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THE CENTER FOR ETHICS AT MEDSTAR WASHINGTON HOSPITAL CENTER

CANCER

Walking the Walk
With Your Patient

MedStar Washington
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- Identify clinical ethical issues in their everyday practice;
- Work through the complex ethical cases they identify, with the tools given in the *Journal;*
- Address any further need for policy development to improve patient care in their practice;
- Recognize the assistance of other departments within a hospital when dealing with ethics cases.

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The Journal of Hospital Ethics

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contents

The Fine Art of Patient Care

Dear Reader,

Thirty years ago, my father died of cancer in hospice care in Florida. I was newly married, finishing my doctoral degree on a student appointment at the National Institute of Mental Health (NIMH), National Institutes of Health (NIH). My mother was a wreck. Hospice not only treated my father's pain (his always sunny nature held fast to the end), hospice cared for my mother's nerves and my grief.

Now, my beloved 80-year-old cousin is also dying of cancer. His case is somewhat different. His disease was caught early. But after months of cascading complications, just as he was finally getting out of the hospital, the cancer—seemingly eradicated—has returned with metastases. All know that there is nothing curative to be done. Fortunately, all also agree that only gentle medical management is in order. My cousin's Advance Directives are clear—no intubation.

For the time being, he is doing well. He is driving again (albeit with his canister of oxygen and his companion to move him in his wheel chair when they reach their destination). Nonetheless, my cousin—also one of the lucky ones whose disposition has always been sunny and continues to be so—is living fully. He is working; he gets into his office and out to meetings. He is engaged with his community; he is able to handle some county affairs, still serving as the County Council Chairman, a volunteer post he has held for years. He still sees his friends; he meets them for lunch several times a week. And he continues to be doted on by his wife of over 5 decades, his daughters, and grandchildren. He is not in hospice and he doesn't want to talk about going into hospice. That's okay for now. That's because his many physicians are doing such an excellent job of providing palliative care, in the broadest sense of the word, that—for now—he continues living a wonderful life.

Thirty years ago, hospice was foreign to many. Fortunately, this was not the case with my parents. My parents' awareness of good end-of-life care was a result of them being particularly well informed. They read the newspapers; they were aware of the Death with Dignity movement sponsored by the Gray Panthers. Also, from the time I was 14 until my doctoral studies, I served as a bedside volunteer in nursing homes. Even as an only child who didn't previously see much death in my own family, my volunteering gave me a bird's eye view of death that I discussed regularly with my father. My parents, even then, had written Advance Directives. Hospice was the logical step for my father.

My cousin is dying in a different time. The fields of palliative care and hospice have matured. But it is also important to note that both my father and my cousin have had the good luck of having excellent physicians—in my cousin's case, some of the best in the country on just this very topic,[1,2] one in particular to whom I shall be grateful for the rest of my days.

But everyone should have access to oncologists at this skill level in both oncology and the palliation of the patient with cancer. Attention to the complete needs of every patient—true palliative care—should be everyone's due.

For all...physicians, learning the skills of attention to all the needs of one's patient and the ability to be fully present is critically important.

To make this kind of excellence the standard of practice everywhere, the road to having all oncologists—and other physicians who treat persons with cancer—skilled in attending palliatively to their patient's needs is to train physicians to pay attention to the social, psychological, and not just physical needs of every patient. This sounds like a tall order but we are convinced it is not as merely aspirational as it sounds. We believe that training physicians in ethics is just to this point. Training in ethics for physicians, especially in cancer, is to sharpen their skills of observation, when possible, the skill of loving attention, and at a minimum, the skill of being able to be fully present when with their patient.

And there is nobody I know or have ever met who is better at all 3 of these skills than the Guest Editor of this issue of JOHE, John J. "Jack" Lynch, MD. To this day, through an esteemed career in oncology, one of Jack's great passions has been training young physicians and medical students in caring for, and being present to, patients with cancer. Almost 25 years ago, from the time I started my own training in research ethics at the NIH Clinical Center, Jack has been one of my most important teachers. For us all in the Center, for most at our hospital, and for many throughout MedStar, the Washington, DC metro area, and nationally, Jack has been one of the greatest champions for palliative care in oncology that one could name. It is an honor to have his fingerprints on virtually every page of this issue.

That he has co-authored our first piece with Christian Carrozzo is the perfect way to introduce Christian to the readers of JOHE. As our newest staff member in the Center for Ethics, carrying the title of Clinical Ethics Educator, he serves as Editor of this journal. We are so grateful to have him—he, too, has had his fingers on every page, and we hope he shall continue to do so for many years.

The next article, by Drs Deliya Banda and Sandra Swain, is on a topic of great importance to progress in cancer care. They provide a balanced view of the need to recruit more patient research subjects while making certain that prospective subjects are well informed and that participants are well protected. The article grows out of a collaborative relationship of student and teacher; Dr Banda just finished her PhD under Dr Swain's guidance. We are particularly thankful for Dr Swain's time, as this year she is not only the medical director of the Washington Cancer Institute at MedStar

Washington Hospital Center, but also President of the American Society of Clinical Oncology (ASCO).

Turning to this issue's policy piece, we thank Marc Boisvert, MD, medical director of the Cancer Institute's Center for Breast Health, for his work on the article about his program. We are all very proud of this program and our pride appears well placed. The Center for Breast Health is seen as a local and national leader in how best to care for patients with breast cancer. Of the many ways this program works, we decided to focus most on its systems organization. A program is only as good as its infrastructure is sound. There has been much attention to the infrastructure of Dr Boisvert's program, and it shows.

Finally, as is our evolving practice, the Residents' Corner brings forward those parts of cancer care that lay the ethical foundation for becoming a well-trained oncologist. Even if oncology is not one's future, it is hard to imagine many subspecialties in which a physician will not, some day, treat a patient with cancer. For all such physicians, learning the skills of attention to all the needs of one's patient and the ability to be fully present is critically important. We expect that the Residents' Corner can provide sound instruction in growing these skills.

We hope this issue brings together attention to ethical matters in the care of patients with cancer that produces some insights for you, our reader. We would love to hear your thoughts. In the meantime, we wish you the best for the New Year.

Sincerely,

Evan

Evan

Evan G. DeRenzo, PhD
Editor-in-Chief

References

1. Levy MH, Adolph MD, Back A, et al. Palliative care. *J Natl Compr Canc Netw.* 2012;10(10):1284-309.

2. Temel JS, Greer JA, Muzikansky MA, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med.* 2010;363(8):733-742.

grand rounds

The Importance of Being Earnest

by John J. Lynch, MD, Medical Director of the Center for Ethics at MedStar Washington Hospital Center

Forty-five years of medical practice as an oncologist and the medical director of ethics has taught me many valuable lessons. First and foremost, it has shown me that relationships count. And to have a healthy and trusting relationship with patients and families, you have to tell the truth from the outset.

Many times over the years, I've been asked, "How do you do it? All your patients die." Well, not ALL my patients die. Many go on to live healthy, productive lives. But more importantly, all my patients are alive at the start, and it's that life that you learn to honor and respect.

Honesty starts at the very beginning, at the first visit. As patients face a possibly tough diagnosis, they are looking to their doctor for information and for reassurance. We must give them that information in a compassionate, truthful manner and offer them our reassurance that we will be their partner in this journey.

Throughout the course of their treatment, we have to help them face the reality of their situation. But that doesn't mean we don't use tact. Typically, we help patients come to terms with their disease in small pieces. As the facts develop, we add information to the total picture.

As time goes on, it's important to repeat key information, be consistent, and remain open to questions. You need to document everything you say, so you know what you have told patients and families. The power of denial is very strong, and you can't let patients continue to deny reality.

Patients are looking to their oncologist for hope. Hope is a spectrum. There can always be hope; we just must continually help our patients refine what that hope is all about. At first, patients hope that a lump is benign. Then patients hope a treatment is available and that there are few side effects during treatment. Then patients hope there is no recurrence. Finally, patients hope for a dignified and pain-free death.

Giving false hope is not doing patients any favors. You don't want to put yourself in a position where patients can say, "That's not what you told me before." It's very easy to block and deny unpleasant information, but if you let that continue, you are doing patients a disservice.

Informed consent is a critical part of the oncologist's job. You have to carefully explain treatment options, advise patients and families (with the patient's permission) about the best course of action, and give them information about the anticipatable outcomes. Here it's best to rely on the literature to give straightforward information about results. But that's not done all in one appointment; often, it takes place over a series of appointments.

When you've used up all the standard treatments and the only options are clinical trials, you should make sure that patients understand the nature of a clinical trial—that they may not benefit, but that participation may help other patients in the future.

Many people think they're coming to an oncologist for a cure. That is too often not the reality, so you prepare patients as you go along. As an oncologist, you have to know when to stop. Don't interfere when interference won't make a difference. Explain to patients what their next option is in order to be kept comfortable. It's up to you to help patients come to terms with the need to stop aggressive treatment.

explain a treatment plan. Patients often report that this information goes in one ear and out the other—they are just too overwhelmed to retain the news, which is often devastating. But having family members present—unless the patient doesn't want family members there—can be key to patients understanding and accepting their diagnosis and treatment. The more families know, the better they can support the patient.

Oncologists should also gather information so patients and families can better understand the disease and know what to expect. Unfortunately, there's a ton of misinformation on the Internet. It's wise for physicians to gather up-to-date, relevant information for your patient, or point them to the best sources. Also, you'll want to caution patients against well-meaning advice from others; such advice likely has little bearing on their case.

Throughout the course of their treatment, we have to help them face the reality of their situation.

A few words about families… Often family members rely heavily on their loved one's oncologist. That's part of your job. It's as important to build strong and truthful relationships with families as it is to build those relationships with your patients.

Families often feel left out. They need to see the whole picture so they can be involved and share the pain, suffering, and treatment. No patient should have to take this journey alone. It is the oncologist's responsibility to interact with families, with the patient's permission.

It's wise to have key family members present at important visits, such as when you give a diagnosis or

If patients lose trust in their doctor, it seriously hampers the doctor's ability to be effective. But remember that trust is a 2-way street. Physicians need to be able to trust patients to follow the plan of care and report their symptoms and side effects.

As a final note, oncologists have to be particularly aware of the dangers of emotional fatigue. By the very nature of oncology, oncologists are going to be involved with patients and families, but sometimes we may have trouble being objective. It is our responsibility to know when our judgment becomes clouded, and we must call on our colleagues for support.

Palliative Care for the Person *With Cancer:*

A Refined Clinical Perception

by Christian Carrozzo, MA and John J. Lynch, MD

Palliative care ought to begin the moment its need is perceived. Definitions of palliative care medicine focus on the goals of treating pain and suffering, relieving stressful symptoms, and improving quality of life for patients and families.[1,2] Properly, these definitions do not emphasize a specific point along a disease continuum where palliative services are imperative. Rather, what is implied in these definitions is that the factor(s) that could mark the need for palliation may become evident at *any* point along the course of a disease or condition. As soon as a patient demonstrates symptoms of significant discomfort or distress in relation to the arduous ills of a debilitating medical circumstance, palliative care services ought to be provided.[3] For some persons with cancer, psychological symptoms may appear the moment of diagnosis or even prior.

The absence of properly assessing and addressing concerns that may or may not be in direct relation to a person's medical circumstance can cause significant distress for patients and families.[4] Responding to this practical need may call for refined clinical skills in being attentive to patients' often subtle indicators. These include, intrinsically, the skills of mindfulness and the ability to be present to one's patient.[5] Palliative care in oncology is far more than therapies designed to reduce physical pain associated with end-stage cancer. Neither is it simply a category of services provided by palliative care specialists.[6] Optimally, palliative care in oncology includes the ability, learned by all clinicians, to see the sometimes very personal and nuanced needs of a person facing cancer.

Table 1 includes delineations from the National Consensus Project[7] illustrating the significant breadth of domains in which quality palliation services ought to exist.

TABLE 1

Domain 1:	**Structure and process of care**
Domain 2:	**Physical aspects of care**
Domain 3:	**Psychological and psychiatric aspects of care**
Domain 4:	**Social aspects of care**
Domain 5:	**Spiritual, religious, and existential aspects of care**
Domain 6:	**Cultural aspects of care**
Domain 7:	**Care of imminently dying patient**
Domain 8:	**Ethical and legal aspects of care**

With the span of these domains taken into consideration, the all-encompassing nature of undergoing treatment for cancer provides insight into why there exists a special focus on palliation in oncology. Oncology's particular dedication to those persons falling under Domain 7 may provide further discernment for why there exists an inappropriately truncated use of palliative care services at the end of life. This narrow understanding of what palliative care can be is not merely held by clinicians. Patients, families, and the general public often connect palliative care to end of life, mistakenly understanding them as conceptually interchangeable and synonymous. Yet at the highest level of oncology practice, they are far from the same.

As soon as a patient demonstrates symptoms of significant discomfort or distress in relation to the arduous ills of a debilitating medical circumstance, palliative care services ought to be provided.

Rather, palliative care is more wisely understood as a philosophy or system of practice focusing on reducing distress and noxious symptoms in all of these domains, whether care is intended as curative or not. Palliative care ought to be central to cancer care; to achieve this goal, several obstacles have to be overcome. They include psychological and cognitive impediments, as well as instrumental barriers such as problems of conceptual definition. But these barriers can be defeated by conscientious and courageous administrators and clinicians, working together to create palliative care service systems that defy its limiting misconceptions and work for patients and families.

RECENT BACKGROUND

In 2009, the American Society for Clinical Oncology (ASCO) released a comprehensive look at progress made over the preceding decade integrating palliative services into oncologic practice.[8] The study reviewed accomplishments, assessed current needs related to the multiple disciplines involved, and perhaps most fundamentally, addressed development of a definition of palliative care. Clinical accomplishments included both an increased awareness of the need for palliative intervention as well as an increase in its general use. Advances demonstrated an increased willingness of health professionals to communicate, collaborate, and inform each other on subspecialty specifics and interdisciplinary perspectives. Yet, even after these relative successes, there remains an inadequacy in identifying the full scope of personal palliative need, accurately discussing the palliation concept with patients, as well as in the proper timing for the introduction and integration of care services.

