of-life care with important manuscripts about issues of emerging importance to palliative care in oncology. As more people in our communities experience an “expected” death from cancer or chronic, progressive end-stage system failure, palliative care provides a structured, rational, patient-centered approach to the provision of high-quality, cost-effective care that better meets the needs of patients, their families, and caregivers. As palliative care is increasingly woven into the fabric of health care, it will be critical to see that it is mainstreamed into the cancer care enterprise. The rewards to be gained will be manifest, and will help redirect patient care back to its roots in relieving suffering and focusing on living.

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Perspectives From the Other Side: A Physician and Cancer Survivor

By Susan C. Stone, MD, MPH

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Introduction

Living with an unpredictable and progressive illness challenges the strongest of humans. Cancer is the ultimate life changer and leaves a significant impact on both the individual and caregivers. Those undergoing treatment will have burdensome symptoms and pain,

psychological and existential distress, which can often go under-treated. ASCO has made great strides to integrate palliative care into the comprehensive care model. However, much work remains to ensure that all patients, whether receiving curative or palliative therapy, have a good quality of life.

The primary cancer care team provides much of supportive cancer care, but there are times when the suffering is so great that consultation with a palliative care specialist is warranted. This has become increasingly clear to me as a physician now battling cancer.

The vantage point of the patient is much different than that of the health care provider. I have been surprised at the excellence of care and what is possible. I have been equally able to experience the gaps that currently exist for the individual undergoing treatment.

In just 2 days I will be admitted for a stem-cell transplant. New chemotherapeutics have extended my life year after year. I am aware without many of these advances I would not be alive. The road now diverges, and the only choice for treatment is a transplant. As a patient, this is a frightening proposition, and the risks are significant.

The pretransplantation process is agonizing for a matched unrelated donor. I waited 5 months for a donor to make it through the screening. During that time, I was unable to work because of transfusion dependence and significant pain. The anxiety of being given a date and then losing each donor for various reasons created the greatest stress I have ever experienced. There is little support for those waiting, and that must be addressed if patient care is to be improved. Although I am quite resilient, I would have benefited from routine phone calls for updates and supportive care. This would help each patient come into transplantation a little more ready.

Lessons Learned

During the time I have battled cancer, I have learned many lessons as a physician and as a human. The first lesson learned is that mutual trust must exist between patient and provider. This is definitely the case for physicians who become patients, such as myself. In the literature, studies find that physicians have a tendency to self-treat, despite poor outcomes. Having a colleague order a laboratory test or imaging study that may be misinterpreted or even unchecked can lead to deadly consequences. Interestingly, the tendency to self-treat is greater among those who have less trust or respect for their physician.¹

If a patient is to trust their team, they must feel that the team provides confidence and honors the total patient. There must be a sense that the care they are receiving is meeting their needs. Patients are literally putting their lives and well-being into the hands of the cancer care team. In my years as a cancer survivor, and now awaiting transplantation, I have found that the primary cancer care team simply cannot meet all the complicated needs of their patient and benefit when palliative care is consulted for a one time consult or repeat visits. Patients feel they are receiving top of the line care and the primary team is also supported.

Palliative care is the specialty that provides expertise in end-of-life care through a comprehensive evaluation aimed at treating suffering. Addressing pain and symptoms, discussing goals

of care, and providing psychosocial and spiritual support are the key elements in this evaluation. It requires time and the presence of interdisciplinary team members (social workers, chaplains, nurses, and physicians).

Using supportive and palliative care teams improves care for the patient. Each patient I have cared for has often had unmet needs. Many presented to the emergency department for pain relief or simply learned to tolerate the discomfort. The patient with intractable pain may need a simple dose change and a sympathetic ear. Often, depression, fatigue, and anxiety are handled superficially, and spirituality is simply not addressed. This is where the involvement of a palliative care team elevates care for both the oncologist and their patient.

There are models throughout the country of palliative care teams working with cardiologists, pulmonologists and oncologists. Many specialists realize that the demands of their practice and training limit their ability to provide this type of care and that their patients benefit from the additional level of care. This has been the case in my care. It is always my primary oncologist that I look to for guidance, but it is good to know that she is making sure I am receiving all the care that is possible to make me comfortable.

