

CHAPTER 15

END-OF-LIFE CARE



Committee Members

Maria LoBianco, RN, MS, CCM (Co-Chairperson) - *Upper Chesapeake Medical Center*

Jack Schwartz, Esq. (Co-Chairperson) - *Office of the Attorney General of Maryland*

Carla Alexander, MD - *Palliative Care Program, University of Maryland*

Barbara Andrews, RDLD, MEd - *Center for Cancer Surveillance and Control, Maryland Department of Health
& Mental Hygiene*

Sydney Morss Dy, MD, MSc - *Johns Hopkins Bloomberg School of Public Health*

Jeanette Ellis, RN, CRNH - *Carroll County Hospice*

Linda Freda, RN, MSN, CHPN - *VNA Hospice of Maryland*

Meghan Higman, MD, PhD - *Johns Hopkins Oncology and Pediatrics*

Elizabeth Reder, MA - *Johns Hopkins Children's Center*

Carole Sharp, LCSW-C - *American Cancer Society*

Joyce Skalinski, RN, OCNC - *Upper Chesapeake Medical Center*

Emily T. Slunt, RN, PhD - *Health Services, Howard Community College*

Kathryn M. Smolinski, LCSW-C, MSW - *The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins*

Guest Speaker

Jean Tucker-Mann, MSW - *University of Maryland Medical Center*

Chapter Writers

Carla Alexander, MD - *Palliative Care Program, University of Maryland Medicine*

Barbara Andrews, RDLD, MEd - *Center for Cancer Surveillance and Control, Maryland Department of Health
& Mental Hygiene*

Sydney Morss Dy, MD, MSc - *Johns Hopkins Bloomberg School of Public Health*

Linda Freda, RN, MSN, CHPN - *VNA Hospice of Maryland*

Jack Schwartz, Esq. - *Office of the Attorney General of Maryland*

END-OF-LIFE CARE

Despite improvements in prevention, early detection, and treatment, cancer remains a terminal illness for many patients. About half of all patients diagnosed with cancer will die from their illness within a few years of presentation.¹ In 1999, more than 10,000 Maryland residents died from cancer. Maryland ranks eleventh in the nation in cancer mortality.²

Cancer care must be as patient-centered during the last phase of the illness as when the emphasis is on cure. Indeed, cancer and end-of-life care have been intertwined since the beginning of the hospice movement. Techniques in palliative medicine for managing pain, dyspnea, bowel obstruction, and other symptoms typically were developed for the care of cancer patients and later were adopted for patients with non-cancer diagnoses.³

The principles that should govern cancer care at the end of life are well-accepted in the field. They include responsiveness to the patients' wishes; truthful, sensitive, empathic communication; and meticulous attention to the physical, spiritual, and psychosocial needs of patients and family.⁴

The vision underlying these principles, however, is often not reflected in the dying individual's reality.

Hospice care directly furthers these goals and allows patients to die in settings that make achieving these principles more likely.⁵ However, of all Marylanders over 65, only 20.5% used hospice services in the last year of life (2000 data); of those who use hospice services, the median length of stay was a mere 20 days (2001 data).⁶ However, hospice is not the only means by which cancer patients can receive excellent palliative care. For example, hospitals can provide these services, but only a quarter of Maryland hospitals offered a palliative care program in 2000.⁷ It is evident that new and improved models are needed to fit the needs of the diverse populations who die from cancer and to support their families and social networks.

This chapter considers various aspects of the gap between the care that ought to be given to cancer patients as life nears its end and the care that they actually receive. This chapter describes barriers and shortfalls with respect to access to care, reimbursement, public and provider education, and research and suggests ways to integrate approaches to end-of-life care.

Access to End-of-Life Care in Maryland

Very few Americans understand the options available for end-of-life care for themselves and their loved ones. Even fewer take advantage of these options. Much of the data about this issue comes from the hospice movement. In a 1999 survey conducted by the National Hospice Foundation, 80% of Americans did not know the meaning of the term "hospice."⁸ Indeed, 75% of Americans were unaware that hospice care can be provided in the home, and 90% did not realize that hos-

pice care is fully covered though Medicare. This same survey also indicated that most Americans desire the type of end-of-life services offered by hospice.⁹

Hospice is a model of care that provides palliative care to patients with life-threatening medical conditions. The hospice model recognizes the need to care for the whole person, including mind, body, and spirit, and to support those who love and care for terminally ill persons. Hospice care can be provided in a variety of settings, including hospitals and nursing homes. However, in the United States, hospice services are most commonly provided at home.¹⁰ Traditionally, hospice has been associated with cancer patients and 63% of diagnoses upon admission to hospice care in Maryland were for cancer compared to 57% nationwide in 2000.¹¹ Although cancer patients and their caregivers continue to be the primary users of hospice care, trends indicate that patients with non-cancer diagnoses, including end-stage heart or lung disease, Alzheimer's disease, or AIDS are increasing their use of hospice services.¹²