OBSTACLES TO INTEGRATING PALLIATIVE CARE INTO THE TREATMENT OF PERSONS WITH CANCER

Perhaps the most significant barrier to integrating palliative care into the treatment of patients with cancer is that many physicians do not yet think of palliative care as a standard clinical resource with extensive application. Rather, palliative care is often considered a narrow clinical resource applicable only when a patient is facing the end of his or her life. Often, the introduction of palliative care is merely contemplated when options for aggressive, curative intervention have been exhausted.

A significant number of reasons behind this problem, such as the psychological mechanisms with which clinicians deal with terminally ill or dying patients, fall beyond the scope of this article to properly explore. However, the 2 particular issues this article will attempt to address are both the misconception of palliation with death, hospice, or end-of-life care, and overcoming what may be a conditoned, perceptual incapacity to identify the palliative care needs of patients. This discussion thus focuses on the conceptual decoupling of palliative care from end-of-life care and the consideration of a particular cognitive mechanism that may contribute to this error.

DECOUPLING THE PRACTICE OF PALLIATIVE CARE FROM THE PRACTICE OF END-OF-LIFE CARE

Hospice services are often triggered within mere days of death.[9,10] Palliative care is not and should not be considered synonymous with end-of-life care.[11] Although palliative care services are ordinarily needed by those at the end of their lives, such services are needed by many other types of patients, especially those with severe, critical, and/or chronic diseases or conditions. What appears pervasive throughout related literature is a conceptual conflation of the terms ***palliation*** and ***end-of-life care***.[12,13] Unfortunately, the use of these terms in actual clinical practice is consistent with this conflation.

As ingrained as this misconception is, adjusting the practice of recognizing the need for palliation to an earlier phase in the care of patients may require methods of intervention from a variety of sources. One method involves working with physicians on how they can become more attuned to the palliative needs of their patients by isolating cognitive processes that may provide an explanation as to why these concepts are confused and particular patient needs often missed.

LIMITED PERCEPTIONS

A specific cognitive effect that is known to account for missing information is the result of a psychological principle physicians sometimes learn and use for its ability to increase speed and efficiency in certain clinical contexts. The resulting perceptual effect in association with this well-known psychological principle is known as Gestalt, by which everything is said to be perceived in its most simple form.[14] The Gestalt effect results in the tendency to make quick and easy associations in appreciating one's environment. In many clinical contexts, this limited perception is of substantial benefit, as it is often seen as a cognitive tool that allows for the quick processing of significant amounts of clinically relevant information.[15]

This cognitive tool is, however, also cause for concern. In many cases, this simple form-generating capability of the senses causes one to miss critical details that expose the true connections between parts that constitute the whole. The Gestalt effect may take place during a clinician's first glance at a patient and his or her environment or upon exposure to new information. In pursuit of improved palliative care, this bracketing can result in missed cues for when palliation is needed.

That is, the Gestalt effect can potentially confuse information both conceptually and practically by creating perceptual blind-spots around defining particulars. These kinds of limited perceptions are arguably both responsible for why the concept of palliation is so regularly confused with hospice and end-of-life care, as well as why it is so difficult to recognize the very particular circumstances and nuances of a patient's life. As a cognitive tool, useful in some clinical situations, when considering palliative care needs can produce false psychological connections and result in an incomplete picture. To counter the inclination toward this immediate and generalized perception, conscious efforts by

Dispositional mindfulness has been demonstrated to result in better self-regulated behavior and positive emotional states.

clinicians to counter this kind of habituated response will be necessary.

The Gestalt effect could be said to provide insight to the space between environmentally triggered, physiologically conditioned behavior and conscious involvement in what one is perceiving and actually doing. Much of human function, especially that which is routine, is executed without dedicating special attention or mindfulness to a given task.

Limited perceptions have recently been studied in relation to human motor function, such as the various movements, reactions, and adjustments one makes in response to a generalized perception of driving conditions while operating a car.[16] These actions are automatic and without incisive contemplation. However, though this may be acceptable for driving a car or even a number of simple, routine clinical activities, it may result in inadequacies when assessing the palliative care needs of an individual person with cancer.

To learn how to avoid the blind spots, conflations, and thus potential errors that it may cause, one must become sensitized to how it works. Table 2 lists the ways in which the Gestalt effect can misinform one's perception, sometimes masking critical detail or proper connections.[17]

TABLE 2 Concepts Associated With Gestalt Effect (in clinical perception)

CONCEPT	OPERATIONAL DEFINITION
Figure-Ground	Clinicians may have the tendency to focus on the most prevalent visual perspective, often missing critical elements outside one's perception.
Closure	Clinicians may have the tendency to fill empty spaces by connecting findings in a unified manner.
Proximity	Clinicians may have the tendency to group findings if they are in close proximity to one another.
Similarity	Clinicians may have the tendency to group findings if they are similar to one another.
Common Region	Clinicians may group findings if they fall within a common region or associative group.
Symmetry	Clinicians may group findings if they are in symmetry with one another.

With practice, however, physicians can learn to identify instances in which they may be unwittingly employing a far too general and habituated perception of a clinical environment. These skills are necessary to see one's entire patient, including the personal subtleties surrounding that patient and suggestive of a perhaps earlier and more refined application of palliative care. Avoiding the negative effects associated with limited perceptions can be achieved by assuming a greater mindfulness when exposed to the delicate nuances in a patient's comments, behaviors, and surroundings.

Dispositional mindfulness has been demonstrated to result in better self-regulated behavior and positive emotional states, and the potential transfer of this mood and disposition to a person with cancer could be considered a form of palliation itself, as increases in patient mindfulness over time and throughout treatment relate to further declines in mood disturbances and stress.[18] The morally aware and focally adjusted physician who breaks from a habituated manner of limited perception will engage with a patient proactively, seeking to identify where these personal and circumstantial distinctions are critical to providing good palliative care.

CONCLUSION

Plainly, the care necessary to address the various domains of palliative care needed by a person undergoing the experience of cancer must involve the patient's physician at a deepened level of attention. This enriched attention to patient needs will demand a new consciousness to the ways in which limited perceptions, such as those associated with the Gestalt effect, sometimes useful, can cause clinicians to miss the particular and perhaps earlier need for palliation. This requires the skill of being present, of being mindful, and not merely scientifically or procedurally effective. These skills call for a clinical disposition and process of analysis that consciously attends to contextual particulars[19] and may only be possible once clinicians adjust their thinking to counter the simplification and conceptual bracketing of information. With the consideration of what can be learned by way of a more careful and enlightened perception of patient need, a refined palliative care strategy for the person with cancer may be realized.

Authors

Christian Carrozzo, MA is clinical ethics educator at MedStar Washington Hospital Center and editor of *JOHE*.

John J. Lynch, MD is medical director of the Center for Ethics at MedStar Washington Hospital Center and medical editor of *JOHE*.

References

1. Center to Advance Palliative Care on Defining Palliative Medicine Web site. 2012, http://www.capc.org/building-a-hospital-based-palliative-care-program/case/definingpc

Accessed January 6, 2013.

2. World Health Organization on Defining Palliative Medicine, 2012. Available at http://www.who.int/cancer/palliative/definition/en/

Accessed January 6, 2013.

3. Reddy SK, Lopez G, Elsayem A. Pain management and symptom control. In: Kantarjian HM, Wolff RA, Koller CA, eds. *The MD Anderson Manual of Medical Oncology*. 2nd ed. New York, NY: McGraw-Hill; 2011.

4. Baile WF, Palmer JL, Bruera E, Parker PA. Assessment of palliative care cancer patients' most important concerns. *Support Care Cancer*. 2011;19(4):475-481.

5. Brown, Warren K, Ryan RM. The benefits of being present: mindfulness and its role in psychological well-being. *J Pers Soc Psychol*. 2003;84(4): 822-848.

6. von Gunten CF, Mullan P, Nelesen RA, et al. Development and evaluation of a palliative medicine curriculum for third-year medical students. *J Palliat Med*. 2012;15(1):1198-217.

7. *National Consensus Project for Quality Palliative Care: Clinical Practice Guidelines for Quality Palliative Care*. 2nd ed. 2009:14-63.

8. Ferris FD, Bruera E, Cherny N, et al. Palliative cancer care a decade later: accomplishments, the need, next steps. *J Clin Onc*. 2009;27(18: 3052-3058.

9. Tang VL, French CJ, Cipher DJ, Rastagi P. Trends in hospice referral and length of stay at a Veterans Hospital over the past decade. *Am J Hosp Palliat Care*. 2012 Jul 20. [Epub ahead of print].

10. Cowall DE, Yu BW, Heineken SL, Lewis EN, Chaudhry V, Daugherty JM. End-of-life care at a community cancer center. *J Onc Pract*. 2012;8(4):e40-44.

11. Milligan S. Optimising palliative and end of life care in hospital. *Nurs Stand*. 2012;19;26(41):48-56.

12. Cheng SY, Dy S, Hu WY, Chen CY, Chiu TY. Factors affecting the improvement of quality of dying of terminally ill patients with cancer through palliative care: a ten-year experience. *J Palliat Med*. 2012;15(8):854-862.

13. Fauci J, Schneider K, Walters C, et al. The utilization of palliative care in gynecologic oncology patients near the end of life. *Gynecol Oncol*. 2012;127(1):175-179.

14. Wagemans J, Elder JH, Kubovy M, et al. A century of Gestalt psychology in visual perception: I. perceptual grouping and figure–ground organization. *Psychol Bull*. 2012;138.(6):1172-217.

15. Kienle GS, Kiene H. Clinical judgment and the medical profession. *J Eval Clin Pract*. 2011;17(4): 621-627.

16. Klapp ST, Jagacinski RJ. Gestalt principles in the control of motor action. *Psychol Bull*. 2011;137(3):443-462.

17. Cook C. Is clinical gestalt good enough? *J Man Manip Ther*. 2009;17(1):7.

18. Brown, Warren K, Ryan RM. The benefits of being present: mindfulness and its role in psychological well-being. *J Pers Soc Psychol*. 2003;84(4): 822-848.

19. Fins JJ. *A Palliative Ethic of Care: Clinical Wisdom at Life's End*. Sudbury, MA: Jones and Bartlett; 2006.

When a Treating Physician Is a Cancer Clinical Trial Investigator:

Making Scientific Progress and Protecting Human Research Participants

by Deliya R. Banda, PhD, MPH and Sandra M. Swain, MD

Patients have described the experience of receiving a cancer diagnosis as destabilizing. Faced with the need to make a series of difficult decisions, often within a short period of time, newly diagnosed patients may find themselves completely overwhelmed by both the definitive nature of their condition and a multitude of uncertainties associated with its potential outcome. The decision whether or not to participate in a cancer clinical trial presents an additional layer of complexity. For most patients, making a fully informed decision to participate in a cancer clinical trial hinges on multiple factors.

Arguably, one of the most ethically complex is when their enrolling physician is also their treating physician. In this dual role, awareness of the importance of the physician's disposition, approach toward the patient, and his or her self-awareness should be heightened. The ability to understand the needs of a patient beyond his or her clinical presentation becomes critically important. How this very delicate decision-making process is managed from the first interaction between patient and clinical and/or clinical research physician can determine whether or not the patient enrolls in the trial and if they are doing so in a well-informed way.

The complexity of a split role of both treating clinician and researcher presents a myriad of ethical questions. What duty do enrolling physicians have when presenting the option of a clinical trial, given their dual role as caregivers and researchers? What ethical obligations do treating physicians have if they are going to offer clinical research as an option in a treatment context? How different are these obligations if the treating physician is also an investigator on a trial being offered as an option? What kind of option is being offered? That is, is the patient being offered entry into a Phase 1 trial because there are no more approved treatments available for his or her specific disease, or perhaps the ones that exist are noxious and minimally effective? Or is the patient being offered entry into a trial because the related drug is at a stage close to approval by the US Food and Drug Administration (FDA) as the next and best available treatment? How coercive might be the differences between roles depending on a patient's sense of desperation? This article seeks to address some of these questions.

We can start to narrow our focus by noting that today's patients rightly assume an increasingly active role in their medical decision-making and expect to be informed of all their options. When an ethically justifiable option includes entry into a cancer clinical trial, a primary ethical responsibility of either a treating physician or a physician-investigator is to ensure that his or her patient fully understands the difference between research and treatment, and appreciates which role the physician is playing at any point in time.[1,2,3,4]

A CURRENT PICTURE OF TRIAL PARTICIPATION AND ACCRUAL

The development of better therapeutic options for cancer patients is contingent on progress produced in the research setting. To achieve such progress, it is necessary to have the voluntary participation of patients in clinical trials. In a clinical trial, participants receive specific interventions according to the research plan developed by investigators. Interventions might include drugs or medical devices, procedures, or changes to behavior. Procedures may test a new medical approach against either an existing standard or a placebo with no active ingredient. (See clinicaltrials.gov for a complete description of clinical trials.)

Trial participation also ordinarily ensures that cancer patients receive excellent medical attention, close monitoring of their disease, and careful attention to their quality of life. If the patient is enrolled in a study that may potentially offer a direct benefit, in particular during late Phase 2 and Phase 3 trials, there is a statistical probability that many of the research participants may experience a positive therapeutic result from their participation. Despite these advantages to study participation, of all adults in the United States diagnosed with cancer, only 3% to 5% will participate in a cancer clinical trial.[5,6]

The accrual of patients for clinical trials remains one of the biggest challenges facing investigators at cancer centers. Barriers to trial accrual are numerous and well documented. They range from systemic factors such as trial availability and eligibility, patient-related factors including fear and lack of knowledge, and factors related to physicians, such as a lack of patient engagement.[7,8,9] Unique ethical challenges arise for physician-investigators who represent an individual study site or when the clinical trial is of their design. Physician-investigators must balance the need to provide their patients with the best available care while also involving patients in research.

