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Cancer Rehabilitation Services
The Road to Survivorship

by Sue Lynne Frymark, R.N., B.S.

Although providing cancer support services in today's increasingly restrictive reimbursement environment may seem like a program luxury, cancer rehabilitation services can help patients maximize their independence. Rehabilitation services allow individuals and their families an opportunity to regain control and confidence within their lives, as well as improve their quality of life. Moreover, rehabilitation services can aid patients with the difficult transition from "victim" to survivor. Indeed, quality of life and degree of control have more to do with being a survivor than the number of cancer-free years.

The functional, emotional, and social needs of the individual with cancer are varied and often complex. They are dependent on such factors as the extent of disease, tolerance of treatment, premorbid medical and functional levels, support system, and coping skills. A patient's needs are interdependent and must be addressed by an interdisciplinary oncology team. The team can offer a variety of skills and a broad spectrum of knowledge and resources to help the individual adapt to his or her situation.

Cancer rehabilitation focuses on practical day-to-day issues, including maximizing strength and adjusting to temporary or permanent changes affecting work, home, and leisure life. The goals are to restore function as well as to provide knowledge and skills to the individual and family so they can maintain that level of function within the limits of the medical status.

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A RESTORATIVE PROCESS—AND MUCH MORE

Historically, cancer rehabilitation has been viewed primarily as a restorative process following treatments such as breast, head and neck, pelvic, or colon surgery. With many individuals now receiving a combination of chemotherapy and radiation and the addition of biologicals and/or transplants, the need for rehabilitative services has expanded. As individuals live longer with a cancer diagnosis, long-term effects of therapy (Table 1) and issues of reintegration into the workplace or school will expand the role of rehabilitation even further.[1,2,3,4,5]

Cancer rehabilitation is an organized approach to providing interdisciplinary services that include such varied areas as social services, physical therapy, nutritional consultation, and vocational counseling (Table 2). In an environment of limited resources, providing these services in a timely and time-efficient manner is a challenge requiring integration of both acute and chronic care.

Assessment of rehabilitation needs should be integrated within the care provided in radiation, surgical, or medical oncology settings. While it is important for rehabilitation staff to be knowledgeable about oncology, it is also important for oncology staff to be familiar with rehabilitation practices and the resources required to address the needs of their patients. In addition, the presence of pain and/or metastatic disease requires a team that is knowledgeable about pain management and the disease process.

A clear delegation of responsibility for assessing rehabilitation needs helps assure that issues are identified on a timely basis, enhances continuity of care among the many services and settings, and allows physicians and nurses time to focus on the management of the disease. Early assessment is critical to expedite referrals for service.

The assessment process and coordination of rehabilitation services can be incorporated into the roles of nurses, social workers, or rehabilitation counselors. Responsibilities include:

- assessing needs
- coordinating referrals
- providing information and guidance
- facilitating care conferences
- providing support and guidance
- facilitating team communication
- accessing community resources
- facilitating support groups.

The majority of cancer patients are outpatients. In many ways, the outpatient setting is a more appropriate location to address the chronic issues of living with cancer. Although individuals may experience some acute side effects from their treatment, generally they are in a more stable medical condition than during hospitalized periods. As outpatients, they are coping with the effects of cancer on their daily lives—physically, emotionally, socially, and spiritually.

Rehabilitation services may be provided in an inpatient oncology unit for those receiving acute care. In addition, inpatient rehabilitation units provide services to patients who typically require at least three hours of therapy per day and meet the admission criteria. This population usually includes those with debilitating neurological involvement, particularly spinal cord compromise. It may also include patients experi-

encing severe deconditioning that disrupts daily functioning. In many cases, early intervention with rehabilitation services could prevent such extreme debilitation.

Since physical therapy is centered on enhancing strength, endurance, and function, most cancer patients—whether inpatient or outpatient—could benefit from short-term, periodic physical therapy. Such services would depend on the patient's physical status, which may fluctuate, affecting function or activity. Assessment may require determining if the patient could benefit from ambulatory assistance or devices.

When physical therapy is initiated, it is common for an occupational therapist to evaluate the degree that weakness has interfered in daily activities. The occupational therapist can suggest assistive devices to enhance independence and safety within the home and workplace. Such devices may include raised toilet seats, grab bars, reachers, and shower benches.

