Follow the Trail: Using Insights From the Growth of Palliative Care to Propose a Roadmap for Cancer Rehabilitation

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Abstract: Despite research explicating the benefits of cancer rehabilitation interventions to optimize physical, social, emotional, and vocational functioning, many reports document low rates of referral to and uptake of rehabilitation in oncology. Cancer rehabilitation clinicians, researchers, and policy makers could learn from the multidisciplinary specialty of palliative care, which has benefited from a growth strategy and has garnered national recognition as an important and necessary aspect of oncology care. The purpose of this article is to explore the actions that have increased the uptake and integration of palliative care to yield insights and multimodal strategies for the development and growth of cancer rehabilitation. After examining the history of palliative care and its growth, the authors highlight 5 key strategies that may benefit the field of cancer rehabilitation: 1) stimulating the science in specific gap areas; 2) creating clinical practice guidelines; 3) building clinical capacity; 4) ascertaining and responding to public opinion; and 5) advocating for public policy change. Coordinated and simultaneous advances on these 5 strategies may catalyze the growth, utilization, and effectiveness of patient screening, timely referrals, and delivery of appropriate cancer rehabilitation care that reduces disability and improves quality of life for cancer survivors who need these services. CA: Cancer J Clin 2019;69:113-126. © 2018 American Cancer Society.

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Introduction

Many cancer survivors experience physical impairments (eg, fatigue, pain, neuropathy, lymphedema), psychological challenges (eg, distress, anxiety, depression), and/or cognitive changes (eg, reduced memory, attention, or processing speed) during and after cancer treatment. Along with social and environmental factors, these impairments can create functional limitations that interfere with survivors’ mobility or ability to do activities of daily living (ADLs) (basic self-care tasks such as dressing or bathing) or instrumental ADLs (IADLs) (ADLs that involve higher mobility or ability to do activities of daily living (ADLs) (basic self-care tasks such as meal preparation, shopping, household maintenance). A recent meta-analysis1 indicated that 37% of adults living with cancer report challenges or needing assistance with basic ADLs, and 55% report challenges or needing assistance with IADLs. The estimate is slightly higher in older adults, in which 64% of older adults with cancer report some form of functional limitation.2 If unaddressed, these functional limitations can affect productivity,3,4 quality of life,5,6 and overall survival.7

Rehabilitation services have the potential to reduce the functional limitations experienced by cancer survivors.8 Cancer rehabilitation is a multidisciplinary field (including, but not limited to, physical medicine and rehabilitation physicians, physical and occupational therapists, speech and language pathologists, exercise...
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Scientists, rehabilitation psychologists, and nurses) with the goal of optimizing physical, social, emotional, and vocational functioning despite the challenges created by cancer or its treatment.9,10 Cancer rehabilitation strategies are similar to those used in recovery from other conditions (e.g., stroke, cardiac rehabilitation) and include interventions such as exercise, functional mobility retraining, retraining in ADLs, energy management, environmental modification, and the provision of adaptive equipment, lymphedema management, dysphagia and dysphasia treatment, physical agent modalities, psychosocial interventions, cognitive rehabilitation, and vocational rehabilitation. These varied interventions, delivered by different specialties, are united in the goal of reducing impairments and maximizing function and quality of life.

Historically, there have been low rates of referral to and uptake of rehabilitation services in oncology.11,12 For example, Pergolotti et al observed that only 9% of older adults with cancer used physical or occupational therapy, despite having a potentially modifiable functional limitation detected by comprehensive geriatric assessment.2 Cheville et al likewise reported that less than 30% of outpatients with cancer and women with advanced cancer who had functional limitations used rehabilitation services.13 The reasons for low utilization include a workforce shortage of rehabilitation physicians and therapists trained in oncology11,14 and a low familiarity and recognition on behalf of patients and referring providers as to the need, value, and function of cancer rehabilitation.11,15

Research has indicated that individual treatments delivered by rehabilitation professionals can reduce impairments or functional limitations of cancer survivors.16,17 For example, meta-analyses or systematic reviews support the use of exercise to reduce fatigue18 and to improve physical fitness, physical and emotional function, and quality of life19; education to manage pain20 and fatigue21,22; nonpharmacological interventions23 or neuropsychological interventions24 to improve cognitive functioning; group-based self-management programs to improve physical functioning25; massage therapy to improve pain, fatigue, and anxiety26; and manual lymphatic drainage to manage lymphedema.27

On the basis of this growing body of evidence, national multistakeholder efforts have convened experts to develop consensus-based guidance articulating the importance of screening for rehabilitation needs and delivering rehabilitation interventions for patients who need them alongside oncology care.28,29 These expert panels built on position papers in which authors called for this screening and referral of patients in need of cancer rehabilitation to occur across disease types at all phases of cancer treatment, including before cancer treatment (referred to as “prehabilitation”),30,31 during treatment,14,32 in the posttreatment survivorship phase,33-35 and in the realm of end-of-life care.36,37 However, as discussed in those articles, progress integrating cancer rehabilitation with oncology care is limited by the lack of a mechanism to screen, triage, and refer oncology patients to rehabilitation; by a lack of health care delivery research and clinical guidance on how to best coordinate and deliver multicomponent interventions; limited knowledge regarding cancer rehabilitation among clinicians and patients; and problems with access to and reimbursement of cancer rehabilitation interventions.

