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CORRECTIONS

In "Promises to Keep" by Carol Jaffarian, MS, ANP-BC, which appeared in the May/June issue of *Worcester Medicine*, the photograph below was omitted from the article.



Staff of the Armenian Relief Society's Mother-Child Clinic and Birthing Center in Akhourian, Armenia, with Carol Bova (first from left, first row) and Carol Jaffarian (third from left, second row).

"Legal Consult" by Peter Martin, Esq., which appeared in the May/June issue of Worcester Medicine, cited a contribution to the article by Terry Briggs. Mr. Briggs did not contribute to the May/June "Legal Consult."

The WDMS Editorial Board and Publications Committee gratefully acknowledge the support of the following sponsors:

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Editorial

Jane Lochrie, MD



Jane Lochrie, MD

By 2020, the number of people living with at least one chronic illness will increase to 157 million. Today, seven out of 10 Americans die from chronic disease. Approximately 6 million people in the United States could benefit from palliative care, and it is estimated that if palliative care were fully penetrated into the nation's hospitals, total savings could amount to \$6 billion per year.

Palliative care is specialized medical care focused on providing patients with relief from the symptoms, pain and stress of a serious illness ~ whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. This issue of *Worcester Medicine* focuses on the importance of palliative care in our community.

In the first article, Maria Dunn, MD, describes the difference between palliative care and hospice. Palliative care is available in both the Worcester health care systems and improves quality of life, patient satisfaction and reduces cost at the end of life. She points out the major shortage of palliative care physicians.

The second article was written by my colleague and good friend, Dr. Ken Kronlund. He suggested the topic for this issue because he thinks that primary care physicians and specialists do not offer enough palliative care to their patients, and when they do, it is late in the course of their illnesses. He believes that many physicians are uncomfortable broaching this subject with their patients because they have not been trained in this and they feel it may take away the patient's hope if they tell a patient there is no cure for their illness. He would like to see all providers develop more comfort and expertise in palliative care discussions and documentation.

Msgr. Beaulieu provides the ethical point of view; he affirms that illness is more than a physical condition. The patient is a person who should be treated in body, mind and soul. He reminds us that the ultimate goal of any healing profession is to "cure sometimes, to relieve often, to comfort always."

The pharmacological perspective is offered by Dinesh Yogaratnam, Phar.D. He comments that when patients or their families request comfort measures only, they often have all their current medications discontinued. The safety and consequences of abruptly stopping each medication should be reviewed carefully. Optimizing drug therapy for the underlying disease state may ensure patient comfort.

Dr. Nasheed Usmani opines that, unfortunately, there is a great opposition to pediatric palliative care, both by health care providers and by the families of children with serious illnesses. This is seen as abandonment of therapies in anticipation of the child's death and giving up hope of recovery. As a result, the child often dies with unmet palliative care needs and suffers from symptoms of the disease, as well as the treatments.

The palliative care team from St. Vincent Hospital includes Julie West, NP; Jessica MacDonald, LCSW; and Bruce Karlin, MD. They advocate for the first discussion regarding prognosis and long-term plans to be early in the course of an illness and to be in the primary care physician's office, not during a crisis in the hospital, where the patients and families do not know the physicians taking care of them. Unfortunately, this is usually when they are called, but they are up for the challenge and give several examples of the ways they can help.

Dr. Suzana Makowski reviews the new state legislature that increases palliative care services by requiring that information be given regarding palliative care to all patients who would benefit from these skills. Palliative care specialists assist in the management of complex pain and other bothersome symptoms, assessment and support of psychosocial and spiritual needs, and help design health care around the patient's values and goals.

Finally, Jean Boucher, Ph.D., RN, NP, is an oncology nurse practitioner at UMass. She emphasizes the importance of the team approach to palliative care, including physicians, nurse practitioners, nurses, pharmacists, social workers and others, such as clergy, to focus on the individual's personal goals for treatment. She highlights the importance of documenting these goals in the medical records, as well as completing a health care proxy.

Please don't close the cover of this copy of *Worcester Medicine* without reading this year's Berlin Writing Contest winner, Laurel Dezieck, UMMS3, article, "La Blanche and the Consumptive." She describes her heart-wrenching experiences as a volunteer in a public hospital in Cameroon.

In closing, I would like to thank Dr. Kronlund for suggesting this topic and for all of his support for this volume of *Worcester Medicine*. If anyone else has a suggestion for future issues, I would love to hear from you.

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^{*} Most recent full-year data (2013): Organ Procurement and Transplantation Network (www.optn.org)

President's Message

Frederic Baker, MD



Frederic Baker, MD

The best ideals of medicine are embodied and championed by you, the members of the Worcester District Medical Society. I am truly honored and humbled to serve as your new president. I wish to thank our immediate past president, Dr. Mike Hirsh, for his great service, stewardship, energy and vision, which has touched and inspired so many of us.

One cannot help but appreciate and admire the tremendous amount of talent, diversity and history that defines this society. The WDMS is the third oldest medical society in the United States. Established in 1794, there were 41 physicians who attended the first meeting. Today, the membership is the second largest district medical society in Massachusetts, with more than 2,000 members. Serving as a role model to other district societies in the Commonwealth, ours is the only district to boast a magazine, TV show and accreditation for past CME programs.

The mission of the medical society remains as true today as when it was founded more than two centuries ago, that is to "advance medical knowledge {and} to develop and maintain the highest professional and ethical standards of medical practice and healthcare." The society is where physicians of all generations, specialties, employment arrangements and geographic settings cast aside any differences and come together as one, in a manner unrivaled by any other organization. The society also represents medical students and enjoys a longstanding collaboration with the Alliance.

We share a common foundation of rigorous training and education, a dedication of service to others and the privilege of having initially complete strangers entrust their care and lives with us, in a manner that they would never yield to their closest friends and loved ones. At times, our roles call for us to be healers, listeners and mediators. We guide people through times

of both great hardship and triumph. Truly, the doctor-patient relationship is a sacred bond that transcends the boundaries of time, geography, economy, ideology and culture. It must always be patient-centered and free of unwelcome corporate, political or special interest. The WDMS is committed to preserving those ideals.

The public has a right to demand more accountability, transparency and a more equitable allocation of limited resources. The concept of enhanced value, or better outcomes at lower costs, is driving much of the transformation in medicine. As physicians, we face many challenges, and we are sometimes charged with some unrealistic expectations to do more, with fewer resources and in far less time. Ideally, our technology should facilitate workflow and enhance productivity, rather than disrupt or disproportionately burden. Health care systems must be designed to better integrate care, rather than alienate or fragment, and everyone should share a sense of great value. We should accept nothing less.

Perhaps, now more than ever, the role of organized medicine could not be more important. Like voting, if we are not engaged, we surrender not only our right to a better future, but we run the risk of others defining the agenda, with greater potential for adverse consequences. Organized medicine is perhaps our best resource to counter or prevent burnout, providing us with the solidarity and resources to best identify and correct disparities and inequities, while promoting dignity of all and the fruition of better outcomes. The same passion and energy that was critical for guiding us through our demanding training and that we call upon daily to make a difference in the lives of others is the same energy the society seeks of and imparts in its members.

The WDMS provides us with opportunities reminding us that that there is a life beyond medicine, whether it is networking, social events, appreciation of the humanities, community service or just the exchange of ideas.