The underlying principle of hospice is palliative care, which focuses on improving the patient's physical comfort and quality of life. Patients receiving palliative care should be able to continue to treat their disease with curative interventions, though it is common for health care systems and practitioners to view palliation as being in conflict with curative efforts. In whatever setting it is administered, palliative care is generally provided by an interdisciplinary team, which may include physicians, nurses, social workers, home health aides, pharmacists, chaplains, physical and occupational therapists, and trained volunteers. A growing number of hospitals are beginning to understand the importance of palliative care and are offering inpatient palliative care services.¹³ However, many end-of-life care providers continue to be concerned about what they call "the irrational choice" patients face in having to relinquish curative options in order to access hospice services. "The either-or approach that was adopted as a cost containment measure imposes a simplistic binary-decision model that is not consistent with either the clinical or emotional reality of the hospice process for patients and their families," according to David Rehm, President and Chief Executive Officer of VistaCare Hospice Foundation.¹⁴

Many patients experience limited access to services due to gaps in the continuum of end-of-life care. An uncertain prognosis or desire to continue with curative efforts while receiving palliative care can present significant barriers to quality end-of-life care. There is a great need for our

health care system to create an end-of-life care model that includes "interdisciplinary teams, continuity and coordination of care, integration of diverse services delivered in a variety of settings, and changes in the orientation of providers."¹⁵ Currently, our health care system fails to care for those with advanced illness by rarely providing a bridge between acute and end-of-life care. Medicare is criticized for the way it funds end-of-life care, including its focus on the provision of acute services and its packages of post-acute services that function as barriers to a seamless continuum in the last stages of life.¹⁶ The tie between prognosis and reimbursement is discussed in further detail in the next section. Often, patients with significantly better prognoses than a typical hospice patient have needs for supportive care that are at least as great, if not greater, than patients already in hospice. Prehospice or "bridge" programs offer patients some of the services of hospice without eligibility restrictions such as a six-month prognosis or forgoing curative therapies.¹⁷ There is a great need for development of these and other creative programs for administering multidisciplinary supportive care for cancer patients, regardless of their prognosis or decisions regarding curative interventions.

There is considerable need to identify patients within all health care settings, especially acute care settings, who may benefit from hospice or similar palliative approaches to care. Analysis of information gleaned from surveys of case managers and administrative databases justified enhanced attention to inpatient palliative care consultation, as well as consideration of the need for acute palliative care inpatient units.¹⁸ Unfortunately, most Maryland hospitals lack hospice or palliative care programs. In 2000, only 19.4% of hospitals in Maryland reported that their services include a hospice program, and only 25.8% of hospitals reported that they offer a palliative care program.¹⁹

Hospitals in Maryland treat a high percentage of critically ill patients in intensive care units (ICUs), which emphasize high-technology treatments, even when a patient is unlikely to recover. This is demonstrated by the 12% of elderly Maryland residents who spent a week or more in an ICU during the last six months of life. This also suggests that health care providers may prescribe overly aggressive treatments that do not take the patient's wishes into consideration and may prolong his or her discomfort.²⁰ Long stays within an ICU are extremely expensive and are often followed by death or disability, the primary motivators for treating the patient aggressively in the first place. In an analysis of patients enrolled in the SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risk of Treatments), median hospital costs were

\$76,501 for patients who had ICU stays of 14 days or longer and \$10,916 for patients with shorter ICU stays. In addition, among the patients who preferred a palliative approach to care, only 29% thought that their care was consistent with that aim.²¹

As of 2002, there were only 34 licensed hospice facilities in Maryland, with a total of 89 inpatient beds to service the entire state.²² All of these beds are located in areas surrounding Baltimore or Washington, D.C., which leaves the vast majority of state residents without convenient access to nearby inpatient hospice services. The majority of these facilities hold a general license (i.e. they provide skilled medical nursing and palliative, psychological, social, and spiritual support to patients and may be in a home-based setting or in a variety of inpatient locations) and not a limited license, which permits non-skilled palliative and supportive services only in home-based settings.²³ While most Maryland counties are served by some form of hospice care, there is an immense shortage of inpatient hospice beds. In addition, there are limited or no beds available for patients under the age of 18 years in most areas of the state.

Marylanders may benefit from enhanced partnership among hospices and long-term care facilities such as nursing homes and assisted-living facilities. In recent years, nursing homes have received increasing criticism for their failure to properly attend to pain and other supportive care needs of dying patients, especially those with cancer.²⁴ Thus, these and other facilities may seek to improve their palliative care services through partnership with hospices. Greater hospice presence in nursing homes may allow identification of the palliative care needs of patients that would otherwise go unrecognized and also provide education to clinicians and other nursing home staff regarding end-of-life care.²⁵

In Maryland, only 26.7% of state residents die at home based on data from 1997,²⁶ though it is well documented that most Americans would prefer to die at home. However, combined data from 1997–2000 indicates that Maryland is doing somewhat better in regard to location of death for cancer patients, with 38.7% of deaths occurring in the patient's residence.²⁷ However, over half of cancer patients in Maryland (50.9%) died in a hospital or nursing home setting during the same time period.²⁸ If these facilities do not offer appropriate palliative care services, then many Marylanders may not receive comprehensive end-of-life care.