To identify patients who may benefit from comprehensive cancer rehabilitation and to integrate those services into oncology care, we need a coordinated strategy involving simultaneous action to drive advances in science, clinician and patient education, practice, policy, and advocacy. The field of palliative care faces challenges similar to those seen in cancer rehabilitation yet has advanced by proactively addressing those challenges. Palliative care is a multidisciplinary specialty in which the objective is to improve quality of life by reducing symptoms, pain, and stress and by promoting values-based care and psychosocial and spiritual support for individuals with serious illness and their families.37,38 Although the delivery of timely palliative care in the United States is far from perfect, palliative care providers and advocates have made steady progress in increasing access to palliative care as an integrated component of comprehensive care for individuals with advanced cancer. In 2016, three-quarters of all hospitals in the United States had a palliative care program, compared with one-quarter in 2000 (a 178% increase).39 There are now guidelines from the American Society of Clinical Oncology (ASCO) advocating for the integration of palliative care early in the disease trajectory,40 and there is a bill in the US House of Representatives and Senate that would legislate early access to palliative care and support

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training providers to deliver palliative care services to meet rising demand.

Palliative care and cancer rehabilitation share several characteristics and challenges that make comparison fruitful. First, although many medical specialties focus on the diagnosis, treatment, and often cure of disease, palliative care and cancer rehabilitation address the symptoms or effects of illness or treatment. Second, both cancer rehabilitation and palliative care interventions are delivered by multidisciplinary teams and involve a broad set of interventions addressing both physical and psychosocial needs.10 Many areas of medicine emphasize the value of multidisciplinary teams; however, for both palliative care and cancer rehabilitation, this perspective is essential and is part of accreditation standards.41,42 Third, both evidence bases have been growing over time; however, palliative care research has purposively expanded from focusing on discrete strategies to manage symptoms or increase rates of advance care planning, to include testing the broad effects of comprehensive models of palliative care. Fourth, similar to cancer rehabilitation, uptake of palliative care has been variable43 and often has not been recognized as potentially helpful by either patients44 and providers.45 Although we acknowledge that the evidence base for palliative care has gaps and that palliative care uptake is not uniform across the country, we believe that exploring the steps taken by the palliative care community to increase the uptake and integration of outpatient concurrent palliative care in oncology in recent years could yield insight and guideposts for the development of cancer rehabilitation.

In this article, we explore the actions that have increased the uptake and integration of palliative care to yield insights and multimodal strategies for the development and growth of cancer rehabilitation. After examining the history of palliative care, we highlight 5 key strategies that have fostered the growth of palliative care: 1) stimulating the science in specific gap areas; 2) creating clinical practice guidelines; 3) building clinical capacity; 4) ascertaining and responding to public opinion; and 5) advocating for public policy change. By using these strategies as guideposts, we then articulate the position of cancer rehabilitation in its developmental trajectory and delineate a roadmap for how to simultaneously move forward in each of those areas. We focus our discussion of palliative care on concurrent palliative care in oncology (ie, multidisciplinary palliative care that is individualized and delivered in tandem with standard oncology care)40 as it is philosophically similar to the call for concurrent cancer rehabilitation all along the trajectory, from diagnosis to survivorship or to the end of life.29

### Strategy 1: Stimulating the Science in Specific Gap Areas

#### Palliative Care

#### The science

Largely in response to 2 large landmark studies documenting the lack of congruence between patient-stated preferences and actual end-of-life care for adults with life-limiting illness,46–48 there was growing interest in integrating palliative care delivery models into oncology. Thus, many feasibility and demonstration projects in palliative care were launched across the United States near the end of the 20th century.49–53 These projects established the feasibility of integrating palliative care services into a variety of oncology care settings and a shared approach that, among other services, included symptom assessment and management (eg, psychosocial distress, fatigue, shortness of breath, pain, appetite, and nutrition).

These feasibility studies were followed by several studies using rigorous research designs that generated reliable evidence of the efficacy of concurrent palliative care delivery and cancer treatment. The first randomized controlled trials (RCTs) published in high-impact journals provided evidence that concurrent palliative care could have positive effects on quality of life,54–56 depression,54,55 symptom burden,56 satisfaction with care,56 and survival55,57 among individuals who were living with metastatic solid tumors. The evidence base continued to expand beyond these seminal studies and demonstrated positive effects on illness communication,58 adaptive coping,59,60 prognostic awareness,61 treatment decision making,60 end-of-life care,62 caregiver outcomes,63,64 and cost-effectiveness.65 As the science matured, palliative care researchers were able to identify mediators and moderators of the beneficial effects of palliative care.59,66–68

