

EXPLORATION OF THE BENEFITS OF EXERCISE ON THE PHYSICAL AND  
MENTAL WELL-BEING  
IN A POPULATION OF YOUNG ADULT SURVIVORS OF  
ADOLESCENT AND YOUNG ADULT CANCER

by

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Submitted in partial fulfillment of the  
Requirements for Departmental Honors in  
The Department of Nursing  
Texas Christian University

May 4, 2015

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## ABSTRACT

According to the Centers for Disease Control and Prevention (CDC), a cancer survivor is a “person who has been diagnosed with cancer, from the time of diagnosis throughout his or her life.” Currently, at least 69,212 adolescents and young adults (AYA) between the ages of 15-39 are diagnosed with cancer each year (National Cancer Institute [NCI], 2014). As a greater number of AYAs achieve remission and live further into adulthood, treatment-related side effects are appearing (Oeffinger & Hudson, 2008). As a result, researchers are beginning to address interventions that will reduce treatment-related complications in AYA cancer survivors.

This study explored the effects of exercise on physical and mental well-being during and after treatment in AYA cancer survivors. Investigators used a mixed-methods approach to examine the physical and mental benefits of exercise on seven AYA cancer survivors who received cancer therapy in a tertiary pediatric institution. To investigate the survivors’ current exercise, sleep, and fatigue levels, the quantitative portion of this study utilized a demographic form and three Likert scales: the International Physical Activity Questionnaire (IPAQ), Pittsburgh Sleep Quality Index (PSQI), and Fatigue Severity Scale (FSS). Descriptive analysis using SPSS 22.0 examined the demographic form and any correlations found among the three Likert scales. The qualitative portion of this study employed open-ended questions during audio-taped focus groups and individual interviews to investigate the effects of physical activity on exercise, sleep, and fatigue levels during therapy. The researchers used qualitative content analysis to analyze the participants’ open-ended responses.

Though this study possesses a small sample size and no statistical significance, the responses of the participants revealed the need to promote physical activity during cancer therapy. Further research is needed with a larger sample size that will examine the effects of exercise during cancer treatment in the AYA population.

## ACKNOWLEDGEMENTS

The student author would like to thank her committee members for the support, time, and mentorship she received:

*Dr. Bashore and Dr. Lockwood*, thank you both for your leadership throughout this entire project. Each of you serves as an inspiration to the nursing community through your passion for working with the oncology population. You both have served as mentors and a continual source of encouragement during this learning process. I appreciate everything you both have done for me and helped me achieve this past year!

*Dr. Bashore*, thank you for being there every step of the way throughout this project. You guided me through multiple IRB approvals, countless research meetings, and hours of essay feedback these past nine months with constant encouragement. Your ability to work with young adult cancer survivors is inspiring and I have learned much from you during the time we've worked together. Thank you for going above and beyond!

*Dr. Lockwood*, your consistent support and kindness has made all the difference. Thank you for taking an interest before my thoughts were clear and helping me transform an idea into a successful research thesis.

*Dr. Phillips*, thank you for your willingness to work with me and guide me through the exercise physiology portion of this project. Your positive feedback and encouragement to further this project is contagious! I admire your expertise and commitment to your line of work.

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## **Introduction**

In 2011, cancer was the highest ranked disease-related cause of death among the adolescent and young adult (AYA) population (NCI, 2014). Of adolescents diagnosed with cancer between the ages of 15 and 19, girls experience an 85.9% survival rate while boys experience an 80% survival rate (ACS, 2014). Though survivors of AYA cancer are living further into adulthood, a number of functional disabilities, such as obesity, pulmonary disease, and osteoporosis, plague this patient population throughout their survivorship (Oeffinger & Hudson, 2008).

In adult cancer survivors, research suggests exercise is safe during and after cancer treatment and provides multiple benefits such as reduced fatigue, improved mood, and enhanced physical functioning (Mutrie et al., 2012). Similarly, studies suggest exercise is feasible during treatment in AYAs and produces physical benefits; however, evidence is limited. (Tanir & Kuguoglu, 2013). With an estimated 69,212 cases of cancer in the AYA population in 2011, further research is needed to explore the benefits of exercise during and after treatment in AYA cancer survivors (NCI, 2014).

The goal of this study was to explore the effects of exercise on the physical and mental well-being in young adult survivors of adolescent or young adult (AYA) cancer.

## **Literature Review**

The care of AYA cancer survivors begins to fragment as they age (Nelson & Meeske, 2005). Most survivors were once patients at pediatric institutions and received treatment through cooperative group protocols (Nelson & Meeske, 2005). However, well-controlled treatments of this patient population diminishes as survivors change geographic locations, lose health insurance, and may have knowledge-deficits regarding

the importance of ongoing health examinations and checkups (Oeffinger & Hudson, 2008). The fragmented treatment follow-up may exacerbate the impact of chronic health problems in AYA cancer survivors.

According to Oeffinger et al. (2006), there are three types of long-term health outcomes in childhood cancer survivors: health status, mortality, and morbidity. In a retrospective study of 20,227 five year survivors of childhood and adolescent cancer, researchers found excess mortality related to relapse of the original cancer and cardiac and pulmonary causes. These mortality risks remain at least 25 years after the original cancer diagnosis (Mertens et al., 2001). Hudson et al. (2003) conducted a study on the health status of 9,535 adult survivors of childhood cancer; 44% reported at least one health domain (mental health, functional abilities, overall health, activity limitations, and cancer-related pain or fear) moderately or severely impaired. Oeffinger et al. (2006) retrospectively analyzed a cohort of 10,397 survivors and 3,034 siblings. The researchers found that survivors were eight times more likely than their siblings to experience a severe or life-threatening chronic health conditions such as: congestive heart failure, myocardial infarction, cognitive dysfunction, myocardial infarction, and secondary cancers. Among the survivors, 73.4% experienced at least one incident related to chronic health 30 years after initial cancer diagnosis. Increased mortality and morbidity and decreased health status of AYA cancer survivors is only worsened by the lack of physical fitness in this patient population (Braam et al., 2013).