As a physician, I have observed the hesitancy to consult with palliative care, often as a result of misperceptions or not recognizing when it would be beneficial. My suggestion would be to refer several patients and see what a difference the team can make.

The second lesson is that we are complicated beings and that suffering extends beyond the physical realm. When I was in training, there was the usual course of introducing students to clinical medicine. Sprinkled throughout the years were modules on ethics and a very sparse amount of education on the end of life. The current changes have identified gaps and are teaching students about whole-patient and end-of-life care. The next generation of health care providers will likely be more aware of the importance of palliative care.

Finally, lesson three: to maintain hope, we must tend to spiritual needs and look deeper than the cellular level. Spirituality is another important domain of care that is often not addressed but has a great influence over quality of life and death. The growing body of literature has demonstrated that patients want to be asked about their spiritual needs and that clinical outcomes are improved when this happens. If we are asking a patient to maintain hope, we must respect their entire being, including physical, emotional, social, and spiritual needs. As a patient, I have learned how important this is during the treatment process because it is so easy to lose hope. Cancer not only involves the physical body but also causes emotional, social, and existential distress. Thus, the palliative care team should have a spiritual care component.

In *Anatomy of Hope*,² Groopman, an oncologist at Harvard, writes about the astonishing effects of hope or its absence on the outcomes of illness. "When you hope for something, we employ, to some degree, our cognition, marshalling information and data relevant to a desired future event. If you are suffering

with a serious illness, and you hope for improvement, even for a cure, you have to generate a different vision of your condition in your mind. This picture is painted in part by assimilating information about the disease, and its potential treatments. But hope also involves affective forecasting—the comforting, energizing, elevating feeling that you experience when you project in your mind, a positive future. This required the brain to generate a different affective or feeling state than the one you are currently in.”

Relatively new programs are adopting meaning-based therapy developed to help patients with cancer reconnect with sources of meaning in life (love, family, nature) and learn that when cancer produces obstacles there is always an internal source of escape and focus. The work was based on the writings of Viktor Frankl, the Austrian psychiatrist who survived Auschwitz with a conviction that people can endure suffering if their life has meaning.

As Frankl says, “Life holds meaning for each and every individual, and even more, it retains this meaning literally to his last breath . . . Even the tragic and negative aspects of life such as unavoidable suffering, can be turned into a human achievement by the attitude which a man adopts toward his predicament . . . transforming despair into triumph.”³

Undergoing this 8-week program helps remove fear and overcome the defeat of suffering. Fortunately I have experienced meaning-based therapy and will take these tools with me into the transplant unit, where I know I will need them.

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Conclusion

Fortunately for patients, many oncologists have participated in available educational programs about palliative care. Education in palliative and end-of-life care for oncology⁵ integrates basic palliative care principles into modern-day oncology, with the intent being to develop basic skills. This will enrich these oncologists’ practice and benefit their patients.

Many will remain skeptical of palliative care, but it will be very difficult to resist in the coming years as measurable indicators show it only improves quality of care. There are many programs from ASCO intended to support the education of the cancer care team.

Illness is part of life. As health care providers we are not immune to the effects of cancer. Remember that if you find yourself visiting the cancer center as a patient, whole-patient care will be the most effective care possible.

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Integration of Palliative Medicine Into Routine Oncological Care: What Does the Evidence Show Us?

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Abstract

Palliative medicine is now a recognized medical subspecialty. The goal of palliative medicine is to prevent and relieve suffering, and to support the best possible quality of life for patients and their families, regardless of the stage of their illness.¹ Typically, palliative medicine teams consist of multiple disciplines (such as physicians, advanced practice nurses, social workers, and

chaplains) to address several domains of the patient experience. Medical oncologists have routinely provided palliative care to their patients along with antineoplastic therapy. Nevertheless, there is a recognized need for an improvement in palliative care delivery to the patient with advanced cancer. This narrative review outlines recent clinical trials of palliative care being integrated into routine oncological care.