



# Rehabilitation for Symptom Management for Patients with Cancer at the End of Life: Current Evidence and Barriers to Care

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## Abstract

**Purpose of Review** The goal of this review is to highlight recent literature that addresses the role of rehabilitation for managing symptoms for patients with cancer near the end of life.

**Recent Findings** Current literature supports the integration of rehabilitation interventions as part of comprehensive symptom management in patients with advanced cancer near end of life. Research is needed to clarify the impact and timing of specific rehabilitation techniques. There is also a need for robust education for both palliative and rehabilitation clinicians about the role for rehabilitation.

**Summary** In this article, we review evidence for the use of rehabilitation interventions to address symptoms commonly experienced by patients with advanced cancer — dyspnea, pain, depression, anxiety, and fatigue. We also touch on communication strategies important for assessing and addressing the complex needs of the patient and caregiver. Finally, we describe barriers to the use of palliative rehabilitation and explore strategies for improving implementation across care settings.

**Keywords** Palliative care · Hospice · End of life · Rehabilitation · Psychiatry · Clinical education · Physical therapy · Occupational therapy · Cancer · Symptom management · Interdisciplinary · Clinical training

## Introduction

Cancer is a common cause of mortality in the USA, second only to heart disease [1]. Five-year relative survival ranges from 9 to 98%, depending on the type of cancer [2]. As recently as 2019, it was predicted that there would be more than 1.7 million new cancers diagnosed in the USA and over 600,000 deaths attributable to cancer [2]. There is recognition that less aggressive care for patients with advanced cancer at end of life may be associated with higher quality of life [3]; there remains a need for interprofessional awareness of rehabilitation strategies and interventions available to optimize comfort and quality of life for patients with advanced cancer as well as their caregivers.

Cheville et al. described the role for palliative rehabilitation in advanced cancer as interdisciplinary, function-directed care aligned with patient values to realize potentially time-limited goals [4]. Despite the need for and articulated value of rehabilitation for patients with advanced cancer, as well as ongoing unmet needs for patients and their families [5, 6], the use of rehabilitation services in routine oncologic care and palliative care is low [7].

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In this article, we summarize current evidence for the use of rehabilitation interventions to address symptoms experienced by patients with advanced cancer, with the goal of empowering both rehabilitation and palliative care clinicians to better support quality of life and quality of death for patients and their caregivers. We describe rehabilitation interventions that may be used alone or as part of a multimodal symptom management plan, highlighting interventions within the domains of a variety of rehabilitation clinicians. We then discuss communication strategies important for assessing and addressing the complex needs of the patient and caregiver as they navigate their path through the last phases of illness. Finally, we describe barriers to the use of palliative rehabilitation in patients with advanced disease and explore strategies for improving implementation across care settings.

## Symptom Management

There are multiple well-described tools available to assess patients with advanced cancer for pain and other symptoms (e.g., shortness of breath, fatigue, anxiety, depression) and the impact of these symptoms on function and quality of life. A list of tools to measure these symptoms and other constructs can be found at the National Palliative Care Research Center website [8]. These tools can be used by interprofessional rehabilitation clinicians to develop meaningful goals and strategies for care.

There are also well-described oncology-specific tools for measuring functional status and assisting with forecasting prognosis. These include the Eastern Cooperative Oncology Group Performance Status, Karnofsky Performance Status, and Palliative Performance Scale. Poor scores on these assessments indicate progressive limitations and dependence on others for daily self-care tasks. Poor scores are also associated with limited life expectancy and often trigger a shift from disease-related intervention to comfort-specific interventions. From a rehabilitation perspective, poor scores may be a trigger for renewed evaluation for minimally invasive symptom management, caregiver support, and interprofessional collaboration as part of a robust continuum of rehabilitation care.

While the most common primary goal for rehabilitation in the general population is restoration of function, a reasonable primary rehabilitation goal for patients with advanced cancer can be restoration or maintenance of comfort, including the elicitation and support of changing goals over time as needed. Rehabilitation clinicians possess a wealth of knowledge, experience, and insight about supporting patients through major life changes, making them well positioned to address symptoms and accommodate progressive limitations that occur with advanced disease [9].