### **Exercise**

Exercise is important to promote physical and mental well-being in survivors of childhood and AYA cancer since this patient population is at an increased risk for

developing chronic disease as a result of their cancer therapy (Järvelä et al., 2012; Oeffinger et al., 2006). Though studies suggest exercise interventions are feasible during therapy and produce modest benefits, there is a lack of quantitative evidence regarding the best type and timing of physical activity (Braam et al., 2013; Tanir & Kuguoglu, 2013). There is a need for more studies with comparable interventions that use a higher participant amount and additionally examine quality of life (Braam et al., 2013). Hocking et al. (2013) collected a series of self-report questionnaires from young adult survivors of childhood cancer regarding their views on physical health, psychological distress, health beliefs, and health problems. These surveys were then compared to the same self-report questionnaires of healthy young adults. Researchers found young adult survivors reported significantly lower levels of exercise due to perceived negative beliefs about their health and cognitive capabilities, and increased psychological distress. Though these surveys provide valuable insight into the views of young adult cancer survivors, overall there is a lack of quantitative and qualitative evidence regarding the benefits of exercise in young adult survivors of childhood and AYA cancer (Götte, Kesting, Winter, Rosenbaum & Boos, 2014; Hocking et al., 2013).

Literature shows there is a need for higher-quality quantitative and qualitative data in order to develop physical activity guidelines during and after cancer treatment in young adult survivors. Investigators must examine young adult childhood and AYA cancer survivors' perception of the physical and mental effects received while exercising during and after treatment. This will ideally promote a greater understanding of how exercise affects a young adult survivor both mentally and physically and contribute to the knowledge base regarding the effects of exercise on childhood cancer survivors.

### **Theoretical Framework**

Dorothea E. Orem, a nursing theorist, created a model of nursing known as the Self-Care Deficit theory (Orem & Taylor, 2011). This theory is composed of three parts: theory of self-care, theory of self-deficit, and theory of nursing system. The theory of self-deficit subsection identifies five methods by which a nurse can fulfill the patient's self-care needs: acting for and doing for others, guiding others, supporting another, providing an environment promoting personal development in relation to meet future demands, and teaching another.

Health promotion through the methods described by this framework supports the idea of using exercise to enhance patient self-care behaviors and to foster an environment of greater patient development. Investigating the effects of exercise on physical and mental well-being during therapy and afterwards will add to existing literature regarding best exercise practices. This literature encourages nurses to provide greater patient education regarding the benefits of exercise and to guide health-promoting behaviors among young adult survivors of childhood or AYA cancer.

The purpose of this study was to explore the effects of exercise on physical and mental well-being in a population of young adult survivors of AYA cancer. The investigators used focus groups and questionnaires to (1) investigate how physical activity helped survivors during treatment and post-treatment, (2) explore how physical activity impacted fatigue, quality of sleep, and cancer side-effects during and after therapy, and (3) assess physical activity concerns a young adult survivor may have had during cancer treatment and possibly continue to have in the present.

## **Methodology**

This pilot study used a mixed-methods approach in studying this survivor population. This study was approved by the Institutional Review Board at a Pediatric Institution and the Texas Christian University Institutional Review Board. Recruitment began in October 2014.

### **Study Sample**

Individuals at least 18 years of age or older and less than 40 years old were eligible to participate if they met the following inclusion criteria: 15 years of age or older at the time of cancer diagnosis, currently receiving follow up care at the pediatric center, free of primary neoplasm, at least six months from completing therapy, and able to speak and understand English. The participants also had to have participated in 90 or more minutes of physical activity per week during and after treatment that resulted in elevated heart rate, blood pressure, or heavy breathing.

### **Recruitment**

Survivors that met the inclusion criteria were recruited by the principle investigator and sub-investigator through telephone calls in order to elicit interest. In addition, eligible survivors attending the oncology center were approached by the principle investigator and sub-investigator and asked about their interest in participating in the study. Each potential participant was mailed a consent document for them to review ahead of time. Informed consent was then obtained just prior to beginning of the attended focus group.

### **Procedure and Measures**

After enrollment, the participants were asked to attend one of two focus groups. The investigators originally planned for six female participants to attend one focus group lasting 60-90 minutes and six male participants to attend the other focus group lasting 60-90 minutes. However, due to scheduling difficulties amongst participants, a modification was approved for mixed-gender focus groups and individual interviews.

The focus groups were conducted by the principle investigator and sub-investigator and took place at the pediatric tertiary hospital at a mutually agreed upon time. Before each focus group began, each participant was formally consented by the principle investigator who answered any questions about the purpose of the study. Each survivor also filled out a demographic form and three Likert scale items, the International Physical Activity Questionnaire (IPAQ), Pittsburg Sleep Quality Index (PSQI), and Fatigue Severity Scale (FSS), prior to the sessions. All measures have undergone extensive testing to confirm reliability and validity. The focus groups were audio-taped and transcribed verbatim with prior participant consent.

During the sessions, open-ended questions were used to gain insight into the survivors' perception of the effects of exercise on physical and mental well-being during treatment and post-treatment, the type of exercise in which the survivor engaged, and the length of a typical exercise session. Probes were used to further discussion.

## Results

### Qualitative Analysis

Interview questions focused on physical activity, fatigue, and quality of sleep. Four themes, with additional subthemes, emerged: cancer is debilitating (subthemes: fatigue and interrupted sleep), benefits of exercise during therapy (subthemes: improved strength and mental well-being), wide-ranging benefits today (subthemes: fatigue lessened and improved sleep), and need for more information (subthemes: guidelines provide goals, a nurse's role, and exercise in the hospital).

