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Embracing Complexity—the Role of Cancer Rehabilitation in Restoring and Maintaining Function and Quality of Life in Cancer Survivors with Radiation Fibrosis Syndrome

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Abstract

Purpose of Review Despite more than 6 decades of growth and transformation, the field of cancer rehabilitation has considerable room to evolve if it is to live up to its full potential. This article will discuss the importance of this evolution in the context of radiation late effects and serve as a call for the clinical and operational expansion of the field so that it can become a key component of comprehensive cancer care.

Recent Findings The clinical and operational challenges inherent in cancer survivors with radiation late effects necessitate different thinking with respect to how rehabilitation professionals evaluate and manage patients as well as how our institutions equip these professionals to practice at the highest possible level.

Summary To achieve its promise, the field of cancer rehabilitation must evolve to embrace fully the scope, scale, and complexity of issues faced by cancer survivors with radiation late effects. Better engagement and coordination of the care team are needed to deliver this care and ensure our programs are robust, sustainable, and flexible.

Keywords Rehabilitation · Cancer rehabilitation · Radiation fibrosis syndrome · Radiation late effects · Head and neck cancer · Hodgkin lymphoma · Medical complexity · Prospective surveillance model

Introduction

Cancer rehabilitation has long been called an "emerging field." While this area of medicine is relatively new compared to others, the discipline's primary mission—namely to restore function and quality of life to cancer survivors—was conceptualized as far back as 1958 by the venerable Dr. Howard Rusk in his seminal work, rehabilitation medicine, which included a full chapter on the topic [1••]. After more than 65 years, it is arguably no longer fair to say that cancer rehabilitation remains an emerging field. A more apt description would be an "evolving" one. This article will discuss this evolution and serve as a call for expansion, both clinically and operationally, of the field of cancer rehabilitation so that it can fulfill the promise of becoming a key component of comprehensive cancer care. The compendium of articles dedicated to radiation late effects that follow will further illustrate the need for cancer rehabilitation clinicians to embrace the complexity of cancer survivors to fulfill this promise.

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Clinical Complexity

In the very recent past, the issues primarily addressed by cancer rehabilitation were fatigue and lymphedema. Comprehensive pain management including high-level opioid prescription and cutting-edge procedures were not routinely in the scope of practice of cancer rehabilitation physicians. Physical and occupational therapists lacked any special training outside of courses dedicated to lymphedema. The concept of cancer rehabilitation—even though devoted to its basic tenants of restoring function and quality of life—was limited in practice, scope, and imagination.

The field of cancer rehabilitation has witnessed a major renaissance in the past few years. The original emphasis on inpatient rehabilitation has exploded into the outpatient realm. The scope of practice of outpatient cancer rehabilitation physicians has become progressively more expansive, sophisticated, and evidence-based. The available rehabilitation workforce with specific training in managing oncology patients has also expanded. There are now at least 12 cancer rehabilitation fellowships for physicians—all of which confer trainees with cutting-edge knowledge and skill in the identification, evaluation, and management of the multiple neuromuscular, musculoskeletal, pain, and functional issues faced by cancer survivors. There are cancer rehabilitation physicians further subspecializing in pain management, radiation late effects, women's health, spinal cord dysfunction, and other sub-subspecialties. Inpatient management of cancer survivors has also become progressively more innovative and forward-thinking [2]. Outpatient options for survivors have been burgeoned not only by a bumper crop of rehabilitation medicine residents choosing cancer rehabilitation as a career, but also by the emergence of interest by therapists of all types. The American Physical Therapy Association has certified 160 board-certified oncologic clinical specialists as of this writing. The American Occupational Therapy Association is developing a similar board certification. The American Speech-Language-Hearing Association has not yet sought to provide a clinical specialty certification in cancer rehabilitation but does support high-level training in the field. The number of outpatient cancer rehabilitation centers seems to be increasing at a rapid pace. At least one national program has emerged—the ReVital Cancer Rehabilitation Program has nearly 1000 therapists from all these disciplines operating in approximately 500 clinics across 25 states. The beneficial impact of this unprecedented expansion of cancer rehabilitation clinicians and services for the 17 million cancer survivors in the USA cannot be overstated.