Whether it is mentoring medical students, providing commu-

Palliative Care 101

Maria C Dunn, MD

Frank (not his real name) is a 57-year-old gentleman with advanced COPD suffering from severe anxiety and dyspnea. He was quite concerned about his frail, elderly mother, who was now home alone without assistance, and felt guilty for letting his mom down. Though initially reluctant, Frank consented to a scheduled, low-dose opioid, which was carefully increased to alleviate his dyspnea, in addition to oxygen and his usual pulmonary medications. Frank also took a benzodiazepine as needed for anxiety not relieved by the opioid and was started on a bowel regimen to prevent opioid-induced constipation. Elder services were brought into to his home to care for Frank's mom, and she was able to receive Meals on Wheels. A staff member brought a laptop to Frank's house, and mother and son Skyped, as they had not seen each other for two weeks. Frank was very grateful. He could not believe services could be set up for his mom so quickly and was happy to see his mom through the computer. As far as medical management was concerned, Frank said, "This really does work. I wish I listened to you sooner. I feel better and can walk longer than I used to."

Palliative medicine provides specialized care for those with serious, life-limiting illnesses such as cancer and/or chronic medical conditions, including, but not limited, to COPD, CHF and dementia. Patients do not need to be at end-of-life to benefit from palliative care services. Care may be provided at any point during the disease trajectory and concurrent with curative treatments.

Procedures include expert communication, pain and other symptom management, as well as psychosocial and spiritual support to provide improved quality of life for patients and their families. Palliative medicine takes a multidisciplinary team approach, which includes physicians, nurse practitioners, nurses, CNAs and social workers, to provide whole-patient and family-centered care in alleviating symptoms and suffering. Hospice, on the other hand, is a health insurance benefit and a service for patients with a prognosis of less than six months as determined by two physicians. Hospice is a subset of palliative medicine that utilizes the same multidisciplinary approach for those who are at end of ife. Hospice also provides bereavement services for 13 months after a patient's passing.

Hospice and palliative medicine is a relatively new specialty, starting with board certification provided through the American Board of Hospice and Palliative Medicine from1996-2006. Since 2006, the American Board of Medical Specialties officially recognized hospice and palliative medicine as a subspecialty by 10 participating boards and, in 2007, by the American Osteopathic Association. As of 2012, physicians wanting to

practice in this field are required to complete one year of fellowship training prior to sitting for the boards. For a complete list of clinical training opportunities, fellowships and hospice hedical Director Certifications, visit http://aahpm.org/career/clinical-training.

Palliative care may be provided in inpatient settings, outpatient clinics and in patients' homes. Medicare, Medicaid and most private insurances cover these services.

Inpatient palliative care services are provided at St. Vincent Hospital, MetroWest Medical Center and the UMass Memorial Hospital systems. In this era of health care reform, palliative care improves quality, patient satisfaction and reduces costs of end-of-life care. For these reasons, most academic medical centers offer inpatient palliative care services.

Outpatient palliative care services in Central Massachusetts, as well as in many parts of the country, are new and growing. With the development of ACOs and population-based healthcare that focuses on the sickest patients, an increased need for community-based palliative care will be needed. However, the majority of Americans do not have access to outpatient services due to constrained resources. A major barrier is the lack of palliative medicine physicians. As reported by NPR in April 2013, there is a shortage of approximately 18,000 palliative care physicians, with only approximately 300 completing a fellowship program each year. Most outpatient services are provided as an outgrowth of inpatient services at the major academic centers. In Central Massachusetts, outpatient palliative care services are currently offered by UMass at the Ambulatory Care Center and Reliant Medical Group at its internal medicine PCP offices. For questions regarding UMass services, call the Palliative Care office at 508-334-8630. For questions pertaining to Reliant Medical Group services, call the Department of Geriatrics at 508-595-2000.

For additional information and resources, you may visit the Hospice and Palliative Care Federation of Massachusetts (HP-CFM) website at www.hospicefed.org. Other useful websites for clinicians, patients and families include http://getpalliative care.org and http://palliativedoctors.org.

Dr. Dunn is a staff physician in the Department of Geriatrics and is the director of outpatient palliative care at Reliant Medical Group and assistant professor of medicine at UMass Medical School. She is fellowship trained and boarded in both geriatrics and hospice and palliative medicine.

The Need for Palliative Care and End of Life Planning

Kenneth H. Kronlund, Jr., MD



Kenneth H. Kronlund, Jr., MD

What matters to me most at the end of life is. ...

In the absence of a crisis, this is a question that probably many of us never really address for ourselves and which many of our patients never address, as well. During all of my routine physical exams, starting at age 50, I bring up the topic of health care proxies, briefly discuss end-of-life planning and

give the patient the standard form, which generally is not returned. After a few years and collecting a small stack of forms at home, many of my patients do return the completed forms, and we have a conversation about what kinds of guidance they might have given to their health care proxies. Truth be told, end-of-life planning is a very slow process, which takes a significant amount of time and multiple visits in otherwise healthy patients; it is also often addressed by avoidance by many, patients and providers alike.

For those patients who are truly approaching end of life, spending the time to help them define and verbalize their goals and objectives of care, as well as how they would like to be treated at the very end of life, not only is associated with longer life but also with better outcomes, better patient and family satisfaction and lower costs of care. Altogether too many people believe that the term palliative care is synonymous with hospice care. Clearly, this is not my intent as I address these issues with patients. When I am able to have the conversation, I start by reminding them that, "After all, life is a terminal illness!" and tell them that my goal in their care is to help them be able to live and enjoy whatever time they may have, consistent with their own goals and objectives. This conversation usually happens over several visits and requires the involvement and participation of the family, as well.

Over the 30 years of my practice in primary care, my long-term patients have become like an extended family, and, while I can step into the role of clinical detachment and objectivity for the medical issues at hand, I also have a personal relationship with many, such that I grieve with their losses and celebrate with their victories. They have also taught me much about life and how to practice medicine. One of those patients was Bill Densmore, whom I took care of for many years. In 2002, Bill, along with Brownell Wheeler, the retired chief of surgery at UMass, founded a nonprofit, Central Massachusetts Partnership to Improve Care at the End of Life, to encourage compassionate endof-life care. We had many conversations about what kinds of barriers existed to discuss and implement end-of-life planning; he noted that Dr. Wheeler had expressed his own frustration for what was often extraordinarily aggressive care provided in the last few days of life, simply because a conversation about patient preferences had never occurred prior to a moment of crisis. Their partnership looked very methodically at the issues that patients faced in discussing end-of-life issues from cultural and personal perspectives, as well as from a provider perspective, and developed a pamphlet, "Guide for a Better Ending," which could be handed out to patients, along with a health care proxy. In our early conversations, we talked about how to have the conversation about hospice care, and in later conversations, we talked about palliative care, as well.

I can think of two family members and a close friend who died of metastatic breast cancer, leukemia and pancreatic cancer. Each of them was clearly aware of their diagnosis, prognosis and treatment options, having discussed this shortly after diagnosis with their treating physicians. Each of them had conversations with me regarding how they wanted to live in the remaining time they had. They defined their goals of treatment, expressed the things that were most important to them for the time that they had left, and two of the three pursued aggressive treatments for their respective malignancies. All received excellent palliative care, with symptom control, transfusions

as needed, and ultimately, hospice care for two of the three at the end of life. In the interim, they also participated in family events, completed projects that were important to them and died surrounded by family members, well supported at the end of life. All of them were able to have a sense of control, maintain and strengthen ties with family and friends, have excellent pain control and appropriate life-prolonging therapies. When I went to the funeral for my friend, the priest made a comment of "how lucky he was to have known he was going to die, as it allowed him to live fully in the time that he had left." In his introductory video at the Better Endings website, Dr Wheeler states that "the best gift you can give your family is advanced care planning," and these three did it well.