By 2016, the evidence base had grown enough to allow meta-analyses to be conducted on palliative care clinical trials. First, Kavalieratos et al69 evaluated 43 studies that tested at least 2 domains of palliative care (eg, depression and quality of life). Although the meta-analysis examined palliative care for any population, a little over two-thirds of the studies included individuals with advanced cancer. That meta-analysis documented clinically meaningful benefits of palliative care on quality of life and symptom intensity, advance care planning, patient and caregiver satisfaction, and health care utilization, although no consistent survival effect was observed across the studies. In 2017, a systematic review of 7 studies with a low risk of bias that examined concurrent palliative care for adults with advanced cancer
was added to the Cochrane Library\textsuperscript{70} and reported results similar to those reported in the meta-analysis.\textsuperscript{69} There were small beneficial effects for quality of life and symptom management but no consistent effects on mood or survival.

Thanks to this body of evidence supporting the value of palliative care for individuals with advanced cancer, concurrent palliative care has been highlighted as a best practice for reducing unplanned admissions to the hospital\textsuperscript{71} and as an important component of value-based care, which is a major national priority for oncology, with a focus on delivering high-quality care with better patient outcomes and satisfaction at a lower cost. The data on cost-effectiveness continue to accumulate, with reports suggesting that the costs of providing palliative care ultimately can be offset by reductions in acute care admissions and costs.\textsuperscript{72}

**Funding and investigator training**

Funding from both foundations and the government has played an important role in catalyzing research in palliative care. Early demonstration projects were funded to explore the feasibility and acceptability of various palliative care delivery models.\textsuperscript{69} Federal funding through the National Institutes of Health (NIH) and its centers has provided both research and training grants in palliative care.\textsuperscript{73,74} The Patient-Centered Outcomes Research Institute also has funded comparative effectiveness studies in palliative care.\textsuperscript{75} Palliative care scientists have established research consortia to facilitate multisite palliative care trials and to develop the research capacity of investigators to build the evidence base for palliative care.\textsuperscript{76,77} These consortia, along with palliative care funding opportunities from the American Cancer Society (ACS) and the American Academy of Hospice and Palliative Medicine, have included an investment in investigator training and professional development, ensuring the future development of the field. Finally, palliative care research networks and dissemination-focused organizations have come together both to conduct palliative care research and to promote its implementation on the front lines of care.\textsuperscript{78}

**Cancer Rehabilitation**

**The science**

Seeking to engineer growth in the evidence base for cancer rehabilitation following the example set by palliative care points to 2 critical types of research that are needed to further test the effects of cancer rehabilitation. The first research gap is testing multicomponent interventions delivered concurrently with oncology treatment and conducting reviews and meta-analyses of these multicomponent intervention studies. As noted above (see Introduction), there is a significant body of research studies, reviews, and meta-analyses supporting individual rehabilitation interventions for a variety of cancer-related impairments, and this is reflected in evidence-based guidelines from organizations such as ASCO\textsuperscript{79,80} and the National Comprehensive Cancer Network (NCCN)\textsuperscript{81} regarding how to treat these impairments. However, in contrast to palliative care, there have been fewer studies of interventions delivered together as comprehensive cancer rehabilitation (ie, a “package” of treatments delivered by a multidisciplinary team). Within the Cochrane database, there are 3 reviews concerning multidisciplinary or multimodal cancer rehabilitation. The review for multidisciplinary rehabilitation for individuals who received brain tumor treatment contains a single study in which the authors conclude that there is low-quality evidence suggesting a benefit of improved mobility after high-intensity outpatient rehabilitation.\textsuperscript{82} A second Cochrane review of multidisciplinary rehabilitation for breast cancer survivors includes 2 RCTs that suggest a short-term benefit of rehabilitation in terms of impairment reduction and quality of life.\textsuperscript{83} A third Cochrane review explored rehabilitation programs for cancer survivors that addressed more than one aspect of functioning (eg, physical and psychological functioning).\textsuperscript{84} There were 12 RCTs in that review, ranging from a moderate to high risk of bias, and they reported a benefit of rehabilitation on physical functioning. Another meta-analysis of multidimensional rehabilitation for cancer survivors included 22 studies and likewise indicated a benefit of rehabilitation versus usual care on physical functioning and fatigue.\textsuperscript{85}

The second critical research gap for cancer rehabilitation includes studies testing the effects of interventions, beyond functioning, on survival, health care utilization, and costs. As reviewed above, the growth of palliative care was spurred by studies demonstrating that patients with earlier access to palliative care not only reported lower symptom burden but also had reduced health care utilization, better survival, and lower costs.\textsuperscript{55} These outcomes are relevant to oncology clinicians and to administrators and payers evaluating value-based care. Similarly, cancer rehabilitation studies are needed that build on the existing evidence for specific interventions and evaluate the effectiveness of models that use screening and referral systems to deliver proactive cancer rehabilitation concurrently with cancer treatment. Studies must document the impact of cancer rehabilitation on other variables beyond impairment reduction, such as role resumption, return-to-work, disability, chronic symptom and late effects management, treatment adherence, health care utilization and costs, and overall survival. These health services and cost-effectiveness studies will be key to determining the degree to which cancer rehabilitation contributes to value-based care and have the potential to align findings with
priorities of the larger oncology community. Studies that test mediators and moderators of intervention effects are needed in cancer rehabilitation to facilitate understanding of the interventions or delivery modalities that work best for given types of patients. Implementation science is needed to identify sustainable ways to implement, tailor, and evaluate interventions that have sufficient evidence to recommend their wide-scale adoption. This research must consider telemedicine approaches and other models of care that increase patient access to treatments and deliver needed interventions in patient-centered ways.