Because such a low percentage of persons with cancer participate in cancer clinical trials, creative recruitment and retention strategies need to be applied to many cancer populations and subpopulations. Research participation of more women, patients from minority populations such as the elderly, or patients from a wide variety of ethnic backgrounds (both genetic and social) could produce much new knowledge. It is, however, beyond the scope of this article to address all aspects of this problem. Rather, while making mention of minorities, generally we focus most closely on issues concerning African Americans in cancer clinical trials.

THE ADDED CHALLENGE OF INVOLVING MINORITY POPULATIONS, PARTICULARLY AFRICAN AMERICANS, IN CANCER CLINICAL TRIALS

When compared with non-participants, patients in clinical trials are likely to be younger, have a higher education, be of higher socioeconomic status, and be overwhelmingly white.[10,11] Minority patients with cancer, particularly African Americans, consistently experience worse prognoses and treatment outcomes in comparison with other ethnic groups. Enrolling African American patients is thus especially necessary in order to collect group-specific data, evaluate the effectiveness of existing treatments within different ethnic groups, and to adapt treatments as may be necessary.[12,13] Demographic imbalances in enrollment limit the extent to which research results from clinical trials can be generalized. Physicians are therefore faced with the need to employ specialized methods to ensure minority patients are given equal opportunity in accessing clinical trials.

In designing clinical trials, comorbidities are most frequently responsible for the exclusion of minorities, regardless of their attitudes or willingness to participate.[14] While these contraindications are often the primary reason, a patient's personal decision is also a significant factor; therefore, the physician's role can be decisive. Physicians need to appreciate differences in ways minority patients are best approached. That research is perceived differently by patients of various minority groups should be taken into account in the design and presentation of a trial. At the root of this is an acknowledgement that different cultures may have particular attitudes and perceptions about clinical trials.[15,16,17]

Both the role of culture as a contributor to health disparities and the potential impact of culturally competent care on improving cancer outcomes in ethnic minorities have been underestimated. A patient's cultural context or lived experience may significantly influence his or her attitude toward clinical trials, ultimately preventing or promoting participation. Cultural beliefs and values are becoming increasingly recognized as integral to decision making in the prevention and control of cancer.

The accrual of patients for clinical trials remains one of the biggest challenges facing investigators...

SPECIAL CONSIDERATIONS IN INVOLVING MINORITY PATIENTS

There is no shortage of literature confirming the importance of a trusting relationship between a physician and any patient considering a clinical trial. Trust plays a critical role in most cultures when making such a decision. In minority populations, this seems particularly problematic when it comes to enrolling patients into clinical trials, but not for the reasons many assume. Mistrust of researchers may come from a variety of places; not all of it comes from the legacy of the Tuskegee Syphilis Study.[18] Physicians could be more successful in enrolling patients in cancer clinical trials if they acknowledge particular concerns minority populations may have, helping physician-investigators gain the trust of the patient and his or her family.[19,20]

A pilot study examining attitudes of African American patients at an urban cancer center toward clinical trials[21] revealed information challenging some of the more commonly held notions about what influences their cancer trial participation. Patients stated that whether or not they were personally ready to enroll in a trial, it was critical that their family members (spouses, parents, and even grandparents) were involved in the patient's ultimate decision to participate. Thus, engaging the entire family in discussions about what the research will entail could be a useful recruitment strategy.

There are definitely attitudinal barriers to trial participation by persons of a cultural heritage associated with a minority group, which include the following concerns:[22,23]

- Being treated poorly or as a "guinea pig"
- Distrust
- Loss of autonomy
- Potential for ethical misconduct by investigators
- Privacy
- Range of knowledge and awareness of the investigators

It might come as a surprise, however, from this list that the sole statistically significant predictor of a patient's willingness to enroll was his or her concern over a potential loss of privacy after signing a research consent form.[24] For these patients, a thorough understanding of what would happen to their personal information, including exactly who would have access to it and how any health data would be transmitted to the trial sponsor and other entities, engendered a far greater level of concern than the experimental nature of a clinical trial. Patients conveyed that physicians did not spend as much time discussing these facts as they did other aspects of the study.

A particularly interesting discussion is about whether a clinician who shares a patient's ethnicity is necessary and/or sufficient to building enough trust for a patient to feel comfortable enrolling in a trial. Part of this discussion is whether such intentional pairings of persons who are more culturally similar may be considered coercive. As more work continues on this particular issue, potential subjects' preferences are likely to emerge more clearly than to date.[25,26,27,28,29]

Patients in one study[30] stated that the approach, disposition, manner, willingness, and ability of a provider to develop a relationship with the patient were all influential in their consideration to participate in a trial. With this understanding, the importance of paying particular attention to minority interests in accrual should not be ignored, especially when considering the increasing and disproportionate burden of cancer among minority patients in the United States. It is projected that by 2030 there will be a 99% increase in cancer incidence for minority patients, compared with a 31% increase for whites.[31] This underscores the need for cultural competence among all providers, regardless of how similar or dissimilar they may be to the patient.

APPROACHING THE PATIENT AS A CAREGIVER/PROVIDER AS OPPOSED TO A RESEARCHER

There is a tendency for physicians to speak to patients about clinical trials in the role of a caregiver/provider when they are actually speaking from their role as a researcher. This is precisely where a distinction should be identified.[32,33] The distinction can be further obscured when a trial is presented to a patient in a manner that suggests it is his or her only treatment option, given the disease. While physicians have the obligation to ensure this is never the case, it can be a difficult distinction for the patient to make when eligible trials are discussed during the same time as treatment options. This point warrants special consideration in the case of a patient with metastatic disease, which is essentially incurable. While a physician's obligation is to ensure the patient understands the facts, as an investigator the obligation is to offer and hopefully place an eligible patient in a trial. If the patient is not presented the option or chooses not to enroll in a trial, a critical opportunity is missed for the advancement of the science, which is the primary goal of the researcher.

When the obligation of the physician is that of a researcher, it is his or her obligation to approach the patient differently than if the information about entering a trial was given by a physician who is neutral as to whether the patient enrolls or not. In either situation, it is necessary to clearly distinguish standard clinical care and what can be done should the patient not opt to participate in research. This nuance is not always clearly conveyed by the physician-investigator, who often believes that any experimental therapy will be at least as efficacious as the standard of care, which may not turn out to be the case. Patients frequently express concerns of being randomized to a section of the study in which they would only receive a placebo as a reason why they would not participate. This suggests a common misunderstanding of the purpose and circumstances of randomization in a clinical trial that can sometimes be further obscured by the clinician's presentation.

CLINICAL TRIALS ARE EXPERIMENTAL: WHY THIS IS AN IMPORTANT POINT TO MAKE

The term "guinea pig" is laden with negative connotations in the world of clinical trials. In an effort to build and maintain trust while promoting necessary discourse, a patient needs to understand that a trial is experimental by definition. Physicians ought to be clear with patients regarding the uncertainty about what the specific outcome will be, and that this kind of uncertainty is what it means to be in a research study. The emphasis of this aspect of clinical research can be easy for the clinician-investigator to downplay if he or she is intent on placing a patient in a study, rather than intent on having an open conversation with a patient about the potential risks, benefits, and alternatives to research participation.

There is a tendency for physicians to speak to patients about clinical trials in the role of a caregiver/provider when they are actually speaking from their role as a researcher.

Understandably, there may be discomfort that focusing on the relative uncertainty in the outcome of an experimental treatment may arouse fear and doubt in a prospective patient-volunteer. When given the option of the better known and likely more predictable outcome of a standard therapy, a patient might be dissuaded from choosing a clinical trial. This, however, is the physician's obligation to address. Physicians should provide appropriate context and help shape perspective by highlighting that it is in fact by such "experimentation" that we develop standards of care.

When patients in a 2011 pilot study,[34] in discussing the nature of clinical trials, were informed by the staff that drugs such as aspirin and other basic remedies are in use today because they were first tested under similar circumstances, they were then able to associate a common medical product with a prior experimental process responsible for allowing its wide-spread availability. Physicians can leverage this angle and focus on the advances made because of clinical trials, and what the results of prior "experimentation" have been (including the standard of care they will receive should they choose not to enroll). This both aids in patients' understanding and places into context the objective of their participation.

This also underscores the importance of fully explaining and assuring the patient understands the trial endpoints or measured outcomes, as well as the trial origin (for example, whether it is a pharmaceutical industry or National Cancer Institute-sponsored trial). Patients also need to fully understand that the trial is asking a meaningful and necessary question, which should be explained in the context of their disease and what is known about the standard treatment compared with what the trial could help researchers further understand. Not all trials are created equal and the physician-investigator has an obligation to present trials to patients in a way that fully explains what may be gleaned from their particular situation and disclosure of what exactly they hope to achieve by performing the study.

CONCLUSION: STRATEGIES FOR MOVING CANCER CLINICAL RESEARCH FORWARD

Developing creative strategies for recruitment is an important task for the cancer clinical trial community. One strategy is to increase access at community hospitals and cancer centers serving minority populations. An example of taking this approach is the Community Clinical Oncology Program (CCOP) of the National Cancer Institute, National Institutes of Health.[35]

Over time, it will be important to increase the diversity of the research team members themselves. Medical schools can begin talking to medical students early on about the satisfactions of adding clinical research to their otherwise strictly clinical care of patients. Fellowships in clinical research need to reach out to the diverse community of medical residents. Although this is a long-range process, it should result in a more diverse researcher community, which can only increase the depth of thought and attention to the needs of a diverse population of patients with cancer—patients who might become interested in research participation.

In the end, approaching the patient with compassion, honesty, and understanding is of paramount importance regardless of whether one's role is that of a caregiver or researcher. The clinician-investigator, however, is required to factor in an added level of specificity about the role he or she is playing while speaking with a patient who may become a research volunteer. Consideration for what matters to the patient is important, but the integrity of the physician-investigator may be more important. It is critical that the patient understands the differences between the role of a clinical physician and that of a physician-investigator in order to ensure that the patient can make a truly informed decision about the options presented. Patients ought to be able to fully recognize the context in which their provider is approaching them as a clinician and the point at which that clinician shifts into speaking as a researcher—a critical distinction that should avoid ambiguity and ultimately result in having more well-informed and understanding cancer clinical research participants.

Authors

Deliya R. Banda, PhD, MPH was a research program manager for oncology at the MedStar Health Research Institute, and is currently a senior health communication researcher for Communicate Health Inc.

Sandra M. Swain, MD is medical director of the Washington Cancer Institute at MedStar Washington Hospital Center and currently serves as president of the American Society of Clinical Oncology (ASCO).

References

1. Largent EA, Joffe S, Miller FG. Can research and care be ethically integrated? *Hastings Center Rep.* 2011;41(4):37-46.

2. Brody H, Miller FG. The clinician-investigator: unavoidable but manageable tension. *Kennedy Inst Ethics J.* 2003;13(4):329-346.

3. Chen DT, Miller FG, Rosenstein DL. Clinical research and the physician-patient relationship. *Ann Intern Med.* 2003;138(8):669-672.

4. Miller FG, Rosenstein DL, DeRenzo EG. Professional integrity in clinical research. *JAMA.* 1998;280(16):1449-1454.

5. Du W, Mood D, Gadgeel S, Simon MS. An educational video to increase clinical trials enrollment among breast cancer patients. *Breast Cancer Res Treat.* 2009;117(2):339-347.

6. Baquet CR, Ellison GL, Mishra SI. Analysis of Maryland cancer patient participation in National Cancer Institute-supported cancer treatment clinical trials. *J Clin Oncol.* 2008;26:3380-3386.

7. Probstfield JL, Frye RL. Strategies for recruitment and retention of participants in clinical trials. *JAMA.* 2011;306(16):1798-1799.

8. Baquet CR, Commiskey P, Mullins CD, Mishra SI. Recruitment and participation in clinical trials: socio-demographic, rural/urban, and health care access predictors. *Cancer Detect Prev.* 2006;30(1):24-33.

9. Lara PN Jr, Paterniti DA, Chiechi C, et al. Evaluation of factors affecting awareness of and willingness to participate in cancer clinical trials. *J Clin Oncol.* 2005;23(36):9282-9289.

10. Adams-Campbell LL, Ahaghotu C, Gaskins M, et al. Enrollment of African Americans onto clinical treatment trials: study design barriers. *J Clin Oncol.* 2004;22(4):730-734.

11. McCaskill-Stevens W, Pinto H, Marcus AC, et al. Recruiting minority cancer patients into cancer clinical trials: a pilot project involving the Eastern Cooperative Oncology Group and the National Medical Association. *J Clin Oncol.* 1999;17:1029.

12. Park ER, Weiss ES, Moy B. Recruiting and enrolling minority patients to cancer clinical trials. *Community Oncology*. 2007;254-257.

13. McCaskill-Stevens W, Pinto H, Marcus AC, et al. Recruiting minority cancer patients into cancer clinical trials: a pilot project involving the Eastern Cooperative Oncology Group and the National Medical Association. *J Clin Oncol.* 1999;17(3):1029-1039.

14. Adams-Campbell LL, Ahaghotu C, Gaskins M, et al. Enrollment of African Americans onto clinical treatment trials: study design barriers. *J Clin Oncol.* 2004;22(4):730-734.

15. Troug RD, Kesselheim AS, Joffe S. Research ethics. Paying patients for their tissue: the legacy of Henrietta Lacks. *Science.* 2012;337(6090):37-38.

16. Reverby SM(ed). *Tuskegee's Truths: Rethinking the Tuskegee Syphilis Study*. Chapel Hill, NC: University of North Carolina Press; 2000.

17. Annas GJ, Grodin MA, eds. *The Nazi Doctors and the Nuremberg Code: Human Rights in Human Experimentation.* New York, NY: Oxford University Press; 1995.

