Research Open

Volume 3 Issue 2

Research Article

Driving Patient Engagement in Exercise Oncology: A Patient's Journey through Maple Tree Cancer Alliance

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Received: May 13, 2020; Accepted: May 21, 2020; Published: May 25, 2020

Abstract

With advances in cancer treatment and intervention, people are living as cancer survivors longer than ever before. This comes with a host of long term and late effects of treatment. Therefore, it is clear that additional ways to care for these patients are warranted. Exercise intervention has shown to be a safe and effective way to mitigate some of the side-effects of cancer treatment. The Maple Tree Cancer Alliance is a non-profit organization that provides free supervised, individualized exercise programming for cancer survivors. What follows is the patient journey through this program, highlighting key components in an attempt to advocate for exercise to become a part of the standard of care in cancer.

Introduction

At present, cancer survivorship is at an all time high. People are living longer as cancer survivors than at any other point in history. Mortality rates from cancer are the lowest they have ever been [1]. This is all very positive news in the war against cancer.

However, there is a downside to this increase in survivorship. With more people living longer as cancer survivors, this means that more people are experiencing the side effects associated with treatment, including fatigue, nausea, cardiac abnormalities, lymphedema and more [2]. Though treatment is beneficial for fighting against the cancer, it can bring forth many different side-effects and hardships later in the life of a cancer survivor. More than 98% of patients experience these effects [3], sometimes even years after cessation of treatment. With increases in survivorship the care that is needed is always advancing [4].

We assert, and decades of research would support, that exercise is a safe and valid measure to mitigate these side effects [6-8]. Numerous studies and professional organizations recognize its safety and efficacy at any point along the cancer trajectory [6, 8].

However, despite these benefits, less than 5% of cancer patients exercise during cancer treatment, nationally [3]. Maple Tree Cancer Alliance is a non-profit organization that was founded in 2011 to try and increase this number, and encourage more patients to embrace the idea of exercise during treatment. Our nationally recognized model has been widely embraced by the medical community and has changed the lives of thousands of patients across the country. We are hoping to use our platform to advocate for exercise to become a part of the standard of care in cancer, as well as expand insurance coverage for these life-enhancing services [9,10]. To do so, we have established a unique-4 phase approach to cancer rehabilitation. Depending on where patients are in their treatment journey when they begin with Maple Tree, we classify them into one of four phases. Each phase is 12-weeks long, with the exception of phase 4, which is ongoing. A brief summary of this phase system is outlined below:

| Phase 1 | Patient is currently in chemotherapy/radiation | |
|---------|--|--|
| Phase 2 | Patient has completed chemotherapy/radiation, or only received surgery and/or hormonal therapy | |
| Phase 3 | Successfully completed Phase 2 | |
| Phase 4 | Successfully completed Phase 3 and is classified as "Apparently Healthy" | |

The purpose of this article is to present the patient journey through our program, including referral systems, assessment, exercise programming, and data analysis. Our hope is that through sharing this information, common questions may be answered allowing for more standardized exercise programs may be implemented into cancer centers throughout the country.

Patient Referral Systems

Patients connect with Maple Tree Cancer Alliance through several channels. Approximately 5-10% of our patients come through word-of-mouth. They may hear through friends, family and/or other patients, social media, health fairs, or other events that Maple Tree Cancer Alliance takes part in.

The vast majority of our patients are referred by their medical team member, which may include, but not exclude Oncologists, Medical Assistants, Physicians Assistants, Primary Care Physicians, and Physical Therapists.

It is important to note, regardless of how a patient initiates contact

with us, a physician's clearance release form is required to partake in our program. This clearance form will make sure that the patient is medically cleared to participate in an exercise program, and verify any restrictions or modifications that we would need to adhere to.

Initial Patient Appointment

After obtaining a medical release form from the physician, the initial appointment is scheduled. During this initial appointment, our team takes time to discuss the individualized aspects of our training, how the phases/intensities are structured, and go over paperwork.