**Funding and investigator training**

A 2016 report released by the NIH listed stimulating research on critical gap areas as one of 10 recommendations from a multidisciplinary expert group on how to advance cancer rehabilitation. By using palliative care progress as a guide, we conclude that, to build this evidence base, there must be: 1) more investigators who are trained in diverse research methods (eg, experimental design, pragmatic trials, implementation science, health services research); 2) funding mechanisms that support this work; and 3) more efforts to synthesize the research using meta-analytic techniques. Currently, there are few specific funding mechanisms (eg, The Foundation for Physical Medicine and Rehabilitation has a mechanism to fund small projects in cancer rehabilitation) and only the beginnings of research networks specifically devoted to cancer rehabilitation research (eg, The Cancer Rehabilitation Metrics Consortium). Funding for cancer rehabilitation research at the NIH is challenging, because researchers must submit proposals based on specific population characteristics or impairments to study section reviewers who may have little expertise or understanding of the team-oriented approach of rehabilitation medicine to addressing complex functional health problems. However, a new research plan on rehabilitation was released by the NIH in 2016 with the aim of coordinating this science across NIH institutes and centers and other funders. Given the vast growth palliative care has experienced with targeted training and funding opportunities, cancer rehabilitation researchers would thrive if there were government and nongovernment funding mechanisms targeted to cancer rehabilitation and additional cancer rehabilitation research networks with cross-network resources for pilot projects and junior investigator training.

One new development that should benefit a synthesis of the evidence base in cancer rehabilitation is the formation of the Cochrane Rehabilitation effort. Cochrane Rehabilitation is a network of rehabilitation professionals working to ensure that all rehabilitation practitioners have access to the knowledge needed for evidence-based practice. The efforts of the Cochrane Rehabilitation group can synthesize the evidence base as it grows so that it is maximally useful in identifying best practices for clinical practice and the remaining scientific gap areas for researchers (Table 1).

**Strategy 2: Creating Clinical Practice Guidelines**

**Palliative Care**

ASCO released a provisional guidance opinion in 2012 calling for the integration of palliative care into standard oncology treatment at the time a person is diagnosed with advanced cancer. Although it was based on the seminal

| Actions Taken by Advocates of Palliative Care                                                                 | Progress to Date and Actions Needed to Implement Cancer Rehabilitation |
|-------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------|
| Developed a robust research base allowing meta-analyses and a Cochrane review on outcomes, including quality of life, symptom burden, survival, cost-effectiveness, and health care utilization | Progress to date: Evidence of impairment reduction from specific rehabilitation interventions Needed: Rigorous research on how to deliver multicomponent interventions and meta-analyses of these studies that inform clinical guidelines; health services research that explores outcomes, including disability, survival, quality of life, health care utilization, and cost-effectiveness; implementation science to understand how to broadly implement evidence-based interventions; moderators of beneficial outcomes; research testing mechanisms to screen and triage individuals into cancer rehabilitation as needed |
| Partnered with foundations and government funding agencies to develop 1) funding mechanisms and 2) networks to foster the development of research and of scientists specializing in palliative care | Progress to date: Limited funding or research networks specifically devoted to cancer rehabilitation research Needed: Government and nongovernment funding targeted to cancer rehabilitation; partnerships across agencies to pool resources for cancer rehabilitation research; development of cancer rehabilitation research networks with cross-network resources for pilot projects and junior investigator training |
research, the 2012 provisional guidance opinion was an expert consensus statement. In response to the accumulating evidence, ASCO revised this statement and issued clinical practice guidelines in 2016.40 Within the 4-year time frame from the provisional guidance opinion to the evidence-based guidelines of 2016, an additional 9 RCTs, as well as quasi-experimental studies and secondary analyses, had strengthened the body of research and expanded outcomes beyond patients to include caregivers and health care utilization and costs. The clinical practice guidelines called for both inpatients and outpatients diagnosed with advanced cancer to receive palliative care services concurrent with active treatment and initiated within 8 weeks of diagnosis. Other organizations have echoed these recommendations, including the Oncology Nursing Society (ONS)89 and the NCCN.90,91

