REVIEW

The Past, Present, and Future of American Cancer Rehabilitation

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ABSTRACT. Cancer rehabilitation in the United States has gone from a small obscure rehabilitation subspecialty to an area of intense interest. American cancer rehab’s recent growth can be attributed to the ever increasing number of cancer survivors. The future of cancer rehabilitation may be accelerated by the concept of exercise as cancer medicine.

Key words: Rehabilitation, Future, American, United States

The field of American cancer rehabilitation has undergone a tremendous increase in interest over the past 15 years from both oncology and rehabilitation professionals. This narrative review article will discuss where the subspecialty has come and where it is going.

The Past

In part due to cancer being viewed largely as an incurable disease in the past century, the field of cancer rehabilitation is very young compared to other subspecialties within rehabilitation. The Handbook of Physical Medicine & Rehabilitation 1st and 2nd editions published in 1965 and 1970 did not have a paragraph regarding cancer rehabilitation. It was not until the late 1970’s that we begin to see some major literature regarding oncology rehabilitation including influential articles published by Dietz in 1980\(^1\) and Lehmann in 1978\(^2\). Physical medicine & rehabilitation at MD Anderson Cancer Center, the largest American cancer hospital, did not begin until the mid-1990’s.

In Lehmann’s 1978 article, multiple barriers to implementing cancer rehabilitation were identified including a lack of identification of patient rehabilitation related problems by oncologists, lack of appropriate referral from oncologists, patients who are often too ill to participate, patients denying a need for rehabilitation, too poor of a cancer prognosis, unavailable rehabilitation, and the lack of financial resources\(^2\). Sadly, many of these barriers continue to exist today in our field. Andrea Cheville, an influential American cancer physiatrist, has studied many of these barriers. In many oncology cases, rehabilitation is dismissed because the perceived expected outcome is unchanged by oncologists\(^3\). The outcome that many oncologists are focused on is survival.

Our past could be characterized by not only a lack of interest from oncologists but also by rehabilitation professionals themselves perhaps due to a lack of clinical demand. Cancer rehabilitation education opportunities were few at conferences and within training programs up until the past 10 years.

The Present - The Era of the Cancer Survivor

The present period of cancer rehabilitation has been associated with a dramatic wave of interest to unprecedented levels. The main driver for this wave of interest is the rapidly increasing numbers of cancer survivors. First, the definition of cancer survivor must first be clarified because it is a bit different from the traditional definition of survivor. Traditionally, the term “survivor” is used to characterize someone who has made it through an unpleasant or life-threatening event like a hurricane, earthquake, or illness. However, in the oncology world, a cancer survivor is anyone who has ever been diagnosed with cancer from the
initial diagnosis until death\cite{11}. Therefore, someone diagnosed with cancer 5 minutes ago, 5 weeks ago undergoing ongoing chemotherapy, and 5 years ago with no evidence of disease are all considered cancer survivors.

There are a number of contributors to the ever-increasing number of cancer survivors both in the United States and around the world. The first contributor is an increased American population from 106.5 million in 1920 to 328.2 million in 2020 (the world population has increased from around 1 billion in 1804 to approaching 8 billion today). If a certain percentage of people will get cancer, then the number of cancer survivors would also increase. Second, the percentage of Americans over the age of 65 has been increasing in part due to increased life expectancy. The greater the numbers of Americans over the age of 65 means a greater incidence of diseases that primarily affect the elderly including strokes, neurodegenerative disorders (like Parkinson’s and Alzheimer’s), and cancer. Approximately 50% of American cancer survivors are over the age of 70 and 72% are over the age of 60\cite{5}. The last and most remarkable part of this phenomenon is that survival rates for cancer have been increasing due to more effective cancer treatments. In the mid 1970’s, the five-year relative survival rate for all cancer sites was only 49%. 40 years later, the survival is at 70\%\cite{6}. These three factors have led to increasing numbers of American cancer survivors from 3 million in 1970 to 17 million in 2020 (Fig. 1)\cite{6,7}. An estimated 4.8% of the US population in 2016 were cancer survivors.

