PERSPECTIVE

Cancer Survivorship: A New Challenge for Surgical and Medical Oncologists

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Increasingly, oncology practitioners are realizing that despite the “success” of cancer therapies, cancer survivors are facing previously unrecognized issues related to survivorship, including physical and psychosocial side-effects of the cancer and its treatment, second cancers, and practical and economic issues related to adjusting to life after their cancer diagnosis. In gastrointestinal cancers, traditionally, the medical and surgical oncologists charged with the care of the patient are not well-equipped to deal with these survivorship issues. At the Penn State Cancer Institute's newly formed Gastrointestinal Cancer Survivorship Clinic, we provide a full array of services to optimize care through a multi-disciplinary approach. By utilizing a multi-disciplinary model with the primary medical and surgical oncologists spearheading the survivorship initiative and psychological and pastoral support as a priority, we hope to optimize cancer survivor care and patient quality of life.

KEY WORDS: cancer; survivorship; oncology; gastrointestinal.

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INTRODUCTION

Survivors of cancer are becoming an increasingly important segment of the population. By current estimates there are more than 10.8 million cancer survivors in the United States, representing 3.7% of the population.¹ Overall, 64% of adults diagnosed with cancer will be alive five years after diagnosis.² As outcomes for cancer treatment improve, this burgeoning group of cancer survivors presents oncology professionals with a new set of medical issues and challenges. In addition to ongoing follow-up and surveillance of their cancer, these patients often face such issues as physical and psychosocial side-effects from the cancer itself and its treatment, second cancers, and a range of practical issues related to adjusting to life after a cancer diagnosis.

Patients with cancer of the esophagus, stomach, liver, and pancreas have among the worst prognosis of all solid organ tumor patients. Most patients diagnosed with these tumors have less than a 20% chance of long-term survival. Despite these difficult odds, with recent improvements in chemotherapeutic treatment regimens, perioperative care, and surgical techniques, more and more of these patients are becoming long-term survivors. Between 1975 and 2003, 5-year survival rates have increased dramatically for colorectal cancer (50% to 66%), esophageal cancer (6% to 18%), stomach cancer (15% to 22%), pancreatic cancer (3% to 5%) and liver and bile duct cancer (4% to 10%).¹

Treatments for gastrointestinal cancers often include complex, toxic chemotherapy regimens, radiation, and major abdominal surgery with a long recovery process. Complex gastrointestinal tract surgery can result in dietary restrictions, altered bowel function, nausea and vomiting, diarrhea, or abdominal pain. Often these symptoms are self-limited, but they may persist to varying degrees. Lack of appetite, altered taste, difficulty swallowing and weight loss may be seen in the post-operative period, or in the face of recurrence in esophageal or gastric cancer. Patients undergoing pancreatic surgery face the long-term risks of diabetes and impaired fat absorption resulting in diarrhea. Impaired wound healing is a higher risk for many of our patients due to lengthy surgeries involving multiple organs. As a result of poor nutrition and wound complications, cancer patients are at higher risk for post-operative herniation after their surgeries.

While the issues surrounding successful treatment are a “good problem” to have, they also engender new requirements for which traditional treatment models may not be adequate. With this therapeutic success comes increasing responsibility on the part of gastrointestinal oncology care providers. It is not enough simply to treat these patients, tell them they are potentially cured, and then send them on their way.

Surgeons and medical oncologists treating patients with gastrointestinal cancers are traditionally among the least trained in survivorship issues and long-term patient follow-up. To these practitioners, who often perform intensive and difficult therapies on very sick patients in a high-stress environment, the issues of survivorship may seem small and insignificant compared to the challenges they and their patients have already overcome to treat their initial cancer.

Unfortunately, our very success in treatment of these aggressive cancers has led to new problems for our patients after their "recovery" from treatment. Faced with significant changes in their anatomy and physiology from surgery, persistent side-effects and late effects from their chemotherapy, and often social and emotional challenges from their treatment and recovery process, the survivors of gastrointestinal tract cancers often do not fully enjoy hearing the words "you are cancer-free".

Recognition of the issues facing cancer survivors has taken on increasing importance as our treatments for cancer have become more successful.³ The Institute of Medicine's 2005 report⁴ highlights the issues for patients as they complete primary therapy and recommends that we recognize cancer survivorship as a distinct phase of cancer care. Historically, guidelines for cancer survivors have been limited to surveillance for recurrence of primary disease. The IOM report goes beyond this and recommends that survivorship plans address the chronic effects of cancer, monitor, prevent late effects from treatment (i.e., heart disease), provide emotional and psychosocial support, including support to address financial and legal issues such as payment of bills and resumption of employment. In addition, many patients face constant uncertainty and worry about whether they are really "cured" and whether or not their cancer will return. Many of these patients are not able to transition back to their normal lives because of anxiety and fear regarding relapse or death.

