

Moving Through Cancer: Setting the Agenda to Make Exercise Standard in Oncology Practice

Short Title: Moving Through Cancer Agenda

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Introduction

There are now multiple international evidence-based exercise guidelines for people living with and beyond cancer. Most recently, the American College of Sports Medicine (ACSM) published guidelines from a roundtable that included 16 major medical or health-oriented organizations from around the world (see Figure 1).

The first two words of the guidance follows the United States Department of Health and Human Services' *Physical Activity Guidelines for Americans*: avoid inactivity.¹ Beyond this, the recommendations vary according to the outcome of interest. For primary and secondary cancer prevention among adults, the recommendation is to do 150-300 minutes per week of moderate intensity aerobic activity or 75-150 minutes per week of vigorous intensity aerobic activity, as well as twice weekly progressive resistance exercise.² In addition, for eight common cancer health-related symptoms or treatment side effects (including fatigue, quality of life, anxiety, depression, physical function, lymphedema, sleep, and bone health), it is now possible to provide a specific prescription with regard to the minimum frequency, intensity, time, and type of exercise that will be safe and effective.³ Table 1 describes these prescriptions.

The dose of exercise needed to alter the cancer disease process as an outcome is larger than what is required to have a meaningful effect on symptoms. There is an increasingly mature evidence base documenting robust positive effects of exercise on a broad variety of important health outcomes in people living with and beyond cancer. As such, there is a growing need to translate this evidence base into practice, to increase the likelihood that an individual with cancer is referred to and engaged in appropriate exercise programming during and after treatment.

Research points to gaps in physical activity participation and referral among cancer patients and survivors. Studies suggest that only 9% of oncology nurses and 19-23% of oncology physicians refer cancer patients to exercise programming.⁴⁻⁷ Further, an analysis of more than 9,000 cancer survivors from the American Cancer Society's Study of Cancer

Survivor-II cohort indicates that between 30-47% meet current physical activity guidelines.^{4, 8} Data from the United Kingdom indicate 31% of people living with and beyond cancer are completely inactive.⁹ Clearly, we have work to do to make exercise assessment, advice, referral, and engagement standard of care in oncology.

Multiple groups are interested in closing the gap between knowledge and practice relevant to exercise oncology. Pergolotti et al. outlined a robust agenda in health services research for cancer rehabilitation relevant to exercise oncology.¹⁰ The proposed health services research agenda includes awareness, involving physicians in change, creating value metrics, creating business models, understanding waste in rehabilitation services, using technology, workforce development, scaling changes, and developing evaluation methods. Basen-Engquist et al. laid out an agenda for translating the existing research on lifestyle interventions (e.g.; exercise, nutrition, weight management) into practice, including expanding the availability of programming, improving screening and referral to services, improving health care provider capacity to screen and refer patients, development of the workforce to deliver interventions, expansion of dissemination and implementation research, and policy changes to support lifestyle interventions.¹¹ Also relevant to this agenda is the oncology community's focus on strategies to improve proactive and personalized survivorship and supportive care in cancer, most notably through new accreditation standards for survivorship care introduced by the American College of Surgeons' Commission on Cancer.¹² Aligning exercise programmatic recommendations with these strategies will improve integration into oncology care.¹³⁻¹⁵

In the wake of the ACSM roundtable, a new initiative has been formed under the umbrella of ACSM's Exercise Is Medicine initiative. The new initiative, called Moving Through Cancer, has the goal of closing the above described knowledge-to-practice gap (exerciseismedicine.org/movingthroughcancer). While the agenda for this initiative includes a research component, the primary focus is practice change, as evidenced by our central mission of making exercise standard practice in oncology by 2029.

An international multi-disciplinary team, inclusive of expertise in physical therapy, oncology nursing, medical oncology, physical medicine and rehabilitation, exercise science, public health policy, and behavioral science forms the leadership of the Moving Through Cancer initiative. The team participated in a retreat in late spring 2019 and created a strategic plan to achieve the above stated central mission. A summary of the major goals of the Moving Through Cancer strategic plan is provided in Figure 2. What follows in this report are detailed objectives across six priority areas that will facilitate a multi-pronged strategy to achieve our mission. The priority areas identified by the team include workforce enhancement, program development, research and evaluation, awareness and engagement, funding and sustainability, and patient empowerment.

Strategic Priorities to Make Exercise Standard in Oncology Practice

WORKFORCE ENHANCEMENT. Ensure all stakeholders have knowledge of and access to appropriately trained professionals in order to enable all people living with and beyond cancer to reach their optimal health, quality of life, and functional goals.