**Cancer is debilitating.** A reoccurring theme repeated by all survivors ( $n = 7$ ) is the idea that cancer and cancer treatment is debilitating. Many survivors stated that they 'could not do as much' due to physical impairments from cancer and cancer treatment. A majority of the survivors mentioned they felt limited as a result of the medications they were taking, stating that the cancer treatment caused them to feel 'dizzy' and like they 'wanted to throw up.' One survivor was unable to participate in school functions since her chemotherapy medication directly affected her walking ability.

"I couldn't march. So I sat out then. But I still did as much as I could. I made an effort; I just couldn't do as much" (Participant G).

Another survivor describes being directly affected by the disease (cancer) itself: "With my cancer treatment I had a tumor in my brain that partially paralyzed my left side. I didn't do as many activities at first because I had to recover from that...I had to learn how to use everything again" (Participant A).

Two subthemes emerged as participants discussed how cancer and cancer treatment changed their daily lives.

***Fatigue plays a role.*** Many of the survivors responded that fatigue played a large role in their day-to-day lives while actively undergoing treatment. Though the survivors are fatigued today with classes, jobs, and other commitments, multiple participants cited they ‘had no energy’ and would ‘sleep most of the time’ during treatment.

“[Cancer fatigue] was a different kind of tired. I’m tired now as a college student who works...I was always tired during classes...I still really struggled to get through days” (Participant G).

Most survivors did not state a specific reason why they were fatigued, but expanded on the idea that the fatigue was so severe they did not want to leave their beds most days during treatment.

“My fatigue during the treatment was a lot...cause most of the time I spent sleeping or wanted to be in bed” (Participant D).

***Increased sleep.*** Several of the survivors mentioned they slept for a greater number of hours during treatment compared to the number of hours they sleep today. Two survivors clearly stated that the hospital noises kept them from sleeping well.

“The amount was greater, but the quality of sleep was less cause the doctors coming in and out of the room. So you’re awake more often but you’re in bed so you can sleep whenever you want to” (Participant E).

Though the quantity of sleep was greater, the quality was poorer for a variety of reasons, such as hospital visits, consistently high levels of fatigue, and nausea from treatment. Other participants attributed the amount of time slept to the pain they were experiencing.

“I slept a lot during treatment, like that’s all I did was sleep because I had so much pain and everything. I just slept everything off” (Participant A).

“Sometimes, you know, just the pain and everything... I really didn’t want to be awake at all anyways. Even when I did wake up I would just try to go back to sleep” (Participant F).

In addition to fatigue and increased quantity of sleep, each survivor spoke of the physical and mental benefits of physical activity during treatment.

**Benefits of exercise during therapy.** Each of the survivors revealed he or she lived an active lifestyle before cancer diagnosis. Many of the survivors participated in high school extracurricular activities that kept them on the move and physically fit. As a result, these survivors continued these habits into their cancer treatment. Though initially exhausted after chemotherapy treatments, many of the survivors spoke of how they were able to exercise after a round of treatment revealed how they benefitted from exercise during a particularly demanding period of their lives.

**Improved strength.** Several of the survivors commented how exercise improved their strength and functional capabilities during treatment. One survivor mentioned how physical activity increased his endurance and another survivor revealed how exercise forced her to strengthen the area of her body weakened by cancer.

“I was able to do more laps every time and then I slowly got less embarrassed. So walking actually helped a lot” (Participant F).

“I would never really have done it myself. I would not have been as strong as I am today” (Participant A).

The physical activity Participant A participated in during treatment helped her to not only strengthen her body at that time, but continues to contribute to her physical capabilities today.

***Mental well-being.*** Each of the individuals specifically talked about how exercise provided mental stimulation and support during therapy.

“It kept me moving and it kept me focused on something else” (Participant D).

For this survivor, exercise served as a distraction from dealing with the cancer and cancer treatment as well as an opportunity to socialize with friends. For two of the survivors, exercise served as a motivator that they ‘could do this’ and ‘still be okay.’

“Volleyball practice was the only thing... It was motivation that I would get better” (Participant B).

Another survivor used physical activity as a method of staying ‘positive’ and as an opportunity ‘clear my head and not think about things.’

Two of the survivors talked about how physical activity boosted their self-esteem since they felt self-conscious about their body-image. One of them revealed that her ‘self-esteem went up so much’ as she exercised during treatment, consequently losing the weight she had gained during that time. Overall, each survivor suggested exercise was a way to return to their pre-cancer routines. In this case, exercise provided both mental stability and the chance to do an activity that was ‘normal.’

“Exercise made me feel...like I was like everybody else. You couldn’t tell I was different, and you know, I just felt better about myself” (Participant B).

As the participants communicated how physical activity provided wide-ranging benefits during cancer treatment, they also expressed the benefits they experience today from exercising.

**Wide-ranging benefits today.** Exercise has been shown to produce modest benefits in AYA cancer survivors ((Braam et al., 2013; Tanir & Kuguoglu, 2013). In accordance with previous studies, these seven survivors also reported numerous physical and mental benefits received from exercising presently. One of the survivors reported he felt ‘less stressed’ and ‘better’ if he exercised more often. Participant F described how exercise gives him a sense of ‘security’ and ‘makes me feel like me.’ One survivor touched on the benefits of group exercise, while another mentioned that he’s motivated to exercise now to prevent the return of cancer in the future.

“I like doing things where I’m around people. Especially now doing group exercise classes. I just love being around people doing stuff like that. It’s exciting that someone’s telling you and you’re like, ‘yeah I can do that!’” (Participant G).