Cancer Rehabilitation

The ASCO guideline recommending earlier access to palliative care for patients with advanced cancer sends a strong importance to the oncology community regarding the importance of this care and provides clinical guidance for integrating palliative care with oncology treatment. An equivalent guideline from ASCO for cancer rehabilitation is needed but is unlikely to happen in the near future given the lack of evidence demonstrating the effects of multimodal cancer rehabilitation on health care utilization and costs. Nonetheless, a consensus-based guideline could be produced now, even as we await this data. This could be accomplished in several ways. Each year, ASCO solicits ideas for guidelines from the community and then prioritizes the new guidelines (for endorsement or adaptation of guidelines of other groups) for that year. An effort could be mounted to submit a cancer rehabilitation guideline to the ASCO committee for consideration. As a preparatory step, rehabilitation professional groups could come together and collaboratively produce a consensus-based cancer rehabilitation guideline. The American Congress of Rehabilitation Medicine (ACRM), as a multidisciplinary group, could spearhead the effort to coordinate across specialty groups. Once a guideline is developed and vetted by multiple stakeholders in cancer rehabilitation, ASCO could be approached to consider endorsement of that guideline. This effort also would serve to bring the cancer rehabilitation community together to create a unified voice in national advocacy for cancer rehabilitation (Table 2).

Strategy 3: Building Clinical Capacity

Palliative Care

Another key strategy for changing health care delivery is improving the training and capacity of health care systems to deliver novel care approaches. Palliative care has benefited from the Center to Advance Palliative Care (CAPC), which helps its members provide institutional trainings, educational resources, mentoring, and consulting to help develop high-quality palliative care delivery in their clinical and community settings. Courses cover the core components of palliative care as well as coding, billing, and other administrative challenges, and CAPC offers quality certifications and has developed 9 Centers of Excellence to highlight best practices. In addition, CAPC hosts Palliative Care Leadership Centers, where teams work for a full year on program design and development with an eye on financial sustainability. CAPC has been cited as a model of diffusion of innovation, helping programs develop both research and clinical capacity.92

CAPC also developed the National Palliative Care Registry to benchmark and track progress in US capacity to deliver palliative care. Currently, the registry, which includes almost 1200 programs (registry.capc.org; accessed April 15, 2018), captures a nationwide picture of palliative care in practice and is used to influence national policy and standards. Registry data have demonstrated growth in palliative care in the United States, in the number of programs that meet recommended staffing standards, and in the current state of hospital-based pediatric palliative care in the United States.93-95 Moreover, CAPC, in conjunction with the National Palliative Care Research Center and data from other organizations, produces the CAPC

| TABLE 2. Strategy 2: Creating Clinical Practice Guidelines | Progress to Date and Actions Needed to Implement Cancer Rehabilitation |
|-----------------------------------------------------------|---------------------------------------------------------------------|
| Actions Taken by Advocates of Palliative Care |
| The American Society of Clinical Oncology developed a provisional guidance opinion in 2012 arguing for concurrent palliative care and developed clinical practice guidelines with the American Society of Clinical Oncology in 2016, with similar recommendations from the Oncology Nursing Society, the American College of Surgeons Commission on Cancer, and the National Comprehensive Cancer Network. |
| Progress to date: Limited guidelines exist for managing specific impairments (eg, lymphedema); limited data are available on best practices for multimodal cancer rehabilitation delivery to create comprehensive cancer rehabilitation guidelines. |
| Needed: Professional societies involved in cancer rehabilitation could develop a consensus-based guideline while science is accumulating and seek endorsement from multiple stakeholder groups. |
Report Card, which is a state-by-state report card on access to palliative care services in US hospitals. These results are published in the scientific literature and in a joint CAPC/National Palliative Care Research Center report with policy implications.11,93,96

Cancer Rehabilitation

If efforts were successful in increasing referrals to cancer rehabilitation providers, then there would not be enough rehabilitation providers in any specialty who have cancer expertise to handle the referrals. Thus, efforts must focus on training more providers in cancer rehabilitation. Many efforts to increase the number of cancer rehabilitation providers are underway through specialty examinations and cancer rehabilitation conference content. These include the American College of Sports Medicine certifying examination for Cancer Exercise Trainers and cancer-specific clinical and research symposia at its annual conferences; the American Board of Physical Therapy Specialties oncology specialization certification examination for physical therapists (beginning 2019) and education from its oncology section; the ACRM Cancer Rehabilitation Networking Group and cancer programming at its annual conferences; and the American Academy of Physical Medicine and Rehabilitation cancer-specific content at its annual conferences and the research, education, and strategic planning subgroups of its Cancer Rehabilitation Physicians Consortium. The Survivorship Training and Rehabilitation (STAR) Program, a commercial entity, offered therapist training and cancer rehabilitation service-line development support, leading to institutional “STAR Program certification.” Although this program is no longer in operation, it provided training to thousands of clinicians in several hundred locations across the United States.

While these national efforts are training the existing rehabilitation workforce, efforts are needed to increase graduate, postgraduate, nursing, and medical school rehabilitation programming specifically in cancer rehabilitation. The example of physical therapy is illustrative here. The American Board of Physical Therapy Residency and Fellowship Education establishes criteria for clinical residency programs and accredits those programs. At the time of this writing, there is one accredited oncology residency program that provides postgraduate training for both physical and occupational therapists. With an additional 2 programs that are candidates for accreditation by the American Board of Physical Therapy Residency and Fellowship Education, this is a model for increasing clinical competence in cancer rehabilitation at the postgraduate level.