Despite the encouraging transformation of cancer rehabilitation, there remains much to do if our specialty is to live up to its full potential and provide the greatest benefit to our patients—we must embrace and address the full scope and scale of complexity inherent in cancer survivors. This call is as relevant to therapists as it is to physicians. As will be discussed, the overwhelming volume and complexity of issues faced by cancer survivors necessitate a complete rethinking of how rehabilitation and cancer care, and survivorship programs are implemented, operationalized, administered, marketed, and maintained.

No group of cancer survivors better exemplifies our need to embrace complexity more than those afflicted with radiation late effects—particularly those treated for Hodgkin lymphoma (HL) and head and neck cancer (HNC). A recent retrospective cohort analysis of 100 consecutive HL survivors evaluated and treated in the outpatient cancer rehabilitation setting demonstrates that nearly all had neuromuscular dysfunction including subacute myelopathy (83%), radiculo-plexopathy (93%), mononeuropathy (95%), and localized myopathy (93%) or a combination of all termed "myelo-radiculo-plexo-neuro-myopathy" [3•]. Dropped head syndrome (83%), cervicalgia (79%) and shoulder girdle dysfunction (73%), and pain (71%) were some of the most common disorders seen. Additionally, a significant number of survivors also had cardiovascular (70%), pulmonary (44%), endocrine (63%), gastrointestinal (29%), and other visceral late effects. A recent review of the functional issues facing HNC survivors addresses dysphagia, xerostomia, dysgeusia, dysosmia, odynophagia, trismus, first bite syndrome, dysarthria, dysphonia, lymphedema, shoulder syndrome, cervicalgia, cervical dystonia and dropped head syndrome, deconditioning, and fatigue [4•]. A more medically focused review listed loss of saliva, osteoradionecrosis, radiation recall myositis, pharyngoesophageal stenosis, dental caries, oral cavity necrosis, fibrosis, impaired wound healing, skin changes and skin cancer, lymphedema, hypothyroidism, hyperparathyroidism, lightheadedness, dizziness and headaches, secondary cancer, and eye, ear, neurological, and neck structure damage as late effects [5]. Baroreflex failure is considered rare but likely underrecognized and diagnosed in HNC and HL survivors [3•, 6]. Radiotherapy-induced carotid toxicity is common in HNC and likely other groups such as HL survivors [3•, 7]. This laundry list of issues faced by these survivors is by no means complete but is given to emphasize the challenges in optimally managing such patients. For instance, medications or procedures utilized for pain management must be carefully chosen and calibrated to avoid destabilizing medical conditions such as heart or baroreflex failure. Physicians evaluating issues as common as fatigue in such patients must have a high degree of experience and an intimate working knowledge of the multiple contributing factors to safely and effectively restore their patient's function and quality of life to the highest possible

level. Such experience and knowledge are extremely specialized and not common.

Operational Complexity

With survivors of radiation facing so many potential issues, and the number of patients expected to be treated with radiation rising to over 4 million in the USA alone by 2030 [8], there is a timely need to develop an "evolved" model of comprehensive care to proactively address these issues. Providing the coordinated, personalized, and effective comprehensive care for these patients need will take evolutions in four current workflows. First, patients should be embedded in a prospective surveillance model (PSM) that regularly assesses their symptoms, function, and needs through and beyond their cancer treatment. The PSM was initially developed specifically as a model for cancer rehabilitation [9] and has now been refined [10, 11•, 12] as a comprehensive assessment that would generate referrals to multiple subspecialists and programs. In this model, a multi-dimensional assessment is conducted preoperatively to establish baseline functioning, identify patients with pre-existing conditions that may place them at higher risk for the development of treatment toxicities and impairments during/after treatment, and facilitate referral for any current problems. Repeated assessments throughout and beyond cancer therapy facilitate the early detection and proactive management of treatment toxicities or other needs. In practice, these comprehensive assessments are increasingly remotely monitoring patient issues outside clinic walls via the collection of electronic patient-reported outcomes (ePROs) [13]. As the number of technologies to passively monitor patient issues grows (e.g., cardiac and blood pressure monitoring; irregular balance and gait detection), many of these issues may be remotely monitored by devices. The increasing integration of data from these assessments into clinical workflows that generate timely care [13] has the potential to improve care and patient outcomes in the future [14, 15].