There are two primary focus areas within this strategy; (i) workforce development to prepare exercise professionals with knowledge and competency in oncology, and (ii) elevated awareness among the health care professional workforce on how to best prescribe and support patients to access appropriate exercise programs.

Workforce development for exercise and rehabilitation professionals starts with the need to integrate oncology content into the curriculum of the degree programs that train clinical exercise physiologists and physical therapists, including the need to build core *knowledge* around the concepts of cancer epidemiology, cancer biology and treatments, and the necessary requisite knowledge to plan and execute safe and effective exercise interventions for this population. Education of exercise and rehabilitation professionals is particularly needed

regarding best methods of communication with the oncology team. Toward this goal, we propose a complete assessment of the current exercise and rehabilitation oncology professional workforce landscape by the end of 2021, so that we may identify the current state and begin to plan for future expansion. Curriculum integration, continuing professional development / education, and clinical mentorship pathways need to be developed to build and maintain knowledge and skills for the exercise oncology workforce. Professionals ideally will be able to develop a career pathway that is self-guided based on their background, interest and setting.

An example, developed in the UK, is the national guidance for prehabilitation (and rehabilitation) for the management and support of people with cancer. The guidance states that patients be screened and assessed using validated tools and then triaged to one of three interventions: universal, targeted or specialist. This allows qualified personal trainers and clinical exercise specialists with the CanRehab qualification (developed by Dr. Anna Campbell) to work with those referred to interventions in a community setting. In the U.K., the Cancer Prehabilitation Consortium was established following the publication of principles and guidelines in cancer prehabilitation. This prehabilitation consortium is working with registered and unregistered professional groups (e.g.; the Chartered Institute for the Management of Sport and Physical Activity (CIMPSA), the British Association of Sport and Exercise Sciences (BASES) the Association of Chartered Physiotherapists working in Oncology and Palliative care (ACPOPC) and CanRehab) to define a competency and training framework for professionals in prehabilitation. This provides an opportunity for translation of this framework into later timeframes of the cancer control continuum.

Another key to the development of the exercise and rehabilitation oncology workforce is a method by which these professionals will access ongoing continuing education programs. Developing and maintaining high quality educational content and disseminating this content across various mediums is essential to achieving broad reach across the exercise and rehabilitation oncology community and instilling confidence for clinical referrals to these

professionals. Dissemination opportunities include development of validated and quality-assured online programming, mentorship programs, train-the-trainer initiatives, worksite training programs through gym and fitness facilities, and specialized clinical residency programs for health care professionals. Online programming is particularly likely to enable rural providers and those with limited time or funding for conference or continuing education opportunities to gain knowledge and skills.

Skills to support behavior change must be embedded within these competencies and are relevant to all professionals working with people living with or beyond cancer. Guidelines from the National Institute for Health Care Excellence, UK set out how this might be achieved. Such courses should be evidence-based and delivered by individuals with appropriate knowledge and expertise. It is also suggested that refresher sessions be provided to improve skills and maintain quality of interactions.¹⁶

A model for cross disciplinary core competency development that the cancer exercise community could utilize is from cancer genetics. Knowledge and skills in this area necessarily cross disciplines. The field of cancer genetics collectively developed a core set of competencies for all disciplines that expands to enable specialty education tracks. Not only would this interdisciplinary approach facilitate appropriate knowledge and skills, it could serve to unite the exercise oncology field across disciplines.¹⁷

In addition to the training of exercise and rehabilitation oncology professionals, it is equally important to elevate the knowledge of oncology care providers (including, but not limited to, physicians, physician assistants, nurse practitioners, nurses, dietitians, and social workers) regarding the strength of the evidence on the many benefits of exercise and the effectiveness of evidence-based exercise interventions. This could help to improve awareness of demonstrated evidence for safety and efficacy of exercise interventions across many types and stages of cancer and phases of the care continuum. Health care professionals need to be able to quickly screen using appropriate screening questionnaires and/or refer to appropriate health care

providers (e.g.; physiatrist, physical therapist, or clinical exercise physiologist) who can assess basic functional ability using simple performance status measures, in order to triage and refer to appropriate exercise oncology programs. Knowledge building and awareness of exercise program components and evidence-based indications across the oncology workforce are needed to help facilitate comprehensive care.

