

The development and feasibility of an at-home, internet-based exercise and nutrition education program in child cancer survivors

Abstract

This development and feasibility study aimed to determine if an online exercise and nutrition education program provided a more feasible mode of accessing health information in child cancer survivors. Exercise and proper nutrition has been shown to aid in the management of cancer-related impairments and natural linear growth. Ten families of childhood cancer survivors agreed to participate in the 8-week study. Families and survivors were required to watch a 10-15minute video each week containing education on proper exercise and nutrition techniques. Child survivors were sent exercise diaries to self-track daily activity and food consumption. Feasibility feedback and considerations from families were the primary measures of the study and were gauged through email and phone conversations. Quality of Life (QoL) was measured through the RAND 36-Item Health Survey and served as our secondary measure. Subjects performed an average of 5hours a week of activity demonstrated in the online videos. Families found online avenues to be less cost and time consuming as well as more convenient way to access this information.

Keywords: exercise, nutrition, child, cancer, survivors

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Introduction

Due to improvements and advancements in health technology and advances in the detection and treatment of cancer, the number of cancer survivors in the US has increased significantly over the years and will continue to increase in upcoming years. Even though the amount of cancer survivors has substantially increased, the quality of life of these individuals tends to remain diminished. Many of these survivors continue to struggle with impaired physical and mental health, spanning from months to years after completion of treatments. Impairments in physical health can include decreased cardiopulmonary function, fatigue, decreased muscle strength, and altered physical function.¹ Impairments seen in the mental domain can include depression, processing information slowly, and problems with understanding and judgment.² Damages to mental health have been reported to lead to issues effecting nutrition including decreased appetite and alterations in taste and smell.³ The combined impairments can all negatively affect and diminish a cancer survivors' health related quality of life (HRQOL). Research in this area has shown that exercise can aide in the management of these impairments and improve a cancer survivor's quality of life in the adult population.⁴⁻⁶

These recent research findings including many others have primarily looked at the effects of exercise in adult populations. Very little research, however, has looked at the benefits of exercise in relation to improvements in HRQoL in child populations a growing group of cancer survivors. Cancer develops in 1 to 500 children before the age of 15years and survival of many of these common cancers is seen in about 1 in 810 individuals under the age of 20.¹ Leukemia, brain and central nervous system tumors, and neuroblastomas were reported in 2015 to be the most common cancer types in child populations.⁷ The percent of 5-year survivors (survivors being the percent of children living at least 5 years after diagnosis) was over 50% for these common cancer types.⁸ This suggests that a majority of cancers in this

population are highly survivable and therefore, research should focus on aspects of recovery and survivorship for these individuals.

Common suggestions for improving health benefits in physical and mental areas can include things like signing up for a fitness program, substituting with whole food-based groceries, and attending a yoga class.⁹ However, implementing fitness and nutrition programs that are specific to cancer survivors can fair to be difficult in any population. When fitness and nutrition programs are available, it tends to be more feasible for adults to participate in relation to children in order to improve their quality of life and implement positive lifestyle and behavior changes. Adults have a greater sense of independence and ability to drive themselves and make their own schedule. In the child and adolescent populations, these luxuries may not be as attainable. This study aims to determine if fitness programs that target the child and adolescent populations by utilizing online avenues and interactive, at-home programming will allow a more feasible way to obtain benefits in quality of life.

Exercise and health related quality of life

Health related quality of life (HRQOL) has been known to be reduced in those who are currently undergoing cancer treatments as well as those who have completed treatments and are years into survival.¹⁰ Studies searching for ways to improve HRQoL in adult cancer survivors have found benefits when analyzing the implementation of an exercise intervention program, both in a in-home setting as well as gym or lab setting.^{11,12} A meta-analysis on the effect of exercise on HRQOL found a positive effect on 4 of 6 studies reviewed. However, three of the four studies that found a positive effect had no control population, making it difficult to attribute these positive outcomes to the interventions performed.^{13,14} The ACSM also states that exercise proves to be a crucial part of recovery for cancer survivors interms of increasing HRQOL by improving aerobic fitness and strength and decreasing fatigue.