In addition to training more cancer rehabilitation professionals, efforts are needed to train other providers who equally influence and contribute to optimizing a patient’s functional capacity. Education should focus on teaching medical students and surgical, radiation, and medical oncology residents and fellows to consider the functional impact of cancer in parallel with cancer biology and treatment. Cancer rehabilitation training for providers in palliative care, psychiatry, oncology nursing, oncology social work, and patient and nurse navigators would help these clinicians understand the types of patient problems in need of referrals to cancer rehabilitation services. Collaborating with fellowship and training organizations, including the Accreditation Council for Graduate Medical Education, to incorporate improved cancer rehabilitation curriculum is needed. Integrating cancer rehabilitation into continuing medical education and/or recertification examinations could be used to educate grandfathered, board-certified physician specialists.

As with palliative care, creating a national registry of cancer rehabilitation programs would be useful to benchmark the availability and growth of these services in geographic locations and over time. Digital tools could be embedded in the electronic health records to connect patient-reported outcome data on symptoms and impairments to treatment algorithms that specify the appropriate referrals using this registry and facilitate appropriate and timely referrals to rehabilitation. Work on these digital tools has begun and was reviewed in a 2018 Roundtable with 40 stakeholder groups led by the ACS and the ONS on Mitigating the Adverse Effects of Cancer and its Therapy. Guides on implementing these digital tools have been published 97–99 and, although such a registry does not currently exist, several professional groups (eg, physical therapists, exercise trainers, mental health practitioners) are creating their own versions of such a registry, and an effort should be made to link these into a central cancer rehabilitation provider registry. Data from the registry could be used by patients and clinicians to facilitate referrals and by state and national advocates and policy makers to inform policy campaigns. Without an organization for cancer rehabilitation equivalent to CAPC, such a registry could be built either by one multidisciplinary organization, such as the ACRM or the ACS, or through a partnership of all the relevant, discipline-specific professional organizations (Table 3).

Strategy 4: Ascertaining and Responding to Public Opinion

Palliative Care

Transforming health care requires educating patients as health care consumers regarding the importance of changes in care and soliciting their insights for the delivery of care in feasible, patient-centered ways. In 2010, CAPC commissioned
a mixed-methods, public opinion survey to understand and benchmark current perceptions of palliative care. This mixed-methods study not only solicited information on public awareness and understanding but also tested definitions and messaging to be used with the public and consumers of palliative care. Key findings included the lack of knowledge regarding palliative care in consumers, the challenges of reaching physician audiences with palliative care, the components of palliative care perceived as most important, barriers, and important insights into the messaging and definition of palliative care. These findings then provided a map for communicating the benefits and goals of palliative care to consumers, policy makers, and medical providers.

The resulting language and definition promoted consistent messaging throughout public and advocacy work to advance the practice of palliative care. In addition, an advertising campaign sponsored by the ACS Cancer Action Network, the advocacy partner of the ACS, was launched in 2012 to raise public awareness of a national legislative action to expand access to palliative care. Efforts to shape public opinion with consistent messaging continues, with recent letters to the editors in high-impact news publications.

**Cancer Rehabilitation**

Existing research suggests that both referring providers and cancer survivors may be ambivalent or disinterested in rehabilitation services, although those who experience rehabilitation generally report perceptions that it was beneficial. As such, national research or public opinion surveys to capture public attitudes and preferences regarding cancer rehabilitation and guide the development of educational campaigns to increase the uptake of cancer rehabilitation care for patients in need of these interventions are important next steps. Professional organizations such as the ACS, the American Physical Therapy Association, the American Academy of Physical Medicine and Rehabilitation, the American Occupational Therapy Association, the American College of Sports Medicine, and ASCO (in their patient-facing cancer.net site; accessed May 14, 2018) have patient-focused cancer rehabilitation materials on their respective Web sites. In addition, rehabilitation facilities and some cancer centers have produced informational and testimonial videos for their Web sites. However, these efforts are limited in their reach, and most National Cancer Institute-designated comprehensive cancer center Web sites contain little information regarding cancer rehabilitation for patients.

To influence and shape public opinion, organizations with interests in cancer rehabilitation will need to come together to survey the public opinion landscape and test messages with patient and caregiver populations to most effectively communicate the evidence for and increase awareness of cancer rehabilitation, as well as to develop models of cancer rehabilitation that reflect patient needs, preferences, and priorities (Table 4).

