Cancer rehabilitation and survivorship

A medical subspecialty improves life, health of cancer survivors

By Nancy Hutchison, MD

There are approximately 12 million cancer survivors in the United States. Most people undergoing cancer treatment survive; recent statistics indicate that long-term survival for many cancers approaches 70 percent. However, the effects of cancer treatment leave many cancer survivors with physical limitations and diminished quality of life. Cancer rehabilitation addresses quality-of-life deficits that include physical as well as psychosocial dysfunction. All must be addressed for survivors to resume optimal life and health.

Physical medicine and rehabilitation (PMR) physicians have unique skills for evaluating and treating functional impairments due to chronic medical conditions. Minnesota is fortunate in having a strong PMR presence in many communities. Cancer rehabilitation is emerging as a subspecialty of PMR, with training to address the acute and chronic effects of cancer treatment.

Cancer surgery, chemotherapy, hormonal therapy, biologic agents, radiation therapy, and stem cell transplants all have specific sequelae that affect function and are amenable to rehabilitation. PMR cancer rehabilitation MDs use evidence-based tools to anticipate and evaluate debilitating effects of cancer treatments and implementing strategies for maximizing function and recovery of cancer survivors. The PMR cancer rehabilitation MD works with a team to develop and coordinate the complex rehabilitation care of cancer survivors.

In the last 15 to 20 years, rehabilitation therapies (e.g., physical, occupational, speech) have become so specialized that oncology and primary care physicians may not know which type of therapist can best treat the physical effects of cancer treatments. For example, rehabilitation therapists may specialize in lymphedema, balance and neuropathy, cognitive effects of cancer treatment, pelvic reconditioning, pelvic floor dysfunction, or swallowing disorders. Cancer rehabilitation physicians are familiar with the network of rehabilitation therapists throughout the state and region. Even a one-time visit to a PMR cancer rehab MD can help cancer patients find the best cancer therapy providers in their area to carry out an individualized program of recovery from the effects of cancer treatment. Since many health plans have therapy caps, it is important that cancer survivors be referred to the correct team of therapists to maximize recovery and minimize out-of-pocket expense.

A documented need for cancer rehabilitation

The American College of Surgeons Commission on Cancer (CoC) accredits many hospitals in the U.S. The CoC has been a pioneer in recognizing the importance of rehabilitation as an essential part of cancer care; indeed, the CoC mandates cancer rehabilitation as a requirement for accreditation. Yet, despite the general awareness that rehabilitation is good for cancer survivors, many clinicians do not know how to find effective services or refer patients to them. For example, some providers may be under the impression that a community-based exercise program (cancer fitness) is the same as cancer rehabilitation. However, a significant number of cancer survivors cannot proceed directly from cancer treatment to community-based exercise because of the severity of deconditioning or physical deficits that must be treated first.

In addition, many exercise facilities and trainers are unfamiliar with the medical complexity of cancer survivors. The American Cancer Society (ACS) and the American College of Sports Medicine (ACSM) have teamed up to establish a certification (ACSM/ACS Certified Cancer Exercise Trainer) for exercise professionals who desire to work with cancer patients. Even so, the cancer survivor with physical deficits, pain, fatigue, and debility will need rehabilitation first.

The Institute of Medicine (IOM) report “From Cancer Patient to Cancer Survivor: Lost in Transition” (National Academies Press, 2005) documented that many patients finish cancer treatment with medical, psychosocial, financial, occupational, and functional deficits that are not adequately addressed. The report estab-
lished the new paradigm that survivorship is a distinct phase of cancer care, with specific concerns that must be addressed by the medical community. To achieve this goal, cancer survivors need a survivorship care plan. Since the IOM report was published, many oncology providers have implemented this recommendation: “Provide a comprehensive summary and follow-up plan (survivorship care plan) to survivors.” Most of the initial survivorship care plans have been geared toward medical surveillance; they are just beginning to address the other aspects of physical chronic illness related to cancer. To address this latter aspect of a survivor care plan, oncology and primary care providers will need to link with cancer rehabilitation providers.

The IOM report’s other recommendations include developing tools to identify and manage late effects of cancer treatment; implementing quality assurance programs to ensure quality of life assessment and follow-up; educating health care providers; improving interdisciplinary care coordination of survivor services; improving access for diverse groups; and eliminating job and insurance discrimination affecting cancer survivors.

**Care coordination and networking**

PMR cancer rehabilitation MDs seek to network with the oncology community to coordinate cancer survivor services, just as we do for other major chronic disabling conditions such as polio, spinal cord injury, stroke, brain injury, musculoskeletal conditions, and chronic pain.