18. Davis JL, Green BL, Katz RV. Influence of scary beliefs about the Tuskegee Syphilis Study on willingness to participate in research. *ABNF J.* 2012;23(3):59-62.

19. Litton P, Miller FG. A normative justification for distinguishing the ethics of clinical research from the ethics of medical care. *J Law Med Ethics*. 2005;33(3):566-574.

20. Pace C, Miller FG, Danis M. Enrolling the uninsured in clinical trials: an ethical perspective. *Crit Care Med.* 2003;31(3 Suppl):S121-125.

21. Banda D, Libin AV, Wang H, Swain SM. A pilot study of a culturally tailored video to increase participation of African Americans in cancer clinical trials. *Oncologist.* 2012;17:708-714.

22. Ford JG, Howerton MW, Lai GY, et al. Barriers to recruiting underrepresented populations to cancer clinical trials: a systematic review. *Cancer.* 2008;112:228-242.

23. Advani AS, Atkeson B, Brown CL, et al. Barriers to the participation of African-American patients with cancer in clinical trials: a pilot study. *Cancer.* 2003;97:1499-15.

24. Banda D, Libin AV, Wang H, Swain SM. A pilot study of a culturally tailored video to increase participation of African Americans in cancer clinical trials. *Oncologist.* 2012;17:708-714.

25. Sweet S, Legro RS, Coney P. A comparison of methods and results in recruiting white and black women into reproductive studies: the MMC-PSU cooperative center on reproduction experience. *Contemp Clin Trials.* 2008;29(4):478-481.

26. Kazdin AE. Evidence-based treatment and practice: new opportunities to bridge clinical research and practice, enhance the knowledge base, and improve patient care. *Am Psychol.* 63(3):146-159.

27. Branson RD, Davis K Jr, Butler KL. African Americans' participation in clinical research: importance, barriers, and solutions. *Am J Surg.* 2007;193(1):32-39.

28. Wyatt SB, Diekelmann N, Henderson F, et al. A community-driven model of research participation: the Jackson Heart Study Participant Recruitment and Retention Study. *Ethn Dis.* 2003;13(4):438-455.

29. Zhu K, Hunter S, Bernard LJ, Payne-Wilks K, Rolan CL, Levine RS. Recruiting elderly African-American women in cancer prevention and control studies: a multifaceted approach and its effectiveness. *J Natl Med Assoc.* 2000;92(4):169-175.

30. Banda D, Libin AV, Wang H, Swain SM. A pilot study of a culturally tailored video to increase participation of African Americans in cancer clinical trials. *Oncologist.* 2012;17:708-714.

31. Smith B, Smith G, Hurria A, Hortobagyi, Buchholz T. Future of cancer incidence in the United States: burdens upon an aging, changing nation. *J Clin Oncol.* 2009;27(17):2758-2765.

32. Pentz RD, White M, Harvey RD, et al. Therapeutic misconception, misestimation, and optimism in participants enrolled in phase 1 trials. *Cancer.* 2012;118(18):4571-4578.

33. de Vries MC, Houtlosser M, Wit JM, et al. Ethical issues at the interface of clinical care and research practice in pediatric oncology: a narrative review of parents' and physicians' experiences. *BMC Med Ethics.* 2011;12(1):18.

34. Banda D, Libin AV, Wang H, Swain SM. A pilot study of a culturally tailored video to increase participation of African Americans in cancer clinical trials. *Oncologist.* 2012;17:708-714.

35. Community Clinical Oncology Program Network Web site:http://ccop.cancer.gov. Accessed January 3, 2013.

CASE 1

When Oncologists and Intensivists Disagree About Appropriate Care

by the Editorial Group of the Center for Ethics at MedStar Washington Hospital Center

PRESENTATION

Mrs C is a 56-year-old woman who is admitted to the Intensive Care Unit (ICU) with stage IVb cervical cancer. She is breathing shallowly (O2 saturation is 90%) and has not been able to eat more than a few bites of food for the past 6 days. A CT scan confirms that she has distal metastases throughout her peritoneal cavity and malignant ascites.

When Mrs C was initially diagnosed 4 years ago, she agreed to have surgery but refused chemotherapy and brachytherapy. At that time, she was adamant about her preference for a homeopathic approach for further treatment. More recently, she began seeing an oncologist who has had her on a chemotherapy regimen that has now made her sick enough to be admitted to the ICU through the Emergency Department (ED).

The ICU attending physician in charge of Mrs C's care has directed the residents to keep her comfortable. She is receiving oxygen and IV nutrition, is sedated to ease her anxiety, and has a fentanyl patch to manage her pain. The interventional radiology consultant says that draining her ascites may relieve her breathing and keep her more comfortable, but will likely have to be repeated.

The patient's husband is understandably distraught. His wife named him as her surrogate decision maker in an advance directive signed 2 years ago, but did not specify treatment preferences. The residents work to establish rapport with him so they can help him come to terms with the fact that his wife is dying. They arrange consultations involving the palliative care and social work teams, with the hope that the patient can return home to die with the aid of hospice care.

On the third morning of her stay, the ICU attending discovers that the patient's oncologist visited the ICU the previous night. She had spoken with the husband without any of the residents present, leaving a note in the chart. The note indicates the oncologist had a conversation with the husband (the wife lacks decisional capacity as a result of sedation and pain medications and is minimally responsive) about trying a particular chemotherapy regimen that she believes could be "of value." The husband became hopeful and agreed to pursue the option.

When the ICU attending discusses this treatment approach with the husband, the attending explains that due to the advanced stage of Mrs C's cancer, another chemotherapy treatment will likely provide no more than a few days of additional life, if at all, and comes with significant side effects. The husband becomes suspicious and distrustful of the attending physician and residents in the ICU, unsure whether they are providing him with accurate information and wanting to believe in the oncologist's more positive perspective.

The attending physician has been reluctant to confront the oncologist. Chemotherapy begins, despite the patient's precarious condition and incapacity. The residents are uncomfortable with the lack of coordination in care and contact the clinical ethicist.

CHART NOTE AND RECOMMENDATIONS

Ethically relevant history: Patient is a 56-year-old woman with stage IVb cervical cancer in rapid decline and admitted to the ICU. Patient underwent surgery after original diagnosis 4 years ago, but has only received chemotherapy recently due to her strong personal preference for homeopathic medicine, which she had been trying since surgery. Patient lacks decision-making capacity due to sedation for her anxiety and pain medications, and has named her husband as her surrogate. Consults are arranged with both the palliative care and social work teams to assist the patient's husband in coping with his wife's imminent death.

In the last 24 hours, the patient has been visited and evaluated independently by an oncologist who suggests a chemotherapy option that she believes would be "of value." This recommendation is made directly to the husband, without prior discussion with any ICU staff. The oncologist leaves a chart note stating that the husband has agreed to the chemotherapeutic intervention. Before starting the new chemo regimen, the ICU attending explains to the husband the lack of expected benefit from this course of treatment. The husband becomes distrustful of the ICU staff, as the information he is being given does not concur with the opinion of the oncologist who has now provided him with a degree of optimism regarding his wife's prognosis.

Although the intensivist and oncologist have yet to discuss the patient's care with one another, chemotherapy is initiated.

Issue: Because the patient's medical preferences were never explicitly communicated, and the fact that she resisted at first but recently decided to try chemotherapy, what the patient might have wanted at this stage of her disease process is difficult to determine. At issue is a disagreement between the intensivist and oncologist about the appropriate treatment plan, which has left the patient's husband uncertain of the care his wife should be receiving and has caused him to develop distrust in the ICU team.

Recommendation: Ethics recommends that the oncologist and intensivist come to a shared conclusion. If this is not possible due to a reasonable difference of opinion, then ethics recommends creating a plan to present both physicians' views of what is realistic, given the patient's full set of medical circumstances, and to assure proper informed choice. The use of hospital resources such as social work and palliative care consultations should continue. Also, spiritual care should be called to provide additional support to the husband, regardless of whether or not his wife receives any more chemotherapy.

If the husband decides to pursue chemotherapy, ethics recommends that clear stopping rules be set so that if the intervention results in substantive burdens to the patient without providing commensurate benefits, the treatment will be stopped and the patient's direction of care shifted to comfort measures only.

REASONING

The recommendations in this case reflect the complexity of its central ethical question: how ought oncologists approach patients and families about what might be "of value" to a person who is clearly dying of cancer? Physicians need to be extremely careful about the words they use with patients and families, especially at the end of life. In this particular case, the term "of value" is emotionally charged. What this patient might have considered and what her husband considers "of value" may now be driven by unrealistically hopeful medical information, or simply by a wish that his wife not die. This deep psychological dread is central to many end-of-life cases.[1] Disagreements among clinicians simply make matters worse.

The disagreements that often occur between oncologists and intensivists distract from optimal end-of-life care. These professional disagreements may say more about psychological differences between the 2 specialties than they do about scientific validity and evidence-based medicine for patients like Mrs C. It is important for achieving excellence in the care of such patients that, rather than settling on an agreement between these differences of opinion, clinicians find the moral courage to sit down with a patient's surrogate and have a realistic talk about what each physician thinks and why. The surrogate ought to understand not only what the disagreements are about but also attain a realistic idea of what each potential intervention can be expected to provide.

It is the responsibility of the physician to identify and remove his or her partiality to the greatest degree reasonable in determining what is of value, in particular when regarding the care of a patient with cancer at the end of life. But it is difficult for clinicians to dismiss their own subjective need for rescue, even when rescue is no longer reasonable and may in fact produce harm. This natural bias ought to be recognized and managed by physicians, allowing for transparency with their colleagues, their patients and respective surrogates, and most critically, with themselves.

Another ethical imperative identified in this case is the need for all medical teams to work in collaboration. Collaboration need not mean agreement, as long as the disagreements and their inherent uncertainties are made clear to a patient and/or surrogate. It is essential for good end-of-life care. When an intensive care team believes a patient is dying and a separate assessment is made by an oncologist that results in a disorganized and unilateral recommendation for aggressive treatment, divisions are created among providers, the patient, and his or her family.

Authors

The Editorial Group of the Center for Ethics at MedStar Washington Hospital Center

References

1. Scarre G. Can there be a good death? *J Eval Clin Pract.* 2012;18(5):1082-1086.

CASE 2

When an Adolescent and Her Parents Disagree About Treatment

by the Editorial Group of the Center for Ethics at MedStar Washington Hospital Center

PRESENTATION

Miss Y is a 15-year-old girl who has spent the last 3 years battling acute lymphocytic leukemia (ALL). She was originally diagnosed after complaining of profound fatigue. She had an initial white blood count of 80,000 and underwent aggressive induction chemotherapy, achieving complete remission 12 weeks later. She continued to receive consolidation chemotherapy, followed by maintenance therapy for the subsequent 2 years.

Miss Y relapsed 6 months ago and received an allogeneic bone marrow transplant using tissue from a sibling who was a near-perfect match. After this procedure and despite initial remission, the leukemia has returned and this time involves her central nervous system. Miss Y's platelets are 30,000, hemoglobin is 7, hematocrit is 21, and leukocytes are 100,000, which indicate a poor prognosis.

The patient's parents are very upset and want to pursue an additional course of chemotherapy in an effort to beat back the leukemia once again, despite their daughter's poor prognosis. However, Miss Y states clearly that she does not wish to fight anymore. She states that her quality of life has suffered dramatically, especially throughout the past 6 months, as a result of the transplant and a virulent course of graph vs host disease. She has been hospitalized much of this time and has not been able to attend school due to the potential for infection. She believes that further treatment will only prolong her suffering and will not lead to any meaningful result.

The parents continue to insist on additional treatment, claiming that she is under age 18 and it is therefore their responsibility to make decisions for her. The oncologist has requested neurological and psychiatric consultations to assure that the patient is free of related problems that may be impairing her cognitive capacity or contributing to a depression and thus an inability to make rational decisions. Both assessments result in an affirmation of her decision-making capacity, giving the oncologist confidence that the choice the patient is making is authentic. In light of the prognosis and his clinical judgment about the clarity of his patient's thinking, he is reluctant to proceed with treatment against Miss Y's will. The medical team requests an ethics consult.

CHART NOTE AND RECOMMENDATIONS

Ethically relevant history: Patient is a 15-year-old female with acute lymphocytic leukemia (ALL). Patient has spent the last 3 years battling her disease, received an allogeneic bone marrow transplant 6 months ago, and has since relapsed with CNS involvement.

Despite the patient's poor prognosis, her parents want to pursue additional chemotherapy. This, however, is not the patient's preference, as she feels her quality of life has diminished significantly and that further treatment will merely prolong her suffering.

Given the patient's status as a minor, her parents continue to insist that it is their decision to make and they want to pursue further curative treatment. The oncologist is uncertain about how to proceed, as he does not wish to go against the clearly stated desire of this underage—but capacitated—patient.

Issue: The core ethical conflict in this case is whether a fully capacitated, underage patient's choice to cease treatment should be allowed in light of her parents wish to continue aggressive therapy and their legal decision-making authority because she is less than 18 years of age. Additionally, there is circumstantial uncertainty and moral distress for the attending oncologist who must make the decision to adhere to either Miss Y's wishes or those of her parents. Other medical team members, who know the patient well, believe she is making a reasonable decision and are also conflicted about their own sense of compassion for both the patient and her parents.

Recommendation: The clinical ethicist supports the oncologist's reluctance to order further chemotherapy against the patient's wishes. The physician and clinical team believe that the patient's request to stop aggressive curative intervention is well justified by her continued suffering and poor prognosis. Therefore, the physician should not force this underage patient to receive treatment against her will. The physician should inform the parents of his decision not to do so and his recommendation that the patient's care plan be shifted to comfort measures only. Hospital resources such as spiritual care, palliative care, and hospice should be made available to support the patient and family.

The physician should explain that assistance will be offered to transfer the patient to another provider or medical facility if the parents remain intent on furthering aggressive, curative treatment for their daughter. The oncologist should discuss supporting this patient with both social work and the hospital's legal department, should she desire to be declared an emancipated minor for the purpose of making this decision. Once the patient has been discharged, ethics recommends the arrangement of a group session with the medical team in order to address any remaining moral distress.