Paperwork that is reviewed during the initial appointment are as follows:

- a. Liability waiver- The patient understands the adherent risk of injury when completing an exercise program. Our organization goes above and beyond to create the safest working environment, but the possibility for injury exists. This form prevents liable against Maple Tree in the event an injury does occur.
- **b.** Attendance policy- This form informs our patients of our attendance, no-show, and cancellation policies.
- **c.** Media release waiver- This optional form allows us to share on our social media platforms the success of patients as they participate in our program.
- **d. Physician release form** Part of the required paperwork before starting. Gives us medical clearance to work with the patient and allows us to understand any restrictions.
- e. Health History- The health history form is used as a means to assess risk, not for diagnostic purposes. This form helps us understand any current or previous condition that may impact a patient's exercise prescription and programming.
- *i. Patient contact form* Basic patient information including phone number, email and address.
- *ii. Pre-existing conditions* Any co-morbidity that may impact the patients individualized plan that we create for them which include but is not limited to issues such as high blood pressure, diabetes, high cholesterol, thyroid problems, etc.
- *iii. Medications/prior surgeries* (non-cancer related)- Helps us understand their medications and prior surgeries that are non-cancer related that may impact their program or certain aspects (such as measuring heart rate during exercise)
- *iv. Cancer history* everything about their cancer is disclosed on this page including treatments, surgeries, and any planned actions made by their physician.
- v. General questions- On this page we can learn more about their concerns about their health and regarding exercise and their current exercise habits (this helps us understand the mindset they may have).

Comprehensive Fitness Assessment

Upon completing the review of paperwork, the patient undergoes a comprehensive fitness assessment. The first step to the fitness assessment is measuring patient vital signs, including weight, height, blood pressure, oxygen saturation levels, heart rate, and body mass index. Next, the Exercise Oncology Instructor performs a complete posture evaluation on the patient. For this assessment, head to toe issues regarding postural deviations are checked and noted. Third, body composition is measured via skinfold analysis. Muscular strength is measured via hand grip dynamometer. Cardiorespiratory fitness testing is completed using the treadmill protocol created by the Rocky Mountain Cancer Rehabilitation Institute. Muscular endurance testing involves a modified sit up test. Flexibility testing is completed with the modified sit and reach assessment.

Exercise Prescription

Once the fitness assessment is completed and scores are calculated, the exercise prescription is then completed by the instructor administering the testing. The exercise prescription serves as a 12week outline of the exercise program. It includes goals that are unique to the patient with progress that can be easily obtained. We also give the patient a rating based on well-established norms by the American College of Sports Medicine and Senior Fitness Testing Protocol.

Depending on where the patient is in their treatment regimen, they are grouped into one of the phases outlined in Table 1. Each phase of our program is designed to last 12-weeks. In order to protect immunity, exercise intensity levels increase as the patient moves through each phase. Initially, Phase 1 begins at an exercise intensity of approximately 30-45%. However, when the patient reaches Phase 3, they are able to tolerate exercise intensities between 50-85%.

The intensity is calculated via the Karvonen Method and is monitored throughout the exercise program with an activity tracker. In cases where treatments or medications may blunt heart rate response, we utilize the Borg Rating of Perceived Exertion scale.

Although the 12-week plan maps out each week's exercise intensity, each day a patient comes in is subject to change based on how the patient feels.

Exercise Programming

After review of the Fitness Assessment and Exercise Prescription, patients are assigned an Exercise Oncology Instructor to work with. This Exercise Oncology Instructor will be responsible for the execution of the Exercise Programming phase of the patient journey. Each patient is allowed one session per week with their Exercise Oncology Instructor. All exercise programming is individualized and tailored to the patient's specific strengths, weaknesses, and goals set forth in the Exercise Prescription phase.

Every exercise program includes an aerobic component, strength training, and flexibility, adhering to ACSM's guidelines for exercise oncology [6-11]. Tables 2-4 detail these recommendations.

| Table 2. | Exercise | Modes | for | Exercise | Oncol | logy |
|----------|----------|-------|-----|----------|-------|------|
| | | | | | | 8/ |

| Fitness Component | Exercise Mode | Comments | |
|------------------------------------|--|---|--|
| Cardiorespiratory Fitness | Walking, jogging, cycling, cross-trainers, swimming (if infection is not possible) | Large muscle groups attend to motor function ability dependent on type of movement | |
| Muscular Strength and Endurance | Free weights and machines, resistance balls and resistance bands | Total body work, weight machines starting weight is too heavy for most cancer patients | |
| Body Composition | Aerobic exercise | Same as for cardiovascular and muscular strength and endurance. | |
| Flexibility | Stretching exercise (static, PNF), Range of Motion wheels, pulleys, flex bands, wall stretching | Attend to surgical and prosthetic areas | |
| Neuromuscular tension/ stress | Progressive relaxation exercise, Tai Chi, movement to music | Depression, anxiety and stress are prevalent in cancer patients. | |