There are many benefits for incorporating an exercise-based program for those who are cancer survivors. These benefits include enhancing good sleep patterns, decreasing pain and increasing appetite which are all areas impacted negatively from cancer and its' treatment. A study done by Marchese et al.,¹³ showed that exercise intervention has the potential to improve cardiopulmonary and musculoskeletal function. These improvements have also been linked to preventing long-term deficits in physical fitness if incorporated during or soon after treatment in children with cancer diagnoses.¹³ Their eight-week training program revealed improvements in the major muscle groups and improved strength gains overall ($P < 0.05$).¹

Exercise intervention has also been found to aide in the management of one of the largest cancer related impairments seen in this population – cancer-induced fatigue. In another study, Yeh et al found reduced levels of fatigue ($P = 0.03$) after the implementation of a six-week home-based aerobic exercise program in children following cancer treatment. Similar studies have found improvements in muscle strength and fatigue following exercise intervention.^{15,16} The ACS and ACSM have also issued guidelines for diet and/or physical activity that target cancer survivors.

Little research has been done on the effects of implementing such a program that focuses on child cancer survivors. Though there are commonalities seen with treatment side effects in child and adult populations, there are also specific differences that occur in these populations as well. It is important to investigate more feasible modes of reaching this population and the important benefits associated with exercise and nutrition interventions that target specific side effects affecting children.

Nutrition and HRQOL

Another important area to consider with cancer populations is the occurrence of a reduced intake of important vitamins and minerals. Decreased consumption of these vitamins and nutrients is commonly seen as an effect of cancer and are lost during its' treatments.¹⁷ Complications such as nausea and loss of appetite contribute to a lack of proper nutrition seen in those undergoing these treatments. Along with that, cancer survivors, especially in the child and adolescent populations, are at a greater risk for developing second malignancies and other health related problems and diseases such as diabetes and osteoporosis.¹⁸ These impairments have been seen to contribute to a decreased HRQOL in cancer survivors.

Cancer treatments can effect metabolic functioning as well as reduce a cancer patient's food intake, both affecting their overall nutritional status.¹⁷ This, coupled with unhealthy eating choices (at both the parent and child level) is associated with morbidity and mortality and can contribute to a decreased quality of life. These patterns have been seen to continue even after treatment is completed, further impairing their nutritional intake. In the child and adolescent populations, optimal nutrition is not only necessary for natural linear growth, but even more crucial for those diagnosed with cancer. In order to improve physical and mental functioning after treatment, an appropriate amount of a variety of nutrients and minerals is important to get these individuals back to their optimal health.

A recent study assessed the quality of life of individuals who lost essential nutrients undergoing cancer treatments and found significant decreases in the physical ($P = 0.01$), cognitive ($P = 0.01$), and emotional dimensions of overall quality of life.³ Other studies have shown similar results.^{17,19}

Online program effectiveness

Little research has been conducted on the benefits of a combined exercise and nutrition program. Recently, online programs have been utilized more frequently as a means to access more individuals for an improved study population. Online programs make accessing important health information more time and cost efficient for individuals and appear to be leading arsenal for health and wellness information gathering. Additionally, one study found that online self-help therapy for depression in people with chronic illnesses was effective.²⁰

The current study seeks to determine if a home-based Internet program would provide a more feasible option for obtaining benefits associated with the management of cancer-related impairments when implementing an exercise and nutrition intervention in child survivors.

Materials and methods

Program design

The study was set up with the intention of implementing an interactive, online exercise and nutrition video program. Our team created a program that keeps the child and adolescent population interested by having them physically get up and perform the exercises as they are happening on the video as well as include a multiple choice question that reflects the topic for each week. Each video ranged in length from 10 to 15minutes in order to hold the attention of this population by not making the videos long and monotonous for the viewer. The Student Coalition for Action in Literacy Education states that children aged 5-14 have an attention span of 6-15minutes (Read Write Act, 2014), so timing of the videos was kept within that time frame for optimal viewing.

