Improving Survivorship Care

Some 13 million cancer survivors may not be receiving the type of follow-up care that addresses their long-term needs, according to Mary Ann Morgan, PhD, FNP-C, of H. Lee Moffitt Cancer Center and Research Institute in Tampa.

In their 2006 report, *From Cancer Patient to Cancer Survivors: Lost in Translation*, the Institute of Medicine (IOM) identified four components that should be part of cancer survivorship care: prevention, surveillance, interventions, and coordination of care (Hewitt & Ganz, 2006). Of these, coordination often falls through the cracks, she said.

"Coordination among specialists and primary care providers is needed so that all health needs are met," she told nurses at the symposium.

The IOM report also contained other important recommendations:

- Raise awareness of cancer survivors
- Develop Treatment Summary and Survivorship Care Plans, and reimburse for them
- Follow evidence-based clinical practice guidelines
- Develop quality assurance programs
- Develop test models for interdisciplinary survivorship care
- Educate healthcare providers about survivorship issues
- Institute federal and state legislation for survivorship care
- Have third-party payers cover the cost of survivorship care
- Foster research initiatives

Among the various models of survivorship, the most common is probably the "shared care" model between oncologists and primary care providers. At Moffitt, many survivorship needs are addressed within the disease programs. In addition, Moffitt has an Adult Survivorship Clinic for long-term follow-up. Dr. Bognar, the medical director, and Dr. Morgan have seen over 350 patients and have had 600 referrals to this clinic.

TREATMENT SUMMARIES AND SURVIVORSHIP CARE PLANS

A Treatment Summary and Survivorship Care Plan is a means of ensuring that patients receive the proper long-term surveillance. For reimbursement, this falls under the CPT definition of counseling.

The first part of the Summary details the treatment history: tests performed and results, cancer pathology, surgeries, therapies, supportive services, and contact information for the providers of care, including the APN.

This should be a detailed but succinct summary, Dr. Morgan emphasized. The cancer surgery history should indicate type of cancer, procedures, dates, and results of lymph node testing, including such information as number of sentinel nodes examined and number positive, Gleason score, margins and capsular invasion results, biomarkers, and so forth. The Summary should also include drugs, dosages, dates administered, radiation fields and dosages, and adverse events. It should contain a section on the patient's relevant ongoing health issues.

WHAT TO WATCH FOR

During follow-up the APN should monitor for long-term and late effects of cancer treatments. "The earlier these are detected the easier they are to treat," she emphasized.

Each provider involved in the care of the patient should have his or her own responsibilities highlighted. For example, the Treatment Plan specifies which provider might order colonoscopy screening. "The delineation of 'who does what' is welcomed by the providers. It saves them time," she added.

Dr. Morgan emphasized that follow-up care should acknowledge not only the physical needs but the potential for psychosocial sequelae. "Cancer survivors live with uncertainty. Their number one fear is of recurrence," she said. Psychosocial aftereffects can extend to their relationships, employment, and health insurance status.

These three reports (on pages 211–216) are from the 2011 National Comprehensive Cancer Network® (NCCN®) Nursing Program: Role of the Advanced Practice Nurse in Quality Cancer Care™, a meeting held on March 9–13, 2011, in Hollywood, Florida. References for these articles can be found on page 216.

Physically, the potential effects from chemotherapy and hormonal agents, for example, are numerous: premature ovarian failure, fatigue, weight gain, mood changes, decreased libido, hot flashes, neuropathy, cognitive decline, impaired immunity, renal dysfunction, myelodysplastic syndrome and leukemia, hemorrhagic cystitis, motility disorders, abnormal liver function, vaginal atrophy, gynecomastia, increased fracture risk, osteopenia and osteoporosis, depression, infertility, and endometrial cancer.

The list of potential late effects of surgery is also lengthy: change in body image, lymphedema, retrograde ejaculation, incontinence, erectile dysfunction, pain, cognitive changes, swallowing difficulty, adhesions, communication problems, impaired breathing, diminished immunity, neuropathic pain, and others.

Radiation therapy can result in second cancers, atrophy and deformities, pulmonary fibrosis, thyroid disorders, cardiac scarring, cataracts, visual changes, cognitive changes, malabsorption, colitis, bladder scarring and reduced capacity, proctitis and prostatitis, renal dysfunction, lymphedema, dental caries, myelodysplastic syndrome and leukemia, testosterone deficiency, sterility, premature menopause, and other disorders.

While the list of potential problems related to treatment is exhaustive, the average patient may have only one of the more common problems, such as fatigue or weight gain. This does not diminish their seriousness, however, Dr. Morgan stressed.