### Strategy 5: Advocating for Public Policy Change

#### Palliative Care

**Quality metrics**

The growth of quality metrics in medicine is a trend that has also been reflected in the field of palliative care, with extensive work conducted by the National Quality Forum and the Institute of Medicine, now part of the National Academies of Science, Engineering, and Medicine. In addition, the American Academy of Hospice and Palliative Medicine conducted a large quality-measurement initiative, Measuring What Matters, a consensus project to design a core set of measures for use by all hospice and palliative care programs. An ASCO Quality Oncology Practice Initiative indicator focusing on the end-of-life component of palliative care also has been developed. Although most of these

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**TABLE 3. Strategy 3: Building Clinical Capacity**

| Actions Taken by Advocates of Palliative Care | Progress to Date and Actions Needed to Implement Cancer Rehabilitation |
|---------------------------------------------|------------------------------------------------------------------------|
| The Center to Advance Palliative Care offers education, mentoring, and certification regarding practice and sustainable models of care; palliative care–specific training mechanisms are available in multiple disciplines | Progress to date: Cancer-specific training/certification is offered by the American College of Sports Medicine, the American Physical Therapy Association, the American Congress of Rehabilitation Medicine, and the American Academy of Physical Medicine and Rehabilitation |
| Created the National Palliative Care Registry to benchmark access to palliative care by state and track program outcomes | Needed: More entry-level education in cancer rehabilitation for students in rehabilitation professions and foundational knowledge of rehabilitation strategies taught to students and members of other disciplines |
| | Progress to date: Some professional organizations keep registries of their practitioners with specific training, and others are planned |
|  | Needed: A geocoded registry of all disciplines of cancer rehabilitation providers and programs for use by clinicians and patients |

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**Strategy 5: Advocating for Public Policy Change**
measures relate to physical symptoms, and there is still a lack of quality metrics related to psychological, spiritual, and social distress. This growth in palliative care quality metrics, combined with CAPC’s technical assistance and registry, have combined to foster high uptake and a significant capacity to demonstrate the value of palliative care at both the program and national levels.

Public policy strategies

Recognizing the need for legislative and regulatory changes to improve and expand access to palliative care and the multistakeholder coalition that would be needed to drive those changes, the Patient Quality of Life Coalition (PQLC) was launched in 2013 (patientqualityoflife.org; accessed April 15, 2018). The PQLC comprises over 40 organizations representing patients, family caregivers, hospitals and health systems, hospices, professional clinical groups, and researchers. To speak with the largest possible megaphone, the group focuses its attention on all patients with serious illness and not just on those with cancer. The PQLC has worked to advance legislative and regulatory policy change to improve public understanding of palliative care, develop the palliative care workforce, stimulate research on palliative care, expand the delivery of palliative care, and ensure access to prescription medication for managing pain and other symptoms in patients with legitimate need. To bring about these changes, the group drove a bipartisan coalition to support the Palliative Care and Hospice Education and Training Act (PCHETA), which was first introduced in the 114th Congress (2015-2016) and was reintroduced in the 115th Congress of 2017 and 2018 (HR 1676/S.693; forwarded from subcommittee to full committee at the time of this writing).

Cancer Rehabilitation

Adopting the policy-related strategies of palliative care also could stimulate cancer rehabilitation care. Quality metrics are one strategy. Patient screening for functional impairments and referrals for cancer rehabilitation interventions for patients who need them should be a component of quality oncology and posttreatment care. Thus, it may be useful to broaden quality metrics to incorporate the frequency of appropriate rehabilitation referrals. These metrics could be developed through existing processes by the National Quality Forum or the ASCO Quality Oncology Practice Initiative.

Accreditation standards are another option. The American College of Surgeons’ Commission on Cancer mandates that institutions must ensure the availability of rehabilitation services for cancer center accreditation. Because it does not require on-site or coordinated delivery of cancer rehabilitation services as a standard part of cancer care, these mandates could be added to stimulate better coordinated care. Another option is the Commission on Accreditation of Rehabilitation Facilities International accreditation standards for Cancer Rehabilitation Specialty Programs, first introduced in 2014. This specialty accreditation can be applied to hospitals, health care systems, outpatient clinics, and community-based programs. Although this may not directly incentivize changes in the delivery of care, it is an excellent first step to catalyze the essential components of a cancer rehabilitation program. Both of these efforts could be leveraged to continue to incentivize cancer rehabilitation as a component of cancer care.

Another option involves broadening the Commission on Cancer accreditation standard on screening for psychosocial distress to identify patients in need of additional support services to manage their distress during cancer treatment. Broadening this standard to screen for both the psychosocial and functional needs of patients would help drive clinician attention to a more comprehensive set of patient needs. Incentivizing routine screening for functional limitations would be in line with the ASCO guideline to assess
and address vulnerabilities of older adults during chemotherapy.\textsuperscript{113} In that guideline (developed by an expert panel), referrals to rehabilitation are recommended in the presence of IADL limitations or falls/mobility limitations.\textsuperscript{114}

A final strategy could involve legislative work to mandate the inclusion of cancer rehabilitation screening and appropriate referrals in oncology care and stimulate the growth of the workforce and the science base, similar to the palliative care PCHETA bill. However, the PCHETA bill has gained traction because its focus is broader than cancer and thus involves many stakeholders. Given that cancer rehabilitation is focused only on cancer, it may be wise to pursue opportunities to promote rehabilitation across disability groups that would include cancer or other ways to build a larger effort. Other policy changes are needed to address patient access to cancer rehabilitation services. For instance, outpatient therapy services for Medicare beneficiaries are capitated at $2010 for either occupational therapy or speech and language pathology and physical therapy combined. This limitation may significantly reduce the total number of therapy sessions allowed because of increased cost associated with medical necessity and therapeutic intervention.