GASTROINTESTINAL CANCER SURVIVORSHIP CLINIC AT THE PENN STATE CANCER INSTITUTE

As part of the efforts of the Penn State Cancer Institute's Program in Liver, Pancreas, and Foregut Tumors, we started a multi-disciplinary Gastrointestinal Cancer Survivorship Clinic, in July 2008, to help address the ongoing follow-up care and special needs of the survivors of cancers of the GI tract. The goal of this effort is to create a multi-disciplinary forum, led by surgical and medical oncologists, to address not only the clinical needs, care coordination, and follow-up of patients, but to address their psychosocial, behavioral, and quality of life issues as well. One of the foundations of this new treatment model for cancer survivors is that the medical and surgical oncologists involved with each patient's cancer therapy will continue to be involved just as closely in their follow-up and continuing care. These practitioners will help ease the transition from active cancer care to surveillance for cancer recurrence and eventually back to routine medical care.

An important issue to be addressed is streamlining the transfer of care from the oncologist to the primary care physician. Our clinic aims to ease that transition by providing detailed survivorship care plans whereby our oncology physicians will help improve communication and coordination between a patient's cancer care team and his/her regular physicians and will identify key survivorship issues specific to each GI cancer survivor patient.^{5,6} For example, primary care physicians and other outside physicians (e.g., radiologists reading the outside CTs) may not know or understand exactly what operation was performed (the new anatomy, expected post-surgical changes, etc.), and may have difficulty discerning which patient complaints are minor and which are worrisome.

Newer technology available through our medical center's electronic records software will allow the patients' primary physicians and community oncologists to have complete access to their patients' notes, test results and reports. The goal is a shared care model where the patients' primary physicians are both aware of and able to address the special needs faced by their patients who are cancer survivors.^{7,8} Too often care of the cancer patient is fragmented among the different specialists and without adequate communication back to the primary care providers, even such basic information as the specific diagnosis, stage, and treatment received.⁹ We aim to test our shared model to improve coordination of interdisciplinary care. The use of treatment summaries and survivorship care plans, along with shared medical records, will be one mechanism to facilitate two-way communication among providers.

Another major initiative of our new clinic is to provide complete care for the patient, beyond what can be found in the usual medical or surgical oncology clinic setting. The GI Cancer Survivorship program is committed to helping patients and their families with all of their psychological, social, and emotional needs. To do this, the clinic is staffed by clinicians and researchers from various medical disciplines to provide services that include surgical and medical oncology follow-up and ongoing care, psychology services, nutrition screening and dietary evaluation, and social work services. Other services include ongoing communication with the patient's primary care physicians and coordination of survivor screening and follow-up care. The GI Cancer Survivors' Clinic also serves as a laboratory for clinical and outcomes-oriented research throughout the Penn State Cancer Institute. As part of the ongoing assessment of patients, we longitudinally track patients' quality of life outcomes. While quality of life evaluation in gastrointestinal oncology is still in its infancy, there have been several recent studies which assess quality of life related to treatment and therapy of gastrointestinal cancer.¹⁰ Mullan¹¹ describes three "seasons of survival" in cancer patients: "acute survival" from diagnosis to initial treatment, "extended survival" relating to the time after treatment during which patients face possible recurrence, and "permanent survival" when the patient is likely to be cured. Unfortunately, few if any studies have been published examining quality of life in GI cancer patients in the "extended" or "permanent" survival stages. We hope our initiative will help us to better understand these stages of survival and the determinants of patient quality of life longer term.

Recognizing that our surgeons and medical oncologists might not systematically address the wider range of patient quality of life issues such as depressed mood or lack of social support because of time constraints or because they are not trained to assess them, we routinely collect cancer symptom and quality of life data using a paper questionnaire completed by the patient. We also include a psychologist or social worker and the hospital chaplain as an integral part of the team onsite at the weekly GI Survivors Clinic. Our premise is that brief screens for depressed mood or distress can identify and streamline patient referrals to ancillary care services. Already two important findings are emerging: a higher than expected occurrence of depression and a spiritual void reported by patients.