Palliative care is difficult for many physicians to approach, if they have not had training in it or an experience base that they can readily reference. Physicians truly want to be able to preserve hope and may have difficulty saying that a cure is not possible. I believe that many physicians are uncomfortable asking about patient choices for hospital versus home treatment, breathing support or comfort care. Offering emotional support can be draining, and many physicians may not have great expertise in palliative symptom management. Helping patients and families with the grief and loss processing involved in a terminal illness can be very time-consuming and may not really be amenable to a 15- or 20-minute visit in the primary care physician's office. Frankly, it is quicker (and more remunerative) to proceed to the next intervention than it is to engage a conversation about palliative care options.

Unfortunately, I see far more situations in which the discussion is never broached or resolved.

Amongst my own patients, some
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of them are unwilling to consider their own mortality and vulnerability, and many family members are unwilling to address the topic, as well. According to the Conversation Project national survey of 2013, 90 percent of people think it is important to talk to their loved ones about their own wishes for end-of-life care, but only 27 percent of people have discussed what they want with their families. There are resources available to the public, such as healthcare proxies, MOLST forms and living wills (such as "Five Wishes"), and there are resources locally at BetterEnding. org. I believe that it would be helpful to have palliative care programs readily available in the hospitals, embedded in our oncology services and available to the outpatient community to serve patients at risk. I would like all of us, specialists and primary care providers alike, to develop more comfort and expertise in palliative care discussions and documentation.

The World Health Association defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." I would maintain that the "prevention and relief of suffering" is the basic mission of medicine. We can do better.

Ken Kronlund, Jr., MD, is an internist, quality chief at Reliant Medical Group for Adult Primary Care Medicine and assistant professor of medicine at UMass Medical School.

nity flu clinics and barbershop health screenings, educating the public or collaborating with elected officials, the WDMS represents some of the best resources that organized medicine has to offer in advocacy, mentoring and empowerment of individuals and communities. One of the most ambitious projects the WDMS has undertaken is that of partnering with various community groups to make Worcester the healthiest city in New England by 2020.

Each one of you is a success story, with success being defined not by what one acquires but by what one accomplishes for others. As members of the society, you are often the unsung heroes in health care. But let us not forget that we are never alone in our journeys. Each one of us is stronger because we are part of a community where people believed in us, supported us, comforted us, sacrificed for us, welcomed us, inspired us and taught us. Likewise, that same sense and strength of community is vibrant in the WDMS. It is that spirit which empowers us and those whom we serve.

As president, I reaffirm what great past presidents of the WDMS before me have pledged: to advocate for you and your patients; to advance knowledge, professionalism, collegiality; to inspire future generations to the joys of service; and to promote the best the Society has to offer in improving the health and welfare of the citizens of Central Massachusetts. In closing, I thank you for this opportunity. I ask for your continued support and engagement; for together we are strong; together we shall meet the challenges of tomorrow; and together we shall succeed. Thank you, and God bless.

Frederic Baker, MD, a board-certified attending physician in family medicine, has a full-time outpatient practice in Holden, MA, providing comprehensive care from newborn to advanced elderly patients in Central Massachusetts. He is also an instructor in family medicine and community health at the University of Massachusetts Medical School.

Curing Sometimes ~ Relieving Often ~ Comforting Always: A word of caution – be careful when the technical achievements outstrips the heart

Msgr. Peter R Beaulieu, MA, STL



Msgr. Peter R Beaulieu, MA, STL

INTRODUCTION

The term palliative is derived from the Medieval Latin term palliare or "to cloak." Palliative care is specialized medical care for anyone who is suffering from a chronic illness, minimizing the advance of the disease or relieving problematic symptoms. Thus, its focus is the relief of the symptoms associated with the condition, legitimate pain manage-

ment and attending to the psycho-social dimensions such an illness entails.

RELIGION V. SPIRITUALITY ~ PRIEST v. PHYSICIAN

From time immemorial, the holistic role of one man as priest and physician was the norm. Thus, priestly and healing functions were accomplished by a single individual. At the dawn of modern scientific medicine, in Western cultures, cure for the body was separated from cure for the soul. Priests were relegated to healing the soul, whereas physicians were deemed to be the healers of the body. In addition, the current tendency to accentuate the existential aspects of the human person, as well as spirituality and spiritual care, have seemingly displaced an emphasis on religion due to cultural developments in the West. Such preconceptions need to be properly understood and, especially in matters of palliative care in the United States, both a patient's religious and spiritual considerations should be included. This insight by the sociologist Peter Berger serves to do so. Berger once remarked that if India is the most religious country in the world and Sweden the least, then the United States is a nation of Indians ruled by Swedes. Having set out the parameters, due to restrictions imposed by personal expertise and space, I will eschew treating the broader notion of spirituality and solely focus on the Roman Catholic position in palliative care.

RELIGION ~ HEALTH ~ PALLIATIVE CARE

Almost every religion develops its principles, values, suppositions and objectives based upon the insights of its founder and its sacred texts and translates those beliefs into rituals and practices surrounding coming into the world and going out of it. Then, in a faith with a central teaching authority and through centuries of ongoing moral reflection and its accompanying give-and-take, a body of knowledge has developed to aid its adherents in making medico-moral decisions in regard to life and death. In 2009, Pope Benedict XVI reiterated what his predecessors said in regard to palliative care when he visited the Hospice Foundation of Rome, "Whoever has a sense of human dignity knows instead that they must be respected and supported while they face the difficulties and sufferings linked with their health conditions. Toward this end, today one takes recourse more and more to the use of palliative care, which is able to soothe the pain that comes from the illness and to help infirm persons to get through it with dignity."

ETHICAL PRINCIPLES GUIDING END-OF-LIFE CARE DECISIONS

Diagnosis and prognosis drive the moral reflection on accepting or declining medical treatment. Thus, from the physician's perspective, the patient should know whether the goal of treatment is cure, rehabilitation, palliation or that only humane, legally and morally upright care is available when the previous three options are no longer realistic. Then, in matters of pain management, in general, there must be physical conditions (e.g., excruciating pain or obvious breathing difficulties) that the patient is manifesting to warrant the use of opioids or palliative sedation. The governing moral principle, widely used, though borrowed from Catholic moral thought, is the Principle of Double Effect: The physician's intention must be to treat the pain or symptoms and not to hasten death by over-subscribing pain medications. The overall paradigm of moral analysis should be the distinc-

Continued on page 16

Medication Management in Palliative Care

Dinesh Yogaratnam, PharmD, BCPS



Dinesh Yogaratnam, PharmD, BCPS

I encountered my first "CMO" (comfort measures only) medication order during my pharmacy residency. The instructions read:
1) discontinue all current medications and 2) initiate morphine drip, titrated to comfort. I needed to call the prescriber. The morphine order would need clarification ("titrate to comfort" orders were not allowed at our hospital; detailed dosing parameters were required). What was

more difficult to reconcile was the order to stop all the other medications. Our patient was receiving more than 20 different medications. There were chronic medications for depression, anxiety, seizures and chronic obstructive pulmonary disease (COPD). Was it safe to shut them all off like a light switch?