Each video was posted to YouTube on the first Monday of each new week at 8am to the YouTube Channel developed solely for this study named "Maple Kids Fitness Program". The link to the video was sent via email to the parents of each child survivor at the beginning of every week. On some weeks, these emails contained tips for fun games and recipes that they could try outside of the program requirements for additional benefits. If the child or parent utilized any of these tips during the 8-weeks of the program, they were to record it in their exercise diaries. As a follow-up, participants received a phone call or email at the half-way point to check-in with the families and see how their child has been responding and adhering to the program.

Exercise diaries

Prior to the first week of the program, exercise diaries were mailed out to the families in order for their child to record exercises they've performed throughout the week. The diaries included areas to record the child's food consumption and exercises performed daily as well as their water intake. To gauge the intensity of each activity, the exercise diaries contained an intensity tracker in order for children to have an easy, understandable way to measure their intensity. The intensity scale is provided in Figure 1. Along with intensity, the duration of time spent on each activity was recorded as well. These diaries served the purpose of allowing the children to set goals for themselves and feel a sense of independence over their own health. This also gave families a means to track their behavior through the 8-weeks and understand their eating and activity patterns. Exercises from the diary were recorded for this study to better understand the child's total activity in relation to their post-survey scores.

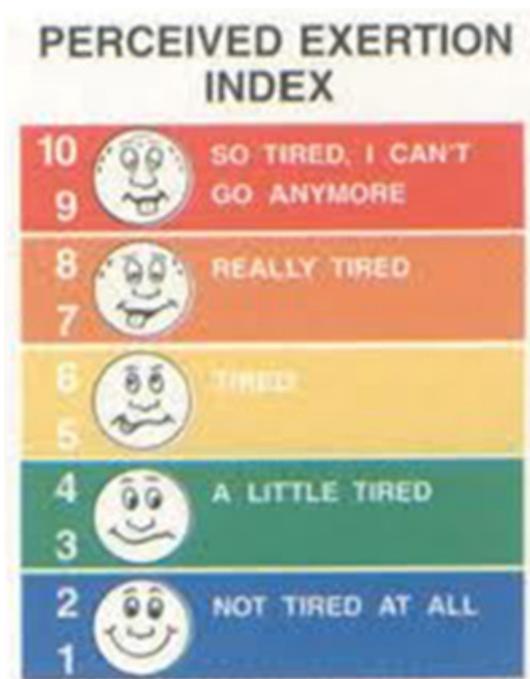


Figure 1 Rating of perceived exertion scale for child's activity intensity.

Video set-up

Each week in the 8-week period included a video that reflected a different health related aspect and nutrition goal (Table 1) that could benefit optimal health in that area. A study done by Wolin et al.,²¹ found significant improvements in muscle strength, functional mobility, aerobic fitness and QoL after implementation of an 8-week intervention combining aerobic and resistance exercises. To gauge similar benefits in the current study, we targeted these areas in weeks 3, 4, 5, and 7. Bone weakness and pain have been seen as common impairments as a result of the cancer itself and/or from the treatments and pharmaceuticals in child populations. As a result of these impairments, fracture prevalence is increased in child cancer survivors. Nysom et al reported a fracture prevalence of 55% in children who are survivors of acute lymphocytic leukemia, with a median of 7.6years (1998). We focused on the importance of bone health and ways to strengthen bones in week 6 of the program. Joint stiffness was also found to be a common side effect seen in both the child and adult survivor populations. Studies done on adult populations have found benefits in joint stiffness with exercise and proper nutrition. The HOPE study found that the benefits of exercise, including increases in strength, range of motion, aerobic conditioning and positive weight fluctuations, all contributed to improvements in joint pain and stiffness.²² We focused on flexibility in week 2 to further enhance improvements associated with joint stiffness. The nutritional topics that accompanied each week's fitness topic reflected optimal nutrition that would assist in best practices for the exercise based on general recommendations.²³ This research suggests that targeting specific areas affecting cancer survivors can provide benefits in many cancer-related side effects.