For many, cancer has become a chronic disease like diabetes or Alzheimer’s. While patients may eventually succumb to their disease, many can live with cancer for years. There are more American cancer survivors than the combined numbers of American traumatic and non-traumatic spinal cord injury survivors (up to 353,000)\cite{8}, traumatic brain injury survivors (5.3 million)\cite{9}, and stroke survivors (7 million)\cite{10} combined. Yet the rehabilitation infrastructure for cancer rehabilitation pales in comparison to that of neurorehabilitation.

Cancer survivors can suffer from a number of impairments that can be addressed through rehabilitation interventions. Deconditioning, asthenia, and cancer related fatigue are very common in cancer patients before and after cancer treatment. Chemotherapy induced peripheral neuropathy can lead to neuropathic pain but also functional impairments like reduced balance and coordination. Chemo-brain is a multi-factorial syndrome (including other cancer related symptoms) which can lead to prolonged cognitive dysfunction including memory and executive function deficits. Steroid myopathy is also quite common due to long term steroid use in stem cell transplant patients for graft versus host disease prevention as well as in a number of other cancer treatments. Steroid myopathy often can be identified by the pattern of significantly greater proximal weakness out of proportion to distal weakness. Patients often have difficulty with sit to stand transfers but do relatively well once standing and ambulating. Lymphedema is common amongst breast cancer patients but can affect any cancer patient where lymphatic damage has occurred (e.g. head and neck as well as gynecologic cancers). Post-mastectomy reconstruction syndrome in breast cancer patients and radiation fibrosis syndrome in head and neck cancer patients are common and are due to radiation related nerve damage and/or nerve stretching/traction damage during surgical dissections. Neuro-rehabilitation may be necessary for spinal cord injury (often due to primary tumors, metastatic tumors, or radiation late effects), brain injury (due to primary brain tumors, metastatic brain tumors, or radiation late effects), and leptomeningeal disease.

A number of recent studies have demonstrated continued difficulty with under-recognition and under-referral by oncology that was described by Lehman et al.\cite{21} Oncology specialists often experience tunnel vision where they are fo-
cused on cancer staging and cancer progression/recurrence and do not consider factors that can affect quality of life. Movsas et al. found 87% of inpatient oncology unit patients had motor/functional needs but only 18% received physiatry consults\(^1\). Cheville et al. found 92% of metastatic breast cancer patients had at least one physical impairment but only 30% received rehabilitation treatment which was mostly inpatient\(^2\). In another study by Cheville of 244 out-patient cancer survivors, 65.8% self-identified functional needs but there was minimal reference in oncology medical records to functional problems\(^3\). Finally, despite the high number of cancer patients with functional needs, only 31.8% of patients with late stage cancer expressed an interest in cancer rehabilitation\(^4\).

**Present Challenges**

Due in large part to the rapidly increasing numbers of cancer survivors, demand for cancer rehabilitation has outpaced supply. Many cancer centers have tried to quickly establish cancer rehabilitation programs including recruiting cancer physiatrists. Unfortunately, currently the needed army of cancer rehabilitation professionals is just not available to meet demand. Educating rehabilitation professionals through school and residency is crucial. However, schools and residency programs are also trying to quickly adapt to incorporate additional cancer curriculum. Currently, the cancer rehabilitation exposure for physiatrists varies dramatically between physiatry residency programs\(^5\). Because of inadequate cancer rehabilitation exposure in residency training, physiatry cancer rehabilitation fellowships have been developed to provide additional training (nine cancer physiatry fellowships in North America). The Commission on Accreditation of Rehabilitation Facilities (CARF) began a certification of cancer rehabilitation programs in 2014. Education and didactic lectures during major rehabilitation conferences have also increased dramatically. The American Congress of Rehabilitation Medicine (ACRM) has grown its Cancer Rehabilitation Networking Group and features multiple continuous tracks of cancer rehabilitation lectures during its annual conference. The American Academy of Physical Medicine & Rehabilitation (AAPM&R) has increased its cancer rehabilitation lectures and a group called the Cancer Rehabilitation Physician Consortium has become an active voice for cancer rehabilitation within physiatry. The National Institutes of Health (NIH) held its first Cancer Rehabilitation Summit in June 2015. In addition, the American Physical Therapy Association (APTA) continues to publish Rehabilitation Oncology, a quarterly cancer rehabilitation journal and recently began an educational course (with hands-on and online components) towards a Certificate of Achievement in Oncology Physical Therapy.