Unfortunately, there is little guidance on how to best transition a patient's therapeutic drug regimen to a more comfort-oriented focus. 1,2 As patients near the end of life, it may be reasonable for caregivers, patients and loved ones to jointly reevaluate the risk-to-benefit ratio for each drug on the patient's medication list. Side-effect profiles, daily pill burden and drug-associated costs may weigh more heavily as the time to clinical benefit approaches or exceeds the predicted life expectancy of the patient. The decision to continue a drug should consider whether the intended therapeutic benefit of a drug is improving quality of life in a manner that is consistent with the patient's wishes.

The safety and consequences of abruptly stopping medications is a crucial factor to be taken into account when transitioning to comfort-oriented care. The risk of either unleashing a distressful feature of an underlying disease or inducing drug withdrawal symptoms should influence the rate and extent of dose tapering. If my patient's neuroleptic agent (phenytoin) were suddenly withheld, would he suffer a seizure before death? Would stopping the antidepressant (fluoxetine) cause him to rebound into major depression during his final days? Might eliminating the anti-anxiety drug (alprazolam) lead to hallucinations secondary to acute benzodiazepine withdrawal?

A major challenge in making these determinations is that accurately predicting the duration of life expectancy, in both terminal illness and the acute care setting, remains a struggle even for expert clinicians.³⁻⁶ Ideally, discussions about the goals of drug therapy should be held as early as possible, and the agreed upon plans should be frequently reassessed.

In contrast to the lack of guidance for withdrawing pharmacotherapy, formal resources are available for prescribing rational palliative drug therapy in the intensive care unit (ICU) setting.⁷⁻¹³ Due to a paucity of published clinical research in palliative drug therapy, however, the recommendations in these clinical practice guidelines tend to be based more on cultural, ethical and legal standards, rather than on objective scientific evidence. Still, these publications should be considered valuable references for health care providers and health systems seeking to standardize and improve symptom management for dying patients.

Pain and dyspnea (the unpleasant sensation of respiratory dysfunction) are frequently reported symptoms of dying patients. ¹² Other unpleasant events, such as agitation, delirium, constipation and nausea may arise as either a consequence of disease progression or as a side effect of palliative drug therapy. Non-pharmacologic interventions that are in concordance with patient and family wishes should be used to alleviate and prevent these symptoms when possible. Similarly, optimizing drug therapy for underlying disease states may useful for ensuring patient comfort. For example, administering inhaled bronchodilators may a useful strategy for managing dyspnea that is due to COPD. Loop diuretics may be appropriate when dyspnea is due to pulmonary edema from heart failure. ^{9,11} When these interventions are maximized, or are no longer desired by the patient, specific comfort-oriented drug therapy should be offered.

Drug therapy recommendations for end-of-life care are generally consistent. Opioid analgesics, such as morphine, fentanyl and hydromorphone, are widely considered first-line agents for treating pain and dyspnea.⁷⁻¹³ Non-opioid analgesics, such as acetaminophen and non-steroidal anti-inflammatory drugs (NSAIDs), can be prescribed for mild pain or used as adjunc-

tive therapy for more severe pain when there is a need to limit exposure to opioid-analgesics (constipation and sedation are common dose-limiting side effects of opioids).^{7,8,10,12,13} Neuropathic pain may require neuroleptic (e.g., gabapentin or carbamazepine) or serotonergic (e.g., duloxetine) drug therapy to achieve optimal symptom control.7 Benzodiazepines, such as lorazepam and midazolam, and propofol are sedative agents that reduce agitation in the dying ICU patient.^{7,8,13} Haloperidol, a butyrephenone antipsychotic agent, may have a role in treating agitated delirium, but robust clinical trials are needed to confirm its efficacy in this setting.^{7,14,15} Similarly, the use of anticholinergic drug therapy, such as atropine, glycopyrrolate and scopolamine, to prevent respiratory secretions and gurgling (sometimes referred to as "death rattle") at the end of life, is not currently considered a standard of care due to a lack of robust research in this area. 16-19 Dosing of these medications can be exceptionally challenging in the palliative care setting.

Medications that are prescribed to treat pain, dyspnea and agitation at the end of life require careful monitoring and screening for adverse effects, drug-interactions and clinical effectiveness. Patient self-report should be used to assess symptom intensity and response to treatment whenever possible. As patients lose the ability to communicate effectively with caregivers and family members, it may be challenging to assess response to therapy. If patients are not able to self-report, objective bedside screening tools for pain, dyspnea, agitation and delirium are available to help caregivers determine symptom severity and assess patients' response to drug therapy.^{7,9,11,13} As therapeutic interventions to sustain life are withdrawn, patients' organ function and mental status may deteriorate. These changes may necessitate frequent reassessment of dosing and drug selection.

A challenging aspect of end-of-life drug therapy involves the concept of palliative sedation. Nhen patient suffering cannot be controlled with typical interventions, drug-induced sedation to the point of patient unconsciousness may be necessary. This may hasten death. As long as the intent of therapy is to relieve pain and suffering, it is considered appropriate to provide escalating doses of analgesic and sedating medications, even if doing so will shorten the duration of the patient's life. This is referred to as the Principle of Double Effect. This distinction between palliative care and euthanasia provides an ethical rationale for not withholding effective doses of comfort-oriented medications.

Achieving the best possible level of patient comfort and dignity is a universal goal for patients, families and caregivers. This is especially true in the palliative care setting. Early inclusion of palliative care services, either integrated into standard health-care practice or as a consultative service, and open and frequent discussion between families and caregivers and amongst health care teams may help to optimize drug therapy and improve quality of life. ^{20,21} Symptoms of distress and discomfort are not only agonizing for the patient, but they can also be psychologically distressing for the patient's family and caregivers. Drug thera-

py can play a useful role in ameliorating and preventing many of the unpleasant symptoms associated with end-of-life care. Unfortunately, these patients may also be especially vulnerable to medication-related errors. ^{22,23} As much careful consideration that goes into prescribing drug therapy should be applied when withdrawing drug therapy. Acknowledging the challenges associated with drug therapy management at the end of life, The Society of Critical Care Medicine's recommendations for end-of-life care include the following statement:

"Although many drugs can be used to treat pain and agitation at the end of life, the importance of the practitioner's familiarity with the drug cannot be overemphasized. In the last few hours of life, there may be only one chance to prevent pain, dyspnea, and delirium. As much expertise is necessary for the appropriate use of drug therapy at the end-of-life as for any other pharmacologic intervention in critical care." ¹³

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tion between proportionate vs. disproportionate treatment. This is an ethical distinction and is not a reference to the current state of medical knowledge or practice. Thus, overly burdensome treatment that provides little or no benefit to the patient can be declined, whereas beneficial treatment, wherein the benefits outweigh the burdens of treatment, is medically and morally indicated. Then, in situations where cure proves impossible, and so, death becomes a real prospect, never underestimate the religious and spiritual aspects of preparing for that event for some who believe death is a door and not an end. Hence, properly preparing for that life-changing occurrence requires attention to spiritual health and the religious rituals surrounding dying and death.