## Dyspnea

Dyspnea is the experience of breathlessness or increased work of breathing. It can persist despite maximal medical management of an underlying condition and is often associated with anxiety and decreased quality of life. Up to 70% of patients with advanced cancer may experience dyspnea [10], with increasing severity as patients approach death [11].

Standard dyspnea management as patients approach end of life includes medications administered through multiple potential routes and supplemental oxygen. Coordinated rehabilitation management can amplify the impact of these interventions through approaches that maximize functional independence, optimize patient positioning, and minimize complications such as aspiration [12]. Interventions can include physical exercises, breathing exercises, neuromuscular stimulation, devices and equipment to facilitate positioning and energy conservation, and strategies to avoid anxiety-induced escalation of distress. Both physical and occupational therapists can provide person-centered care that addresses both physical and psychosocial aspects of dyspnea [13, 14].

A meta-analysis of holistic services for breathlessness, which included components such as relaxation and breathing techniques in addition to psychological intervention, concluded that such a program could reduce distress due to breathlessness in patients with advanced disease, including cancer [15•]. Both physical and occupational therapists include provision of these kinds of supports as within their purview [13, 14], as may other members of the rehabilitation team.

To provide the most comprehensive patient-centered, non-pharmacologic approach to dyspnea management at end of life, rehabilitation clinicians might also provide or suggest the inclusion of music therapy and acupuncture. Guided imagery with theta music (music selected to encourage theta range brain waves, thought to be associated with relaxation) can reduce modified Borg exertion scale scores and respiratory rate [16], and music therapy generally can both improve mood and reduce shortness of breath [17].

Highlighting the value of using standard physical therapy interventions to guide creative individualized approaches to dyspnea management is a recent case report in which a physical therapist was able to reduce breathlessness for a patient with metastatic breast cancer through the application of kinesiology tape to the diaphragm, ribcage, and abdominal areas [18].

Fan therapy directed at the face is commonly employed in the palliative care setting; rehabilitation therapists caring for patients near end of life can incorporate fan therapy

into their interventions and educate caregivers to do the same. Recent studies have highlighted a role for fan therapy for dyspnea reduction in patients with advanced cancer [19•, 20].

While there is not robust data for many non-pharmacologic interventions, rehabilitation clinicians can trial and/or recommend a range of therapies within existing dyspnea management programs to augment symptom relief and strengthen therapeutic alliance with families by demonstrating commitment to maximizing symptom relief. Rigorous research to evaluate the efficacy of rehabilitation interventions for dyspnea management is needed to guide development of generalizable, evidence-based care for patients with this distressing symptom at end of life.

Pulmonary rehabilitation, which includes breathing techniques, exercise, and education, can improve exercise capacity and also potentially improve dyspnea [21].

Of note, however, a Cochrane review in 2019 evaluated evidence for exercise training in patients with advanced lung cancer; there were no rigorous randomized controlled trials to include in the evaluation, but the existing studies suggested that exercise training might ultimately improve exercise capacity without affecting the experience of dyspnea [22]. Similarly, a 2019 pilot of smartphone-based pulmonary rehabilitation in this population found improvement in exercise capacity without affecting dyspnea [23]. These reports might help therapists counsel patients as they identify goals and analyze costs and benefits of available interventions.

## Pain

One of the most common hopes for patients with advanced cancer at the end of their lives is to be pain free [24]. As two-thirds of patients with advanced, metastatic, or terminal cancer experience pain [25], it is critically important to identify and effectively address this symptom [26]. The European Federation Task Force on Cancer Pain provides its strongest recommendation (grade 1A) for including rehabilitation as a component of an individualized multimodal treatment plan to address pain and its functional consequences [27•].