One example is oncology nurses, who have extensive contact with patients and should play a key role in exercise promotion. Unfortunately, most do not have the knowledge, the time or the confidence to promote exercise or an understanding of the evidence-based benefits of exercise. Common barriers to exercise promotion by nurses include a misperception that patients are too frail, fear of 'blaming' patients and loss of connection, and a perception that the strength of the evidence linking exercise with primary and secondary prevention is not definitive.¹⁸ There is a clear opportunity exists for Moving Through Cancer (and other interested parties) to partner with oncology nursing organizations to educate nurses regarding the safety and effectiveness of exercise for their patients as well as building confidence to discuss and refer.

The Moving Through Cancer initiative goals include development and delivery of continuing education trainings for health professionals on the value of exercise and the use of clinical pathways to make timely and appropriate referrals by 2022. This could take the form of changing academic programmatic expectations for undergraduate and graduate education and continuing education or certificate programs for currently credentialed professionals. More generally, the Moving Through Cancer initiative sets a goal to increase the workforce capable of providing exercise oncology programming by 2025 so that 80% of all exercise professionals have some basic education in cancer and cancer survivorship. We are actively working to develop partnerships with broad groups of stakeholders to ensure this goal is reached.

PROGRAM DEVELOPMENT. Ensure exercise and rehabilitation programs are available to maintain or restore all people living with and beyond cancer to their optimal health, quality of life, and function.

Cancer exercise programs are specialized versions of general exercise programs. An array of programs exists and a near term approach to broad dissemination is to develop and share common program components. Opportunities for rapid expansion of the reach of exercise and rehabilitation programming exist across fitness facility partners. For example, a partnership with the International Health, Racquet, and Sportsclub Association (IHRSA) could lead to the development of an online training for fitness professionals at 9,200 commercial fitness facilities within and outside the U.S. This could greatly expand the reach of exercise oncology programming appropriate for low risk patients. Expansion of the community-based **LIVESTRONG** at the YMCA program to include all YMCAs across the United States would allow exponentially more cancer survivors in the U.S. to have the opportunity to benefit from that popular and effective program.¹⁹ Another example is broadening the reach of the MoveMore program, currently offered in Scotland and Northern Ireland, which is a physical activity behavior change program standardized in terms of brand, referral pathway, workforce training and content.

As our first act toward program development, we have developed an international registry of exercise oncology programs that can be found at exerciseismedicine.org/movingthroughcancer. In addition, the Moving Through Cancer initiative has four goals for program expansion. First, we have a goal of identifying all the cancer exercise and rehabilitation programming across the U.S. in 2020. There are deficits in the geographic availability of programs and lack of awareness of programs that do exist.²⁰ Second, we seek to identify two national brand fitness facilities willing and able to take on staff training and program development for cancer exercise programs. Third, we have a goal that 25% of newly-diagnosed cancer patients surveyed will recall being advised to exercise by their

oncologist by 2022. People living with and beyond cancer will require a variety of people, places, and programs to meet their exercise needs. Some will have the skills, confidence, and physical ability to exercise at home, unsupervised. For others, a structured supervised program setting will facilitate adopting and maintaining exercise during and after treatment. To support the goal of ensuring more exercise programming is available to people living with and beyond cancer, we seek to partner with those who are interested in developing virtual programming, as this has potential to reach populations previously untouched by in-person programming. Finally, we aim to ensure that there is at least one cancer exercise or rehabilitation program in every metropolitan area in the US with a population of at least 50,000 by 2025.

Program development also includes enhanced assessment and exercise referral mechanisms in oncology clinical workflows. Integrating guideline concordant thresholds facilitates rapid and efficient referrals for exercise and rehabilitation programs. For example, aligning exercise program development with new standards for survivorship care (such as the American College of Surgeons Commission on Cancer standards) could enable oncology referral to exercise and functional assessment, enhanced exercise prescription and ultimately improved quality of life and health of people living with and beyond cancer.

RESEARCH and EVALUATION. Evaluate service gaps and study new models of care and novel approaches to care delivery in order to optimize workforce, program development, referral, triage and sustainability of exercise and rehabilitation programs for people living with and beyond cancer. Ensure all aspects of exercise and rehabilitation programs for people living with and beyond cancer are routinely and centrally evaluated using an agreed upon standard and meaningful metrics to identify and disseminate best practices. Continue to evaluate the efficacy of exercise interventions for to clarify timing and dose considerations. Funders should take these needs into consideration when designing their research budgets and priorities.