CONCLUSION

Arguably, one of the primary purposes of medicine in treating and caring for the chronically ill patient who can benefit from palliative care is the relief of the full gamut of pain and suffering caused by their medical condition. Yet, illness is more than a physical condition alone. The patient remains a person and must be treated in body, mind and soul. It is the ultimate goal of any healing profession "to cure sometimes, to relieve often, to comfort always."

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Pediatric Palliative Care

G. Naheed Usmani, MD

The World Health Organization defines palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

The current model of palliative care as applied to children embraces the concurrent administration of curative and supportive care with attention to physical, psychosocial and spiritual concerns from diagnosis through the trajectory of their illness. Such comprehensive care requires input from a multidisciplinary team that includes teams of physicians, nurses, social workers, chaplains, child-life specialists, pharmacists and physical/occupational therapists. In actuality, there is great resistance to pediatric palliative care, as health care providers and families of the children see it as synonymous with end-oflife care, connoting an abandonment of intensive therapies in anticipation of the child's death with giving up hope for a cure or recovery (Wolfe, 2000; Boldt, 2006). As a result, infants and children who die following a protracted period of aggressive, curative care often die with unmet palliative care needs as they suffer from symptoms of advancing disease, as well as ongoing treatments (Feeg, 2005; Galloway, 2000; Meyer, 2002; Wolfe, 2000).

Recently, experts from the American Academy of Pediatrics (AAP) and the Institute of Medicine (IOM) released reports calling for the development of programs that integrate pediatric palliative care into ongoing medical management from the time of diagnosis through the end of life. In the Institute of Medicine's patient-centered model, a) patients and families are kept informed and actively involved in medical decision-making and self-management; b) patient care is coordinated and integrated across groups of health care providers; c) health care delivery systems provide for the physical comfort and emotional support of patients and family members; d) health care providers have a clear understanding of patients' concepts of illness and their cultural beliefs; and e) health care providers understand and apply principles of disease prevention and behavioral change

appropriate for diverse populations.

From 1985-2003, survival data was available for 99 percent of 10,964 of live births of children with congenital anomalies in the United Kingdom (Tennant et al. 2010). Twenty-year survival was 89.5 percent for cardiovascular system anomalies, 79.1 percent for chromosomal anomalies, 83.2 percent for digestive system anomalies and 66.2 percent for nervous system anomalies. While the proportion of terminations for fetal anomaly increased throughout the study period (from 12.4 percent in 1985 to 18.3 percent in 2003; p<0.0001), overwhelming majority were carried to term. Technologic advances and medical expertise have led to improved outcomes, but many of these surviving infants are left with complex chronic conditions and severe neurodevelopmental disabilities with special health care needs and technology dependence. Breakthrough of chronic seizure disorders, chronic lung disease exacerbated by intercurrent illness or aspiration events, ventilator dependence and other problems related to their primary conditions require frequent emergency medical care, extended ICU stays and hospitalizations over longer life spans. (Graham, 2007, Carter, 2006), but incurable conditions continue to lead to premature death.

Feudtner et al. reported in JAMA on the 896,509 deaths that occurred during infancy, childhood or adolescence in the United States from 1989-2003. During those years, 22.1 percent of the deaths were attributed primarily to an underlying complex chronic condition, 92 percent of all deaths occurred in hospitals, with most deaths occurring in the pediatric (49 percent-59 percent) and neonatal intensive care units (31 percent-33 percent) (Feudtner, 2007). In a UK tertiary care pediatric hospital death data analysis, the majority (57.7 percent) were among infants, with leading diagnoses at death of congenital malformations (22.2 percent), perinatal diseases (18.1 percent), cardiovascular disorders (14.9 percent) and neoplasia (12.4 percent) (Ramnarayan, 2007). Most of the deaths occurred in an intensive care unit (ICU) environment (85.7 percent), with a significant increase in ICU admissions over the years (80.1 percent in 1997 to 90.6 percent in 2004). Inspite of IOM, AAP and WHO recommendations, so far there has not been a widespread adoption of such pediatric palliative care services.

Palliative care programs, which are a relatively recent phenomenon in pediatric departments, are being offered to help assist with these CCC patients, but their utilization remains low, and palliative consultations are often sought only after all else has failed, as end-of-life care in the last week or hours of a dying patient. Palliative care programs can do much more but are often viewed as an unacceptable mode of care because they are seen as synonymous with end-of-life care, connoting an abandonment of intensive therapies in anticipation of the child's death.

This current model of treating children with CCC through episodic, aggressive, intensive therapies, which are often uncoordinated among multiple specialists, places immense burdens of cost and care on the health system and families, not to mention the toll on these pediatric patients (Widger 2007, Knapp 2009). Yet caregivers, in their desire to do everything possible during each episode of hospital/ER/ICU admission, implement aggressive, intensive therapies, while patient families go along without feeling much sense of control or having an overall care plan in these extended, expensive ICU stays. Families also bear huge personal financial burdens during such hospitalizations, which include travel, stay, food, transportation, co-pays and lost work income (Alexander 2003, Galbraith 2005, Wasserfallen 2006, Board 2003).

Can we do better? Can we start implementing holistic patient and family centered care that alleviates all dimensions of suffering for our population of children with complex chronic conditions? (Liben, 2008)

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Palliative Care at Saint Vincent Hospital

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Patients need time to grapple with the losses brought by chronic disease. Ideally, trusted caregivers and their patients discuss prognosis and plans during calm outpatient visits. Early discussions afford patients the time needed to grieve the losses engendered by their diseases. Unfortunately, disease crises often preempt the opportunity for calm contemplation. In crisis, patients rarely progress far through the stages of grief, often denying or raging about their situation. Furthermore, the trusted primary care team is not often available, and the care is given by a hospitalist team that is new to the patient. In end-stage disease, a failure to grieve leads to a search for futile, burdensome care. The first discussion about the natural course of Alzheimer's disease should not be during the patient's major stroke. The first discussion about the natural history of COPD should not be during an episode of respiratory failure. A patient should know that a prolonged death is far more likely than a robust recovery when he opts for resuscitation.

Palliative care is the new discipline that addresses this problem by promoting quality of life through symptom management and holistic support of patients, families and caregivers. More and more, physicians turn to palliative care as they witness how the palliative care teams smooth the course of chronic disease management. Palliative care focuses on quality of life for people with life-limiting conditions or significant symptom burdens. Studies clearly show that palliative care prolongs life and eases death.

When, suddenly and unexpectedly, a patient finds himself in crisis, we at Saint Vincent Hospital use a trigger system to incorporate a palliative care discussion in his care. This is often the first introduction of patients and families to our new, valuable discipline. We can then optimize care by discussing the patient's and family's wishes for advanced care planning. We also assist these patients and families to process the change in condition and how it may affect the future, so they make informed medical decisions. Many triggered consults are simply informational, but sometimes those simple consults can clarify important issues before a crisis. For example, one health care proxy misunderstood a physician question and changed his mother's status to a full code, contrary to her wishes. During a discussion with the palliative care consult, the proxy recognized that mistake and reinstated the DNR status. Soon after, the patient had a cardiac arrest and passed quickly, according to her wish. Palliative care supported the proxy in his bereavement, and he stated his appreciation for our discussion and the pain it avoided.