A systematic review of physical therapy in the palliative care setting found that the most commonly reported benefit of physical therapy was reduction in musculoskeletal pain [28]. In a more recent study of a 6-week biweekly individualized physical therapy program for patients enrolled in home-based hospice, 60% of whom carried a diagnosis of cancer, the intervention (including strength, gait, balance, function, and breathing exercises) was shown to significantly reduce pain as measured by the visual analog scale [29••]. A randomized trial of telerehabilitation inclusive of walking and resistance training guided by a physical therapist and physician team suggested that this may also be useful for reducing pain among patients with advanced cancer [30••].

Physical therapy can also provide improvement in other kinds of cancer-associated pain, e.g., lymphedema [31•].

While there are no clinical trials evaluating the role of positioning, equipment, and/or individualized daily activity planning for the reduction of pain, these foundational physical and occupational strategies can be applied in the setting of end of life. For example, recommending carefully selected equipment for positioning and mobility, timing movement around peak impact of pharmacologic analgesic effect, offloading pressure points, and validating patients' experiences of often variable and fluctuating pain can provide valuable reassurance and management [4]. It is important for rehabilitation clinicians to attend to a range of cancer-specific sources of pain (e.g., bony metastases, chemotherapy-induced neuropathy) and to remember that non-oncology-specific rehabilitation interventions may be of value. As Chevillat et al. note, "gait aids, positioning, foam bolsters, seat cushions, mattress overlays, and the many other devices used to remove pressure from painful structures are underused in general palliative care" [4]. These seemingly small interventions can both improve patient comfort and reduce caregiver burden and distress — and should not be overlooked.

Complementary and alternative therapies that can be performed by rehabilitation clinicians may be useful adjuncts for treating cancer-related pain near the end of life. A review of complementary therapies for cancer-related pain in patients receiving palliative care reported positive effects of guided imagery, progressive muscle relaxation, and massage; the effects of acupuncture were inconsistent [32•]. One recent study of transcutaneous electrical nerve stimulation for patients with cancer pain of a range of etiologies (including primary tumor, treatment-related, secondary to immobility) suggests safety without pain reduction over placebo [33], while another suggests TENS can reduce pain scores and total number of opioid rescue doses [34].

TENS, massage, and acupuncture have all been performed by physical therapists practicing in palliative care settings [14].

Rehabilitation clinicians can also play a role in referring patients for adjunctive treatments they themselves may not be trained to provide. For example, among patients with severe chronic diseases, including cancer, clinical hypnosis added to standard palliative care decreased pain by over 50% at 2 year follow-up [35].

## Psychological Symptoms and Mental Health

Mood disorders affect 30–40% of patients with cancer receiving palliative care [36]. Among those admitted to palliative care units, receiving rehabilitation services (physical, occupational, or speech language therapy) can help maintain a sense of hope and pleasure [37••]. Exercise in group and

home settings can also improve emotional well-being and quality of life [38, 39, 40•]. Among chemotherapy-treated patients with advanced lung cancer, a physical therapy program consisting of a combination of group-based physical and relaxation training plus individual home-based walking and relaxation training significantly improved emotional wellbeing [39]. In the 6-week biweekly individualized physical therapy program conducted by Cwirlej-Sozanska and colleagues, the intervention also significantly reduced depressive symptoms as measured by the Geriatric Depression Scale [29••].

Both physical and occupational therapists working in the palliative setting can view their roles as inclusive of providing psychosocial support and addressing patient and family emotions [13, 14, 41]. Psychosocial support adds an additional layer of care for patients participating in therapist-led exercise programs. Other members of the rehabilitation team, including, but not limited to, rehabilitation psychologists, chaplains, social workers, nurses, psychiatrists, and physiatrists, can offer support in this manner as well.

Patients with advanced cancer receiving hospice services who experienced anxiety expressed a desire not only for symptom control, but also for a safe environment and for information sharing [42]. Rehabilitation therapists who provide home care routinely provide safety assessments and recommendations and give education for patients about their functional status, needs, and anticipated trajectory. For all of these reasons, physical and occupational therapists may be ideal clinicians to address anxiety, especially when anxiety relates to functional tasks, safety, and the home environment.