The length of a patient's stay within a hospice facility is another significant indicator of the availability of appro-

priate end-of-life services. A minimum sixty-day stay is considered necessary for the patient to receive maximum benefit from the hospice program.²⁹ Unfortunately, the actual length of stay for many hospice patients is significantly shorter than 60 days. Nationally, the average length of time a patient receives hospice services has declined from 64 days to 48 days from 1992 to 2000. Over the same time period, the median length of time a patient receives hospice services in the U.S. has decreased from 29 to 25 days. The median length of stay in hospice care is generally accepted as a more accurate way to understand the experiences of typical hospice patients, due to the high frequency of short stays.³⁰ Maryland's median length of stay was a mere 20.5 days for 2001, even less than the national median.³¹

The most significant barrier to effective utilization of hospice services may be its rising operational costs. In part this is because of dramatic improvements in palliative care that have reduced the duration of care provided to hospice patients. Many palliative treatments have become easier to provide in a home setting, which has driven up outpatient costs. Decreasing lengths of stay have increased costs to hospice due to patients seeking hospice care later in their terminal illness, creating a shorter period over which to balance the high cost of care. In addition, the demanding nature of hospice work coupled with limited resources may contribute to low staff satisfaction and retention. This puts hospice care providers at a particular disadvantage in a field where shortages of nursing staff are endemic. To balance these shortages, hospices have had to concentrate more effort on fundraising, which places additional burdens on hospices as well as the communities that support them.³²

Much of the accessibility of end-of-life care is determined by the overriding attitudes and culture of the health care system. Persons with advanced disease tend to represent failure to the health care system. Increasingly, it is crucial to understand how patients with advanced illness want to spend the rest of their lives. It is important for policy makers to change their focus from a procedure- and pharmacy-oriented health care system to a continuum of care that ensures those with chronic illness have a range of options from which to choose. "Only then will the definition of 'success' in caring for persons with advanced illness begin to gradually take on new meaning; the degree to which the quality of patients' lives is enhanced and their suffering relieved will become a measure of success."³³

Disparities

Although end-of-life care is improving in the U.S., these improvements have been slow to impact the African-American and other minority communities. It has been well documented that African Americans in particular underutilize palliative and hospice care services. African Americans make up 13% of the total U.S. population, but only 8% of hospice patients.³⁴ Maryland has a higher rate of minority participation in hospice than the U.S. (approximately 16%). However, participation by minorities varies by region across Maryland. In Prince George's County, where 74% of the population is non-white, only 53% of hospice patients are non-white. In Montgomery County and on the Eastern Shore, the ratio of the non-white population to non-white hospice patients indicates that non-whites utilize hospice at a higher rate than whites. Despite these variations, hospices generally experience less minority participation than non-minorities. Cultural differences may contribute to the lower overall use of hospice services of these various populations.³⁵ Socioeconomic disparities also exist in end-of-life care, and are often indicated by the location of a patient's death. In a recent national study of where people die, decedents who were black, less-educated, and enrolled in an HMO were more likely to die in a hospital,³⁶ though it has been shown time and again that most Americans would prefer to die at home.

Pediatric Care

Disparities in end-of-life care for pediatric patients also exist. Children are often diagnosed with more advanced stages of cancer than adults; 80% of children have metastases at diagnosis, while only 20% of adults have advanced cancer at diagnosis.³⁷ And while the number of children diagnosed with cancer is certainly lower than adults (approximately 8,000 children under the age of 15 are diagnosed nationally each year, about 0.6% of all cancer diagnoses), this number threatens more years of life than any single type of adult cancer.³⁸ The most common childhood cancers are hematologic malignancies (leukemia). Children with leukemia are more likely to die from therapy-related conditions such as infection, while patients with solid tumors are more likely to die from their disease.³⁹ Thus, providing end-of-life care for children with cancer that meets the unique needs of these patients and their families is crucial. Families need access to quality pediatric hospice programs, as well as excellent palliative care programs within hospital settings.

In Maryland there are few hospice programs with staff specifically trained in pediatric end-of-life care. Hospice regulations were originally designed for adult cancer patients dying from their disease rather than therapy-related conditions, so parents of pediatric patients are often forced to make an “all or nothing” choice—either choose hospice services *or* continue with therapies. This is the same choice many adult cancer patients face when deciding between the continuation of curative efforts and hospice care. Many children also die in the hospital setting and these patients and their families deserve the best care possible in this situation, including staff trained in end-of-life care, psychosocial, spiritual, and bereavement support. It is often difficult to find and retain staff that is able to work with terminally ill children.⁴⁰

Reimbursement for End-of-Life Care

In palliative care, as in most of American medicine, services that meet a patient's needs are available only to the extent that a funding mechanism pays for them. Payment mechanisms include the hospice benefit under the federally funded Medicare program; the hospice benefit under the Medicaid program, which is funded jointly by federal and state governments; and hospice benefits under private health insurance, which is subject to state regulation. Given the epidemiology of cancer, Medicare is the most important source of payment for palliative care services, but the scope of Medicaid and private insurance is of particular concern for pediatric patients requiring end-of-life care.