While many of our palliative care consults are for late-stage disease, we still see a fair number of cases where we can plan. For example, a young woman with advanced coronary disease and an ischemic cardiomyopathy had multiple admissions for recurrent chest pain. Part of her chest pain was cardiac, but another part was "noncardiac" anxiety. The unmanaged chest pain frustrated the patient, while hospitalizations interfered with the life she wanted to lead. Her goal was to control the pain more aggressively at home and have a plan in place if the pain or anxiety needed additional interventions. When she balanced the safety of hospitalization versus its intrusion into her freedom, she accepted a different trigger for hospitalization, reducing her hospitalizations. She even opted for hospice as a better means to achieve pain control. She understood that hospice did not mean giving up or "just being comfortable"; it meant managing, with an eye to quality of life rather than quantity of life. In end-stage conditions like heart failure, aggressive care may eke out a few days but impede living well during limited time.

In another case, palliative care provided an opportunity for a family to support its 77-year-old dying mother without intubation or feeding tubes while allowing time for relatives to return from overseas and arrange for post-death rituals. The family members realized that they could let their mother go, optimize her quality of life and still respect cultural and spiritual beliefs. Strong relations that develop during these intense discussions make the palliative care team a resource for planning. Families often turn to the hospice team for advice during the hospitalization. One 85-year-old woman deteriorated quickly after initial discussions. The bond with palliative care allowed the family and patient to quickly accept hospice care at home.

Palliative care helps patients and physicians tune their expectations to the disease reality while enhancing the supports for realistic goals. Palliative care helps patients live fully and then die well.

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Speaking of Palliative Care: Responding to a New State Mandate

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"After January 1, 2015, no original license shall be granted to establish or maintain a health care facility, health maintenance organization or acute care hospital, as defined by section 25B, unless each has established a system for identifying patients or residents who could benefit from palliative care and provides information about and facilitates access to appropriate palliative care services for patients or residents with serious illness."

~ Bill H.2104: Chapter 111 of the General Laws, Section 51: https://malegislature.gov/Bills/188/House/H2104.

The state legislature passed a bill to increase access to palliative care services by mandating that any patient who might benefit will be given information about palliative care. The responsibility of this generally falls to the attending physician.

Introducing palliative care services to patients can seem, to many, another layer of giving bad news. Palliative care is a relatively new field, and it is still often misunderstood. It has historically been equated with what is offered to patients when "nothing more can be done." As a consultant in palliative care, I often meet colleagues who share with me that they have a patient who could benefit from palliative care services but that they are "not there yet." You may be familiar with these scenarios:

A patient with advanced lung disease, who frequents the hospital many times a year for COPD exacerbation, is oxygen dependent and rightly fears decreased medical attention or care.

Another patient with metastatic non-small cell lung cancer with pain from bony metastasis who is a fighter and has never been known to give up. Speaking about palliative care to these patients may seem as, if not more, daunting than divulging the diagnosis. Sharing a diagnosis explains the why of a patient's symptoms or concerns. What usually follows is the explanation of a plan that will help things return to normal. But when palliative care is introduced, it usually implies that things are unlikely to be normal again. For many providers I speak with, introducing palliative care to a patient suggests a failure of health care or of our skills as physicians to heal or to help. To many, it implies giving up hope.

My experience has been different: Introducing what palliative care has to offer patients and their families may actually help redefine hope, alleviate distress, assist in designing health care around a patient's values and goals and can help ensure non-abandonment. The data supports this perspective: Access to early palliative care services has been shown to increase longevity in some patient populations, as well as provide increased quality of life and decreased hospitalizations. (Reference ~ NEJM)

As a fellow in palliative care, I remember sitting with an oncologist whose introduction to hospice care was so clear. She reminded the patient and family of how optimal care had been offered from the time of diagnosis ~ at times with the help of chemotherapy, at times with radiation and other times with surgery. Now, she explained, optimal care could be achieved with the help of hospice, which could ensure symptom control, support the patient and family and help the patient achieve unmet goals as best as possible.

Instead of introducing palliative care as a solution when little can be offered, referencing what the specialty provides is another means to introduce the services.

Management of complex pain and other symptoms. Palliative care specialists can help guide clinicians in managing exceptionally complex symptoms that exceed usual practice experience or training (such as pain requiring high doses of opioids).

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The Hope of Palliative Care

Jean Boucher, Ph.D., RN, NP



Jean Boucher, Ph.D., RN, NP

As an oncology nurse practitioner, I have been asked many times, "What does palliative care mean? Is it the same as having hospice care or end-of-life care? Am I going to die soon? Are you giving up on me?" Provided by health care professionals for persons with serious illnesses, palliative care is specialized care that includes medical therapies to palliate disease-related conditions throughout the course

of the illnesses. Palliative care also involves transitioning to end-of-life care ~ providing comfort while maintaining dignity at the end of life and, thus, a hope for each day. Palliative care can also relieve distress from associated symptoms, including pain and depression, while providing support for related stressors.

The risk of not understanding what palliative care provides can lead to hopelessness and despair, including an inability to pursue further goals with purpose and meaning. How do we, then, talk to patients and families when opportunities arise to discuss what palliative care is all about? And how do we maintain the hope of palliative care to sustain quality of life with comfort and dignity for an individual, including not giving up on them? Palliative care can be offered to persons with serious, life-threatening illnesses or diseases that are chronic or may not be curable. Examples of such diseases include cancer, heart disease, lung diseases such as chronic obstructive pulmonary disease (COPD), kidney disease, neurological diseases (such as Lou Gehrig's disease or Amyotrophic Lateral Sclerosis, Alzheimer's or Parkinson's disease) and other serious medical conditions. The goal of palliative care can include hope-filled outcomes to maintain and preserve an individual patient's quality of life, using therapies given at all stages of serious illness to end-of-life care.

A team approach for palliative care includes physicians, nurse

practitioners, nurses, pharmacists, social workers and others, such as clergy, focused on the individual person's goals of care. Participation by the individual patient (including family members and loved ones) in goals of care conversations is essential for providers to communicate the prognosis of the illness involving options for treatments that support positive outcomes. Discussing a patient's wishes regarding care involves meeting with the multi-disciplinary team to plan for consistent goals of care that include appropriate therapies and services. Such goals include discussing information regarding the prognosis of the patient's illness while reviewing options for care that also consider the individual's values and choices. A suggested way to approach these conversations is to also involve trusted family members and loved ones in knowing one's personal goals or wishes. Plans of care involve providing medical care and emotional support; addressing social needs involving family life, work, insurance and financial resources; and discussing spiritual needs involving one's personal life, meaning or religious practices. Writing down a list of these goals and concerns in a notebook can be helpful in a review with the person's health care provider. Setting up a formal meeting about a palliative care plan is an important component. Documenting the goals of care plan in the patient's medical record also includes completing a health care proxy form that identifies the person to make medical decisions if the patient is unable to do so.

Palliative care includes a path for revisiting goals of care when therapies are no longer beneficial. Communication about patient/family preferences as goals of care focus on comfort-related outcomes when medications, such as chemotherapy, or procedures no longer benefit the patient's well-being, while acknowledging illness progression. Hospice care is available to persons who are in the late stages of serious illness or at end of life and provides medical services, emotional support and spiritual resources. Such end-of-life care can be provided as hospice care at home, in a health care facility or in a hospice residence. The transition to end-of-life care maintains patients' hopes for quality of life care that include consistent communication with the health care team, a supportive caring environment, comfort

and relief from suffering. This quote by Dame Cecily Saunders, founder of the hospice movement, reflects the most important aspect of end-of-life care ~ to strive to maintain a person's comfort and dignity: "You matter because you are, and you matter to the last moment of your life."