The impact of preparing and supporting family caregivers for caring for patients with cancer has been an important subject of study [43], yet more research is needed to quantify the impact of rehabilitation interventions on caregiver outcomes such as anxiety, depression, and quality of life. Innovative work by Smith et al. [44] makes progress toward this goal; Smith et al. developed a pilot rehabilitation program focused on the provision of family training (e.g., activity modification, transfer training, home safety planning, etc.) for patients with serious, life-limiting illness and their caregivers. Although this program was developed as part of a quality improvement initiative, and therefore did not systematically assess caregiver outcomes, it did suggest that participating patients had higher rates of discharge to home and higher rates of palliative care support than counterparts who had not participated in the program.

## Fatigue

Cancer-related fatigue is a persistent state of exhaustion unrelieved by rest that may worsen as cancer progresses. More than half of patients with advanced cancer experience this function-limiting symptom, with higher rates in some

sub-populations [45, 46•]. Fatigue can arise from the cancer itself and as a side effect of treatments. As patients near end of life, factors such as anemia, malnutrition, and polypharmacy contribute to fatigue as well. Energy conservation, distraction, and individualized physical activities may help to mitigate the distressing experience of fatigue [47].

Exercise is one of the most well-supported rehabilitation interventions for cancer-related fatigue, with studies investigating both home-based and ambulatory programs [12]. A randomized controlled trial found that a 2-week therapy program including exercise, myofascial release, and proprioceptive neuromuscular facilitation significantly reduced fatigue in patients with advanced cancer receiving palliative care [48]. Among patients with advanced lung or colorectal cancer, fatigue and sleep quality were both improved after an 8-week course of walking and strength training [49]. Half of the studies examined in a 2018 systematic review of exercise interventions for patients with advanced cancer found a significant improvement in fatigue with exercise [40•].

Both physical and occupational therapists play important roles in the management of fatigue. In addition to educating patients about the fatigue itself, therapists teach energy conservation techniques, help patients set goals, and provide adaptive equipment to reduce energy expenditure [13, 14]. These interventions can be taught and/or reinforced by other members of the interdisciplinary team as well.

## Communication and Caregiver Support

While rehabilitation clinicians tend not to receive explicit training in care for patients and families with serious illness at end of life, highlighted recently within psychiatry [50], there are palliative care communication tools that all clinicians can learn and apply to enhance their ability to support both patients and caregivers. For example, clinicians can learn to sensitively elicit a patient's prognostic awareness — what the patient understands about their illness and its trajectory — to guide patient education and collaborative goal setting. Rehabilitation clinicians can also learn to carefully use changes in functional status to help patients recognize changes in overall disease process and identify opportunities to re-frame bigger-picture goals. As Wilson and Barnes describe in their call for increased physical therapy integration in interdisciplinary palliative care and hospice teams:

“The vast majority of PTs [physical therapists]/PTAs [physical therapy assistants] practice in settings that require demonstration of functional improvement to justify care. This requirement may inhibit the effectiveness of physical therapy for people with life-limiting conditions, many of whom have prognoses of inevitable functional decline... Traditional PT/PTA outcomes, such as range of motion (ROM), strength, or ambulation distance, may be replaced

or augmented with less familiar, patient-reported measures of QOL, affect, and physical function. This cultural shift not only is necessary for PTs/PTAs to provide patient-centered care for people with life limiting conditions but also provides a valuable opportunity to demonstrate the value of PT/PTA integration in the HPC [hospice and palliative care] interdisciplinary team.”[51]

Finally, when providing care in the palliative setting, rehabilitation clinicians across specialty interests can harness their broad understanding of the physical and emotional impact on caregivers of supporting a loved one with functional impairment and disability. Caregivers experience higher levels of stress when their loved ones have higher symptom intensity and/or unmet needs at end of life [52]. By building a strong therapeutic alliance with patients and families, rehabilitation clinicians have the opportunity to mitigate some of this burden.