Data collection/instruments

Our primary measure of the program was determining the feasibility of online avenues as a means to gather and deliver specific health and wellness information to child cancer survivors. The feasibility of the study was gathered by a Q&A session with the parents at the end of

the 8weeks that included questions such as "Did the video hold the attention of your child all 8weeks?" and "Did you feel the program's intended benefits were easier to gain through online routes with the independence to choose viewing times?"

Table 1 Each week of the 8-week program with associated fitness and nutrition topics provided in each video

Weeks	Fitness Topic	Nutrition Topic
Week 1	Introduction to exercise	Introduction to nutrition
Week 2	Flexibility	Importance of drinking water (how much?)
Week 3	Muscular Endurance	Fruits and vegetables
Week 4	Muscular Strength	How protein is used in anaerobic energy
Week 5	Cardiovascular Fitness	How carbohydrates are used in aerobic energy
Week 6	Bone Health	Calcium
Week 7	Body Composition	Healthy, balanced diets
Week 8	Closure/Take away points	Closure/Take away points

Fitness Video Topics.

Our secondary outcome was to measure quantitative physical and mental improvements in HRQoL received using these online modalities. To measure HRQoL in these survivors, we used the RAND 36-Item Health Survey 1.0 Questionnaire. This survey has been utilized in health research since 1993 and was derived from an original Short-Form 36-Item Survey (SF 36). The survey contains 36 questions that measure 8 distinct dimensions of current HRQoL physical function, role limitations due to physical health, role limitations due to emotional health, emotional well-being, social function, energy/fatigue, bodily pain, and general health. Scores were determined from the Rand Survey's specific scoring instructions that resulted in numeric measures for each of the 8 health dimensions. Scoring of the survey was measured on a scale of 1 to 10 with higher scores indicating a higher level of functioning or wellbeing.²⁴

The RAND survey is a well-validated survey in assessing HRQoL in cancer survivors.²⁴ However, most research done in this population that has measured HRQoL has looked only at adult survivors. Utilization of this survey on adult cancer survivors was able to determine that assessing HRQoL is an important endpoint for evaluating the results of treatment for prostate cancer. Unfortunately, to our knowledge, an ideal HRQoL survey targeted and well-validated in child cancer survivors has yet to be developed. Our team then had to make a decision on whether to use a well-validated survey that was used as a self-assessment for adults or a child specific survey that has been used in healthy child populations. The team decided to alter the wording of the adult survey so that it reflected a survey that could be filled out by the parent/guardian on behalf of the child survivors. Surveys were given out through email to parents of the survivors to fill out on week 1 of the program as well as week 8 to determine changes in overall health of the subject.

Subject recruitment

Inclusion criteria included children that ranged in age from 6-14 and were in complete remission (had no trace of the cancer left in their system). Hormone therapies or medications taken after treatment

was acceptable, however, the child could not have any pending surgeries or be currently recovering from a surgery within the last 6 months. There were no restrictions on the type of childhood cancer or times of remission. Participants were excluded if they were currently undergoing cancer treatments or had any cancer related surgeries scheduled for a future date. Participants were also excluded if they were wheelchair bound or exceeded the age of 14.

Program information was posted through Maple Tree Cancer Alliance’s Facebook page where interested parties were required to email the director of Maple Tree with contact information. Baseline information was gathered through the RAND 36-Item Health Survey for quality of life and through a general questionnaire of the child’s cancer type, age, etc. that was sent via email prior to the first week of the study. Final data was collected on the last week of the program using the same HRQOL survey to assess effectiveness.