REASONING

In this case, the oncologist would be right in his refusal to provide chemotherapy if he believes that Miss Y is dying and that it would only prolong suffering.[1,2] It is also his right to decide that he does not want to go against the clearly stated desire of his patient, as long as her preference is permissible within acceptable standards of medical practice.

Parents may hold a legal right to make decisions for their 15-year-old daughter, but this patient's moral "right"[3,4] to avoid pain and suffering should be honored as well. Physicians have a moral obligation to avoid providing any treatment they feel is not indicated. That the patient is a minor only makes decision making more complicated. Here, the patient is old enough that she can be expected to understand her medical circumstances and future outcome. Minors who have suffered a chronic disease and demonstrate maturity ought to be respected in terms of their desire to extend or cease any particular kind of care. Of significant debate in national and foreign legislative systems is what is referred to as the "mature minor" doctrine.[5,6] This consists of the recognition that under certain (albeit unspecified) circumstances, a minor may have the maturity and intelligence necessary to be allowed to make his or her own medical decisions. This doctrine functions as a statutory or common law, but has not found concrete legislative footing at the federal or state level.

Legal matters aside, what should be emphasized ethically is the imperative for the physician to generate a conversation with the parents that will allow him to thoughtfully convey why, in his medical judgment, additional chemotherapy is not in their daughter's best interest. He has a clear obligation to be truthful with the parents about their daughter's prognosis. The oncologist must engage the parents in a discussion that shows respect for their wishes and, at the same time, shows respect for the patient's wishes. The oncologist ought to allow multiple opportunities for the parents to understand their daughter's point of view.[7]

One of the most difficult and emotionally fraught times in the practice of oncology is when circumstances involve the impending death of a child. An oncologist with an appropriate degree of moral awareness and a skilled sensibility ought to assist the family in accepting that the child is in fact dying.[8] This may be the first step in substantiating their ability to help their beloved child, rather than dispute the validity of her wishes.

Surely, the ethically optimal outcome is for the physician to broker a resolution between Miss Y and her parents, so she may die free of conflict and discord. If this cannot be achieved, supporting the moral right of a mature and dying minor to refuse a non-beneficial intervention when it is consistent with the physician's best medical judgment is the ethical imperative.

Authors

The Editorial Group of the Center for Ethics at MedStar Washington Hospital Center

References

1. Epelman CL. End-of-life management in pediatric cancer. *Curr Oncol Rep.* 2012;14(2):191-196.

2. Wolfe J, Grier HE, Klar N, et al. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med.* 2000;342(5):326-333.

3. Nussbaum MC. Capabilities as fundamental entitlements: Sen and social justice. *Feminist Economics.* 2003; 9(2-3):33-59.

4. Nussbaum MC. *Creating Capabilities: The Human Development Approach.* Cambridge, MA: Belknap of Harvard University Press; 2011.

5. O'Connor CM. What rights do minors have to refuse medical treatment? *The Journal of Lancaster General Hospital.* 2009;4(2):63-65.

6. Carpenter CM. The mature minor exception and the provision of medical treatment. *Florida Nurse.* 2009; 57(1):13.

7. Oppenheim D, Brugieres L, Corradini N, Vivant F, Hartmann O. An ethics dilemma: when parents and doctors disagree on the best treatment for the child. *Bull Cancer.* 2004;91(9):735-738.

8. Beringer AJ, Heckford EJ. Was there a plan? End-of-life care for children with life-limiting conditions: a review of multi-service healthcare records. *Child Care Health Dev.* 2012 Nov 30. Epub ahead of print.

CASE 3

When Is Non-Cancer Surgery Warranted in a Cancer Patient?

by the Editorial Group of the Center for Ethics at MedStar Washington Hospital Center

PRESENTATION

Mr B is a 79-year-old man presenting to the Emergency Department (ED) with abdominal pain. Sent from his assisted care facility, the facility's staff informs the ED that he has stayed in bed the past 2 days. When Mr B arrives at the ED, he has diarrhea and frank blood in his stool. Palpation of his abdomen suggests areas of hardness, suspicious for colon cancer. Blood tests show that he is severely anemic and has compromised liver function.

Mr B's previous medical history is notable for a vascular stroke at age 43, which left him paralyzed on his left side. He is wheelchair bound, fully alert, and responds appropriately to questions, albeit with some difficulty. He has been in an assisted living facility for the past 25 years. He never married and has no children or other family members.

Upon hospital admission, he has a CT scan that confirms he has a significant mass, structurally consistent with a malignancy; it is almost certain that the patient has late-stage cancer of the transverse colon with identifiable metastases throughout his pelvis. There is no sign of bowel obstruction. When the radiologist reads the results, however, he is alarmed to note a previously undiagnosed 10cm abdominal aortic aneurysm (AAA), which ordinarily constitutes a surgical emergency. He contacts a vascular surgeon to look at the results.

In the meantime, an oncologist visits Mr B and tells him of his probable colorectal cancer. The oncologist tells him that they are almost certain that he has advanced colorectal cancer and, if that is the case, the outlook is not good. The oncologist does not, however, discuss with him the explicit details diagnostically, nor that there is a low probability of survival beyond 3 to 6 months..

Separately, after the vascular surgeon reviews the CT, he goes directly to Mr B's room and informs him of the AAA finding. The surgeon explains that a AAA of this size could burst at any time, leading to sudden death. He explains to Mr B that the patient has two main options. First, Mr B can undergo immediate surgery, which is considered a high-risk operation that could result in his death. Or, Mr B can take his chances and forego the surgery in light of the possibility that the patient may have advanced colon cancer. After hearing these choices, Mr B opts for the surgery. The surgeon leaves the patient's room expecting to perform the operation within the next 12 to 24 hours.

Within minutes of the surgeon's departure, the palliative care team arrives, as requested by the oncologist. Mr B tells the palliative care Nurse Practitioner (NP) that he's agreed to surgery because, "I don't want to just die; I can lick this cancer. I had a cousin who they said was going to die of cancer and he lived another 10 years." The NP is uncomfortable with the patient's stated decision given the high-risk nature of the AAA surgery, and because nobody has completed the colon cancer workup so it is not clear what his prognosis really is. She tells the patient she will be back in a few minutes and steps outside to page the on-call clinical ethics consultant.

CHART NOTE AND RECOMMENDATIONS

Ethically relevant history: The patient is a 79-year-old man who presented to the ED with abdominal pain. It is likely he has advanced colon cancer. He also has been found to have a 10cm AAA. He has significant left-sided paralysis from a stroke at age 43. He lives in an assisted living facility. He has no wife, children, or other family members but is a cognitively capable decision maker. Patient has been made aware, but only in general terms, of his possible advanced colon cancer. Patient has consented to a AAA repair.

Issue: Must the AAA repair proceed at this time or might there be time for further exploration of the patient's clinical status, along with more detailed discussions with the patient?

Recommendation: Ethics recommends that, if it is within reasonable surgical standards of practice, surgery not be performed at this time. This would allow for further clarification of the patient's oncologic status along with more detailed discussions with the patient to produce a more coordinated plan of care.

If such a long-range plan still includes Mr B wanting to move forward with the AAA surgery, it is recommended that the patient's oncologist documents (as with all previous patient conversations) the patient's preferences for future care, in the event that there are complications. It would be ideal if the patient identifies a surrogate and documents his own advance directives using hospital forms.

REASONING

Today, ordinary care often looks like the disjointed scene portrayed in this case. All the clinicians are working hard to do their best for the patient. But the lack of coordination may result in an outcome that will turn out not to have been the best possible for the patient. Here, it is difficult to know if pursuing AAA surgery is best. For one reason, it is uncertain as to whether or not Mr B really has metastatic colon cancer because there has yet to be definitive testing. Even if a CT scan can be considered sufficiently diagnostic, there has been insufficient discussion with Mr B about the implications of all the new possibilities.

One possibility is that if Mr B has aggressive, advanced colon cancer, he could survive with his aneurysm for a period long enough to allow the course of his cancer to dictate his remaining time, avoiding the discomforts of the surgery.

Another possibility is that a recommendation against the surgery is a result of unacceptable ethical reasoning. That is, one can imagine that there will be kind and caring clinicians who think that life, wheelchair bound, in a facility, for a 79-year-old, is not a quality of life good enough to warrant life-extending surgery. Rather (so this thinking sometimes goes, consciously or not), the best care approach would be to transition the patient to hospice. While acceptable at a personal level, professionally this is not acceptable ethical reasoning; at least in the United States it is no longer the clinician's call. That is because some see such thinking as discriminatory on the basis of age or disability.

So, at a minimum, it is best to slow down the decision-making process, if only to allow for better coordination across clinicians and a fuller set of conversations with the patient. Because if Mr B proceeds to surgery after all, there should be clear stopping rules in place in case of complications. In taking this approach, everyone can feel comfortable that 1) the patient has had the opportunity to make a fully informed decision and 2) a preventive ethics approach has been taken.

Authors

The Editorial Group of the Center for Ethics at MedStar Washington Hospital Center

The Center for Breast Health at MedStar Washington Hospital Center:

An Example of Why the Communities of Practice Model Works for Hospital Quality

by Marc E. Boisvert, MD, MBA and the Editorial Group of the Center for Ethics at MedStar Washington Hospital Center

Today, hospital quality is all about getting the systems right.[1] Atul Gawande, MD, in a recent article in the *New Yorker*,[2] may have taken this thought to its most logical extreme. In the article, he suggests that in order to get it right, hospitals should look to the restaurant industry. We are not quite sure that is the best place to turn. Rather, we think the approach taken by the Washington Cancer Institute's Center for Breast Health, built on the Communities of Practice (CoP) model,[3] exemplifies how to best create and sustain a cancer care program (or perhaps even a program for any therapeutic area). Some restaurant chains may have a great system for replicating simple functions such as introducing new recipes, but when it comes to taking care of sick patients, analogies to easy and repetitive processes fall apart.

Likely, every hospital is working to design systems of excellence with patient-specific outcomes as the markers for quality.[4,5,6] But hospital quality is also affected by how we attend to the relevant needs of patients' families, as well as clinicians and other hospital employees. Further, quality involves outreach to the many communities a hospital serves.

It is not the *what* of quality that is lacking; it is the *how*. For many years, hospital administrators and physicians have been trying to transform the mounting knowledge about how complex organizations function into improved systems operations. The understanding that hospitals are organic learning institutions[7] has introduced the language of interdisciplinary meetings and teamwork into the medical lexicon. But the spirit of these new ways of collaborating, in which physicians work with each other as well as with non-physician members of the team, have been slow to take hold in functionally meaningful ways. The hierarchy of medicine and the isolationism of the physician-patient dyad have been slow to evolve into a more democratic model of practice, with the specialness of the physician-patient relationship protected in newly imagined ways.

Likely, every hospital is working to design systems of excellence with patient-specific outcomes as the markers for quality.

To reach excellence, the many systems involved in care delivery must interact, cooperate, and collaborate at the highest levels of competence and collegiality. The CoP model connects the dots between the structural changes already instituted but functionally moribund, and the way to bring these structural changes to life. The Center for Breast Health is the perfect example of how hospitals can make it all work.

WHAT IS THE COMMUNITIES OF PRACTICE MODEL?

Taking a systems approach to hospitals has been in vogue for many years.[8] At first, the focus was on structural changes: creating interdisciplinary teams and identifying systems of care delivery. Although this kind of thinking began to reshape practice, it was not sufficient to transform the general climate and functioning of an acute care hospital. Even today, many hospitals remain at a level of dysfunction, with isolated (and often competitive) subspecialists and departments.[9,10] Implementing a CoP model may be the fundamental change needed to recalibrate the gears of a hospital system for good.

Implementing a CoP model may be the fundamental change needed to recalibrate the gears of a hospital system for good.

The CoP model is relatively new to the acute care hospital setting. It has been used successfully in corporate settings, such as Royal Dutch Shell, Xerox, and IBM; in the development world of the World Bank; and is now being considered for national implementation across Canadian cancer care systems.[11] Of the components of the CoP model we focus on here, the CoP model involves the notion of "aliveness" in how to enliven interdisciplinary practice. In a hospital, the CoP model employs voluntary interdisciplinary groups of clinicians who come together to take care of sick patients. Although this inherent quality of voluntariness is essential for the model to work, it also acts as a barrier to establishing the model. That is because, at first, starting to work in a CoP way may seem like an additional time drain on physicians.

Hospital clinicians are both short on time and busy trying to generate funds, either in payment for them or their hospitals. These two facets of contemporary hospital care conspire to act as barriers to shifting from the old way of doing things—the siloed, competitive, non-cooperative, non-collegial groups, interspersed with functionally impotent interdisciplinary teams—to a transformed and transformative way of working.

WHY OUGHT COP BE THE HOSPITAL MODEL OF THE FUTURE?

Interdisciplinary care practiced at its highest level of excellence is what patients need. This is a non-controversial, even platitudinous, statement. Implementation is where the difficulty lies. The CoP model may provide the solution. Specifically, this model may have what it takes to leap the divide in systems functionality embedded in the CoP model notion of "aliveness." No clinical professional has the time, interest, or money to sit in a boring and time-wasting meeting. Such meetings sap clinicians' time and psychic energy away from attending to the needs of hospitalized patients. But attending a meeting that feeds clinicians' thirst for new knowledge, and may spawn creative solutions to problems in the care of a specific patient, is well worth the time. In fact, this "aliveness" may give back to busy, often exhausted, clinicians the energy necessary to return to the practice of high-performance hospital medicine. The energy that is generated comes from new knowledge that a clinician takes away from the meeting, not only of assistance in the care of the patient under discussion, but also applicable to care planning for multiple patients.