## Optimizing Delivery of Rehabilitation-Based Symptom Management

### Improving Interprofessional Collaboration

Although interdisciplinary collaboration in palliative rehabilitation is valued, collaborative care models remain limited in real world clinical settings. A 2018 systematic review by Phongtankuel et al. [53] examined the disciplines of providers administering various components of palliative care interventions. Of the 71 intervention studies included, the majority were delivered by nurses and/or physicians, and 27% of interventions were delivered by a single discipline. Moreover, 62% of interventions lacked a defined communication pathway for care coordination between palliative care providers and the primary team. In addition, only 29% of hospices in the USA employ art therapists, music therapists, or massage therapists, indicating that practitioners of these complementary disciplines and rehabilitation therapists may be underutilized in the end-of-life setting as well [54].

Interdisciplinary collaboration in palliative rehabilitation is critical to optimally address the co-occurring, intense, and frequently dynamic symptoms experienced by individuals living with advanced cancer and other serious illnesses [51, 55–58]. To realize the benefits of symptom management through rehabilitation interventions, communication among palliative care and rehabilitation providers (including physiatrists) is essential. Research is needed to systematically quantify effective interventions and models of collaboration. In concert, education must be expanded about opportunities to improve patient and family experiences through palliative rehabilitation [53, 55, 59]. Clinical training in palliative care is typically interdisciplinary in nature, yet is often tailored to physicians, social workers, chaplains, and nurses while

training opportunities in palliative care for other rehabilitation clinicians (physical therapists, occupational therapists, speech language pathologists) remain limited in scope and availability.

To improve integration of rehabilitation into palliative care, palliative care training programs can explicitly teach trainees about the contributions of rehabilitation clinicians throughout the continuum of serious illness end of life care [28, 60–63]. This increased attention would also help programs teach content amplified in the newest edition of Clinical Practice Guidelines for Quality Palliative Care [64]. For the first time, these guidelines attend to the impact of functional status on quality of life, the provision of palliative care in post-acute care settings, and the role of disability as part of the patient experience. Rehabilitation clinicians hold expertise in all of these areas [65].

The National Comprehensive Cancer Network has set forth guidelines regarding palliative care integration into care plans for patients with cancer [66]. These guidelines list relief of pain and other symptoms, sense of control, relief of caregiver burden, and optimized quality of life as goals of palliative care. Although there is not an emphasis on function per se within the guidelines, an interdisciplinary team inclusive of rehabilitation clinicians can help to meet the benchmarks set forth.

Physiatry, physical therapy, occupational therapy, speech-language pathology, and other rehabilitation clinician training programs can also play a role in amplifying rehabilitation-palliative care collaboration in care for patients at the end of life. For example, by committing to educate trainees in advanced communication skills (eliciting prognostic awareness, navigating conversations about serious illness) and in the principles of palliative care, training programs will empower their graduates to advocate for and contribute to care for patients with serious illness. Interprofessional training around care for patients at end of life is both feasible and valuable for improving attitudes toward caring for patients near end of life [67•].

### Identifying Functional Decline and Burdensome Symptoms to Optimize Palliative Rehabilitation Delivery

An additional barrier to the use of palliative rehabilitation services for symptom management is the difficulty providers face in efficiently identifying or monitoring functional limitations and increasing symptoms among patients with advanced illness. A systematic review by Wang and colleagues identified that physical symptoms, anxiety, and quality of life comprised the majority of unmet needs reported by patients with advanced cancer [68]. A number of clinical trials [69] and a large population-based cohort study [70] have demonstrated the value of using patient-reported outcome

measures in routine oncologic care to improve patient functioning, symptoms, and healthcare utilization. In fact, results from these investigations and advocacy in the field have led payor groups, such as the Centers for Medicare and Medicaid Services to begin to incentivize collection of patient-reported outcome measures in value-based oncologic care models [71].

Moving forward, systematic implementation of psychometrically validated measures is necessary to improve our ability to identify changes in patient status and respond accordingly [72]. An important part of this process will be ongoing psychometric assessment of measure performance across disease types and stages to ensure reliability, validity, and responsiveness, and minimize potential bias in scoring.