The annual number of cancer rehabilitation research publications has quadrupled since 1992\(^6\). While this is a dramatic increase, more quality research is sorely needed. Our specialty has made significant progress within oncology and rehabilitation; however, public policy makers and payers including health insurance companies have been slower to join. Cancer rehabilitation research studying the beneficial economic impacts of cancer rehabilitation on survival and cost savings are sorely needed.

Influential oncology organizations including the Commission on Cancer, the National Comprehensive Cancer Network (NCCN), the American College of Surgeons Cancer Program, and the American Cancer Society have established that rehabilitation should be a part of cancer care. However, our specialty must do more to advocate for public policy change in the American federal government and within Medicare and create clinical practice guidelines that are endorsed by major and respected cancer organizations\(^7\).

**The Future - The Era of Exercise as Cancer Medicine**

Rehabilitation has traditionally been a specialty about improving the quality of life and not as focused on improving survival or saving lives as other medical specialties. There are exceptions to this: we as rehabilitation professionals treat life threatening complications on our rehabilitation unit like autonomic dysreflexia and pulmonary embolism but most of what we do is geared towards improving quality of life. Our efforts are noble, and patients are grateful for the qualitative improvement in their lives obtained through rehabilitation interventions.

However, we are beginning to see a new era in cancer rehabilitation on the horizon. Can our rehabilitation interventions make patients live longer and survive cancer? We’ve known that patients with better performance status are more likely to endure cancer treatment and live longer. What if we tried to improve performance status through rehabilitation interventions to improve survival? There has been an increasing body of evidence that supports that physical activity can improve survival in a number of cancer populations\(^8\).

The Era of Exercise as Cancer Medicine is taking shape along the cancer rehabilitation continuum described by Dietz in 1980 (preventative, restorative, supportive and palliative)\(^9\). The area of prehabilitation has gained immense interest over the past decade. Cancer prehabilitation is similar in concept to Dietz’s preventative cancer rehabilitation. Prehabilitation involves interventions (which can include exercise, nutrition, and education) aimed at improving patients’ health before an anticipated upcoming major cancer intervention with the goal of improving outcomes\(^10\). Prehabilitation is not unique to cancer rehabilitation and had been used in other areas of rehabilitation for decades. However, it has recently garnered intense interest (in particular in sur-
There are a number of mechanisms for the beneficial survival effects of physical activity in cancer patients including hormonal changes and reduction in inflammation. Inflammation is an area of significant academic interest. High levels of inflammation have been known to be associated with the development of a number of chronic diseases including cardiovascular disease, Type II diabetes, neurodegenerative disorders (such as Alzheimer’s Disease) and cancer. Ironically, cancer and cancer treatments (including chemotherapy and radiation) are pro-inflammatory. That increased inflammation may actually help cancer progress. The substantial symptom burden in cancer patients undergoing active treatment can be attributed to the increased inflammation generated by cancer and its treatment. Many cancer patients feel like they have the flu. Fatigue, insomnia, cognitive dysfunction, anorexia, pain, dyspnea, and nausea are common in both an influenza infection and cancer. In both situations, inflammation is elevated due to the immune response to a systemic influenza infection or the pro-inflammatory effects of cancer and its treatments. These symptoms can have a tremendous negative impact on quality of life.

Physical activity has been demonstrated in a number of studies to be anti-inflammatory. Myokines, which are anti-inflammatory cytokines produced by muscle activation, are produced with physical activity. Therefore, physical activity reduces inflammation and the reduced inflammation reduces cancer related symptoms. Cancer patients with high symptom burden typically do not feel well and this can discourage physical activity. Breaking through this barrier, can be challenging for cancer rehabilitation professionals. Patient education regarding how physical activity will actually make patients feel better is key. Figure 2 demonstrates steps to break the cycle of inactivity and fatigue. For example, in a patient who has been bedridden long term due to an extended intensive care unit (ICU) stay, the first step towards increasing activity is often starting to sit in a chair daily. Patients are encouraged to gradually increase the duration of chair sitting in addition to participating in physical and occupational therapy offered.