Second, providing multi-disciplinary care to address the issues identified by the PSM requires referrals to an expanded and coordinated team of clinicians, working side by side with the oncology team through and beyond cancer treatment [16]. This includes cancer rehabilitation physicians and therapists and may also include endocrinologists, cardiologists, pulmonologists and other specialists, audiologists, dieticians, exercise physiologists, psychologists, social workers, and dentists. It is critical for cancer rehabilitation professionals of all types—including physicians and therapists—to effectively partner in the patient's cancer-related care. The complexity inherent in radiation survivors requires clinicians to step outside their silos and eschew the tunnel vision blinding them to issues that fall outside the traditional scope of rehabilitation. This is not to say that rehabilitation clinicians should endeavor to directly treat all these issues themselves, but they must recognize them, understand how they interfere with function, and ensure that they are being addressed. For instance, a rehabilitation physician evaluating a patient for fatigue who fails to identify that a patient has heart failure or valvular abnormalities is failing their patient and putting them at risk. Similarly, a physical therapist evaluating a HNC survivor for fatigue who does not identify that the patient has severe dysphagia and is chronically aspirating is unlikely to get a good outcome no matter how inspired their progressive exercise program is.

Third, multiple care delivery modes and settings are needed in addition to traditional clinic daytime visits in order to address patient barriers to accessing care. Extended evening or weekend hours at existing clinics can help patients who have exhausted their sick leave and cannot take time away from work for care. In-home care delivered in person can help immuno-comprised or otherwise medically vulnerable patients receive care. Additionally, many systems have been expanding telemedicine services as a response to the COVID-19 pandemic. Continuing to offer tele-medicine services can help patients with transportation or other barriers access care as well as provide expert clinical help to patients in systems that lack cancer rehabilitation care locally.

Fourth, developing a robust and sustainable clinical program to identify and ensure the management of such a vast array of complex issues requires more than just systems to detect issues and astute clinicians available for referrals. The infrastructure in which clinicians practice must be conducive to care. To evolve current care delivery models, it is necessary to plan for and pilot test approaches to ensure the right people, processes, and technology are in place; leadership is supportive; the program is marketed appropriately to patients and referring clinicians; and business models are sustainable [17••]. The evolved model of care should create multi-sector return on investment (ROI) across the system and meet the quadruple aim of health care. Pilots of new approaches to care must carefully choose and measure outcomes to ensure this care creates (1) better patient outcomes by enabling access to standardized multi-disciplinary care, toxicity management, and functional preservation that optimizes long-term patient outcomes; (2) better patient experience by coordinating the patient's care and overcoming access barriers; (3) improved care efficiency through timely referrals to appropriate clinicians, leveraging telemedicine, and driving appropriate healthcare utilization (e.g., decreasing downstream emergency department visits, hospitalizations, and toxicity management visits in oncology); and (4) improved clinician quality of life by enabling clinicians to practice at the top of their license and proactively help their

patients [17••]. Outcomes of care delivery pilots can be used to create marketing materials that convey the value proposition of the program to leadership, to referring clinicians, and to patients. To create sustainable programs, pilot outcomes should also be used to build business models that balance clinicians/staff, supplies, space, and capital requests needed for the program with projected revenue from the program. Business models must also address how direct and indirect revenue streams will be maintained, how growth and scale plans will be feasible, and how the program will be flexible to adapt to health system or outside changes.

Conclusion

More than six decades after Dr. Howard Rusk's call for cancer rehabilitation to restore function and quality of life to cancer survivors, it is high time we aim our collective efforts to achieve this goal. Patients are looking to their cancer care team not just to save their life, but to make sure they can continue to participate fully in a meaningful life, regardless of how long they have to live: evolving our care to embrace the complexity and diversity of patient issues stemming from their cancer treatment; better engage and coordinate the team of clinicians needed to deliver this care; and ensure our care delivery programs are robust, sustainable, and flexible is the path to delivering on this promise.

Declarations

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

Conflict of Interest The authors declare no competing interests.

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