When the Medicare hospice benefit was adopted in 1983, some heralded it as “the gold standard of end-of-life care”.⁴¹ This characterization is based on the fact that the hospice benefit includes many services that are not typically part of Medicare coverage, including care planning, personal care nursing, medication, family support, chaplaincy, and bereavement counseling.⁴² However, the hospice benefit gained approval by Congress only on the basis that it would not add substantially to Medicare's costs.⁴³ Consequently, qualification for the benefit is narrow. A patient qualifies only by agreeing to forgo curative treatment for cancer or other terminal illness, and the patient's physician must certify that the patient's life expectancy is six months or less if the disease runs its normal course. The continuation of therapy, including chemotherapy intended for palliation of symptoms, is often not allowed at all, or permitted only after prolonged negotiations with Medicare representatives.

This “either/or” choice effectively bars access to a range of palliative care services for patients who could benefit from them but who are not ready (or whose physicians are not ready) to concede that curative efforts ought to be abandoned. The culture of high-tech cancer care has had difficulty assimilating the idea that a good death is part of good cancer treatment;⁴⁴ the terms of the Medicare hospice election only reinforce the false dichotomy between treatment and palliation. Moreover, physicians who are unsettled by such a specific prognosis requirement, and who fear regulatory scrutiny if a patient lives “too long,” delay hospice referral. In the words of one hospice association official, “It’s just so very difficult to say when . . . the six-month clock is going to start ticking . . . and the result [is that] the referral occurs about two weeks before the death.”⁴⁵

By contrast, Maryland law on hospice benefits does not incorporate an explicit, time-linked prognosis prerequisite. The statute that sets up the basic framework for the Medicaid Program authorizes the Department of Health and Mental Hygiene (DHMH) to reimburse “for services provided by a hospice care program,” as defined elsewhere in state law.⁴⁶ That definition, in the part of the law requiring licensing of hospice programs, refers to “a coordinated, interdisciplinary program . . . for meeting the special physical, psychological, spiritual, and social needs of dying individuals and their families . . .”⁴⁷ The “dying” are those “who have no reasonable prospect of cure as estimated by a physician.”⁴⁸ There is no mention of a prognosis of death within six months or any other specific period, nor has DHMH adopted such a prerequisite by regulation. The pertinent regulation, for Medicaid managed care, simply requires that each managed care organization “include in its benefits package medically necessary and appropriate hospice care services to enrollees who are terminally ill.”⁴⁹

Similarly, private health insurers are required by Maryland law to “offer benefits for hospice care services” to their insureds.⁵⁰ The law does not define hospice care in this context, so a private insurer could provide a hospice benefit that covered palliative care intertwined with curative efforts, well before any definitive terminal prognosis. Nevertheless, the Medicare construct for defining a terminal illness has permeated the field, so that public and private insurers and providers routinely equate hospice eligibility with a six-month prognosis for death. Hence, reform in Medicare is a key to reform in other settings.

Public Education

A coordinated public education agenda on end-of-life cancer care should address the lack of knowledge and the misconceptions that exist in understanding the end-stage disease process, the choices of treatment options, advanced care planning, and the services that are available for end-of-life care.⁵¹ Public education should be the responsibility of the patient’s health care providers, interdisciplinary specialists in end-of-life care, and state health officials. Educational efforts need to be directed at not only those who have end-stage cancer, but their caregivers and the networks of community systems impacted by the illness, including workplaces, schools, places of worship, and social support services. It is important to note the cultural, religious, and personal biases towards end-of-life care that can influence both health care providers and the public when planning educational initiatives.⁵²

The general public should be able to understand the full realm of treatment options for advanced cancer, the possible benefits and burdens associated with each option, and the common physical, psychosocial, and spiritual concerns associated with end-stage disease. Learning effective coping strategies for relieving pain and suffering should be a primary goal in any cancer care program that values comfort.

Although Maryland has made great strides in advanced care planning, educators need to be particularly adept and sensitive to religious, ethical, and legal implications when facilitating decision-making related to resuscitative measures, artificial hydration and nutrition, and pain control. It is best to address these issues as well as the process for surrogate decision-making prior to crisis situations in order to give patients and caregivers adequate time to thoughtfully consider their options.

In planning for end-of-life care, Marylanders should be able to identify the full realm of services available to them, including palliative and hospice care and any bereavement services that are offered to caregivers. Additionally, they should understand how services may be coordinated in a hospital, in a hospice residence, at home, at a nursing home, or in an assisted-living facility. Studies have shown that most Americans are unaware of their care options at the end of life and are usually referred to palliative care and hospice programs very late in their disease process. The length of stay in hospice programs has gradually decreased since the inception of the Medicare hospice benefit over twenty years ago. Unfortunately, most patients and families have been

unable to fully benefit from comprehensive supportive services. Thus the public would benefit greatly from end-of-life educational resources made available in a wide variety of settings.

The public deserves a coordinated and comprehensive effort that fully engages health care providers, the end-of-life care professional community, and state officials in addressing these many educational needs. All Marylanders must be given the opportunity to receive high quality and timely end-of-life care.