The Cancer Rehabilitation Medicine Metrics Consortium (CRMCM) is identifying instruments to assess important patient-centered domains in cancer care [73], recently conducting a large-scale study to psychometrically validate the Patient-Reported Outcomes Measurement Information System (PROMIS) Cancer Function Brief 3D Profile [74]. The PROMIS measure changes as a patient's disease advances, allowing for capture of functional decline as part of data collected [74]. Other validated measures include the Edmonton Symptom Assessment System (ESAS) [75] and the Functional Assessment of Cancer Therapy – General (FACT-G) scale [76].

While these patient-reported outcome measures have been validated for use in cancer populations [74–76], it is important to consider both limitations to their use and potential application in non-cancer populations. Patient-level limitations to the use of patient-reported outcome measures include difficulty interpreting questions, difficulty recalling the severity of their symptoms within a certain time frame, insufficient time to complete questionnaires, and mismatch between patient experience and types of questions being asked [77]. Patients could also over- or under-report symptoms in order to influence treatment decisions or relationships with their healthcare providers. At the provider and systems levels, barriers to use of patient-reported measures center around infrastructure to collect and distribute data and clinician ability to integrate data in real time [77]. Future research could complement psychometric validation of measures with qualitative study designs to understand potential sources of responder bias and logistic and educational barriers to implementation across clinical settings. Study and validation of cancer-centered patient reported outcome measures in other populations with serious illness could provide opportunities to expand data collection and identify a larger population of patients who could benefit from palliative rehabilitation.

Once implemented into clinical care settings, assessment data can be aggregated and used to delineate trajectories in serious illness and allow providers to develop novel

palliative rehabilitation interventions that can be readily adapted to the fluctuating needs and goals of patients as they approach end of life. Engaging rehabilitation clinicians in this research will add important perspective, given their expertise in evaluation and treatment of pain, fatigue, psychological distress, and other symptoms [58]. Ultimately, data from patient-reported outcome measures may facilitate improved communication around care planning and prognosis between interprofessional providers, patients, and families.

### Scaling Palliative Rehabilitation to Other Serious Illnesses

The benefits of palliative rehabilitation in managing symptoms are not restricted to individuals living with advanced cancer; they can be readily transferred to patients living with other serious illnesses [56]. For example, over half of patients with serious illness experience breathlessness that restricts their activities [78]. Patients with advanced illness describe that dyspnea has physical, emotional, spiritual, and social impacts [79].

There is growing momentum to promote earlier palliative care evaluation and intervention for patients with heart failure (HF) [80] and chronic obstructive pulmonary disease (COPD) [81]. Although increasing awareness of the importance of palliative care in these chronic conditions is unquestionably important, these efforts often focus on medical therapies to improve symptoms while briefly discussing referral to rehabilitation — and disparately emphasize referral to cardiac and pulmonary rehabilitation programs in outpatient or home-based settings. While rehabilitation services provided in these settings are critical, the nuance inherent in providing rehabilitation across the continuum of chronic, life-limiting illnesses, such as HF and COPD, remains underexplored. There is a tremendous opportunity to translate conceptual models of palliative rehabilitation, such as those from Dietz [82, 83] and Chevillat [4], in oncology to develop analogous rehabilitation programs for patients with progressive HF and COPD.

### Conclusion

Cancer and other life-limiting diagnoses are associated with high symptom burden at the end of life and rehabilitation is an underutilized tool to address these symptoms. Rehabilitation can meaningfully address dyspnea, pain, fatigue, anxiety, and depression at the end of life and provide support for caregivers as well. Rigorous research is needed to fully specify the details of interventions, sub-populations, and degree of impact. Barriers to rehabilitation at the end of life include identification of needs and integration of

interprofessional rehabilitation clinicians in the palliative care setting. Rehabilitation is an important component of an interdisciplinary approach to reducing suffering and maintaining quality of life for patients throughout the trajectory of illness, including at the end of life.

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