When I think of explaining palliative care, I think about explaining the journey of palliative care from caring for serious life-threatening illness to end-of-life care. I would answer anyone that palliative care provides hope through therapies, including supportive care for individuals with such illness, until the last moment of life. The hope of palliative care is reflected in sustaining the individual's quality of life, spirit and meaning throughout the course of illness, including a peaceful death. Emily Dickinson described this hope for such care as "that thing with feathers that perches in the soul and sings the tune without the words and never stops ... at all."

Jean Boucher, Ph.D., RN, NP, is an oncology nurse practitioner and assistant professor at University of Massachusetts Worcester Graduate School of Nursing.

State mandate, continued from page 20

Assessment and support for psychosocial and spiritual needs. The interdisciplinary team (which includes physicians, nurses, social workers, chaplains and others) can provide support when the suffering is other than physical, domains that usually fall outside of the expertise of most physicians. (Reference ~ CAPC)

Assuring that patient wishes are followed. Finally, palliative care can also help patients and families with challenging decisions and transitions in their care. I explain to patients that part of my team's role is to help design health care around the patient's values, hopes and goals within the context of their medical condition.

Having direct conversations about palliative care and hospice ser-

vices with patients and their families will likely not be the only way physicians can help ensure that this licensing requirement is met. Having and documenting goals of care discussions with patient will likely also meet this need. Additionally, health care facilities likely will need to develop educational pamphlets for patients, including definitions and a list of regional hospice and palliative care services. Finally, as part of this bill, the Department of Public Health will also develop educational resources for clinicians and patients on its website.

Suzana K.E. Makowski, MD, MMM, FACP, FAAHPM, is the cochief of palliative care at UMass Memorial Healthcare, UMass Medical School.

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La Blanche and the Consumptive

Laurel Dezieck



Laurel Dezieck

The Gerald F. Berlin Prize is awarded for an essay, a poem or series of poems, or a work of short fiction. The annual contest is open to UMass medical students and residents and fellows affiliated with UMass Memorial, Berkshire Medical Center and Worcester Medical Center/St. Vincent Hospital. It is named in honor of Dr. Richard Berlin, a poet

and psychiatrist in private practice in Lenox, Mass., and an associate professor of psychiatry at the University of Massachusetts Medical School's Berkshire Campus in Pittsfield. For additional information about the Berlin Awards and to read previous winning submissions, visit Dr. Berlin's website at http://www.richardmberlin.com/creative.html.

L'Hôpital-Central is a public hospital, but even so, there is a crowd of people locked outside the front gate, languishing in the sub-Saharan heat. The smell of sweat and spoiled meat, combined with the stench of poultices from healers or scam artists and the smoke of coconut frond fires lingers with the masses. The colors of cheap, patterned cotton, with dark skin and dusty legs from the scooter-taxis blend together into a desperate kaleidoscope, sectioned off by the pattern of the chicken-wire fence.

The girl from Boston, a volunteer who often feels like a tourist or a gawker depending on the day, has watched people bleed out at those gates. She has seen women weep and pray to their God and any others that might listen and families grieve at their collective silence. Today, she rushes past the chicken wire to the main hospital building. It isn't fast enough to escape notice. Behind her, she hears the shouts: "La Blanche, La Blanche!

S-il vous plaît." She doesn't turn around, in part because she's afraid that if she does, she'll lose her nerve completely, and in part because she knows she can't give any of them what they beg her for. The first day she came, the desperation and poverty nearly overwhelmed her. She handed out her spare change feverishly and wept every night behind her mosquito net for the rest of the week. Now, the impact of the scene has dulled with repetition, but still the volunteer aches as her naiveté is slowly stripped away each morning, like Prometheus's liver, only to be slowly re-grown each day by the unwavering optimism of a young woman with an able body and an expensive education.

The ward is little more than a line of rickety beds, a few with stained curtains separating them. Fine red dust covers everything, from sheets and wrinkled IV bags to people of all ages in various states of misery. The physicians are already harried; the patients are crying out for water, medicine, mercy. Someone is begging for help. La Blanche searches for the source, desperate to be asked for something she can provide. She kneels next to an old man that is clutching his chest, his eyes closed as he mutters nonsensically, and the girl whispers meaningless words of comfort in broken French, as they fall on deaf ears.

A young boy, no more than 4 or 5, coughs in the corner, and the girl knows that something is seriously wrong, not from any of her fledgling medical training, though she sees his cracked lips and sucked in ribs, but rather a human instinct that senses impending calamity. She turns from her charge, who remains oblivious to her presence, and calls for help. There are two Cameroonian physicians on the ward, but one is busy pushing what seems like the entire lower portion of a young man's small bowel back into his abdominal cavity, and the other is whispering urgently to an increasingly hysterical young woman in the corner. There is a Swedish physician, an ex-pat or

a missionary. He is a grey-haired, fair-skinned man in his 50s who stands across the room from the child as he argues with his mother about antibiotics. She has tuberculosis, but stopped taking the pills weeks ago when she felt better. The rest she saved and gave to her son when he started coughing. Now she is sick again, and her son is bent over double, sweating and grunting at her feet. The woman argues that if she takes all the pills, even when she's not sick, she won't have any to give to her son. Besides, she doesn't really think that they will work anyway. In fact, she knows that a vindictive neighbor cast a spell on her last week. Her son shivers at her feet. She touches his shoulder, and the Swedish man wrings his hands and bites his tongue.

The Cameroonian physician gives up on the small bowel, which is stinking and gray, and turns to the child, who is now a similar color. La Blanche is pulled away from her fruitless ministrations to help. Once she sees that her son is being tended to, the child's mother departs for work. She knows she needs to make enough money that day to keep the doctor's hands on her child, or at least to pay the bills she's already incurred, so that the hospital will release his body to her if he dies.

He does an hour later, quietly, without much ceremony. The girl remains crouched next to him and holds his hand. It's cold and limp, but she clutches it anyway, unwilling to acknowledge that he is gone, another person she couldn't help.

The Swedish doctor noticed first that the child's lips had turned blue, that the muscles in his chest and abdomen that had struggled to keep him alive now are finally still. Someone carries the boy from the room quickly to make space for the next patient in his corner of the floor, next to the kneeling girl. She stares at the cracks in the wood of the floor, a handprint smudged in the dust and decides not to move for the moment. For some reason she worries that if she gets up and leaves, the boy will be completely forgotten and will cease to have existed as soon as that handprint is wiped away.

The child's mother returns late that evening, and still La Blanche hasn't moved from her solitary post. No one has to tell her, and no one does. She covers her mouth with one hand and quietly sinks to her knees, clutching a dirty curtain to her body as though to shield herself from the grief that hurdles towards her. The girl rouses herself from her vigil in the dead child's corner and sits down next to the young mother, now satisfied that someone else will remember that the boy was there. The woman holds the curtain to her mouth and coughs, staining it with flecks of red that smudge pink when they mix with tears and dust.