As for the business aspect, one may assume a short-sighted or a long-sighted perspective.[12] The short-sighted perspective is, of course, the belief that anything that takes time away from what can be billed, such as direct patient visits and care, is money lost. But this is definitely the short-sighted view. Because once the group gets going, as has been true for our Center for Breast Health, the results of this effort contribute to more patients coming to your hospital rather than your competitors' because the care is simply better. And that has always been the marker for excellence in relation to the bottom line.

THE CENTER FOR BREAST HEALTH

MedStar Washington Hospital Center established the Washington Cancer Institute in 1992. At that time, a virtual program was in effect for breast cancer with informal conferences among surgical, medical, and radiation oncologists, but with no formalized processes.

In 2006, the hospital's Women's Auxiliary funded the Center for Breast Health, which has a separate space within the Cancer Institute. It holds weekly meetings during which patients are reviewed by the full complement of team members, occasionally including the patient's community internist. Out of the 8,039 cancer cases managed by the Cancer Institute between 2009 and 2010, almost 600 were breast cases diagnosed or treated at the Center for Breast Health (Washington Cancer Institute Annual Report, 2010).

BACKGROUND ON INTERDISCIPLINARY BREAST CENTERS

Breast cancer is the most common cancer affecting women. Approximately 1 in 8 women will have breast cancer at some point in their lives. The American Cancer Society estimates 226,780 new cases of invasive breast cancer and an additional 63,300 new cases of *in situ* breast cancer among women in the United States for the year 2012.[13]

As mass screening has led to earlier detection, the smaller size of tumors renders further complexity to the decision-making process, involving the efforts of mammographers, pathologists, and the full cohort of oncology specialists. Breast centers bring together all members of the team for optimal performance.[14]

It is likely, though, that breast cancer has been a leader in interdisciplinary care for more than technical and scientific reasons. There are multiple social, sexual, political, and familial aspects of breast cancer and breast cancer treatment that naturally inclines the treatment of this disease toward an interdisciplinary care model.

There are multiple social, sexual, political, and familial aspects of breast cancer and breast cancer treatment that naturally inclines the treatment of this disease toward an interdisciplinary care model.

Breast cancer, and by extension breast cancer centers, enjoy the support of a strong lobby and good funding, such as from the Susan G. Komen Foundation. Since 1982, Susan G. Komen for the Cure has partnered or funded programs in more than 50 countries and invested nearly $1.5 billion in breast cancer research, education, and community programs,[15] including direct support for fellowships and several research projects conducted by the Center for Breast Health.

But simply setting up breast cancer centers on an interdisciplinary model is not sufficient. Even the best-funded centers, if lacking a CoP philosophy, are doomed to systems mediocrity. Rather, it is the "aliveness" generated by the CoP model's philosophy of voluntary participation and bottom-up organization that allows these centers to actually work as hoped.

At the Center for Breast Health, improved quality is demonstrated both by its success through such outcome measures as patient satisfaction and patient load and by its accreditation from the American College of Surgeons' National Accreditation Program for Breast Centers (NAPBC). Our program is one of only 58 centers nationwide that has participated in this rigorous accreditation process and earned the NAPBC designation. NAPBC sets standards for center leadership, clinical management, research, community outreach, professional education, and formalized continuous quality improvement.

MEETING THE NAPBC STANDARDS THROUGH ALIVE INTERDISCIPLINARY CARE

A full discussion of many of the NAPBC's program standards of care that ought to be included in a comprehensive breast cancer center are beyond the scope of this article. Examples are the use of minimally invasive biopsy methods for diagnosis, and sentinel node biopsies rather than axillary dissections for staging.

But central is the interdisciplinary model that makes the delivery of this care cohesive. Our team has grown over the years. It began with a breast surgeon, medical oncologist, radiation oncologist, and reconstructive surgeon, later incorporating a radiologist and a pathologist with additional training in breast cancer diagnosis. This kind of specialized approach has been shown to work—at the Center for Breast Health, survival for patients with stage III and IV breast cancers is well above the national average.

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Medical services have been added along the way. A palliative care team helps manage pain and noxious symptoms, a geneticist counsels and tests women at high-risk for breast cancer, and a physiatrist at our hospital's sister organization next door, MedStar National Rehabilitation Hospital, manages a full-service cancer rehabilitation program staffed with professionals who are fellowship trained in the lymphedema specialty.

The Center for Breast Health has added a host of additional services that complete the care spectrum. These services begin with screening women for breast cancer and determining who is at higher risk for developing the disease, supplemented by a free Breast Cancer Prevention Kit. The Center's Patient Education Resource Center has an extensive collection of materials, as well as Internet access. A patient health educator is available to answer questions, as is a program-dedicated nurse navigator. A nutritionist helps patients maintain a healthy diet during and after treatment. Dedicated social workers provide individual, group, and family counseling, and arrange for support from community resources as needed. Relaxation and stress reduction techniques including guided imagery and Reiki, a light touch therapy, are also available. Our chaplains provide spiritual support along the way. All these professionals attend meetings when their patient's care is being discussed.

Clinical trials are an important part of the Center for Breast Health's program. Various members of our team participate in cooperative group, investigator-initiated, and industry-sponsored clinical trials, with the help of a clinical research nurse. The Center for Breast Health specifically collaborates on clinical trials sponsored by the National Cancer Institute (NCI), National Institutes of Health (NIH), and with the Lombardi Cancer Center at MedStar Georgetown University Hospital. Our clinician-investigators are generally regular members of a core team that holds meetings together and with the breast researchers at the Lombardi Cancer Center to cross-fertilize new knowledge and approaches to breast cancer care. The idea is to make the interdisciplinary meetings useful to the participants and interesting for all, a hallmark of the CoP model.

It is time to imagine and implement evolved ways of delivering breast cancer care—and care in a host of other therapeutic areas.

WHY THE CENTER FOR BREAST HEALTH IS A MODEL FOR ALL MEDSTAR

In considering traditional modes of practice in breast cancer treatment versus those that reflect the state-of-the art, traditional care can be understood as disintegrated.

The disintegrated approach: A woman goes for an annual exam with her gynecologist or primary care physician and is given a prescription for a mammogram. She takes that prescription to an imaging center where she undergoes mammography. She is notified that there is an abnormality on her mammogram and is told to make an appointment with a breast surgeon for further evaluation. She picks up her films from the imaging center and brings them to the breast surgeon. The breast surgeon may send her back to the imaging center for an ultrasound exam or MRI. She brings these additional results back to the breast surgeon, who decides to perform an excisional biopsy. After a diagnosis of breast cancer is made, the woman may also have to visit a medical oncologist, radiation oncologist, and reconstructive surgeon, with little guidance about how best to determine the most appropriate treatment amid often differing recommendations. Further, these specialists are often located separately and may be at significant distances from one another, creating logistical impediments for patients in addition to delays in diagnosing and thus treatment.

This is the picture of breast cancer care today across many locales. But for the women who have to go through this, it is the picture of miserable care. It is time to imagine and implement evolved ways of delivering breast cancer care—and care in a host of other therapeutic areas. Let us consider what this care can look like.

The integrated approach: Consider the same woman, but in this scenario she has come to the Center for Breast Health. The woman takes her prescription for a mammogram to a breast center with specialized imaging services. When there is an abnormality, she is referred to a breast surgeon at the center. During her initial visit, she is examined and her imaging is reviewed in detail with the center's radiologist. Together, they make a decision regarding further testing. A patient navigator arranges any suggested studies on the day of her visit or subsequently by telephone, and then schedules the interdisciplinary consultation, usually within one week. At this consultation, the woman meets with the breast care team, including the radiologist, surgeon, medical oncologist, radiation oncologist, and reconstructive surgeon. The team reviews the test results with the patient and discusses the next steps for staging and treating the disease, with a nurse navigator at her side throughout the process. All appointments are coordinated by the patient navigator, supplemented by education and support from the nurse navigator. All care is provided in a patient-friendly space, whether designed especially for women, or in general oncology. Help is available for transportation, financial arrangements, and a full range of non-medical support. Because this woman is a single parent of 2 teenagers (many of the patients at the Center are single parents), particular attention is paid to this social reality in her life so she can be assured that the needs of her children are managed adequately while she manages her own health needs.

Certainly this kind of integrated approach is what any patient with breast cancer, or any serious medical problem, deserves. Critical to the successful implementation of such state-of-the art integration is effective communication. In 1992, there were monthly meetings of specialists involved in the evaluation and treatment of breast cancer patients. Within a few years, the prospective reviews became weekly, with the team members meeting with new patients later the same day to outline the treatment strategies that were discussed during the meeting.

The form below demonstrates a typical Multidisciplinary Oncology Consultation Service (MOCS) form. Implementation of the CoP model requires weekly interdisciplinary meetings that are useful to the participants and interesting for everyone.

Multidisciplinary Oncology Consultation Service (MOCS)

Lead Physician: Dr Marc Boisvert
Month and Date, 2012

Thank you for agreeing to participate in the MOCS for:
Ms XXXX MR#000000
XX-year-old Female

Ms XXXX comes to MWHC for evaluation and recommendations from the MOCS team regarding her care. All available medical reports are attached. She is aware that these recommendations are preliminary and final recommendation of care will depend upon her pathology results from her definitive surgery. The MOCS will be held in the Cancer Institute, Oncology Specialty Center, 1st floor, on Wednesday, Month and Date, 2012.

If you have any questions, please contact Senta Benson, RN, BSN, OCN, Breast Oncology Nurse Navigator at 202-877-9343.

MOCS Schedule:

12:00 pm	**Senta Benson RN** (Breast Oncology Nurse Navigator)
12:30 pm	**Dr Marc Boisvert** (Breast Surgeon)
	Dr Janice Sicat (Surgical Breast Fellow)
1:00 pm	**Dr Karen L. Smith** (Medical Oncology)
1:30 pm	**Colleen McLain LICSW** (Social Work)
2:00 pm	**Dr Michael Porrazzo** (Radiation Oncology)
2:30 pm	**Dr Rafael Convit** (Plastics and Reconstructive Surgery)
3:00 pm	**Yvonne Francis PT** (NRH Breast Cancer Rehab Program)
3:15 pm	**Lynette Wray** (Clinical Research)

Surgeon:	Dr Marc Boisvert		Dr Lana Bijelic		
Date of Abnormal finding:		Referral Source:			
Diagnostic mammography	Facility:				
Screening mammography	Facility:				
MRI/other	Facility:				
Breast self exam					
Clinical breast exam	Physician:				
Abnormality noted:		**Location**	Right/Left	breast.	
Mass	Calcification	Other:			
Other Imaging/Date:	PET/CT	MRI	Ultrasound		
Date of Biopsy:	Ultrasound guided		MRI guided	Excision	Other:
Type of Breast Cancer	**Confirmed Pathology/ date:**				
New	Recurrence				
Ductal Carcinoma In Situ	Invasive Ductal Carcinoma				
Lobular Carcinoma In Situ	Invasive lobular Carcinoma		Inflammatory Breast Cancer		
Hormone Receptors:					
ER	Positive	Negative	Pending		
PR	Positive	Negative	Pending		
HER 2-neu	Positive	Negative	Pending	**Genetics consult:**	Yes No

With offices in close proximity to each other, the physicians and other team clinicians keep in frequent touch through impromptu hallway conversations, supplemented by a generous use of e-mail. Much of the group's interaction and communication is increasingly managed by use of an internal SharePoint Web site.

When the Center for Breast Health started, there were only nurse navigators, who managed all aspects of patient interaction. But as the patient load increased, this function was split into 2 separate roles. The patient navigator manages all appointments, coordinates schedules, and is generally in charge of the many logistical aspects of care. The nurse navigator provides education, support, facilitates physician interaction, and becomes the contact point for patients and families whenever they have a concern related more specifically to clinical factors.

What is important is that the specialists and subspecialists come out of their silos to form a community of practice centered on a common interest in breast cancer, focused on the care of individual patients and families. This illuminates another hallmark of the CoP model, which is that members of the group share a common passion: excellence in breast cancer care. At the Center for Breast Health, the intellectual diversity optimizes patient care by strengthening group cohesiveness. The group is currently working toward allowing other breast programs within the MedStar system to join their meetings via the Internet in order to help seed replication throughout the MedStar hospital system.

What has helped the Center for Breast Health to thrive is the team's willingness to stay flexible and keep ahead of the curve.

ADDING VALUE

What has helped the Center for Breast Health to thrive is the team's willingness to stay flexible and keep ahead of the curve. An important example of this is the establishment of a fellowship for breast surgeons, the first and only such fellowship in the DC area. The Center is now training their 11th fellow. Educating new physicians keeps the group on top of its game while supplementing patient care.

There is also a Cancer Registry that shares a strong collaborative relationship with the Center for Breast Health, while generally associated with the Washington Cancer Institute. This relationship provides Center personnel, as well as hospital leadership, important information about patients and their progress. This information allows celebration of successes and helps improve treatments for new patients.

The Cancer Institute's Cancer Support Services offers many classes, programs, and other services for patients, including a survivorship program dedicated especially to breast cancer patients. Although the Center for Breast Health has long been an active participant in Komen's Race for the Cure, the team wants to find additional ways to bring our survivors together for their benefit and for the benefit of our newly diagnosed patients.

The Center for Breast Health adds new technologies and advanced therapeutic approaches as they are proven effective and become available. A regional anesthesia protocol has been implemented for patients facing surgery, providing better pain control, and limiting the effects of an anesthetic to a single section of the body, such as a limb, or the lower or upper half. This method also results in significantly fewer side effects for patients and allows them to be awake during many procedures, enabling communication with the surgeon when necessary. Currently, the Center's leadership is considering intra-operative radiation therapy for selected patients. Both within the MedStar system's 10 hospitals and outside, it is clear that the manner in which the Center for Breast Health's program connects new systems of organization, knowledge, and interdisciplinary efforts is the direction in which hospital medicine is moving, in general.