Provider Education

Improving the quality of end-of-life care for cancer patients will require improved awareness, knowledge, and skills of the health professionals who provide their care. These include symptom management, application and limits of life-prolonging interventions, prognostication and recognizing dying, conveying difficult news, providing information and guidance on prognosis and options, sensitivity to religious, ethnic, and other differences, and understanding palliative and hospice services.

Deficits in end-of-life care education, knowledge, and practice among health care professionals have been well documented. The Institute of Medicine report, “Improving Care at the End of Life,”⁵³ notes three major deficiencies:

- “A curriculum in which death is conspicuous mainly by its relative absence.
- Educational materials that are notable for their inattention to the end stages of most diseases and their neglect of palliative strategies.
- Clinical experiences for students and residents that largely ignore dying patients and those close to them.”

A recent survey of pediatric oncologists regarding end-of-life care revealed a high reliance on trial and error in learning to care for a dying child, pointing to the ongoing need for education and strong role models.⁵⁴ The American Society of Clinical Oncology has developed a policy for improving end-of-life cancer care⁵⁵ and the National Comprehensive Cancer Network (NCCN), of which The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins is a member, has developed palliative care guidelines.⁵⁶ These and other resources are available, but these programs are not widely used in Maryland. Educational curricula and supports have been developed for a variety of groups, such as medical stu-

dents,⁵⁷ internal medicine residents,⁵⁸ nurses,⁵⁹ and social workers, and end-of-life education is now available in many training programs. Maryland programs should be encouraged to share and use these materials and curricula and to participate both in the development of new programs, such as for oncology fellows, and in research to improve the effectiveness of existing programs.

A survey of best-selling medical textbooks found that the oncology and hematology textbooks were in the quartile of specialties with the least end-of-life content. Follow-up research has shown that two of the six editors of the oncology/hematology textbooks, and many editors of other textbooks, report that they plan or have completed expansion of end-of-life content in these textbooks for future editions.⁶⁰ Maryland health professional training programs should be encouraged to use textbooks that have responded to this initiative and include adequate information on end-of-life care.

In order to truly improve care for terminally ill cancer patients, end-of-life care should not be marginalized in special courses or a single visit to a hospice program but integrated throughout curricula and clinical practice. In addition, resources and support should be available to expand the number of professionals with advanced training in end-of-life care to serve as teachers, consultants, and role models, and hospice professionals should be incorporated into Maryland training programs.

End-of-Life Research

This chapter has explained how the care of terminally ill cancer patients in Maryland may be improved by enhancing access to health services, reworking reimbursement, engaging the public, and educating providers. Implementing these important initiatives will be much more successful if accompanied by high-quality, targeted research. Improving health services and access will require knowledge of the main barriers to quality end-of-life care faced by Maryland residents with cancer. Improving clinical practice will require assessments of quality of care deficits and their impact on patients’ quality of life. Engaging the public will be more effective with information on why end-of-life care is important. Quality improvement programs will be more effective and disseminated more widely when careful evaluations have demonstrated efficacy.

An active research agenda including data collection is a critical part of the effort to improve end-of-life care for Maryland citizens. Improved and uniform data collec-

tion throughout the state, in collaboration with the Hospice Network of Maryland and local cancer centers, is one method for evaluating existing end-of-life services. The collection of such data will make it possible to document barriers and gaps in care. Once this type of framework is available, further research regarding access, satisfaction, and other outcomes will be possible. Funding agencies may begin to consider investing in end-of-life care initiatives at the encouragement of the consumer and when initiatives are evidence-based. Providing opportunities and incentives for collaboration will allow end-of-life research to become better incorporated into our outstanding cancer centers and assist in recruiting world-class experts in end-of-life care and research to Maryland.

Data from the *Dartmouth Atlas*⁶¹ and the *Last Acts Report on Dying in America Today*⁶² compares end-of-life care in Maryland to that delivered in other states. This data is retrospective in nature and applies only to the very end-of-life rather than patients living for years with a chronic cancer. These reports are derived from population and health care delivery data and they do not address the clinical concerns of patients. Real improvement in end-of-life care in Maryland would benefit from:

- developing current data sources, such as the Maryland Discharge Database.
- promoting collaboration between hospices, which often have their own databases, for research purposes.
- encouraging inclusion of end-of-life care issues in longitudinal studies of cancer patients in clinical trials.
- reviews of medical records to determine quality deficiencies.
- systematic surveys of patients, families, and providers to identify barriers they faced in obtaining quality care at the end of life.
- better epidemiological statistics related to death rather than only support care geared to prolonging survival.
- cost analyses of end-of-life care in a variety of settings and via various funding mechanisms.

Important information that could be obtained from improved data sources or targeted research projects might include:

- longitudinal experience of patients dying from cancer.

- how, when, and where patients die.
- quality of end-of-life care among hospices, nursing homes, hospitals, and characteristics associated with improving quality care.
- symptom prevalence and degree of symptom control obtained.
- barriers encountered by Maryland cancer patients searching for quality end-of-life care, including hospice and nursing home issues.
- novel service delivery models with potential for dissemination.
- successful quality improvement programs.
- successful partnerships that improve end-of-life care.
- disparities in access, preferences, and quality of end-of-life care.
- staffing needs for proposed improvements in health services at the end of life.