It is important to educate patients about wellness and prevention. She emphasizes positive lifestyle changes: smoking cessation, sunscreen protection and skin assessment, proper diet, exercise (YMCAs sometimes offer free programs for cancer survivors), and standard cancer screenings. Controlling weight and blood pressure, lipids, thyroid-stimulating hormone levels, and hemoglobin A1c are other considerations for health maintenance.

In closing, Dr. Morgan acknowledged that developing the individual Treatment Plan can be tedious and time-consuming. “It’s an hour’s visit with the patient, and I do preparation for this ahead of time,” she said. “Survivorship care is still a work in progress.”

Depression in Cancer Patients Often Neglected

Cancer patients are at increased risk for depression, and the APN is well positioned to recognize this and coordinate treatment, said Caryl Fulcher, RN, MSN, CS, of Duke Cancer Institute, Durham, North Carolina.

“Sometimes the psychosocial and emotional aspects of cancer get shortchanged in the care of our patients,” she said, “but depression is rated as one of the top 10 most common and persistent symptoms for people with cancer.”

Depression has widespread impact: increased cost of care, decreased adherence to treatment, exacerbation of other symptoms, increased provider time, poorer quality of life, reduced survival, and negative impact on families.

Essentially, depression is a state of feeling sad, discouraged, hopeless, and worthless. Reported prevalence rates vary widely, depending upon the stage at which it is diagnosed, but the general prevalence is believed to be 15% to 25% among cancer patients, according to the most recent figures from the National Cancer Institute (NCI, 2010).

RECOGNITION IS ENCOURAGED

The 2007 Institute of Medicine Report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, recommended that cancer care should include the identification of psychosocial health needs, facilitation of effective communication, and design and implementation of plans that include links to psychosocial services.

According to the NCCN Practice Guidelines in Oncology, as well, the standard of care for cancer patients includes the recognition, monitoring, documentation, and treatment of *distress* at all stages of disease and in all settings (Holland et al., 2010). “Distress can be a trigger that further explanation is needed,” Ms. Fulcher noted.

The diagnostic criteria of major depressive disorder are the following: at least five key symptoms present during the same 2 weeks, representing a change from previous function. Two of these symptoms *must* include depressed mood and diminished interest or pleasure; the other three can be any of the following: significant weight loss or gain or appetite change; insomnia or hypersomnia; psychomotor agitation or retardation; fatigue or loss of energy; feelings of worthlessness or excessive guilt; diminished ability to think or concentrate, indecisiveness; and recurrent thoughts of death, suicidal ideation, suicide plan, or attempted suicide.

"But cancer patients may be more likely to meet the criteria for adjustment disorder than major depressive disorder," she noted. This includes:

- Development of emotional or behavioral symptoms in response to an identified stressor, occurring within 3 months of the stressor's onset
- Marked distress in excess of what would be expected, OR
- Significant impairment in social or occupational functioning

Cancer patients may also have an underlying dysthymic disorder that was present even before the cancer diagnosis. This is depressed mood, most of the day, on most days, for a period of at least 2 years, plus the presence of related depressive symptoms.

KNOW THE RISK FACTORS

In addition to a diagnosis of cancer, there are universal risk factors that increase the risk for depression, key ones being past psychiatric illness, family history of psychiatric illness and substance abuse history. Other universal risk factors include white race and unmarried status.

But cancer patients have unique contributors to depression as well, such as cytokine production, metabolic disturbances, and tumors involving the central nervous system. Certainly, cancer patients may be on medications that enhance depression risk: steroids, sedatives, anticonvulsants, hormonal agents, antihistamines, certain analgesics, and certain antineoplastic agents, she said.

Advanced disease at diagnosis and having cancer of the lung, stomach, oral cavity, pharynx, or larynx raises the risk (Misono et al., 2008).

DEPRESSION MAY BE DIFFERENT IN CANCER PATIENTS

"The main thing to understand is that depression is not normal in cancer patients," Ms. Fulcher emphasized. "That is a misconception."

The other key point is that traditional somatic symptoms of depression are not always applicable in cancer and cannot serve as the sole indicators. Anorexia, fatigue, insomnia, and weight loss are all common. "You have to look at the other symptoms to identify depression in cancer patients," she said.

Psychological symptoms are more reliable. Feelings of hopelessness, helplessness, dysphoric mood, loss of self-esteem, feelings of guilt or worthlessness, and loss of pleasure in normally pleasant activities can be good indicators. "I try to get a sense of these in my patients," she said. "Is the patient talking with a future orientation?" She often asks the spouse if the patient has lost interest in usual activities.

Suicidal intent may also be present and should not be ignored. Cancer patients have nearly twice the incidence of suicide as the general US population.