CREATING A MODEL BREAST HEALTH CENTER—OR A CENTER FOR ANY CANCER THERAPEUTIC AREA—IN YOUR HOSPITAL

Although it is true that the Center for Breast Health enjoys wide support throughout the hospital and the MedStar system (defined as both material and political resources), it had to build that support when it started, just as any program must. That is, it does not matter if a hospital is large or small, sophisticated systems for integrated care delivery can and must be established in all health care institutions.

Our experience is that the place to start is with a physician champion. For it to become a high-functioning program, there needs to be a physician champion: a leader who can move the program from his or her heart to reality. Some physicians are natural leaders. But whether naturally gifted in leadership or not, when a physician champion surfaces, it is useful for that physician to become well trained in state-of-the art hospital management. In that way, the program's physician champion can begin to discuss the prospects for such a program with hospital administrators—departmental directors and unit chiefs, Chief Executive Officer (CEO), Chief Operating Officer (COO), and hospital president, et al—in language that the hospital's formal leadership can appreciate.

It is wise to convene a task force that represents all clinical specialties. To create a new, fully integrated breast health program (or other program), there will need to be buy-in and a sense of ownership among a wide range of subspecialties; hospital support departments such as social work, physical and occupational therapy, and pharmacy; and of course, hospital administration. Establishing an enthusiastic and active task force is an ideal way to show the rest of the hospital how important developing this program is to others.

Perhaps opportunities can be created for the task force, or at least some task force members, to visit other programs to see how they operate and to learn about how they were put together. Such visits can also build new collegial and cross-program relationships that can be nourished as time progresses. Like-minded clinicians and administrators are bound to run into each other at professional meetings where tips can be shared and new insights sparked.

Once the idea of a program has taken root, seeking community partners and identifying fund-raising opportunities will be essential. But it is important, too, to realize that the heart of the MedStar Washington Hospital Center's program is its interdisciplinary meetings focused on providing breast care in a coordinated, efficient, integrated way that works best for patients, patients' families, and clinicians. Creating this kind of model needs only dedicated clinicians willing to put in the effort required to shift from a traditional, disintegrated delivery model to a delivery system of integrated services. Resources help, but they are not what drive the program. It is commitment to a better health care service delivery model that is the driver.

> For there to become a high-functioning program, there needs to be a physician champion: a leader who can move the program from his or her heart to reality.

CONCLUSION: CONFRONTING BARRIERS AND MOVING FORWARD

Building the Center for Breast Health, however, has not been without resistance. Anyone who has ever worked in a hospital can imagine the barriers. Many of these are reducible to the willingness and disposition of traditionally trained health professionals who may find it difficult to reconfigure the manner in which they relate with one another and ultimately to the systems in which they practice medicine. Invariably, it is such persons who tend to make it challenging for others to move toward a more evolved organizational structure. When the process involves conceptualizing and creating centers of care delivery that function organically and are equipped with a purely voluntary staff, it is not difficult to see why those who have practiced for a significant time within a more traditional and rigidly structured care system may be resistant.

The hurdles of 1) having to convince others that the additional meeting time will be well spent, 2) creating physical space within which professionals are in close proximity, allowing for impromptu, spontaneous conversations regarding care, and 3) growing a voluntarily present group of physicians and support clinicians in a bottom-up, CoP-like process are high. Building a breast cancer center, or any other therapeutic care delivery on the CoP model, requires vision, leadership, and a masterful hand to the politics. But it is worth it, as patients, physicians, families, and the community all benefit. Toward that end, organizations representing all types of hospitals from various regions across the country have come to the Center for Breast Health to view these practices and learn. Our team wants to encourage other hospitals and centers to adopt this way of serving patients with cancer and their families. The Center for Breast Health's Annual Report is available upon request.

Building a breast cancer center, or any other therapeutic care delivery on the CoP model, requires vision, leadership, and a masterful hand to the politics.

Authors

Marc E. Boisvert, MD, MBA is a breast surgeon and medical director of the Center for Breast Health at the Washington Cancer Institute at MedStar Washington Hospital Center and director of the hospital's breast oncology fellowship.

The Editorial Group of the Center for Ethics at MedStar Washington Hospital Center

References

1. Committee on Quality of Health Care in America, Institute of Medicine. *Crossing the Quality Chasm: A New System for the 21st Century.* Washington, DC: National Academies Press; 2001.

2. Gawande A. Big med: restaurant chains have managed to combine quality control, cost control, and innovation. Can health care? *The New Yorker.* August 13, 2012:52-63.

3. Wenger E, McDermott R, Snyder S. *Cultivating Communities of Practice: A Guide to Managing Knowledge.* Cambridge, MA: Harvard Business School Press; 2002.

4. Brown DL, Clarke S, Oakley J. Cardiac surgeon report cards, referral for cardiac surgery, and the ethical responsibilities of cardiologists. *J Am Coll Cardiol.* 2012;59(25):2378-2382.

5. The Leapfrog Group. Leapfrog releases hospital safety scores. *Hosp Peer Rev.* 2012;37(7):78-7.

6. McDonald TB, Helmchen LA, Smith KM, et al. Responding to patient safety incidents: the "seven pillars." *Qual Saf Health Care.* 2010;19(6):e11.

7. Renesch J, Chawla S. *Learning Organizations: Developing Cultures for Tomorrow's Workplace.* Portland, OR: Productivity Press; 2006.

8. Longest BB, Darr K. *Managing Health Services Organizations and Systems.* 5th ed. Baltimore, MD: Health Professions Press; 2008.

9. Schwarze ML, Bradley CT, Brasel KJ. Surgical "buy-in": the contractual relationship between surgeons and patients that influences decisions regarding life-supporting therapy. *Crit Care Med.* 2010;38(3):843-848.

10. Penkoske PA, Buchman TG. The relationship between the surgeon and the intensivist in the surgical intensive care unit. *Surg Clin North Am.* 2006;86(6):1351-1357.

11. Bentley C, Browman GP, Poole B. Conceptual and practical challenges for implementing the communities of practice model on a national scale—a Canadian cancer control initiative. *BMC Health Serv Res.* 2010;10:3.

12. Ward WJ Jr, Spragens L, Smithson K. Building the business case for clinical quality. *Healthc Financ Manage.* 2006;60(12):92-98.

13. American Cancer Society. *Cancer Facts & Figures 2012.* Atlanta, GA: American Cancer Society; 2012. (http://www.cancer.gov/cancertopics/factsheet/detection/probability-breast-cancer). Accessed December 29, 2012.

14. Kaufman CS. Letter to the editor. *Breast J.* 2004;10(5):469-472.

15. Susan G. Komen for the Cure Web site: http://ww5.komen.org/AboutUs/GlobalReach.html. Accessed December 29, 2012.

Oncology and Ethics 101

by John J. Lynch, MD and the Editorial Group of the Center for Ethics at MedStar Washington Hospital Center

Whether treatment is provided acutely by a surgeon, hospital intensivist, or for an extended period of time by a patient's oncologist, cancer care is most often ethically complicated. Much of this complexity stems from the disease process in combination with emotional components brought in by patients and physicians alike.

For many patients with cancer, the disease progression—whether over months, years, or decades—ends in death. According to the National Cancer Institute, from 2005–2009, the annual age-adjusted death rate in the United States was 178.7 per 100,000 men and women.[1] Because so many die from cancer each year, virtually everyone knows something about the disease and fears a diagnosis.

Having cancer is not like having, for instance, an uncomplicated appendicitis. But the skills needed to take good care of a patient with appendicitis, or any number of benign conditions, are well learned through the care of a patient with cancer. For both, the need to have excellent technical skills is no different. Technical competence is always the baseline, regardless of the disease entity.

The difference, however, between caring for a patient with an uncomplicated appendicitis and a patient with cancer lies not in mere competence in a skill set related to interpersonal relations, but the special demand on that skill set. This competence requires that a physician learn how to:

1. Manage emotions, especially those of fear, hope, grief, anger, and dread. This includes those of the patient, any involved family and friends, and those of the physician.
2. Communicate clearly, genuinely, and in ways that convey empathy and compassion.
3. Identify and come to terms with the person, not just the patient.

The progressive decline often associated with cancer is perhaps its most terrifying and unsettling characteristic for patients and families. This makes it essential for physicians to master interpersonal skills in the care of these patients.

LEARNING THE INTERPERSONAL SKILLS NEEDED TO TAKE CARE OF PATIENTS WITH CANCER

In a 2002 article, 2 medical researchers described their personal experiences with cancer. Drs Tierney and McKinley's experiential model[2] is ideal for learning important interpersonal skills. Their work involves the delineation of 8 general concern areas (the 8 "Ds") drawn from their own experience as patients with cancer. The following is guided by their project, and teases out the ethical skills that all good physicians should master. In focusing on these particular skills and concerns, this *JOHE* residents' training module can teach new physicians how to reduce the pain and suffering of those who become their patients. In oncology, perhaps more poignantly than in any other medical specialty, the most basic of ethics lessons is that a physician's obligation to treat pain and suffering is as important as treating the disease.

1. DIAGNOSIS

A diagnosis of cancer is shocking. "The shock of the cancer diagnosis was painful and introduced chaos into our daily routines…The overall feeling was one of loss and uncertainty."[2] Patients diagnosed with cancer find themselves inevitably having to restructure well-established routines in their daily lives. This restructuring does not pertain solely to how an individual receiving cancer treatment may have to limit certain physical aspects of everyday life. Response to a cancer diagnosis is also influenced by differing degrees of psychological acceptance or denial related to the effects of these anticipatable limitations. This reconfiguration affects a patient's relationships with family, friends, and others. Having the physician address this aspect of the diagnosis can build trust and provide needed reassurance.

To master an ability to address the inner concerns of patients, residents need to identify and acknowledge their own levels of discomfort in discussing difficult topics with them. It takes practice to overcome a natural inclination to withhold news that is distressing. It is also critical to take note of a patient's psychological and practical restructuring subsequent to a cancer diagnosis.[3] How a patient manages this restructuring may guide the physician in how to engage with his or her patient during this time. Watching a patient, and perhaps those close to him or her, carefully enough for the physician to determine what coping strategies are being employed may offer the physician clues on how to best approach the patient with sensitive news in the future.

2. DYING

Another powerful psychological component for a physician to understand is the conceptual framework with which a patient with cancer regards the possibility, and often inevitability, of dying. This is different from fear associated with death. Rather, concerns about dying include fear related to pain and suffering as well as the kinds of selfless concerns a patient may hold regarding practical and emotional burdens that will fall to others as the dying process progresses.

An interpersonally skilled physician ought to be aware that many patients think about dying through their exposure to others dying in comparable circumstances. Visions of people they have known to have died from cancer, in perhaps excessively debilitated states, may flood their mind. These visions and the patient's resulting anxiety are often suffered in silence. If fortunate enough to not have experienced such circumstances, at the very least patients have likely formed a concept of the dying process and how it must feel. It is important that the physician gently probe to learn about these thoughts.[4]

Once learned, these notions about the dying process should be addressed honestly. Accurate information should be given, and assurance that pain and other symptoms will be managed should be emphasized. Patients should be informed that assistance can be provided with other aspects of dying, including those of a psychosocial and spiritual nature. Also, it is important to future care planning that these conversations be fully documented in the patient's chart, including the patient's spoken fears, hopes, and expectations.

3. DISCOMFORT

Discomfort for cancer patients who are undergoing treatment may depend on the aggressiveness of the protocol, as well as their own physical capacity to withstand such treatment. Aside from the necessity to be compassionately honest while communicating the range of adverse effects, pain, and other symptoms associated with a given treatment, physicians ought to consider the interpretive effects of the pain experience for patients. That is, the interpersonally and ethically astute physician works to learn each particular patient's potential for linking the severity, location, or chronic nature of pain to the quality and progression of his or her disease. These may not be necessarily correlated. A misinterpretation of this kind by patients only reinforces fear and insecurity related to the state of their disease.

Additionally, a physician ought to introduce and accurately describe the idea of palliative care at the beginning of the treatment process. Too often, patients and physicians confuse this with end-of-life care, but palliative efforts should begin with the onset of symptoms, providing pain relief and symptom management throughout the course of treatment. In fact, there are data emerging that demonstrate that palliative intervention early after diagnosis may extend survival.[5]

To learn the skills involved in managing patients' discomfort throughout their cancer disease process, physicians need to remember that discomfort is both physical and psychological. Focusing only on physical concerns and failing to attend explicitly to those of a psychological nature provides inadequate cancer care. Further, a failure to address psychological distress may undermine efforts at treating physical discomfort.[6,7]

4. DISABILITY

Patients undergoing cancer treatment may suffer progressively through many losses in physical ability because of the adverse effects of their given therapy and their advancing cancer, often resulting in decreases to body mass and function. It is not unusual for patients to attempt to counteract some of these effects by engaging their body in activities known to help produce what is being lost, such as an increase in weight training or muscle building exercises when initially experiencing myopathy.

It is essential for the physician to both be truthful about expected physical adversities and be willing to engage in conversation. The physician should explain simply and clearly what a patient can expect. A physician who is less than compassionately honest about the physically disabling ramifications of cancer treatment encourages unrealistic quality-of-life goals, which may produce frustration, anger, and other negative emotions in patients and families.

5. DRUG AND OTHER TREATMENT EFFECTS

Drs Tierney and McKinley report suffering many of the common adverse effects of cancer treatment, and that they suffered these side effects in silence. In fact, they report that "… we rarely complained about these adverse treatment effects unless we were explicitly asked… Even then, we tended to minimize their severity and impact on our lives."[2] They suffered in silence so as not to upset their physicians or to appear weak. This disclosure should be an important warning to physicians. It is essential that physicians ask their patients about the effects of their treatments, exploring what negative symptoms they may be experiencing.

The ethics lesson here is that the physician needs to understand the ways in which each particular treatment may be affecting the patient. Only with this information can the physician adjust his or her sense of the harms and benefits a particular treatment entails for the patient at any point along a cancer continuum. A morally aware physician seeks to understand this balance so that recommendations for continuing and/or changing treatments or a plan of care can be tailored to a patient's prognosis. This requires courage on the physician's part to face straightforwardly what, in this sense, is going to be in the patient's best medical interest.