Subject characteristics

Sixteen families initially agreed to participate in the 8-week online study program. Three of the families dropped out during the program for unrelated reasons while one family was not able to complete the study due to the subject being wheelchair bound. We decided to exclude wheelchair bound individuals from our study due to our target topics for the 8weeks reflecting full body workouts. To avoid swaying the results, we discarded the individual’s results from our data, though the family continued to utilize the program. Two families could not be reached at the halfway point of the program and the other family had computer and financial issues and could not complete the program at the current time. Characteristics of the remaining ten subjects are provided in Table 2. Parents were the primary mode of communication throughout the duration of the program and gave informed consent for their child to participate in the program.

Table 2 Subject characteristics: age (in years), weight (in kg), and type of cancer.

Age	Weight (kg)	Cancer Type
10	49.1	Acute Lymphocytic Leukemia

Mean Subject Characteristics

Results

Primary outcomes

Feedback and feasibility: Families were encouraged to provide feedback on the program in terms of feasibility, enjoyment, and considerations for improving the program. The most common feedback received from families was that the program was not terribly time consuming, in that they could receive similar benefits from this program without having to leave the house. All ten families that we followed from week-1 of the program to week-8 had a household that contained more than one dependent. Scheduling events and activities in these circumstances have been proven to be difficult for the families. They were able to watch the videos at home, at any time of day, and free of cost and time constraints. All child survivors stated they enjoyed the videos and the videos were able to hold the attention of the children each week. Excitement for each week’s exercises got whole families involved and served as a means to get each family member participating in the exercise or activity. The families also stated that adhering to the program was easy to manage because they were able to determine when that day they wished to view the video and there wasn’t a mandated time they had to conform to.

As for future directions for the program, families stated that incorporating an even more interactive video with the hopes of increasing the length of the videos while still holding the attention of their child. Families hoped that they could gather even more information from the videos if the duration of the video was lengthened. They appreciated the multiple choice question that was included in each week’s video and accessing online avenues made it possible to watch the videos on their phone or tablet, making the program more accessible to watch even away from home.

Secondary outcomes

Survey Scores: Parents of the child survivor participants were emailed a Word Document version of the RAND 36-Item Health Survey. All parents highlighted the best-fit answer for each question and emailed the same document back for analysis. The same process was repeated for gathering post- program survey scores. The main purpose for the survey was to determine if there were any changes seen from pre- to post-program. Our results show there was an increase of scores between all ten subjects and seen in many of the eight health dimensions as shown in Table 3. The current intervention program resulted in a positive trend in HRQoL scores after 8-weeks.

Table 3 **Survey scores pre- and post-intervention using specific RAND-36 Item Health Survey Scoring protocol

	Subject Means	
	Pre-	Post-
Physical Functioning	50	85
Bodily Pain	75	100
Role Limitation-Physical Health	100	100
Role Limitation-Personal or Emotional Problems	35	70
Emotional Well-Being	80	88
Social Functioning	87.5	90
Energy/Fatigue	77.5	80
General Health Perceptions	30	45

Exercise diaries

Subjects performed a variety of exercises throughout the 8-week program that were recorded in the exercise diaries. Most exercises occurred at the beginning of the week (videos were available for viewing each Monday) and each week’s exercises tended to reflect the exercise topic of that week. Exercises that strayed from the expected included bike riding and games such as tag and hide and seek. Subjects performed close to the same amount of recorded activity a week, seeing a decline in activity towards the end of the week. Intensities of each exercises and duration of time spent on activities are recorded on Table 4. Common trends seen in each subject were similar exercises performed each week that reflected that week’s fitness topic and a decline in overall activity time from pre- to post-intervention.

Children’s recorded nutrition each week included several homemade meals and easy snacks such as peanuts, toast, and fruit. As with the exercises, a variety of food groups were consumed each week by each participant. Our team did not quantify these data, as this part of the methodology served as a means for families to track their behavior. No measureable trends were recorded.