Unfortunately, patient discussions and education are infrequent. If exercise is cancer medicine, we have a responsibility to make patients aware of its benefits. Less than half of cancer survivors maintain their pre-diagnosis activity and only 21.5% of cancer survivors can recall a discussion about exercise with a healthcare professional (compared to 24% of adults without cancer). 84% of cancer survivors have indicated that they would like to discuss exercise during their cancer treatment experience. More emphasis needs to be placed on physical activity during cancer treatment. When discussing exercise with patients, the guidelines most often utilized are the 2019 American Col-
Currently, cancer rehabilitation is often under-referred or referred late in the cancer treatment process.

Fig. 3 The Present-Day Cancer Rehabilitation Referral Model

After cancer diagnosis, patients are referred to an oncologist. In the case of a new breast cancer diagnosis, for example, the oncologist will refer the patient to a surgeon for mastectomy, a radiation oncologist for post-mastectomy radiation, and a physiatrist for prehabilitation and monitoring of the anti-inflammatory effects of exercise.

Fig. 4 The Potential Future Cancer Rehabilitation Referral Model

The guidelines are still broad and additional tailoring to a patient’s capabilities is recommended. If exercise is a medicine, it should be dosed like a medicine. We can “underdose” or have inadequate amounts of exercise, but we can also “overdose” or have excessive exercise (e.g. exces-
sive exercise may lead to too little inflammation and make already immunocompromised cancer patients more susceptible to infection). Determining the right dose is still very much an art rather than a science. We just don’t know enough to really get exercise prescriptions for cancer patients down to a science. Perhaps in the future, regular blood tests of inflammatory cytokine levels could be performed. By then, more detailed knowledge of the myokine effects of aerobic vs anaerobic exercise, isotonic vs. isometric vs. isokinetic strengthening exercise, and the different muscles themselves (e.g. quadriceps vs pectoralis) would be known. In addition, the optimum anti-inflammatory anticancer cytokine levels would also be known. Currently, there is much that needs to be learned, but the future of this emerging area in cancer treatment is exciting.

The role of nutrition in reducing systemic inflammation in cancer treatment cannot be overlooked. Data from the Women’s Health Initiative, a study of over 122,000 post-menopausal women, found a high inflammatory diet was associated with increased mortality in breast cancer patients [30,31]. An anti-inflammatory diet has been associated with a lower risk of colorectal cancer [32]. Patient education and promoting the intake of anti-inflammatory foods such as fruits and vegetables that are rich in anti-oxidants is important. Protein intake is often emphasized for cachectic cancer patients and typically includes encouraging the intake of meat (which can be pro-inflammatory). While ingesting anti-inflammatory foods may be beneficial, ingesting anti-inflammatory supplements or medications is more controversial. The intake of anti-oxidant anti-inflammatory vitamin supplements has not been shown to reduce cancer mortality and may increase mortality [33]. There has also been interest in the use of anti-inflammatory medications, such as non-steroidal anti-inflammatory drugs (NSAID’s), in the treatment of cancer. However, the evidence to support the use of NSAID’s has been mixed [34].

The current model for cancer rehabilitation referral has been characterized by under-referral and late referral (Fig. 3). The future cancer rehabilitation referral model may be characterized by more frequent rehabilitation referral early on in cancer treatment (Fig. 4).
Conclusion

American cancer rehabilitation has undergone tremendous growth in interest from a small obscure rehabilitation subspecialty to becoming a major component of mainstream rehabilitation. The rise of cancer survivor numbers has fueled much of the recent growth in demand for cancer rehabilitation. That trend will continue as cancer treatments continue to become increasingly effective. In addition, the new and emerging field of exercise as cancer medicine will emerge as another major driver of growth in cancer rehabilitation (Fig. 5).

Conflict of Interest: The authors declare no conflicts of interest.

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