La Blanche looks at the young mother and suddenly sees not a stricken fruit vendor from West Africa but the heroine of a 24 | Worcester Medicine JULY/AUGUST 2014 19th-century novel. She sees Helen, Marguerite or Fantine, instead. They sit, wasting behind the dilapidated curtain, the martyrs of the tuberculosis that, until now, resided in romantic novels in a well-lit classroom in Boston. She remembers the beauty of the romantic consumptive and wonders if the loveliness of Hugo and Dumas's crafted deaths was a coping mechanism. She supposes that the novelists spun tales of the ethereal Madonna to combat the helplessness and frustration of inevitable death in filthy poverty, as she did now. Old books coming alive in the worst possible sense, winding their way onto the dusty ward. She realizes the absurdity of this comparison, but it's her only frame of reference; the only way that she's even known this disease, because in her life before this one, comprised of suburbs and lofty goals, tuberculosis was flowery prose and doomed red-cheeked girls.

The girl puts her hand on the young mother's shoulder, and the woman turns to her, eyes automatically shuttering her internal anguish. She notes the color of the girl's skin and lowers her eyes. La Blanche decides against speaking but leaves her hand on the woman's shoulder, and the young mother doesn't shrug it off, out of a desire for comfort or for the sake of politeness.

La Blanche closes her eyes to the chaos of the room and, for the first time, hates Hugo and Dumas and Mann and even Murger and maybe Bronte for making their consumptives tragic and lovely. The tuberculois of the novel was so twisted by the horrifying blue child on the dusty floor. She feels betrayed and angered that they had set up a false expectation for her, pained that the reality was so horrifying and devastated that this reality exists at all. It was distasteful to her that death from tuberculosis was so esoteric in one part of the world, that it had become nothing more than a symbol in the western literary canon of pretty tragedy. The whole time, the disease thrived, unchecked and ugly, if one knew where to look for it.

The young mother eventually wanders off to find her son's body, and the girl from Boston stirs and leaves the ward slowly, glancing back at the spot where the boy had died, outside of the pages of any book she knew. The handprint in the dust was gone. She trudges out, past the chicken wire fence, deaf to the calls, "La Blanche, La Blanche!"

Two months later, the volunteer flies back to Boston. She immediately has two tuberculin skin tests and they both come back negative, but she feels as though she's contracted something nonetheless.

Laurel Dezieck is a third year medical student at Umass Medical School. She is a graduate of the College of Letters and Romance Language programs at Wesleyan University.

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Updates in Oral Health ~ How Does This Affect Your Patients?

Hugh Silk, MD



Hugh Silk, MD

Oral health is everywhere. What do you first notice about someone? His or her smile. Alternatively, tooth pain makes daily function impossible. Oral health has profound effects for our overall health and health care system. This article covers updates in trends and guidelines across the lifespan.

ADULTS

Visits to the emergency department for dental issues now comprise more than 2 percent of all visits. And more people are being hospitalized for dental abscesses than ever; there has been a 40 percent increase from 2000-08, costing \$858.9 million and causing 66 deaths. When oral disease is not hospitalizing us, it contributes to other conditions. The American Heart Association (2012) declared that coronary heart disease and periodontitis are associated, but the effect of treatment is unclear. Meanwhile, evidence mounts that diabetes is worsened by periodontitis. A practitioner deciding between adding another medication for such patients versus counseling them about proper hygiene and dental visits should consider the latter. Efforts are underway nationally to include oral health in the patient-centered medical home.

A large study by United Concordia concluded that patients who receive dental care cost the health system \$3,291 less for a diabetic and \$3,964 less for a person with rheumatoid arthritis per year. As local systems contemplate cost containment, they should include dental care as a health benefit.

Access to dental care is improving in Massachusetts. On March 1, MassHealth expanded dental coverage for adults to include restorations/filings for all teeth. MassHealth now boasts that 95 percent of their members have access to at least two dental providers within five miles of their homes. (You can help a patient find a provider or transportation at 1-800-207-5019).

CHILDREN

Pediatric providers should take note of key updates. First, the American Dental Association is now advising parents to brush their children's teeth twice daily with a smear of fluoridated toothpaste from the eruption of the first tooth until age 3 and then a pea-size amount thereafter. Secondly, for those without fluoridated water, fluoride supplements should be given to high-risk children only. Lastly, the U.S. Preventive Services Task Force now recommends (level B) that medical providers offer fluoride varnish to all children, which results in a 37 percent to 63 percent reduction in cavities. In Massachusetts, providers are paid \$26/visit by MassHealth to apply varnish two to four times per year at well-child visits. (For more information or to schedule an office training, contact Eslassoc61@aol.com or 978-371-8816.)

PREGNANCY

Some of the biggest news has come in obstetrics. The American College of Obstetrics and Gynecology recently published a committee opinion and supported National Consensus Guidelines stating, "Women should routinely be counseled about the maintenance of good oral health habits throughout their lives, as well as the safety and importance of oral health care during pregnancy." These guidelines include evidence that dental care, X-rays and most dental medications are safe throughout pregnancy.

Many people visit a medical provider while neglecting to see a dental provider for various reasons. In this case, you are their connection to better oral health. Ask, assess, advise and refer.

Hugh Silk, MD, MPH is clinical associate professor at UMass Medical School in the Department of Family Medicine and Community Health and practices with Massachusetts Partnership for Correctional Healthcare and Reliant Medical Group.



Music Worcester Season 2014-2015

"Music Worcester has crafted a series of concerts and events for 2014-2015 that really celebrates the many successes of the organization while trying out a couple new ideas at the same time. From the legendary Academy of St Martin in the Fields to the Brentano Quartet, Dave Brubeck's son Chris and his trio Triple Play to renowned pianist Jeremy Denk, and violinist extraordinaire Mark O'Connor to the Mexico State Symphony Orchestra – there really is something for everyone next Season." - Adrien Finlay

usic Worcester is pleased to announced its 2014-2015 Season, the second led by Executive Director Adrien Finlay, and will include the return of Academy of St Martin in the Fields, Russian National Ballet Theatre, and the St. Petersburg Symphony. The Season also brings several groups to Worcester for their area debuts, including Chris Brubeck's Triple Play, Mark O'Connor's Hot Swing, and the Brentano Quartet. Subscriptions now available (at least four concerts required). Single tickets on sale late Summer 2014.



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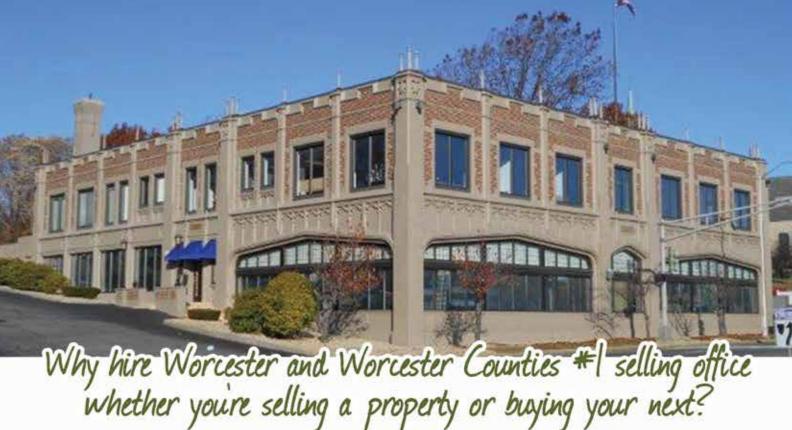
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