Research will be needed on a variety of delivery models for exercise and rehabilitation programming, including evaluation of the cost and cost effectiveness of each approach.^{21, 22} In particular, there is a need for evaluation of whether exercise training during cancer treatment may alter healthcare utilization in a way that would be cost neutral or cost saving and preferable to providers and patients. Effects of early exercise on downstream health care costs in cancer patients are currently unknown and will require investigation through health services and economic research models. Further, while there is already a robust evidence base underlying the current international guidelines for exercise after a cancer diagnosis, there continues to be value in research on the optimal time to initiate exercise and exercise dose to maximize health, quality of life, and function, and to minimize treatment-related side effects and to understand how these interventions impact downstream health services (utilization and cost)¹⁰ and survival endpoints.

STAKEHOLDER AWARENESS, EMPOWERMENT, and ENGAGEMENT. Ensure everyone living with and beyond cancer is aware of the benefits of physical activity and exercise and is enabled to choose to become and stay active at a level appropriate for them. Ensure all relevant stakeholders are aware of, endorse, and facilitate engagement in appropriate exercise and rehabilitation programming for all people living with and beyond cancer. We will use marketing approaches to make all stakeholders aware of the benefits of and need for appropriate exercise and rehabilitative programming for people living with and beyond cancer.

For the purpose of the Moving Through Cancer Initiative, 'Stakeholders' are defined as all those who could be referring people living with and beyond cancer to exercise or rehabilitation (healthcare professionals), those who provide the exercise or rehabilitation interventions (exercise and rehabilitation oncology professionals), those who receive the

interventions (patients, survivors), those who support patients (caregivers), and all the professional organizations associated with each of these groups.

Awareness by patients will be facilitated by the development of marketing materials, and the planning and execution of a communications campaign directed at patients and other stakeholders. This communications campaign could include print media, social media, and educational efforts with relevant professional organizations (e.g.; Oncology Nursing Society, American Society for Clinical Oncology, Society of Surgical Oncology, American Society for Radiation Oncology). As noted earlier, the Moving Through Cancer Initiative seeks funding for this and hopes to accomplish this in 2020. To evaluate this effort, systems need to be developed to measure levels of engagement which will be optimized by embedding behavior change support in available programs. Engagement will be defined by attendance at clinical and community-based programs, social media traffic, website traffic for the initiative and similar activities around the world, continuing education credit activity, access of online resources, referrals to programming, and development or expansion of new programs. Systems are also needed to evaluate levels of knowledge and engagement/implementation about exercise and rehabilitation for all stakeholders.

To improve awareness for all stakeholders, we have developed a website that includes a registry of exercise oncology programs from around the world (exerciseismedicine.org/movingthroughcancer). In addition, marketing approaches may be a viable manner of improving stakeholder awareness of the benefits of, need for, and initiatives to support appropriate exercise and rehabilitation programming for people living with and beyond cancer. Success of these efforts can be documented through the production of Moving Through Cancer branded consumer-focused videos, as well as tracking educational postings, social media, and editorial pieces. In general, we seek to find ways to help patients be more engaged in their own health during and after cancer therapy, through the medium of exercise.²³ The Moving Through Cancer initiative seeks to develop marketing materials to carry out a marketing

and advertisement campaign by the end of 2020. A goal is to measure improvement in the levels of knowledge and engagement of patients and oncology providers by 2022.

POLICY, FUNDING, and SUSTAINABILITY. Advocate for policies that will ensure that all people living with and beyond cancer have access to affordable exercise and rehabilitation programming. Ensure all people living with and beyond cancer have access to appropriate exercise and rehabilitative programming regardless of ability to pay. Sufficient and sustainable funding is needed to achieve this goal. All aspects of exercise and rehabilitative programming will be financially sustainable.

The first task in impacting policy is to identify the levers for policy change at all levels of government within the U.S. as well as within organizations. To accomplish this, a review will be undertaken of policies and other social determinants and structural factors that affect exercise and rehabilitation in the setting of oncology by 2021.¹⁴ Understanding whether access to programming is equitable across social determinants such as race, ethnicity, age, geography, and economic status will be a priority. Measuring the current state of access to services will allow us to set the baseline from which we strive to improve access. Key barriers and facilitators to access to be assessed may include services covered, eligible providers, social determinants, and patient access barriers for both public and private insurance plans, and utilization measures (patient satisfaction, patient needs assessment, patient engagement, caregiver burden).²³ Armed with data from this review and having identified policy levers that are important to address, meetings with the appropriate public policy and non-government decision makers will elucidate what would be needed to affect the necessary changes. A gap analysis of policies at all NCI-designated cancer centers regarding provision of exercise and rehabilitation programming could also assist with setting the baseline from which we improve. The health and fitness industry and corporations can also be queried on policies of providing access to exercise and rehabilitation services for people living with and beyond cancer. By 2023, an action plan will be developed based on these data and feedback from meetings with key stakeholders. One