Maryland residents are fortunate to have many providers contributing to end-of-life care, but there is an increasing need for partnerships to improve the effectiveness of research in end-of-life cancer care. Since terminally ill cancer patients may often use multiple sources of care, including hospitals, private physicians, nursing homes, and hospice, integrated data may be necessary to provide an accurate picture of patients' longitudinal experiences. And although Maryland has many small hospice programs, an organizing framework already exists through the Maryland Hospice Network. Potentially, this could be expanded to include collaborative data collection that would provide a more complete picture of hospice and palliative care in Maryland. Furthermore, since few providers or researchers specialize in end-of-life care, collaboration between the University of Maryland, Johns Hopkins University, and any other interested research entities would also greatly enhance the quality of research initiatives.

Ensuring that Maryland's investments in such programs are worthwhile and determining whether to disseminate small pilot programs to larger populations or other health systems will require careful evaluations. Proposed initiatives that might benefit from accompanying program evaluation include waiver programs for hospice, hospice collaboration to provide care to complex patients, longitudinal palliative care programs, home caregiving programs, public education, and provider education.

Improving the quality of end-of-life care, and of the research evidence in this area, will require incorporation of end-of-life issues into other cancer research. To better describe and provide care during the current chronic trajectory that many cancer patients experience, it will be necessary to integrate palliative and supportive efforts long before patients are within days to hours of dying. Integration will indicate factors that might be helpful in predicting prognosis. For example, advance care planning may be beneficial after diagnosis and after treatment has begun, when the patient feels less anxious. This approach may or may not be more effective coming from a neutral health worker rather than the physician. End-of-life issues, such as the control of pain and fatigue, occur throughout the cancer trajectory. Studies that focus solely on the end of life may be jeopardized by high mortality and difficult data collection; incorporating this research into longitudinal cancer studies and clinical trials may greatly improve its effectiveness.

Research into issues faced by terminally ill cancer patients would benefit from incorporating these issues into other cancer funding initiatives. Symptom management, documenting quality of life, and measurement of patient and family satisfaction with the type of care received should all be incorporated into funding initiatives from the Maryland Cigarette Restitution Fund. Experts on end-of-life care should be included on committees approving these expenditures to ensure that issues faced by terminally ill persons are included in proposals where appropriate. An evaluation component must be written into every study to ensure that results are meaningful and useful for dissemination.



End-of-Life Care Goals, Objectives, and Strategies

Goal:

Increase the number of Maryland cancer patients, as well as their family members and friends, receiving quality end-of-life care and related services.

Target for Change

By 2008, develop a system to monitor the availability and quality of end-of-life care services for cancer patients in Maryland, with specific attention to the needs of special populations including pediatrics and minorities.

Objective 1:

Expand provider education and training related to end-of-life care.

Strategies:

1. Require end-of-life education as part of core curriculum for *all* health care providers in training. Content areas should include, but not be limited to: aggressive symptom management; application and limits of life-prolonging interventions; prognostication, communications and conflict resolution; providing information and guidance on prognosis, options, and decision-making; sensitivity to cultural, religious, and other differences; understanding palliative and hospice services; understanding grief and loss issues; and sensitivity to the psychosocial and spiritual needs of patients and their family members and caregivers.
2. Require specialized end-of-life education for providers that care specifically for cancer patients (e.g., oncologists, primary care providers, social workers, chaplains, etc.) and specialized training for providers caring for pediatric oncology patients, recognizing the unique needs of children and their families at the end of life.
3. Promote membership in and support of organizations that work to improve end-of-life care.
4. Support organizations engaged in proactive outreach including end-of-life training of health care and insurance providers.



Objective 2:

Increase public awareness of end-of-life issues.

Strategies:

1. Support organizations engaged in proactive outreach including community education and political advocacy on end-of-life issues.
2. Increase public awareness of existing end-of-life educational resources such as websites and hotlines.
3. Provide community based end-of-life education for minorities and underserved populations, including multilingual education campaigns and outreach.
4. Provide comprehensive end-of-life care educational resources in all oncology clinics, cancer centers, nursing homes, and assisted-living facilities, and make this information readily available on corresponding websites.

Objective 3:

Improve access to end-of-life care for all Marylanders with specific attention to improving physician reimbursement for appropriate end-of-life care.