“I would say I’m physically strong...I know I have to do some exercise...Cause’ if I don’t, or, not saying I want [cancer] to happen again... But I think, knowing that I need to be in shape is what motivates me to exercise more” (Participant D).

For these two participants in particular, exercise continues to provide mental stimulation and support, whether through social interaction or security. Participant D highlighted how physical strength is a benefit received from exercise.

A specific subtheme, improved sleep, emerged as the survivors discussed how exercise impacted them presently.

**Improved sleep.** The entire cohort touched on the idea that exercise improved their quality of sleep.

“[Physical activity] helps my sleep since I don’t get a lot of sleep. I’ll just try to tire myself out” (Participant C).

Similarly, another survivor highlighted that he ‘sleeps better’ the more active he is. All seven survivors reported that fatigue is no longer a side effect they experience today.

“Now that we’re not going through all that stuff, the medications, the surgeries...it does not make me get that fatigue anymore” (Participant D).

The survivors’ fatigue levels have fallen since they are no longer undergoing cancer treatment, and may be attributed to improved quality of sleep.

Each survivor is able to recall how beneficial physical activity was for them during and after cancer therapy. The survivors, however, wished they would have received more guidelines regarding the type of exercise he or she should be doing.

**Need for more information.** A majority of the participants were told to ‘start slow and go slow’ or ‘take things slow.’ Participant A, who was the only survivor who went through physical therapy, stated that she received guidelines ‘at home and during therapy.’ However, of the six remaining survivors who were not prescribed physical therapy, only one of them received a list of recommended activities he should be performing. Two of the survivors mentioned they wished they could have received more detailed information regarding physical activity and its benefits during and post-treatment,

“I got a little bit of guidelines...I should have gotten more” (Participant C).

“I think that if they gave reasons explaining why, then I probably would have done it more to their way” (Participant E).

On the other hand, a few of the survivors agreed that although physical activity guidelines would have been helpful, they also might not have participated in the activities regardless.

“Obviously it’s kind of depressing having cancer, so I still probably wouldn’t have done much” (Participant F).

After reviewing the survivors’ opinions regarding physical activity information, three subthemes emerged: guidelines provide goals, a nurse’s role, and exercise in the hospital.

***Guidelines provide goals.*** Three of the survivors expressed that guidelines could have served as goals during treatment.

“Well, it’s hard for me to deny a challenge, so I probably would have done it” (Participant F).

“Sometimes things [physical activity guidelines] like that do work for me. Especially if a doctor says to do things I tend to do them because I trust people” (Participant G).

“The guidelines probably would have motivated me more because then I would have been able to pass that barrier of limitation after I had all of my treatments done” (Participant C).

In these three cases, detailed physical activity guidelines during and after treatment could have given the survivors an achievable target and source of motivation.

*A nurse's role.* All of the survivors expressed that nurses could have played a larger role in encouraging physical activity during treatment. Many of the survivors distinguished between two types of nurses. Some nurses were there to just 'draw your blood' and 'check your blood pressure.' On the other hand, some nurses made a special effort to ensure the participants were active.

"Then there were the other nurses who took a personal interest in everyone they met. And yes, they pulled me out of bed" (Participant F).

"Some of them had the enthusiasm to go door to door to make sure you did it, which helped me out a lot because then I had a reason to go out" (Participant E).

Participant F also stated that since he spent the most time with the nurses, he thinks nurses 'could have played a bigger role' and 'hearing it from them would have mattered a lot.'

Not only did the survivors appreciate nurses who forced them out of bed, but they also appreciated nurses who took an interest in them and motivated them to be physically active.

*Exercise in the hospital.* The participants showed interest in the idea of a group exercise program for AYA cancer patients during treatment.

"It probably would have helped if I had more people on my level...it probably wouldn't have put me down as much" (Participant C).

"Having people to exercise with...that would have made it easier" (Participant F).

However, one survivor was uncomfortable with the idea of group exercise.

“I probably wouldn’t have felt comfortable...everyone would have been able to do more than I would” (Participant A).

This particular survivor did acknowledge, however, that group exercise would have ‘helped just the same.’ Another survivor revealed that although he doesn’t like to work out in group settings, he would have been more apt to exercise if the hospital had ‘an open gym with a treadmill or something.’ Overall, the survivors expressed that an option to participate in group exercise during treatment with other AYA cancer patients would have been comforting and beneficial.

### **Quantitative Analysis**

A total of seven survivors, three males, four females, participated in this study. The majority of the participants were diagnosed at the age of 16 years (57.1%) with a variety of cancer diagnoses. Further demographic data are summarized in Table 1.

Each of the Likert scales (IPAQ, PSQI, and FSS) completed by the participants measured their current exercise, sleep, and fatigue levels, respectively. According to the IPAQ, moderate physical activity is defined as three or more days of vigorous activity of at least 20 minutes per day or five or more days of moderate-intensity activity and/or walking of at least 30 minutes per day. Vigorous activity is defined as three days of vigorous-intensity activity that accumulated at least 1500 MET-minutes/week or seven or more days of any combination of walking, moderate, or vigorous intensity activities accumulating at least 3000 MET-minutes/week. A metabolic equivalent (MET) represents an activity’s energy requirements. One MET is equal to a resting oxygen consumption of 3.5 ml/kg/minute, which is similar to an average resting metabolic rate for most individuals. Therefore, a higher MET score indicates greater oxygen

consumption, or a more physically demanding activity. A MET-minute is computed by multiplying an activity's MET score by the minutes performed. Preliminary data indicates that all the participants currently participate in either moderate or vigorous physical activity each week. These data are summarized in Table 2.