Although, when possible, the intended good of providing chemotherapy is remission or a cure, it is also important for the physician caring for a person with end-stage cancer to understand death as equally ethically permissible when such an intervention will bring relief from pain and misery. An ethically skilled physician acts courageously under both circumstances, honestly talking with patients and family members, shaping hope for appropriate goals of care.

6. DEPENDENCY

Closely linked to disability and treatment effects are the social effects these circumstances cause to a patient's personal and professional support structures. That is, as patients recently informed of their disease reconfigure their lives, those who surround and constitute their social sphere are likely to feel the need to find ways to somehow ease their burden. This may be a psychologically arduous adjustment to persons who have difficulty accepting help. It is essential to understand the relational dynamics and be respectful of the choices of patients and family members.

7. DOUBT

Patients may feel overwhelmed with insecurity in terms of what their physiological capacity may be to withstand a treatment course that leads to remission and the return to a healthy and productive life. If the relationship between patient and physician is one assisted by honest communication of the clinical circumstances, chances are these uncertainties are in fact shared by both patient and physician. The virtue of being honest, however, does not require focus on the negative. Patients often find comfort and optimism in the stories of patients who have faced similar clinical adversity, and the careful sharing of this knowledge by a sensitive physician does not necessarily constitute a provision of false hope. Nonetheless, an ethically and interpersonally skilled physician is careful to choose stories that build a patient's confidence in ways that are appropriately tailored to the stage of that patient's disease. Even when a cure is no longer possible, stories that increase a patient's confidence in the hope of a comfortable death may bring them the solace that is their physician's obligation to provide.

8. DEATH

For many patients, experiencing the fear of dying is entirely distinct from the consideration of imminent death. Once death is actually approaching, many anxieties related to the concrete aspects of a patient's everyday life that may have been present very shortly after the initial diagnosis are replaced with a more profound set of inquiries related to existence, the particular meaning of the patient's life, and often a wide spectrum of sometimes religiously substantiated trajectories of thought and contemplation. For many, it is simply regret for the sorrow and grief the end of their lives will bring to their loved ones; for others, there may be a sense of relief provided by what will constitute the end to their own pain and suffering. These reactions can vary greatly, and a skilled physician must support the patient in a way that provides the most comfort.

CONCLUSION

For the compassionate physician, the lessons learned through caring for a patient with cancer, regardless of where in that patient's disease process the physician intercedes, may serve to elevate his or her ethical awareness in all patient relations. These lessons may assist in how to:

- Be fully present during difficult conversations, such as when communicating bad news.
- Be honest and sincere with a seriously ill patient.
- Be sensitive to the religious and cultural aspects of a patient's life.
- Engage in discussions related to advance planning in the early stages of a disease's progression.
- Find within one the moral courage necessary to face the patient's death, and guide the patient's dying process.
- Genuinely explore with a patient what he or she wants during a complicated informed consent discussion.

As noted earlier, the progressive decline associated with cancer is perhaps its most terrifying and unsettling signature quality. It is this quality, however, that allows the physician multiple points of necessary intervention and the opportunity to develop a relationship that provides care for the patient in every sense of that word. The experience of caring for the person, not just the disease, ultimately benefits all future patients.

Internet Sites

www.cancer.net (sponsored by American Society of Clinical Oncology)

www.cancer.org (sponsored by American Cancer Society)

www.cancer.gov (sponsored by National Cancer Institute)

Additional Reading

End of Life: Helping With Comfort and Care

National Institute on Aging
National Institutes of Health

Downloadable at: http://www.nia.nih.gov/health/publication/end-life-helping-comfort-and-care

Authors

John J. Lynch, MD joined MedStar Washington Hospital Center as an oncologist in 1964, and is now medical director of the Center for Ethics at MedStar Washington Hospital Center.

The Editorial Group of the Center for Ethics at MedStar Washington Hospital Center

References

1. National Cancer Institute, Surveillance Epidemiology and End Results (SEER) Stat Fact Sheet. http://seer.cancer.gov/statfacts/html/all.html#incidence-mortality. Accessed January 6, 2013.

2. Tierney WM, McKinley ED. When the physician-researcher gets cancer: understanding cancer, its treatment, and quality of life from the patient's perspective. *Medical Care.* 2002;40(suppl 6)III20-27.

3. Klikovac T, Djurdjevic A. Psychological aspects of the cancer patients' education: thoughts, feelings, behavior and body reactions of patients faced with diagnosis of cancer. *J BUON*. 2010;15(1):153-156.

4. Temel JS, Greer JA, Adams S, et al. Longitudinal perceptions of prognosis and goals of therapy in patients with metastatic non-small-cell lung cancer; results of a randomized study of early palliative care. *J Clin Oncol.* 2011;29(17):2319-2326.

5. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med.* 2010;363(8):733-742.

6. De Sousa A, Sonavane S, Mehta J. Psychological aspects of prostate cancer: a clinical review. *Prostate Cancer Prostatic Dis.* 2012;15(2):120-127.

7. Stavraka C, Ford A, Ghaem-Maghami S, et al. A study of symptoms described by ovarian cancer survivors. *Gynecol Oncol.* 2012;125(1):59-64.

Acknowledgments

Each issue of *JOHE* requires the input of many individuals. For this issue, these authors shared their points of view about cancer.

Authors

Deliya R. Banda, PhD, MPH is a senior health communication researcher for Communicate Health Inc, a health education and communication firm that specializes in improving health literacy. Prior to that, she was research program manager for oncology at the MedStar Health Research Institute, where she worked with Sandra M. Swain, MD on a National Institutes of Health (NIH) bioethics/health disparities grant.

From 2006 to 2009, Dr Banda was a program manager at the National Cancer Institute in the Division of Cancer Epidemiology and Genetics. Previously, she worked for the Association of American Medical Colleges (AAMC) and for the Center for Science in the Public Interest (CSPI). In 2000, she was a research intern for the Framingham Heart Study at Massachusetts General Hospital in Boston.

Dr Banda is an adjunct faculty member at the School of Public Health at the University of Maryland, where she earned her PhD in behavioral & community health. She also has an MPH in cancer epidemiology from The George Washington University. She is an associate member of the American Association for Cancer Research and has written and lectured extensively about the participation of African American patients in clinical research.

Marc E. Boisvert, MD, MBA is medical director of the Center for Breast Health at the Washington Cancer Institute at MedStar Washington Hospital Center and director of the hospital's breast oncology fellowship. He is a clinical associate professor of surgery at Georgetown University School of Medicine and an associate member of the Georgetown Lombardi Comprehensive Cancer Center.

Dr Boisvert earned his MD from the Johns Hopkins School of Medicine and his MBA in medical services management at the Carey Business School at Johns Hopkins. He completed his surgery residency at the Hospital of St. Raphael in New Haven, Connecticut, which is affiliated with the Yale University School of Medicine. He joined the Hospital Center as a breast surgeon after completing his residency.

He is a member of the Society of Surgical Oncology (SSO), the American Society of Clinical Oncology (ASCO), the American Society of Breast Disease (ASBD), and the American Society of Breast Surgeons (ASBS). He has lectured widely on breast cancer treatment and has maintained a career-long interest in medical ethics.

Christian Carrozzo, MA is clinical ethics educator at the Center for Ethics at MedStar Washington Hospital Center and editor to the *Journal of Hospital Ethics (JOHE).* Mr Carrozzo completed his undergraduate degree with significant coursework in philosophy and psychology, and earned his MA in philosophy with a concentration in ethics & public affairs at George Mason University, in Fairfax, Virginia, where he was awarded the College of Humanities and Social Science's Dean's Challenge Master's Fellowship.

He is a previous member of Kaiser Permanente's Mid-Atlantic States Bioethics Committee, where he additionally held a clinical position in oncology. He has lectured or presented on topics ranging from virtue ethics to human capacity. Mr Carrozzo plans to continue pluralistic research in these and other areas of engaged philosophy at the doctoral level.

He is a member of the American Philosophical Association (APA), the International Association of Bioethics (IAB), and the American Society for Bioethics & Humanities (ASBH).

John J. Lynch, MD first joined MedStar Washington Hospital Center as an oncologist in 1964. In 1982, he left private practice to become associate medical director of the Washington Cancer Institute at MedStar Washington Hospital Center, retiring in 2004. He has served as medical director of the Center for Ethics for more than 25 years, and is *JOHE's* medical editor. He also is a clinical assistant professor of medicine at Georgetown University School of Medicine.

He has earned more than 25 awards throughout his career, including the Moral Courage Award from the Center for Ethics in 2011, the American Cancer Society 20-Year Service Award, and the Jackson-Newman Foundation James H. Jackson Award for Leadership and Outstanding Performance in Cancer Treatment for Individuals of All Races, Cultures, and Creeds.

A native of Washington, DC, Dr Lynch graduated from New York Medical College, interned at DC General Hospital, and then completed his internal medicine and pulmonary residency at Mt. Alto Veterans Administration Hospital in Washington, DC. He completed an oncology fellowship at Roswell Memorial Hospital in Buffalo, New York.

Sandra M. Swain, MD is medical director of the Washington Cancer Institute at MedStar Washington Hospital Center, professor of medicine at Georgetown University School of Medicine, and adjunct professor of medicine at the Uniformed Services Health Science Center. She currently serves as president of the American Society of Clinical Oncology (ASCO), the world's leading professional organization for oncologists.

Dr Swain joined the Washington Cancer Institute in 2007, following 8 years at the National Cancer Institute (NCI) as head of the breast cancer section in the Center for Cancer Research. Prior to these appointments, Dr Swain worked in a leadership capacity at the Lombardi Cancer Center at MedStar Georgetown University Hospital.

During her career, Dr Swain has led more than 20 clinical trials and published more than 200 articles focusing on innovative breast cancer treatment. She has received numerous awards for her efforts to improve the lives of cancer patients, including the Award of Distinction for Community Service from Susan G. Komen for the Cure.

Dr Swain received her medical degree from the University of Florida, and completed her residency at Vanderbilt University in Nashville, Tennessee, followed by a fellowship in medical oncology at NCI.

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1. **In the case titled "When Oncologists and Intensivists Disagree About Appropriate Care,"** 2 physicians disagree about the treatment plan for a terminal cancer patient. How should this be resolved?

☐ A. Leave it up to the patient.

☐ B. Flip a coin.

☐ C. Both physicians should present treatment plans in a joint meeting with the patient/surrogate for his or her decision.

☐ D. Involve the hospital administration.

☐ E. The intensivist makes the choice because the patient is in the ICU.

2. **In the case titled "When an Adolescent and Her Parents Disagree About Treatment,"** a 15-year-old girl with leukemia wants to stop treatment, but her parents disagree with her wishes. Should her refusal of chemotherapy be accepted?

☐ A. No, the patient is underage so her parents must decide.

☐ B. The physician should make the call.

☐ C. The courts must decide.

☐ D. If a minor demonstrates maturity given these circumstances, she should be allowed to make her own medical decisions.

☐ E. Yes, but the patient must seek emancipation.

3. **In the case titled "When Is Non-Cancer Surgery Warranted in a Cancer Patient?"** a 79-year-old man with probable late-stage colon cancer is found to have a 10cm abdominal aortic aneurysm (AAA) that requires a high-risk surgical procedure. Should this surgery be performed?

☐ A. The surgeon and oncologist must decide.

☐ B. It doesn't make sense to do the surgery in light of the patient's prognosis.

☐ C. The surgeon has to perform the surgery if the patient wants it.

☐ D. After providing all the information to the patient, the patient can decide if he wants the surgery, despite its risk and his likely cancer diagnosis.

CME Post-Test *for JOHE Winter 2012/2013 Volume 3, Number 2*

1. **In the case titled "When Oncologists and Intensivists Disagree About Appropriate Care,"** 2 physicians disagree about the treatment plan for a terminal cancer patient. How should this be resolved?

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☐ D. After providing all the information to the patient, the patient can decide if he wants the surgery, despite its risk and his likely cancer diagnosis.

CME Answers *for JOHE Winter 2012/2013 Volume 3, Number 2*

1. **The correct answer is C.** Although ordinarily the patient/surrogate is ultimately the decision maker, it is important that the physicians jointly meet with the patient/surrogate to discuss the treatment options. This allows both physicians to present their views about what is realistic so the patient/surrogate can make the most informed choice.

2. **The correct answer is D.** Given this patient's long history with the disease and the terminal prognosis, her feelings deserve to be given the most weight. The physician can serve as an advocate for her, and every effort must be made to help the parents accept her decision so this family can achieve some measure of peace.

3. **The correct answer is D.** Only the patient can decide if he wants the AAA surgery, despite its risk. Accepting this risk, or refusing surgery to avoid it and perhaps be assured a little more time before his probable cancer takes its full course, is a decision the patient should make in accordance with his own values after being properly informed.

The mission of the *Journal of Hospital Ethics* (JOHE, pronounced Joe), published by The Center for Ethics at MedStar Washington Hospital Center, is to provide an educational periodical for and by physicians, other clinicians, and hospital administrators to enhance the knowledge and skills needed to recognize and manage ethical issues in everyday hospital practice.

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Just as importantly, we recognize that the more complicated an ethical issue, the more likely it is that persons of good judgment will disagree. Thus, the opinions and perspectives offered in *JOHE* reflect only the views of the authors and editors, and do not necessarily represent the views of others within the MedStar Health system or of any other institution or organization with which any of the *JOHE* editorial group are affiliated.

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Presentations by specialists in critical care, palliative care, ethics law, group dynamics, and other subjects essential to the practice of clinical ethics round out the program.

Courses run twice each year, the first weekend in June and again the first weekend in November. Space is limited to 6 participants per session.

Tuition is $1200 and includes all course materials, meals, and daily transportation between the hotel and MedStar Washington Hospital Center.

For more information, please call 202-877-0247.