"This can be difficult to bring up, but do not hesitate to ask," she advised. "I say something like, 'It sounds like you are miserable. Have things ever been so bad you have thought of ending it?' Occasionally a patient answers 'yes,' and we explore this."

Importantly, the APN should recognize the difference between grief and depression. "Obviously, these patients have experienced many losses and grief and depression can occur together, and mimic each other," she noted. "The main difference is that some of these symptoms, such as sad mood, hopelessness, and guilt, tend to come and go in the grieving process but are more persistent with depression."

SCREENING FOR AND MANAGING DEPRESSION

"Subclinical depression is often undetected and patients rarely volunteer about their depression. Since many of us don't ask about this, we need a screening tool," she said.

A number of self-report depression screening instruments take less than 10 minutes, including the PHQ-9, Profile of Mood States, and Distress Thermometer (though this measures distress, not depression). Just asking, "Are you feeling depressed?" has been shown to be a credible screening approach.

The Oncology Nursing Society has published interventions for depression and anxiety as part of a project called *Putting Evidence Into Practice* (PEP). Interventions are categorized as recommended for practice, likely to be effective, having benefits balanced with harms, effectiveness not established, and based on expert opinion only. "This is a quick way to bring evidence-based practice into your setting," she noted.

The most evidence-based intervention is cognitive behavioral therapy. Other forms of psychotherapy and counseling are also recommended, along with patient education and supportive therapy.

"The goal of psychotherapy is to reduce emotional distress and improve morale, coping ability, self-esteem, sense of control, and resolution of problems," Ms. Fulcher explained. "It is geared to the present moment."

In addition, the APN can do a number of things in his or her daily practice:

- Ask about the patient's emotional state at each visit
- Employ active listening to learn about fears and concerns
- Provide resources about counseling, financial aid, and so forth
- Make referrals to social workers and other mental health professionals, or pastoral care

MOST HELPFUL MEDICATIONS

Antidepressants are helpful, especially selective serotonin reuptake inhibitors (SSRIs), i.e., fluoxetine, paroxetine, sertraline, citalopram, escitalopram, and serotonin norepinephrine reuptake inhibitors (SNRIs), i.e., venlafaxine and duloxetine. The SNRIs may have fewer drug interactions than the SSRIs. Both classes have about a 3-week onset of action.

The norepinephrine/dopamine reuptake inhibitor (NDRI) bupropion has a side-effect profile similar to the SNRIs but less potential for sexual issues. "It is also good for patients whose symptoms are on the sluggish side," she added.

Mirtazapine, which acts on 5HT and alpha-adrenergic receptors, is more sedating, and therefore useful for sleeplessness. It is also associated with weight gain, so it is good for patients with appetite problems. Methylphenidate, a short-acting stimulant, has a quick onset of action and can be used while waiting for other antidepressants to take effect.

"The expert opinion is that a combination of antidepressant treatment and psychoeducational or psychosocial therapy is more effective for severe and chronic depression than either alone," she added.

Management of Prostate Cancer Should Be Multidisciplinary

A multidisciplinary approach to managing prostate cancer is greatly appreciated by the patient, who is often faced with puzzling choices, said Lydia T. Madsen, RN, MSN, AOCNS®, of the University of Texas MD Anderson Cancer Center, Houston.

"A multidisciplinary prostate cancer clinic provides an opportunity to present the multiple treatment options in a single setting," she said, "and the advanced practice nurse (APN) is an essential member of the team."

Ms. Madsen described her experience at the MD Anderson clinic in a presentation at the National Comprehensive Cancer Network (NCCN) 2011 Nursing Program, which was part of the annual conference.

MULTIPLE OPTIONS AVAILABLE

The problem is that prostate cancer is highly heterogeneous. Determining the patient's risk and optimal treatment—especially since the potential for serious side effects must be considered—can be challenging.

Although one man in six will develop and be diagnosed with prostate cancer, only one man in 36 will die of this disease. "With these odds, how much are we overtreating prostate cancer?" she questioned.

This means that men who are diagnosed with low-risk early-stage disease may be candidates for several treatment options. Choosing among them can be stressful for the patient. A multidisciplinary approach to management helps him sort through the alternatives, Ms. Madsen said.

LOOKING AT THE OPTIONS

Radical prostatectomy has long been considered the gold standard treatment for organ-confined prostate cancer, either by an open method or with robotic system assistance. Its advantages are that it is a one-time procedure and provides the best information about the extent of the cancer, since the prostate is completely removed.