A global PSQI score was calculated for each participant based on the participant's answers. A global PSQI less than or equal to five indicates the participant is a good sleeper, while a global PSQI of six or greater indicates poor sleeping habits (Buysse, Reynolds, Monk, Berman, & Kupfer, 1988). Five participants (71.4%) ranked as poor sleepers and 2(28.5%) ranked as good sleepers overall. However, within the PSQI, 6(85.7%) ranked their sleep quality as either fairly good or very good, and 1(14.3%) ranked her sleep as fairly bad. These data are summarized in Table 2.

An average FSS score was determined for each participant. A higher FSS indicates greater fatigue, while a lower FSS indicates less fatigue. The mean FSS score for a normal, healthy adult is 2.3 (SD  $\pm$  0.7) (Neuberger, 2003). Three participants (42.9%) possessed a mean FSS score greater than 2.3, and 4(57.1%) possessed a mean FSS score less than or equal to 2.3. These data can be found in Table 2.

Overall, no significant correlations were found between the participants exercise, sleep quality, and fatigue levels. Due to the small sample size, the findings should be interpreted with caution. Data analysis was performed using SPSS 22.0.

### **Discussion**

Based on past research findings, the investigators expected physical activity levels would influence the sleep and fatigue of AYA cancer survivors as well as produce mental and physical benefits during treatment. According to their responses during the focus

groups and individual interviews, the main physical benefits of exercise the survivors experienced during therapy are improved strength and functional capabilities. These findings are consistent with the systematic review conducted by Braam et al. (2013). The participants also revealed numerous mental benefits received from exercise during therapy. The most notable of these mental benefits include enhanced motivation, opportunities for socialization, and improved self-esteem.

The investigators of this study predicted that physical activity levels would affect quality of sleep and fatigue levels today. However, the researchers found no correlation between exercise and quality of sleep. Though all of the survivors participate in moderate to high levels of physical activity, most survivors (71.4%) ranked as poor sleepers. Similarly, regardless of physical activity levels, only N=57.1% of the survivors reported a mean FSS score that is equal to or lower than a normal, healthy adult. These findings are consistent with the study conducted by Mulrooney et al. (2008), indicating increased fatigue levels and poorer sleep quality in adult cancer survivor when compared to the sleep and fatigue levels of their siblings. Among survivors, there was a statistical significance difference in mean scores on FSS and PSQI. Using nonparametrics, the statistics indicated an association between higher levels of fatigue and poorer quality of sleep.

Though the quantitative analysis did not indicate that exercise improves sleep and reduces fatigue, the survivors offered multiple statements that suggest otherwise. Regardless of their self-reported global PSQI and FSS scores, a majority of survivors affirmed that exercise improves their quality of sleep and fatigue is no longer a side effect they experience today. The survivors also mentioned how performing physical activity

keeps them physically strong and provides mental stimulation. Similarly, Götte, Kesting, Winter, Rosenbaum, & Boos (2014) conducted a mixed-methods study with a group of adolescent survivors of pediatric cancer and found that physical activity enhances self-esteem, provides a sense of normalcy, and improves physical strength and stamina. Consistent with the investigators' hypothesis, six out of seven survivors indicated that in-depth physical activity guidelines, as well as opportunities to participate in group exercise classes, would have been helpful and acted as a form of motivation during therapy. However, the survivors also acknowledged that they might not have followed the guidelines regardless.

The major barrier to this study was the difficulty in recruiting this patient population. A majority of this patient population no longer lived near the pediatric institution, which made the study infeasible for most. Since most young adults are involved with college or a career, it was also difficult to find a common time that agreed with everyone's schedules.

### **Limitations**

There are several limitations to this study. The study sample was from a single institution and small in size. The small sample size can be attributed to the difficulty in recruiting this patient population and the difficulty in coordinating interview times that agreed with survivors' schedules. Another limitation to this study is the lack of a control group. Comparing the results of the IPAQ, PSQI, and FSS and answers to the focus group questions between cohorts of physically active AYA cancer survivors to AYA cancer survivors who did not exercise during treatment would have strengthened the results of this study.

### **Nursing Implications**

Though limitations are present within this study, nurses can still learn from the AYA cancer survivors' focus group and interview responses. Nurses should spend more time discussing the benefits of physical activity during treatment and should strongly encourage and enforce physical activity as recommended both inpatient and outpatient. Educating AYA patients about the benefits of exercise and the type and amount of exercise is likely to increase their physical activity levels. Nurses also play a strong role in the education and advocacy of the patients they serve and can be actively involved in the development and implementation of physical activity programs for survivors.

### **Implications for Future Study**

Future studies that analyze the effects of exercise on physical and mental well-being in AYA cancer survivors during and after treatment should attempt to recruit a larger sample to increase statistical significance. This can be done by recruiting participants through multiple pediatric institutions. The larger sample size will allow the possibility of more focus groups rather than individual interviews, which will result in richer participant responses.

APPENDIX A: INTERVIEW QUESTIONS

During your cancer treatment, tell me how your physical activity was different from what you described in the IPAQ now since you've completed your cancer treatment?

During your cancer treatment, tell me about your level of fatigue and how it was different from what you described in the Fatigue Severity Scale now since you have completed cancer treatment?

During your cancer treatment, how was your quality of sleep different from what you described in the Pittsburgh Sleep Quality Index now since you've completed your cancer treatment?

During your cancer treatment, what were the greatest barriers (reasons for not being able to) to performing physical exercise?

How did exercising during treatment make you feel stronger?

How did exercise help you sleep better at night (fall asleep and stay asleep)?

Is fatigue one of the greatest side effects from your treatment that persists today?  
If yes, how does this side effect affect your ability to exercise?

Now that you are done with cancer treatment, what are the physical and/or mental benefits you feel you have from exercising?

During or after treatment, did any health care provider give you information on physical activity guidelines?

Do you feel that more detailed (written) information regarding the benefits of exercise during and post-treatment would have been beneficial?