Furthermore, inpatient rehabilitation for oncology patients is often underused. Reimbursement structures, as established by the Centers for Medicare & Medicaid Services, do not account for oncological diagnoses within inpatient rehabilitation facilities, skilled nursing facilities, or long-term care hospitals. Expanding the criteria for admission and recognizing that these services may help to provide medically complex care at a lower cost than acute care settings could help boost referrals of patients in need of this care and overcome patient cost barriers to care. Testing the inclusion of cancer rehabilitation in bundled payment initiatives and the Oncology Care Model would provide the opportunity to test whether this care improves quality and outcome measures with lower cost intervention (Table 5).\textsuperscript{115}

**Conclusions**

The needs of patients with cancer and long-term survivors present compelling problems, including increased rates of impairment and compromised functional health and the challenges of returning to work and daily activities. To address these challenges, screening for cancer rehabilitation needs and facilitating appropriate referrals for patients who need it must become part of standard oncology care. This report presents a visionary roadmap for multimodal actions that will catalyze the development of cancer rehabilitation based on an analysis of the history of palliative care. Although palliative care and rehabilitation care share several key differences (eg, all patients with advanced cancer will likely need palliative care, and not all patients will need rehabilitation; different disciplines of providers are involved in the care; each faces different reimbursement challenges), the number of similarities in the fields is far greater and the comparison is illustrative. This report was written to catalyze a national discussion and process that would lead to coordinated strategies to better integrate cancer rehabilitation and oncology care to facilitate rehabilitation care for the patients who need it.

Analyzing the growth in palliative care points to specific priorities as immediate next steps for each stakeholder. Researchers should conduct clinical trials testing the effects of coordinated delivery of multimodal cancer rehabilitation interventions on outcomes that can demonstrate the

| TABLE 5. Strategy 5: Advocating for Public Policy Change |
|--------------------------------------------------------|
| Actions Taken by Advocates of Palliative Care | Progress to Date and Actions Needed to Implement Cancer Rehabilitation |
| Developed accreditation standards | Progress to date: American College of Surgeons Commission on Cancer and Commission on Accreditation of Rehabilitation Facilities Accreditation Standards exist for cancer rehabilitation services; no quality metrics for cancer care include referrals to cancer rehabilitation |
| Developed quality metrics to track implementation and outcomes | Needed: Existing American College of Surgeons Commission on Cancer and Commission on Accreditation of Rehabilitation Facilities standards could be strengthened to drive coordinated delivery of cancer rehabilitation services |
| Launched the Patient Quality of Life Coalition in 2013 to advance legislative and regulatory policy change | Progress to date: None |
| | Needed: Quality metrics from the American Society of Clinical Oncology Quality Oncology Practice Initiative or the National Quality Forum could measure referrals to cancer rehabilitation |

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value of this care beyond impairment reduction, including return-to-work and other roles versus disability; the management of chronic and late effects of cancer; adherence to anticancer treatment; and overall health care utilization, costs, and survival. Research also should identify patient opinion regarding cancer rehabilitation and guide the development of educational campaigns. These grants should include research training for junior investigators where possible to build a pipeline of cancer rehabilitation researchers and involve researchers from other disciplines (eg, oncology, health economics, or rehabilitation outside of cancer) as needed. We call on research funders to prioritize funding for these projects and consider issuing funding opportunities using dedicated funds for both primary research grants and training grants. Addressing these research gaps is critical so that, as the evidence base matures, the Cochrane Rehabilitation Group87 and other reviews and meta-analyses can synthesize the evidence base. These reviews can then inform the development of clinical guidelines for cancer rehabilitation written by professional societies (ASCO, NCCN, ONS). However, even as this evidence accumulates, professional societies involved in cancer rehabilitation can develop consensus-based guidelines to provide consistent care with today’s knowledge. With clinical guidelines in place, advocates and policy makers can pursue the legislative or regulatory strategies needed to support these new practices. Simultaneously, clinician educators can increase the educational content devoted to cancer rehabilitation in medical, nursing, and related coursework for trainees and for continuing education for the existing workforce. Clinicians from all disciplines involved in oncology and cancer follow-up care can take advantage of these training opportunities to expand their competency in treating the functional needs of patients with cancer.

As current consensus-based recommendations for cancer rehabilitation are refined with a new understanding of how best to identify and provide appropriate care, these strategies will need to be refined accordingly. The execution of these strategies calls for coordinated efforts across stakeholders. Success depends on this call to action being answered and extended by scientists, clinicians, educators, research funding institutions and foundations, insurers, advocates, cancer survivors, policy makers, and professional societies.

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