But radical prostatectomy has several limitations: a catheter is left in place for 7 to 14 days, which is a concern for many men; recovery and resumption of normal activities may take several weeks; there are risks associated with surgery and anesthesia; and quality of life can be compromised by issues with urine control and erectile function postsurgery.

“The last point is the biggest reason that patients question this surgery,” she noted.

Surgery may not be the best choice for some of these patients, she pointed out. Alternative treatments can be effective, and in fact, outcomes for these modalities are comparable to surgery 5 and 10 years post-treatment.

Active surveillance has gained recent support, and is now a recommended approach in the NCCN 2011 guidelines for select individuals: men who have very-low-risk disease and a life expectancy of less than 20 years (i.e., age 58) and those with low-risk disease and a life expectancy of less than 10 years (i.e., age 68). But while side effects of possibly unnecessary treatment are avoided, there are drawbacks to the “watch and wait” approach: risk of progression or missed opportunity for a cure, heightened anxiety, need for frequent followup and biopsy, and the possibility that subsequent treatment options will be less optimal.

External beam radiotherapy is an option for patients with low-risk disease; intermediate-risk disease may benefit from 6 months of concomitant androgen deprivation therapy (ADT) and pelvic lymph node radiation; and high-risk cancers should be considered for pelvic lymph node irradiation and 24 months of concomitant ADT.

For select patients, brachytherapy, intensity-modulated radiotherapy, or proton beam radiotherapy may offer some advantages over standard radiotherapy. Cryotherapy is no longer routinely recommended.

Standard treatment options have similar cancer-free outcomes and survival, but each option has treatment-specific short-term side effects and long-term complications that will likely impact quality of life, she emphasized, discussing the need for full disclosure to patients.

“Patients are often confused and may not always get a balanced, unbiased accounting of the options,” she explained. “We tell patients their best opportunity to get all the information they need for their individual case is through our Multidisciplinary Prostate Cancer Clinic.”

CLINIC GOALS, LOGISTICS

The goal is to thoroughly assess the patient’s cancer (provide diagnostics); offer all appropriate treatment options based on the patient’s lifespan and cancer/medical/psychosocial specifics; and provide a joint recommendation from all the specialists, listing a “preferred” choice and multiple “good choices.”

The patient is also provided with follow-up and decision-making assistance, and ancillary services as necessary, by the APN in the clinic (Ms. Madsen).

“We include a treatment map showing the schedule for radiation therapy, because they also need these factors to make their treatment choice,” she added.

“I spent half my time talking with the patient about what he heard, helping the patient work his way through the decision process,” she said. A printed summary of the treatment options and their advantages and limitations is helpful.

Along with the APN, the clinic staff includes a urologist (and fellow, nurse), radiation oncologist (and resident, nurse), and medical oncologist as necessary for a same-day consultation. Patients see all specialists in one visit. MD Anderson also has a clinic just for patients aged 75 and older (“senior” clinic).

The visit follows this order: business center registration, vital signs taken; meet with the APN; history and physical taken by APN, resident, fellow, or physician assistant; meet with urologist; meet with radiation oncologist; receive summary letter with consensus statement (after doctors confer); wrap-up with APN; follow-up with APN 3 to 10 days after the visit.

Prior to making treatment recommendations, every patient receives prostate-specific antigen (PSA) testing, a digital rectal exam, and a history and physical exam. With PSA > 10 ng/mL, palpable disease, or high-grade disease, patients undergo computed tomography of the abdomen and pelvis, bone scan, endorectal magnetic resonance imaging, and internal medicine consult if they opt for surgery. Many patients arrive at the clinic with diagnostic test results.

WHAT DO PATIENTS CHOOSE?

Data from 1,375 patients seen at the clinic between 2004 and 2008 showed that 50% of patients chose surgery, 34% chose radiotherapy, 11% chose active surveillance, and a small percentage chose other options.

CLINICAL TRIAL ENROLLMENT VERY HIGH

Patients are encouraged to enroll in a clinical trial, and 73% of the 1,375 patients did so. Almost 30% actually consented to more than one clinical trial, she reported.

"Our participation in trials is very high because we incorporate discussions of research and specific trials at the time of treatment recommendations," she explained. "We include a recommendation for trials in the summary letter. The consult service is responsible for trial enrollment on the day of the initial visit. And we follow-up with the patient regarding the clinical trial options."

In conclusion, Ms. Madsen emphasized the many benefits of a multidisciplinary clinic for prostate cancer patients. "First and foremost," she said, "patients should hear all the evidence-based treatment recommendations that are appropriate for their specific stage and grade of prostate cancer, to make an informed treatment decision. Even if they are leaning toward a certain treatment when they arrive, they should consider the options so they will have no regrets later."

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