Table 3. Frequency of Cancer Exercise Sessions

| Status | Frequency | | |
|------------------------------------|--|--|--|
| Sedentary, poor health and fitness | More than once per day for short bouts Minimum 3 days per week Daily exercise to improve health, alternate types of exercise | | |
| Active, good health and fitness | • 2 to 4 days per week to maintain fitness | | |

Table 4. Recommend Intensity Levels

| Status | Recommended Intensity Levels | | |
|--|------------------------------|--|--|
| Sedentary, poor health and fitness | 30%-45% HRR; RPE = 1-3 | | |
| Active, moderate health, average fitness | 50%-60% HRR; RPE = 4-5 | | |

HRR = Heart Rate Reserve; RPE = Rating of Perceived Exertion

As a general rule, we do not address a specific time frame for exercise progression (i.e. after one month increase treadmill duration to XX...). Rather, we focus on increasing exercise duration and frequency first, before increasing exercise intensity.

The role of the Maple Tree Cancer Alliance Exercise Oncology Instructor is to create a safe and effective protocol to help the patient improve their quality of life. The typical progression of strength training includes beginning with range-of-motion movements so the prescribed exercises are performed with optimal biomechanical form. In order to do this, the Exercise Oncology Instructor must perform manual muscle testing in different planes and take notes on where compensation occurs, or range-of-motion is sub-optimal.

Once optimal range-of-motion can be performed without any pain/negative symptoms, then the patient is assigned exercises to strengthen the motor pathway while maintaining the joint's range-ofmotion. Trainer should monitor for pain, pulling, stiffness, fullness, radiating pain, sharp pain, or dull pain during the exercise. When the patient has a well-established weekly exercise habit that allows them to no longer be trained as a "sedentary" individual, the trainer may safely increase exercise intensity.

The ultimate goal of each session is to have the patient feeling better than when they came in. Of course, there will be days when the

patient may not be feeling well. On those days, and it is important to modify the workout, as needed.

Follow-up Assessments

At the completion of each 12-week phase, a follow-up assessment is performed. The goal of the follow-up assessment is to see how the patient has progressed in each area of fitness. Each test that was performed in the original fitness assessment is conducted again. Any changes in performance, whether positive or negative, is noted. New normative values are obtained, and exercise intensity is changed for the new 12-week Phase Plan, accordingly. The patient is given a Certificate of Phase Completion to celebrate this milestone.

Reporting to Physicians

All patient metrics are stored in a master database which can be used to generate reports and forms. These reports and forms showcase:

- Patient treatment types
- Commonly served patient populations
 - Age
 - Gender
 - Ethnicity
 - Cancer type
- Patient progress across all phases completed

Communication is important between the site-coordinators and the medical professionals. It is our goal to keep an open door of communication with the medical team. Specifically, we communicate when:

- A referred patient begins the Maple Tree Cancer Alliance Exercise Oncology program.
- The medical records for the patient have been received.
- The referred patient completes a Phase of our program, and we share the results from the re-assessment.
- The referred patient leaves the Maple Tree Exercise Oncology program. Patients may exit the program for various reasons, the most commonly stated reasons include cancer remission, and the patient feels they have adapted to the health modifications that we have taught them, and they are self-sufficient regarding taking care of their own health.

Conclusion

With cancer survivorship increasing, the promotion of care after treatment is continually evolving. Patients and physicians are looking for ways to cope with side effects of cancer and cancer treatments. Several studies have shown that exercise is not only safe for people at several points along the cancer spectrum but can also aid in fighting against some of these side effects.

The Maple Tree Cancer Alliance has developed a phase program that is able to reach people at every part of their cancer journey so that they may start their journey with exercise intervention. The phase program at the MTCA is created with the guidelines set out by the American College of Sports Medicine. Prior to starting an exercise program, the patient will go through a thorough screening and fitness assessment in order for their trainer to put together a personalized program. If the patient completes their phase, they have the opportunity to move up in their phases to increase their exercise capacity and possible physical function. The goal is that each patient will have the opportunity to move through each phase of our program on their way to increasing their exercise and physical activity habits while also relieving some of their side effects related to their diagnosis and treatment.

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Citation:

Karen Wonders, Nicholas Foggia and Rob Wise (2020) Driving Patient Engagement in Exercise Oncology: A Patient's Journey through Maple Tree Cancer Alliance. J Clin Res Med Volume 3(2): 1-4.