Strategies:

1.
 - Identify existing information about the end-of-life care needs of populations including pediatric, adult, and geriatric patients and special needs groups such as the developmentally disabled and minority populations. Develop additional data as needed to prepare a comprehensive needs assessment for these populations.
 - Develop and implement strategies to meet the needs identified in the above assessment.
2. Encourage the Centers for Medicare and Medicaid Services to implement pilot programs, with careful attention to the collection of data on both cost and patient satisfaction, that would reimburse providers for a full range of palliative care services for patients with any type of cancer that frequently results in death, with no requirement that life expectancy be six months or less. The benefit should be available whether or not a patient continues to pursue therapies aimed at remission or cure.
3. Encourage the Maryland Medicaid program to contract with managed care organizations to implement pilot programs, with careful attention to the collection of data on both cost and patient satisfaction, that would reimburse providers for a full range of palliative care services for patients with any type of cancer that frequently results in death, with no requirement that life expectancy be six months or less. The benefit should be available whether or not a patient continues to pursue therapies aimed at remission or cure.
4. Encourage the Maryland Insurance Commissioner to study industry compliance with Section 15–809 of the Insurance Article, which requires insurers and nonprofit health service plans to offer benefits for hospice care services, and take appropriate steps to remedy any noncompliance.
5. Support the development of tax credits for informal caregivers, such as family members and spouses, in an effort to alleviate the devastating financial burden of providing end-of-life care.
6. Increase provider reimbursement for the longer evaluations and more extensive management required for terminally ill patients. In addition, adequately reimburse health care professionals for time spent discussing advance care planning with patients.

**Objective 4:**

Enhance access to the continuum of end-of-life care services throughout the state.

Strategies:

1. Enhance existing partnerships and create new ones among hospices and facilities such as hospitals, home care agencies, nursing homes, and assisted living facilities caring for patients with cancer and other terminal illnesses.
2. Promote the creation of palliative care teams in acute care settings.
3. Support the use of care managers to serve as a constant as patients and their families move among different care settings from diagnosis to bereavement.
4. Support the development of, and reimbursement for, pre-hospice or bridge programs which offer some of the services of hospice with less stringent eligibility requirements.
5. Support and provide funding for the development of new inpatient and residential hospice facilities.

Objective 5:

Enhance scientific research into all aspects of end-of-life care.

Strategies:

1. Support and develop funding mechanisms for end-of-life research. Recognize and promote the importance of research, even with vulnerable populations, to better understand difficulties experienced by cancer patients throughout the trajectory of illness.
2. Develop a statewide mechanism for coordination and dissemination of interdisciplinary end-of-life research among various professional schools, professional organizations, and government agencies.
3. Support use of Cigarette Restitution Funds for end-of-life research and programs.