Studies are underway now, however, our preliminary data suggests that even in patients who are doing well clinically and completing their treatment, the impact on overall quality of life is significant. Patients report lingering physical and functional

side effects of their treatment such as lack of energy, inability to engage in fulfilling work or enjoy things they use to do for fun. Many report feeling sad or worrying that their condition will get worse, and we are seeing a higher than expected report of mild to moderate levels of depression based on validated patient self-reported written tools. We know that depression may cause avoidable decrements in quality of life and can adversely affect the course of cancer and survival. While we are pleased that the majority of our patients do remarkably well after surgery, we are increasingly sensitive to possible long-term issues of adjustment after such extensive surgery and after chemotherapy given that studies have shown an increased prevalence of pain, depressed affect and fatigue in cancer patients that is often underdiagnosed and under-treated. We are convinced that by identifying and referring patients for appropriate interventions for the treatment of depression, oncologists and mental health professionals can collaborate to enhance quality of life in cancer patients.

A second emerging finding is that patients are often reporting a spiritual void as they cope with their cancer and its treatment. To assess their health related quality of life, we are including a validated written, patient self-report instrument, the Functional Assessment of Cancer Therapy-Spiritual (FACIT-Sp), at each clinic visit. While it is too early to report any formal research findings, it is becoming clear that our patients are concerned about the sense of purpose, meaning and productivity in their lives. While some patients find comfort and strength in their faith and spiritual beliefs, others do not. Although we have included a chaplain in the GI Survivors' Clinic from its beginning, we are now exploring ways to expand and enhance this service.

We know that in the busy clinical setting, human relationship is easily overlooked, yet nowhere is relationship more important than in life-threatening illness. A diagnosis of cancer affects the body, mind, and spirit, and tests the faith and hope of patients, their families and caregivers. Our goal is to transform a clinical practice that historically has been focused on diagnostic and treatment procedures (laboratory tests, CT and MRI scans, surgical procedures) to a practice that provides complete care for the patient that goes beyond what can be found in the usual medical or surgical oncology clinic setting and acknowledges the profound healing capacity of the relationship between patient and health professional. While some of our surgical patients will be seen frequently for follow-up, many will transition back to their primary care physician upon completion of their treatment. For the physicians who will provide ongoing care for these GI cancer survivors, we believe that these observations are important.

CONCLUSION

By utilizing a multi-disciplinary model with the primary medical and surgical oncologists spearheading the survivorship initiative and pastoral support as a priority, we hope to optimize cancer survivor care and patient quality of life. We believe that this paradigm could serve as a model to be embraced by other oncology practitioners in order to provide the best cancer care across the treatment continuum to help achieve the optimal quality of life during all of the "seasons" of cancer survival.

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REFERENCES

- Office of Cancer Survivorship - National Cancer Institute. Estimated US Cancer Prevalence Counts: Who Are Our Cancer Survivors in the US? Available online at <http://dcccps.nci.nih.gov/ocs/prevalence/index.html>. 2007. Accessed April 28, 2009
- National Cancer Institute. Facing forward - life after cancer treatment. Bethesda, MD: National Institutes of Health; 2006.
- Rowland JH, Hewitt M, Ganz PA. Cancer survivorship: a new challenge in delivering quality cancer care. *J Clin Oncol*. 2006;24:5101-4.
- Hewitt M, Greenfield S, Stovall E. From cancer patient to cancer survivor: lost in transition. Washington, DC: The National Academies Press; 2005.
- Earle CC. Failing to plan is planning to fail: improving the quality of care with survivorship care plans. *J Clin Oncol*. 2006;24:5112-6.
- Ganz PA, Casillas J, Hahn EE. Ensuring quality care for cancer survivors: implementing the survivorship care plan. *Semin Oncol Nurs*. 2008;24:208-17.
- McCabe MS. Survivorship: models of care. *J Support Oncol*. 2008;6:136-8.
- Oeffinger KC, McCabe MS. Models for delivering survivorship care. *J Clin Oncol*. 2006;24:5117-24.
- Earle CC. Long term care planning for cancer survivors: a health services research agenda. *J Cancer Survivor*. 2007;1:64-74.
- Conroy T, Uwer L, Deblock M. Health-related quality-of-life assessment in gastrointestinal cancer: are results relevant for clinical practice? *Curr Opin Oncol*. 2007;19:401-6.
- Mullan F. Seasons of survival: reflections of a physician with cancer. *N Engl J Med*. 1985;313:270-3.