Table 4 Averages of intensity and duration of activity per week

	Duration	Intensity
Subject Means	3.4 hours	5

Discussion

The current study intended to determine if an online, 8-week exercise and nutrition program was more feasible for families when it comes to improving the health of child cancer survivors. This feasibility study determined that accessing online avenues for exercise and nutrition education was easier, more feasible, and less time consuming than physical programs. This contributed to greater program adherence for these families because they were able to determine times for viewing that was ideal for the entire family.

The information contained within the videos were specific for improving the health of child cancer survivors specifically, however, improvements in these areas can also contribute benefits to healthy populations as well.²⁵ The program was also a means to get whole families involved in order to add a system of support and encourage health and wellness for everyone. Being able to invite healthy populations to participate in the study has the potential to provide a control population to compare benefits to, as well as extend an opportunity to expand benefits in quality of life to include this population.

Exercise has been shown to be an effective way of reducing symptoms and impairments associated with cancer and its treatments that can last long after treatments are done.²⁶ The current study is in agreement, showing positive trends in physical functioning after implementing exercise for eight weeks. Physical domains that found a positive trend in the current study included physical functioning, role limitations due to physical health, energy/fatigue, pain and general health that parallel other studies investigating the same domains.^{1,15,27} In addition, mental domains contributing to a survivor's overall quality of life that showed a positive trend after the eight weeks included role limitations due to emotional health, emotional wellbeing and social functioning. These data follow in line with other studies that showed improvements in overall quality of life after implementation of an exercise intervention.^{4,6,24} However, our team did not analyze this data statistically, as it was not our primary outcome of the study. This suggests that further studies, possibly containing a larger sample size, could produce similar positive benefits in overall health that are statistically significant.

Exercises recorded in the child's exercise diaries throughout the 8 weeks mimicked exercises performed in that week's video. Because of that, children were able to incorporate a variety of exercises that targeted varying aspects of overall health as measured in the survey. The positive trend seen in all eight domains of the survey could be contributed to the variety of exercises performed throughout the program. Future studies should aim to determine if one type of exercise (resistance or aerobic, for example) would produce greater improvements in quality of life scores in regards to functional abilities and linear growth.

Having greater knowledge of essential vitamins and nutrients that are specific in cancer survival will provide added benefits when in combination with exercise.²⁸ Fewer studies have examined the combination effects of an exercise and nutrition program on overall quality of life. The current study utilized the exercise diaries as a

means to track food consumption as well as exercise to compare their post-survey scores in relation to their food intake and activity. The variety of foods recorded in the diaries could suggest a correlation between healthy eating and exercise on improvements in overall quality of life if quantitatively measured.

Study limitations

One limitation with the study was the small sample size that was used (n=10). However, this is a pilot program and we expected around this number of participants for the first trial of the program. Further trials run with the same program should yield a better number of participants. We were able to use these subjects as more of a case series to better understand lifestyle behaviors and feedback on the program throughout the eight weeks. We also did not compare our intervention group with a control group to see if similar results may have been found through day to day living. It could be safe to assume, however, that with the poor quality of life reported in this population that any healthy lifestyle change may accompany improved quality of life scores. All of our survey scores were self-reported by the parents of their child. This is a limitation of the study because self-perceived information might vary from actual information especially if the perceived information is portrayed of your child and not yourself.

Conclusion

Managing impairments and cancer-related symptoms is a lifelong battle for survivors and may require a full lifestyle change. For child survivors, this lifestyle change may need to be implemented at an early age, typically while the child is still growing. Currently in the US, few studies have demonstrated the feasibility of exercise interventions on child and adolescent cancer survivors.¹⁶ The feasibility study will allow an additional mode of bringing exercise and nutrition wellness into these survivors' households. The current study has shown that utilization of an online, at-home exercise based program and education on essential nutrients and their role in the body can provide a more feasible way of implementing health lifestyle and behavior changes to improve quality of life.²⁹⁻³⁷

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Conflict of interest

The author declares no conflict of interest.

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