References

- 1 Institute of Medicine; Foley KM, Gelband H, eds. Improving palliative care for cancer: Summary and recommendations. Washington, D.C.: National Academy Press; 2001. p. 1.
- 2 Ries LAG, Eisner MP, Kosary CL, et al, editors. SEER Cancer Statistics Review, 1973–1990; 1973–1995; 1975–2000. Bethesda, MD: National Cancer Institute, 2003. (Accessed at http://seer.cancer.gov/csr/1975_2000.)
- 3 Lynn J, Schuster JL, Kabcenell A. Improving care for the end of life: A sourcebook for health care managers and clinicians. Oxford and New York: Oxford University Press; 2000. p. 235.
- 4 American Society of Clinical Oncology. Policy on cancer care during the last phase of life. 1998. (Accessed February 6, 2003, at http://www.asco.org/ac/1,1003,_12-002174-00_18-0010346-00_19-0010351-00_20-001,00.asp.)
- 5 Last Acts. State Fact Sheet: Maryland. 2002. (Accessed at <http://www.lastacts.org/files/publications/Fact%20Sheet%20MD.pdf>.) Adjunct to: Means to a better end: A report on dying in America today. Washington, D.C.: Partnership for Caring.
- 6 Ibid.
- 7 Ibid.
- 8 Last Acts. Care beyond cure—palliative care and hospice. Fact Sheet, 2001. (Accessed February 24, 2003, at http://www.lastacts.org/scripts/la_res01.exe?FNC=FactSheets__Ala_res_NewHome_html.)
- 9 National Hospice and Palliative Care Organization (Research Department). NHPCO Facts and Figures. Alexandria, VA: Updated August 2002.
- 10 See note 8.
- 11 Maryland Health Care Commission, Health Resources Division. Issue Policy Brief: Hospice services. May 2002.
- 12 See note 8.
- 13 See note 8.
- 14 Matherlee, K. Managing advanced illness: A quality and cost challenge to Medicare, Medicaid, and private insurers. National Health Policy Forum Issue Brief No. 779. Washington D.C.: George Washington University; June 20, 2002.
- 15 Ibid.
- 16 Ibid.
- 17 Casarett DJ, Abrahm JL. Patients with cancer referred to hospice versus a bridge program: Patient characteristics, needs for care, and survival. *J Clin Oncol* 2001 April; 19(7):2057–63.
- 18 Billings JA, Gardner M, Putnam AT. A one-day, hospital-wide survey of dying inpatients. *J Palliat Med* 2002; 5(3):363–74.
- 19 See note 5.
- 20 See note 5.
- 21 Teno JM, Fisher E, Hamel MB, et al. Decision-making and outcomes of prolonged ICU stays in seriously ill patients. *J Am Geriatr Soc* 2000 May;48(5 Suppl):S70–4.
- 22 Maryland Department of Health & Mental Hygiene, Office of Health Care Quality. Hospice Care Program directory. (Accessed at http://www.dhnh.state.md.us/ohcq/listings/web_hospice.doc.) Last updated February 10, 2003.
- 23 See note 11.
- 24 Bernabei R, Gambassi G, Lapane K, et al. Management of pain in elderly patients with cancer: SAGE Study Group (Systematic assessment of geriatric drug use via epidemiology). *JAMA* 1998 Jun 17;279(23):1877–82.
- 25 Casarett DJ, Hirschman KB, Henry MR. Does hospice have a role in nursing home care at the end of life? *J Am Geriatr Soc* 2001; 49:1493–8.
- 26 See note 5.
- 27 Maryland Department of Health & Mental Hygiene, Division of Health Statistics. Health statistics and cancer data. Unpublished data. Baltimore Data Center: July 21, 2002.
- 28 Ibid.
- 29 Last Acts. Means to a better end: a report on dying in America today. Washington, D.C.: Partnership for Caring. 2002.
- 30 See note 9.
- 31 See note 5.
- 32 See note 11.
- 33 See note 14.
- 34 Last Acts. Improving care for African Americans near the end of life. Fact Sheet, 2002. (Accessed February 24, 2003, at http://www.lastacts.org/scripts/la_res01.exe?FNC=FactSheets__Ala_res_NewHome_html.)
- 35 See note 11.
- 36 Weitzen S, Teno JM, Fennell M, Mor V. Factors associated with site of death: a national study of where people die. *Med Care* 2003 Feb;41(2):323–35.
- 37 Children’s Environmental Health Network 2002. Childhood Cancer Fact Sheet. (Accessed July 26, 2002, at <http://www.cehn.org/cehn/CongBriefCancer.html>.)
- 38 Ibid.
- 39 Klopfenstein KJ et al. Variables influencing end-of-life care in children and adolescents with cancer. *J Pediatr Hematol Oncol* 2001;23:481–6.
- 40 See note 11.
- 41 See note 14.
- 42 Institute of Medicine; Foley KM, Gelband H, eds. Improving palliative care for cancer: Summary and recommendations. Washington, D.C.: National Academy Press; 2000. p. 6.
- 43 Moon M, Boccuti C. Medicare and end-of-life care. Washington, D.C.: Last Acts; 2002. p. 5.
- 44 Back A. Cancer. In: Curtis JR, Rubenfeld GD, eds. Managing death in the ICU: The transition from cure to comfort. Oxford and New York: Oxford University Press; 2001.
- 45 Friedman BT, Harwood MK, Shields S. Barriers and enablers to hospice referrals: An expert overview. *J Palliat Med* 2002;5:73–84.
- 46 Health-General Article, Maryland Code, § 15–128.
- 47 Ibid., 19–901(d).
- 48 Ibid., 19–901(d)(1).
- 49 Code of Maryland Regulations, § 10.09.67.23A.
- 50 Insurance Article, Maryland Code, § 15–809.
- 51 Harris Interactive, Inc. A study about end of life care. Prepared for: The National Hospice and Palliative Care Organization. January 28, 2002. (Accessed at <http://www.nhpco.org/public/articles/020402survey.pdf>)
- 52 National Hospice Organization. Caring for our own with respect, dignity, and love the hospice way. National Hospice Organization. 1994.

- 53 Committee on Care at the End of Life; Field MJ, Cassel CK eds. Division of Health Care Sciences, Institute of Medicine. *Approaching death: Improving care at the end of life*. National Academy Press: Washington, D.C.; 1997.
- 54 Hilden JM, Emanuel EJ, Fairclough DL, et al. Attitudes and practices among pediatric oncologists regarding end-of-life care: Results of the 1998 American Society of Clinical Oncology survey. *J Clin Oncol* 2001 Jan 1;19(1):205–12.
- 55 American Society of Clinical Oncology. Cancer care during the last phase of life. *J Clin Oncol* 1998;16(5):1986–96.
- 56 Levy MH, Weinstein SM, Carducci MA. National Comprehensive Cancer Network Practice Guidelines in oncology: Palliative care. *Cancer Control* 2001;8(6 Suppl):66–71.
- 57 Ross DD, Fraser HC, Kutner JS. Institutionalization of a palliative and end-of-life care educational program in a medical student curriculum. *J Palliat Med* 2001;4(4):512–18.
- 58 Weissman DE, Mullan PB, Ambuel B, von Gutten C. End-of-life curriculum reform: Outcomes and impact in a follow-up study of internal medicine residency programs. *J Palliat Med* 2002;5(4):497–506.
- 59 Sherman DW, Matzo ML, Rogers S, McLaughlin M, Virani R. Achieving quality care at the end of life: A focus on the End-of-Life Nursing Education Consortium (ELNEC) Curriculum. *J Prof Nurs* 2002;18(5):255–62.
- 60 Rabow MW, McPhee SJ. Better books: End-of-life care content in best-selling oncology textbooks. *Oncology* 2001;61:323–4.
- 61 Center for the Evaluative Clinical Sciences at Dartmouth Medical School. The Dartmouth atlas of health care. (Accessed at: <http://www.dartmouthatlas.org>.)
- 62 See note 29.