Would this have changed your physical activity levels during treatment?

If given the chance, would you participate in an exercise program with other childhood, adolescent or young adult cancer survivors? Or other persons who are not cancer survivors?

APPENDIX B: DEMOGRAPHIC DATA FORM

Age at Diagnosis: _____	Gender:  Male: _____  Female: _____	Ethnicity/Race:  Caucasian: _____ African America: _____ Hispanic: _____ Asian: _____ Pacific Islander: _____ Bi Racial: _____ Other: _____
Age at time of study: _____	Diagnosis:  Acute Lymphoblastic Leukemia: _____ Acute Myeloid Leukemia: _____ Hodgkin's Lymphoma: _____ NonHodgkin's Lymphoma: _____ Wilms' Tumor: _____ Ewing's Sarcoma: _____ Osteogenic Sarcoma: _____ Brain Tumor: _____ Neuroblastoma: _____ Hepatoblastoma: _____ Rhabdomyosarcoma: _____ Other: _____	Education:  Less than high school: _____ Some high school: _____ High school graduate: _____ College or technical school: _____ Graduate school: _____ Post-Graduate/professional: _____
Marital Status:  Single: _____ Married: _____ Divorced: _____ Widowed: _____	Income:  <\$10,000: _____ <\$10,001-\$20,000: _____ <\$20,001-\$40,000: _____ <\$40,001-\$60,000: _____ <\$60,001-\$80,000: _____ <\$80,001-\$100,000: _____ >\$100,000: _____	

APPENDIX C: FATIGUE SEVERITY SCALE**FATIGUE SEVERITY SCALE (FSS)**

Date \_\_\_\_\_ Name \_\_\_\_\_

Please circle the number between 1 and 7 which you feel best fits the following statements. This refers to your usual way of life within the last week. 1 indicates “strongly disagree” and 7 indicates “strongly agree.”

Read and circle a number.	Strongly Disagree	→	Strongly Agree
1. My motivation is lower when I am fatigued.	1	2	3 4 5 6 7
2. Exercise brings on my fatigue.	1	2	3 4 5 6 7
3. I am easily fatigued.	1	2	3 4 5 6 7
4. Fatigue interferes with my physical functioning.	1	2	3 4 5 6 7
5. Fatigue causes frequent problems for me.	1	2	3 4 5 6 7
6. My fatigue prevents sustained physical functioning.	1	2	3 4 5 6 7
7. Fatigue interferes with carrying out certain duties and responsibilities.	1	2	3 4 5 6 7
8. Fatigue is among my most disabling symptoms.	1	2	3 4 5 6 7
9. Fatigue interferes with my work, family, or social life.	1	2	3 4 5 6 7

**VISUAL ANALOGUE FATIGUE SCALE (VAFS)**

Please mark an “X” on the number line which describes your global fatigue with 0 being worst and 10 being normal.

0	1	2	3	4	5	6	7	8	9	10
_____										

APPENDIX D: PITTSBURGH SLEEP QUALITY INDEX

Subject's Initials \_\_\_\_\_ ID# \_\_\_\_\_  
 Date \_\_\_\_\_ Time \_\_\_\_\_ PM/AM

**PITTSBURGH SLEEP QUALITY INDEX****INSTRUCTIONS:**

The following questions relate to your usual sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month. Please answer all questions.

1. During the past month, what time have you usually gone to bed at night?

BED TIME \_\_\_\_\_

2. During the past month, how long (in minutes) has it usually taken you to fall asleep each night? NUMBER OF MINUTES

\_\_\_\_\_

3. During the past month, what time have you usually gotten up in the morning?

GETTING UP TIME \_\_\_\_\_

4. During the past month, how many hours of actual sleep did you get at night? (This may be different than the number of hours you spent in bed.)

HOURS OF SLEEP PER NIGHT \_\_\_\_\_

**For each of the remaining questions, check the one best response. Please answer all questions.**

5. During the past month, how often have you had trouble sleeping because you . . .

- a) Cannot get to sleep within 30 minutes

	Not during the more	Less than	Once or twice	Three or
past month _____	once a week _____	a week _____	times a week _____	

- b) Wake up in the middle of the night or early morning

Not during the past month _____	Less than once a week _____	Once or twice a week _____	Three or more times a week _____
------------------------------------	--------------------------------	-------------------------------	-------------------------------------

- c) Have to get up to use the bathroom

Not during the past month _____	Less than once a week _____	Once or twice a week _____	Three or more times a week _____
------------------------------------	--------------------------------	-------------------------------	-------------------------------------

d) Cannot breathe comfortably

Not during the past month_____	Less than once a week_____	Once or twice a week_____	Three or more times a week_____
-----------------------------------	-------------------------------	------------------------------	------------------------------------

e) Cough or snore loudly

Not during the past month_____	Less than once a week_____	Once or twice a week_____	Three or more times a week_____
-----------------------------------	-------------------------------	------------------------------	------------------------------------

f) Feel too cold

Not during the past month_____	Less than once a week_____	Once or twice a week_____	Three or more times a week_____
-----------------------------------	-------------------------------	------------------------------	------------------------------------

g) Feel too hot

Not during the past month_____	Less than once a week_____	Once or twice a week_____	Three or more times a week_____
-----------------------------------	-------------------------------	------------------------------	------------------------------------

h) Had bad dreams

Not during the past month_____	Less than once a week_____	Once or twice a week_____	Three or more times a week_____
-----------------------------------	-------------------------------	------------------------------	------------------------------------

i) Have pain

Not during the past month_____	Less than once a week_____	Once or twice a week_____	Three or more times a week_____
-----------------------------------	-------------------------------	------------------------------	------------------------------------

j) Other reason(s), please describe \_\_\_\_\_

---

How often during the past month have you had trouble sleeping because of this?