Our current systems of health care and health care education have not done enough to break down the medical silos that impede patients’ access to cancer rehabilitation and survivorship care. Most health professionals are not trained to evaluate for rehabilitation and survivorship concerns of cancer patients. Even when problems are identified, there is a gap in methods of referral to effective services. The many barriers include timing, access, cost, psychosocial support, healthy behavior change, and collaboration with oncology supportive care and integrative medicine. Mary Vargo, MD, a cancer rehabilitation PMR specialist, discussed these issues in an excellent article in the June 2008 issue of the Journal of Clinical Oncology.

The goal of the PMR cancer rehabilitation physician is to provide the platform and “one-stop shop” to access the most appropriate, cost-effective, and conveniently located rehabilitative and survivorship care plan for patients. Cancer rehabilitation services are generally covered by insurance. The physician visit is covered according to the patient’s insurance care network. The PMR cancer rehab physician can then help the patient find covered rehabilitative services in his or her locale, as well as assist with return-to-work resources, disability assessment, psychosocial supports, referral to integrative medicine interventions, and fitness resources for transition to self-management and healthy lifestyle. The case study described in the sidebar demonstrates how this expertise can benefit both patients and their physicians.

In response to the need for cancer rehabilitation, programs such as Oncology Rehab Partners’ STAR (Survivorship Training and Rehabilitation) Certification are being developed to meet the need for education and training of medical professionals and to assist cancer centers and rehabilitation providers in developing their own programs and training. As the number of cancer survivors continues to grow, PMR cancer rehabilitation MDs will play an essential role in helping to return these patients to a high quality of life.

**Cancer rehab: A case study**

Mrs. X is a 50-year-old woman undergoing radiation therapy for breast cancer. She had a mastectomy and axillary node dissection followed by chemotherapy with Adriamycin, Cytoxan, and Taxal and now is getting herceptin. She will be placed on a hormonal agent in the future. During radiation therapy, she tells her providers that she has severe pain shooting down her arm and it feels swollen. Instead of assuming she has lymphedema and referring her to a lymphedema therapist, the providers refer her to a PMR cancer rehab physician, to address the cause of the pain and determine whether she has lymphedema or another condition that mimics lymphedema.

At the visit with the PMR cancer rehab physician, Mrs. X is found to have a combination of chemotherapy-induced peripheral neuropathy, axillary web syndrome from the surgery (axillary node dissection), and shoulder bursitis from the position for radiation therapy. She also has severe insomnia, and cognitive and fatigue complaints are affecting her ability to perform daily functions. She worries that she will not be able to function when she returns to her job.

The PMR cancer rehab physician asks Mrs. X about her energy and exercise. Mrs. X says she used to exercise regularly, but now she “crashes” when she gets home, has gained 25 pounds since starting cancer treatment, and feels as if she is sinking into depression, as she has no idea how to reverse this downward spiral. She thought she would be looking forward to finishing her cancer treatment, but now she is afraid that this is her “new normal” and she “will have to live with it.” She doesn’t want to go to a gym because she is concerned about lymphedema and pain and feels embarrassed by the changes in her body. She has no current evidence of swelling in the arm, but has sensory changes mimicking a feeling of swelling. She doesn’t know what to tell her employer, as she does not know what to expect for recovery.

The PMR cancer rehab MD offers a plan to roll out over several weeks to months and reassures Mrs. X that her recovery plan will take on the various concerns in a prioritized fashion. The doctor also gives Mrs. X a trial of gabapentin for neuropathic pain and a referral for acupuncture, and refers her to a physical therapist or occupational therapist with specific expertise in the management of shoulder and arm problems of breast cancer survivors. The PMR cancer rehab MD places Mrs. X into a protocol for surveillance for lymphedema, which she does not currently have but is at risk for developing. After radiation therapy, once she is feeling better, she will follow up with the PMR cancer rehab MD, who will recommend fitness and weight-loss protocols. Specific evidenced-based exercise protocols have been shown to reduce the risk of developing lymphedema and osteoporosis as well as improve fatigue, quality of life, and weight management.

At subsequent follow-up visits, the cancer rehab MD helps Mrs. X find a way of exercising that addresses her fears and concerns, and also refers her to a healing coach. If the insomnia, cognitive, and fatigue problems do not resolve, she will be referred to a therapist who specializes in strategies for addressing cognitive deficits after cancer. She may also need a referral to a mental health professional for treatment of depression. The PMR cancer rehab MD assesses Mrs. X’s vocational demands and develops a return-to-work strategy with her employer.

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