REHABILITATION AND FATIGUE

Fatigue, which can disrupt daily life, is well recognized as one of the most frequent symptoms of cancer treatment.[6,7] From 60 to 96 percent of cancer patients may experience fatigue at some time during their treatment. Rehabilitation services can intervene with exercise programs to restore strength, endurance, and function. Incorporated into the rehabilitation are energy conservation techniques. Individuals are taught ways to pace themselves through their day and to use assistive devices to reduce the effort needed in daily activity. The goal is to help individuals manage their life at work, home, or leisure in ways that are less physically demanding. Using assistive devices in activities of daily living can make

Table 1. Rehabilitation Issues for Cancer Survivors

Chronic fatigue	Sexual dysfunction
Cognitive changes	Incontinence
Memory loss	Stenosis of ostomy or laryngeal stomas
Learning difficulties	Myelopathy with paresthesia, weakness, and bowel and bladder dysfunction
Communication/ swallowing difficulties	Role changes
Neuropathy, impairing fine motor skills	Altered growth affecting limb length and function
Upper or lower lymphedema	Amputee issues
Survivors' stress	Workplace issues
Changes in interpersonal relationships	Financial and insurance limitations
Increased risk for osteoporosis	Postradiation fibrosis affecting range of motion
Vision/hearing changes	

Table 2. Cancer Rehabilitation Services*

Social services	Physical therapy
Formal counseling	Occupational therapy
Spiritual care	Speech/language therapy
Nutritional consultation	Vocational counseling
Enterostomal therapy	Recreational therapy
Stress management	Exercise classes
Relaxation and yoga classes	Lymphedema management
Music and art therapy	Support/education groups
Family support services	Information/education
Cancer specific rehabilitation**	Survivorship services

*Frymark S. Providing cancer rehabilitation services. *Cancer Management*. 1998;1:11.

**Laryngectomy, transplant, breast, colon, prostate, etc.

life manageable and prevent further deconditioning and weakness from reduced activity. Rehabilitation services should be an integral part of any fatigue management program.

Therapeutic exercises provided by rehabilitation therapists are focused on increasing strength, range of motion, and function. Other physical exercise, such as walking programs and programs provided in fitness centers, have also been shown to be beneficial for survivors. These exercise programs focus on strengthening, maintaining flexibility, and endurance, and can be progressed to an aerobic level based on individual tolerance.

Services provided by oncology physical and occupational therapists require access to standard but relatively simple equipment, such as weights, mat tables, raised treatment tables, upper and lower extremity fitness equipment, TENS units, and ultrasound. As the number of patients increases, stair platforms, parallel bars, and other equipment can be added. Walkers, canes, commodes, and bath benches are needed in an exercise facility and at home.

Exercise programs that provide fitness activities for cancer patients require equipment found in fitness centers, such as treadmills, exercise bikes, and universal gyms. Just as rehabilitation therapists must understand cancer, treatments, and physiologic guidelines for safe exercise, so, too, must exercise physiologists understand the precautions required for those receiving cancer treatment or living with metastatic disease. Fitness programs traditionally have not been reimbursable; they have been provided as a community service by medical fitness centers and private fitness clubs.

Exercise not only helps in recovery but has also been shown to have other benefits for survivors as well, including maintaining and improving fitness level and reducing side effects of cancer treatment.[8] Exercise also has a role in managing fatigue and possibly stress. Eric P. Durak and colleagues from the Santa Barbara Athletic Club in Santa Barbara, Calif., have been providing exercise classes to women with breast cancer for more than five years. Their Cancer Wellfit Program has become an award-winning role model for other fitness programs in the country. They have published an instructional manual for other programs interested in offering such classes. Durak's data and outcomes indicate strength improvements of up to 50 percent, mood scores (based on the Modified Rotterdam Quality of Life Survey) up by 29 percent, and a 35 percent improvement in performance of activities of daily living. This is a further indication of the value of rehabilitation services.[9]

In addition to exercise classes, some wellness programs have included yoga, movement classes, and nutritional guidance. The combination of exercise with nutrition and stress management has become the mainstay of wellness programs.