Not during the past month_____	Less than once a week_____	Once or twice a week_____	Three or more times a week_____
-----------------------------------	-------------------------------	------------------------------	------------------------------------

6. During the past month, how would you rate your sleep quality overall?

Very good \_\_\_\_\_

Fairly good \_\_\_\_\_

Fairly bad \_\_\_\_\_

Very bad \_\_\_\_\_

During the past month, how often have you taken medicine to help you sleep (prescribed or "over the counter")?

Not during the past month \_\_\_\_\_    Less than once a week \_\_\_\_\_    Once or twice a week \_\_\_\_\_    Three or more times a week \_\_\_\_\_

7. During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?

Not during the past month \_\_\_\_\_    Less than once a week \_\_\_\_\_    Once or twice a week \_\_\_\_\_    Three or more times a week \_\_\_\_\_

8. During the past month, how much of a problem has it been for you to keep up enough enthusiasm to get things done?

No problem at all \_\_\_\_\_

Only a very slight problem \_\_\_\_\_

Somewhat of a problem \_\_\_\_\_

A very big problem \_\_\_\_\_

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*Buysse DJ, Reynolds CF, Monk TH, Berman SR, Kupfer DJ: Psychiatry Research, 28:193-213, 1989.*

## APPENDIX E: INTERNATIONAL PHYSICAL ACTIVITY QUESTIONNAIRE

**INTERNATIONAL PHYSICAL ACTIVITY QUESTIONNAIRE  
(October 2002)****LONG LAST 7 DAYS SELF-ADMINISTERED FORMAT****FOR USE WITH YOUNG AND MIDDLE-AGED ADULTS (15-69 years)**

The International Physical Activity Questionnaires (IPAQ) comprises a set of 4 questionnaires. Long (5 activity domains asked independently) and short (4 generic items) versions for use by either telephone or self-administered methods are available. The purpose of the questionnaires is to provide common instruments that can be used to obtain internationally comparable data on health-related physical activity.

***Background on IPAQ***

The development of an international measure for physical activity commenced in Geneva in 1998 and was followed by extensive reliability and validity testing undertaken across 12 countries (14 sites) during 2000. The final results suggest that these measures have acceptable measurement properties for use in many settings and in different languages, and are suitable for national population-based prevalence studies of participation in physical activity.

***Using IPAQ***

Use of the IPAQ instruments for monitoring and research purposes is encouraged. It is recommended that no changes be made to the order or wording of the questions as this will affect the psychometric properties of the instruments.

***Translation from English and Cultural Adaptation***

Translation from English is encouraged to facilitate worldwide use of IPAQ. Information on the availability of IPAQ in different languages can be obtained at [www.ipaq.ki.se](http://www.ipaq.ki.se). If a new translation is undertaken we highly recommend using the prescribed back translation methods available on the IPAQ website. If possible please consider making your translated version of IPAQ available to others by contributing it to the IPAQ website. Further details on translation and cultural adaptation can be downloaded from the website.

***Further Developments of IPAQ***

International collaboration on IPAQ is on-going and an ***International Physical Activity Prevalence Study*** is in progress. For further information see the IPAQ website.

***More Information***

More detailed information on the IPAQ process and the research methods used in the development of IPAQ instruments is available at [www.ipaq.ki.se](http://www.ipaq.ki.se) and Booth, M.L. (2000). *Assessment of Physical Activity: An International Perspective*. Research Quarterly for Exercise and Sport, 71 (2): s114-20. Other scientific publications and presentations on the use of IPAQ are summarized on the website.

## INTERNATIONAL PHYSICAL ACTIVITY QUESTIONNAIRE

We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. The questions will ask you about the time you spent being physically active in the **last 7 days**. Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

Think about all the **vigorous** and **moderate** activities that you did in the **last 7 days**. **Vigorous** physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. **Moderate** activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal.

### ***PART 1: JOB-RELATED PHYSICAL ACTIVITY***

The first section is about your work. This includes paid jobs, farming, volunteer work, course work, and any other unpaid work that you did outside your home. Do not include unpaid work you might do around your home, like housework, yard work, general maintenance, and caring for your family. These are asked in Part 3.

1. Do you currently have a job or do any unpaid work outside your home?

Yes

No →

***Skip to PART 2: TRANSPORTATION***

The next questions are about all the physical activity you did in the **last 7 days** as part of your paid or unpaid work. This does not include traveling to and from work.

2. During the **last 7 days**, on how many days did you do **vigorous** physical activities like heavy lifting, digging, heavy construction, or climbing up stairs **as part of your work**? Think about only those physical activities that you did for at least 10 minutes at a time.

\_\_\_\_\_ **days per week**

No vigorous job-related physical activity →

***Skip to question 4***

3. How much time did you usually spend on one of those days doing **vigorous** physical activities as part of your work?

\_\_\_\_\_ **hours per day**

\_\_\_\_\_ **minutes per day**

4. Again, think about only those physical activities that you did for at least 10 minutes at a time. During the **last 7 days**, on how many days did you do **moderate** physical activities like carrying light loads **as part of your work**? Please do not include walking.

\_\_\_\_\_ **days per week**

No moderate job-related physical activity



**Skip to question 6**

5. How much time did you usually spend on one of those days doing **moderate** physical activities as part of your work?

\_\_\_\_\_ **hours per day**

\_\_\_\_\_ **minutes per day**

6. During the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time **as part of your work**? Please do not count any walking you did to travel to or from work.

\_\_\_\_\_ **days per week**

No job-related walking



**Skip to PART 2: TRANSPORTATION**

7. How much time did you usually spend on one of those days **walking** as part of your work?

\_\_\_\_\_ **hours per day**

\_\_\_\_\_ **minutes per day**

### **PART 2: TRANSPORTATION PHYSICAL ACTIVITY**

These questions are about how you traveled from place to place, including to places like work, stores, movies, and so on.

