayal of the effectiveness of cardiopulmonary resuscitation, ventilator support, survival rates and quality of life. The current culture in the United States does not recognize or embrace aging and death as a natural process that is part of life. Some people are even under the false impression that hospice is an organization that ends patients' lives.

The patient and family are influenced by their values and customs associated with their culture, religion and ethnicity. For some cultures, hospice is seen as a substandard type of care, due to the perception that non-aggressive interventions are seen as “doing nothing,” thereby providing inadequate care. A physician may be limited by the patient/family in disclosing the diagnosis and prognosis to the patient due to cultural, religious, or ethnic beliefs.

Nursing home staffs are often reluctant to accept hospice care for their residents for many reasons. These reasons include their own cultural and ethnic beliefs about end of life and death, the belief held by some people that hospice kills patients, the perception that they will lose control of the patient, and an unfounded fear of being cited by state regulators for failing to institute potentially life-prolonging interventions for a hospice patient despite regulatory guidance from the Centers for Medicare and Medicaid Services requiring nursing homes to give care that is consistent with a patient’s right to refuse treatment.

RECOMMENDATIONS

Establish a Maryland End of Life Bill of Rights

The workgroup recommends that an End of Life Bill of Rights be established. An End of Life Bill of Rights could effect change by educating patients and encouraging them to advocate for themselves. The use of an End of Life Bill of Rights as an educational tool in conjunction with other educational materials would help to make patients aware of their options for quality end of life care. Considering the numerous barriers to engaging in end of life discussions, the emotional charge of the topic, the difficulty of changing medical practice patterns, and the fact that the right to choose rests with the patient, it is vitally important to give patients the tools they need to obtain quality care at the end of life.

The workgroup has agreed to a draft End of Life Bill of Rights which can be found in Appendix A attached to this report. This draft is being submitted by the workgroup for the Office of the Attorney General’s consideration in consultation with the State Advisory Council on Quality Care at the End of Life, the Department of Health and Mental Hygiene’s Office of Health Care Quality and Medicaid Program, the Department of Disabilities, and other interested organizations, to be finalized and distributed as part of an educational campaign regarding hospice, palliative care, and end of life counseling. This educational campaign would encourage healthcare facilities and practitioners to disclose the End of Life Bill of Rights and supporting educational materials to patients with advance directives and to patients who have a limited life expectancy as clinically appropriate.

Educate the Public

Interested government agencies, professional associations, and nonprofit organizations devoted to improving quality care at the end of life should collaborate on a broad educational campaign to educate Maryland residents about hospice, palliative care, and the new End of Life Bill of Rights. Utilizing multi-media resources for the educational campaign, this campaign should provide residents with resources that can educate and support their end of life care decisions. Indeed, education regarding these issues should start early to promote a broader understanding of these issues among the general population. This can be accomplished by offering end of life education as part of the core health curriculum for high school and college students.

Educate Practitioners

The education of practitioners in end of life counseling is critical to the improvement of patient and family satisfaction with the quality of end of life care. Thus, the workgroup recommends that hospitals and professional schools be encouraged to improve end of life counseling education at teaching hospitals/professional schools in Maryland for all provider levels. Topics could include sharing disappointing news, accepting the futility of further aggressive intervention, and palliative medicine core content.

Health care facilities should be encouraged to develop systems to utilize physicians, physician assistants, nurse practitioners, and clinical social workers currently trained in end of life discussions focused on ascertaining the patients' values, to explore potential options for the goals of care, to identify available resources, and to assist with advance planning in the abstract, at the time of, or even prior to a determination of a terminal illness. Facilities should be encouraged to expand educational opportunities for health care providers by encouraging health care facilities to train all their practitioners working in end of life care to provide end of life counseling, including physicians, physician assistants, nurse practitioners, and clinical social workers. These facilities should also be encouraged to monitor the frequency and quality of such counseling provided by their practitioners for terminally ill patients.

The workgroup recommends that an end of life provider competency program be established that could operate through professional associations that may independently or collaboratively develop or identify training programs, and that the Department of Health and Mental Hygiene collaborate with these associations to develop a method through which such training would be recognized by relevant licensing boards as meeting continuing education license renewal requirements.

Establish End of Life Quality of Care Indicators

The workgroup recommends that the Centers for Medicare and Medicaid Services working with the Maryland Health Care Commission establish quality indicators looking at the best practices approach to include data on family satisfaction with end of life care as a quality indicator on the report cards for facilities and practitioners.

Simplify Reimbursement

The workgroup recommends that Maryland's congressional representatives urge the elimination of the Medicaid "pass through" billing process for hospices and facilities.