Some interdisciplinary services in cancer rehabilitation programs are now called "complementary" services. They are offered in addition to the cancer treatment provided because of their positive effect on the quality of life or the benefit they have during the cancer treatment process. An example is the use of guided imagery or relaxation techniques when an individual undergoes a procedure such as marrow aspiration or the first chemotherapy infusion. These services should be considered part of cancer rehabilitation, as they enhance the effect of the more traditional rehabilitation services.

PSYCHOLOGICAL SERVICES

Rehabilitation services help the cancer patient cope both physically and psychologically. Although formal mental health counseling is often unnecessary, some patients with personal issues and/or stressed family relationships may benefit. Support groups and counseling can be integrated into physical rehabilitation services. Staff providing physical services should understand the emotional needs of patients. They must be aware that many cancer patients need to grieve as they confront the possibility of temporary or permanent changes, such as the loss of hair, amputation, and/or employment that may be disrupted during treatment. Patients should be encouraged to express their feelings in support groups as well as to seek information, set realistic goals, and maintain independence.[10]

Complementary services, particularly those involving the arts, can facilitate this psychological healing process. Through music, dance, or the visual arts, patients may find outlets for expression. Some patients can speak more objectively about their feelings when they participate in the arts, whether actually creating the art or participating as a listener or viewer.[11]

A recent report, "Ensuring Quality Cancer Care," by the Institute of Medicine's National Cancer Policy Board indicates that there is a wide gap between what we know is good care and what is provided. This is particularly evident in psychosocial support for pain management. Physicians frequently do not recognize the psychological long-term effects of cancer and its treatment.[12] With less time to spend with each patient, it is understandable that these issues may be overlooked or underappreciated. Moreover, some physicians are concerned that they may uncover issues they have no resources available to address. A cancer rehabilitation service can both assist with the assessment process and identify necessary professional and fiscal resources.

REIMBURSEMENT

Physical rehabilitation services and physical, occupational, and speech therapies are reimbursable. Although Medicare reimbursement has been affected by the Balanced Budget Act of 1997, the changes are dependent on the setting of care. Skilled nursing facilities and home health services are moving from cost reimbursement to prospective payment. Outpatient services have transitioned from cost reimbursement to a fee schedule based on CPT codes and modalities. Although hospital outpatient therapy services will not have a cap, other outpatient rehabilitation providers will have a $1,500 cap for physical and speech therapy combined and $1,500 for occupational therapy.

Many other insurers have reduced the annual number of allowable visits. Fortunately, because many cancer patients do not require long periods of therapy, they are not as vulnerable to visit restrictions as others needing therapy on a long-term basis. Since there is so much variation in billing requirements among insurers, it is up to rehabilitation personnel and therapists to be familiar with billing and to know when to request third-party authorization. To make authorization more likely, treatment plan goals must be functional. Obtaining reimbursement for psychosocial services can be even more challenging. Many support services, such as groups, informal coaching, and educational sessions, are not reimbursable. There clearly is a role for foundations and endowments to cover such services. Cancer programs that offer integrated rehabilitation services may offset these expenses with rehabilitation revenue.

A CARING ENVIRONMENT

The goal of cancer rehabilitation is to allow patients with cancer to return home in the best possible physical and psychological condition. This goal enhances the confidence of the individual and family and may prevent unnecessary readmissions.

For years, hospital inpatient oncology units have focused on the family and on providing a caring environment. More recently, humor carts, music and art therapy, and areas for physical rehabilitation and fitness-related activities are providing a more comprehensive approach. Today, new treatment centers are designed to create an even more relaxed treatment environment, some with waterfalls and saunas.

Nonprofit organizations such as the American Cancer Society and the Leukemia Society have always maintained the importance of rehabilitation care for cancer patients. Together with other advocacy groups, they have been valuable resources for information. However, these organizations do not have the resources to provide one-on-one counseling and guidance to the number of individuals in need. The assistance they do provide is important, but they are most effective in an advocacy role. Their ability to educate the public about cancer and create sensitivity to the needs of cancer patients has resulted in greater community involvement. Many services are now offered on a local level by the YWCA, fitness centers, church-sponsored cancer support groups, and parish nursing programs.

Rehabilitation services for cancer patients will remain underutilized until oncology and rehabilitation professionals better understand each others' practice. Those cancer programs with integrated rehabilitation services can help cancer survivors—and their families—reach their maximum level of independence within the limitations of their illness. As one woman said, "I knew I could die from cancer. What I needed to learn was that I could live with it."

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