aspect of this action plan could be advocacy for quality metrics regarding exercise and rehabilitation, such as through ASCO's Quality Oncology Practice Initiative (QOPI). Another approach would be development of Merit-Based Incentive Payment System (MIPS) metrics, as there are already MIPS measures for falls and other rehab/exercise-related problems. It would not be difficult to map how these fit with exercise and rehabilitation for oncology.

All of this work will require the development of a multi-stakeholder coalition for policy advocacy. In addition to advocating for improved access to exercise and rehabilitation programs and services for individuals living with and beyond cancer, this coalition could advocate for funding for exercise oncology research and programming from multiple possible sources (e.g.; government, philanthropy, not for profit organizations, industry). Policy changes could also be addressed through partnerships with state-level cancer control programs.

Data gathering is needed to discern the cost and cost effectiveness for exercise and rehabilitation programs and how patients, payers, providers, and corporations pay for them. In the UK, a standard evaluation tool was developed and used by all providers of the MoveMore exercise programs to evaluate their effectiveness to positively change physical activity behavior, quality of life, self-efficacy and fatigue levels. This enabled the calculation of the cost per improvement in these four outcome measures and quality adjusted life years (QALYs).²⁴ Of particular interest is the percentage of funding for cancer care that is allocated to exercise and rehabilitative programming. It is also of interest to elucidate the funding needs of exercise oncology programming by clarifying the costs to run programs and funding provided by various sources (e.g.; government, philanthropy, nonprofit, industry). It is acknowledged that the short term funding sources may not be sustainable long term. Cost and return on investment of the largest programs that exist in the U.S., including but not limited to the Livestrong at the YMCA program, could be of particular help in program dissemination. In order to better understand costing of these programs, a service-costing template for all programs will be developed and

made freely available on the Moving Through Cancer Website (exerciseismedicine.org/movingthroughcancer) by the end of 2020.

In addition, a patient survey to ask about ability to pay for exercise programming during and after cancer treatment could be helpful in discerning the need for funded, sustainable programming. We will ensure that the survey will include patients from a variety of social circumstances (e.g.; race, ethnicity, geography, economics), to increase the representativeness of our findings. Publications and publicity of these data will highlight and help to address any disparities. In addition, research is needed on how to sustain programming once initial charitable or grant funding for program development is complete, including considering the potential for revenue generation via billable professionals. Funding agencies are asked to consider these issues when deciding on their priorities.

In addition, as noted previously, advocacy for exercise oncology research and program funding should be part of a policy agenda and could be an effective method for making forward progress toward program dissemination.

Conclusion

All of the work proposed herein will be facilitated by partnerships. We propose to host an influencer conference of researchers and oncology providers by 2023 to align agendas and determine how to leverage the strengths of each organizational and individual partner, toward the goal of coordinated forward progress. Further, we aim to partner with the appropriate standard setting and accreditation bodies in oncology (e.g.; NAPBC, CoC, NAPRC-new, APTA, ASCO) to develop agreed-upon standards to assess program quality and preparedness of exercise and rehabilitation professionals to work in the oncology arena.

The overall mission of the Moving Through Cancer Initiative is to ensure that all people living with and beyond cancer are assessed, advised, referred to, and supported to engage in appropriate exercise and rehabilitation programming as standard of care. Our bold goal is to

achieve this by 2029. Progress to date includes the formation of a website with resources for patients and oncology providers (exerciseismedicine.org/movingthroughcancer), an international registry of programs (available on the same website), and the formation of the ambitious agenda outlined in this paper.

When considering the recommendations of other experts for making exercise, rehabilitation, and lifestyle interventions a greater part of cancer care,^{10, 11} there is agreement on the need to focus on workforce development, public policy, and research. This broad agreement lends credence to efforts in these areas. Collaborative efforts will be strongest in these areas of agreement.

Over the next 18 months, the primary focus of the Moving Through Cancer initiative will be on an awareness campaign, as well as assessing the current landscape for programming, the workforce, and public policy. We seek partners in carrying out this work. Over the long term, the mission of the initiative is to make exercise standard practice in the setting of oncology. We seek to achieve this mission by 2029.

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