Reimburse End of Life Counseling: Pilot Program

Finally, the workgroup recommends that Maryland's congressional representatives urge the Centers for Medicare and Medicaid Services to develop a pilot program authorizing a reimbursement mechanism to enable the provision of end of life counseling by physicians, physician assistants, and nurse practitioners; and by clinical social workers authorized under the Maryland Health Occupations Article to provide such counseling and who work with facilities, programs, or physician's offices that serve persons who have potentially life-threatening conditions. The pilot program would also have as its goal the assessment of whether such end of life counseling results in increased referral and utilization of hospice and palliative care services and increased family satisfaction with pain management and compliance with the patient's stated wishes for care at the end of life.

Workgroup Participants

Marni Abrams (Maryland Disability Law Center)
Pat Alt (Towson University and Joseph Richey Hospice)
Paul Ballard (Attorney General's Office)
Kimberly Barrett, MPH, LCSW-C (St. Agnes Health Care)
Barbara Blaylock, MD (Montgomery County Coalition for End of Life Care)
Harold Bob, MD
Delegate Elizabeth Bobo
Lynne Bonde (Calvert Hospice)
Louis Breschi, MD (Med Chi)
Ken Capone (Cross Disability Rights Coalition)
Linda Cole (Maryland Health Care Commission)
Christine Crabbs (Hospice and Palliative Care Network of Maryland)
Virginia Crespo (United Seniors of Maryland)

Michele Douglas (Alzheimer's Association)
Kathy Dunn (Aide to Senator Jennie Forehand)
Robyn Elliott (Maryland Advocacy)
George Failla, Jr. (Department of Disabilities)
Lucy Fetting (Johns Hopkins Oncology Clinical Social Workers)
Ann Goldscher (Aide to Delegate Elizabeth Bobo)
Margaret Hadley, RN, MS (Holy Cross Home Health and Hospice)
Tara Hochstein (Hospice and Palliative Care Network of Maryland)
Steve Johnson (Med Chi)
Danna Kauffman (LifeSpan)
Timothy Keay, MD (State Advisory Council on Quality Care at the End of Life)
Marion Keenan (Coastal Hospice)
Louise Knight (Johns Hopkins Oncology Clinical Social Workers)
Mike Lachance (Department of Aging)
James Lieberman, MD (Compassion and Choices, National Capital Area)
Rachel London (Maryland Developmental Disabilities Council)
Delegate Roger Manno
Lori Mostofsky, LCSW-C (Maryland Society for Clinical Social Work)
Sr. Karen McNally (Stella Maris)
Ted Meyerson (State Advisory Council on Quality Care at the End of Life)
Ann Mitchell (Montgomery Hospice)
Ethan Moore (Health Facilities Association of Maryland)
Alice Neily Mutch (Capital Consultants of MD)
Tricia Nay, MD (Medical Director, Office of Health Care Quality)
Nancy Paltell (Maryland Catholic Conference)
Leslie Piet (Johns Hopkins HealthCare)
Lorna Rice, LCSW-C (Carroll Hospice)
Kerrie Wille Schultz, LCSW-C (Maryland Society for Clinical Social Work)
Doris Scott (Maryland Nurses Association)
Joyce Sexton (Director, JSSA Hospice)
Lisa Stone
Barbara Supanich, RSM, MD, FAAHPM (Holy Cross Hospital)
William Vaughan (Chief Nurse, Office of Health Care Quality)
Cari Watrous (Department of Disabilities)
Clare Whitbeck (Voices for Quality Care)
Nancy Cedar Wilson, LCSW-C (Greater Washington Society for Clinical Social Work)
Ramona Wilson, Social Work Intern (Maryland Legislative Council of Social Work Organization)

APPENDIX A

Patients' Bill of Rights: Quality End-of-Life Care

Patients have a right to:

- Be informed about their diagnosis and illness and about potential benefits and burdens of available treatment options throughout their illness, including their options for end of life care.
 - These options may include disease-targeted treatment, palliative care, and hospice care.
 - Care may be provided by a team of licensed professionals to manage pain and symptoms, including doctors, nurses, social workers, chaplains, pharmacists, dietitians, acupuncturists, physical therapists, and alternative care professionals such as massage therapists and music therapists.
 - Choose which of the available end-of life treatment options are desired and best for them.
 - Participate in end-of-life care planning while still able to express individual wishes.
 - Reasonable accommodations for a language or communication barrier, a cognitive or sensory impairment, and/or a physical or mental disability.
 - Choose their end-of-life care providers.
 - Have all aspects of their pain and symptoms addressed. This includes:
 - Access to pain relieving medications and treatments and expert guidance from those providing end of life care.
 - Actively participating in pain and symptom management decisions.
 - Expert care that addresses their physical, spiritual, psycho-social, and emotional pain and suffering.
 - Confidentiality and the protection of personal health information.
 - Non-discriminatory, considerate, and respectful care and treatment from physicians, health plan representatives and all other health care providers.
 - Expect patient advocacy for their individual concerns within their own healthcare delivery system, including the right to be informed about grievance procedures and appeals processes.
-
- Have their authorized proxy decision maker exercise these rights on their behalf.