8. During the **last 7 days**, on how many days did you **travel in a motor vehicle** like a train, bus, car, or tram?

\_\_\_\_\_ **days per week**

No traveling in a motor vehicle



**Skip to question 10**

9. How much time did you usually spend on one of those days **traveling** in a train, bus, car, tram, or other kind of motor vehicle?

\_\_\_\_\_ **hours per day**

\_\_\_\_\_ **minutes per day**

Now think only about the **bicycling** and **walking** you might have done to travel to and from work, to do errands, or to go from place to place.

10. During the **last 7 days**, on how many days did you **bicycle** for at least 10 minutes at a time to go **from place to place**?

\_\_\_\_\_ **days per week**

No bicycling from place to place



**Skip to question 12**

11. How much time did you usually spend on one of those days to **bicycle** from place to place?

\_\_\_\_\_ **hours per day**  
 \_\_\_\_\_ **minutes per day**

12. During the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time to go **from place to place**?

\_\_\_\_\_ **days per week**

No walking from place to place



***Skip to PART 3:  
HOUSEWORK, HOUSE  
MAINTENANCE, AND  
CARING FOR FAMILY***

13. How much time did you usually spend on one of those days **walking** from place to place?

\_\_\_\_\_ **hours per day**  
 \_\_\_\_\_ **minutes per day**

### ***PART 3: HOUSEWORK, HOUSE MAINTENANCE, AND CARING FOR FAMILY***

This section is about some of the physical activities you might have done in the **last 7 days** in and around your home, like housework, gardening, yard work, general maintenance work, and caring for your family.

14. Think about only those physical activities that you did for at least 10 minutes at a time. During the **last 7 days**, on how many days did you do **vigorous** physical activities like heavy lifting, chopping wood, shoveling snow, or digging **in the garden or yard**?

\_\_\_\_\_ **days per week**

No vigorous activity in garden or yard



***Skip to question 16***

15. How much time did you usually spend on one of those days doing **vigorous** physical activities in the garden or yard?

\_\_\_\_\_ **hours per day**  
 \_\_\_\_\_ **minutes per day**

16. Again, think about only those physical activities that you did for at least 10 minutes at a time. During the **last 7 days**, on how many days did you do **moderate** activities like carrying light loads, sweeping, washing windows, and raking **in the garden or yard**?

\_\_\_\_\_ **days per week**

No moderate activity in garden or yard → **Skip to question 18**

17. How much time did you usually spend on one of those days doing **moderate** physical activities in the garden or yard?

\_\_\_\_\_ **hours per day**  
\_\_\_\_\_ **minutes per day**

18. Once again, think about only those physical activities that you did for at least 10 minutes at a time. During the **last 7 days**, on how many days did you do **moderate** activities like carrying light loads, washing windows, scrubbing floors and sweeping **inside your home**?

\_\_\_\_\_ **days per week**

No moderate activity inside home → **Skip to PART 4:  
RECREATION, SPORT  
AND LEISURE-TIME  
PHYSICAL ACTIVITY**

19. How much time did you usually spend on one of those days doing **moderate** physical activities inside your home?

\_\_\_\_\_ **hours per day**  
\_\_\_\_\_ **minutes per day**

#### **PART 4: RECREATION, SPORT, AND LEISURE-TIME PHYSICAL ACTIVITY**

This section is about all the physical activities that you did in the **last 7 days** solely for recreation, sport, exercise or leisure. Please do not include any activities you have already mentioned.

20. Not counting any walking you have already mentioned, during the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time **in your leisure time**?

\_\_\_\_\_ **days per week**

No walking in leisure time → **Skip to question 22**

21. How much time did you usually spend on one of those days **walking** in your leisure time?

\_\_\_\_\_ **hours per day**  
\_\_\_\_\_ **minutes per day**

22. Think about only those physical activities that you did for at least 10 minutes at a time. During the **last 7 days**, on how many days did you do **vigorous** physical

activities like aerobics, running, fast bicycling, or fast swimming **in your leisure time**?

\_\_\_\_\_ **days per week**

No vigorous activity in leisure time



**Skip to question 24**

23. How much time did you usually spend on one of those days doing **vigorous** physical activities in your leisure time?

\_\_\_\_\_ **hours per day**

\_\_\_\_\_ **minutes per day**

24. Again, think about only those physical activities that you did for at least 10 minutes at a time. During the **last 7 days**, on how many days did you do **moderate** physical activities like bicycling at a regular pace, swimming at a regular pace, and doubles tennis **in your leisure time**?

\_\_\_\_\_ **days per week**

No moderate activity in leisure time



**Skip to PART 5: TIME SPENT SITTING**

25. How much time did you usually spend on one of those days doing **moderate** physical activities in your leisure time?

\_\_\_\_\_ **hours per day**

\_\_\_\_\_ **minutes per day**

### **PART 5: TIME SPENT SITTING**

The last questions are about the time you spend sitting while at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading or sitting or lying down to watch television. Do not include any time spent sitting in a motor vehicle that you have already told me about.

26. During the **last 7 days**, how much time did you usually spend **sitting** on a **weekday**?

\_\_\_\_\_ **hours per day**

\_\_\_\_\_ **minutes per day**

27. During the **last 7 days**, how much time did you usually spend **sitting** on a **weekend day**?

\_\_\_\_\_ **hours per day**

\_\_\_\_\_ **minutes per day**

**This is the end of the questionnaire, thank you for participating**

Table 1

*Demographic Data*

Parameter	Frequency	Percent
<b>Gender</b>		
Male	3	42.9
Female	4	57.1
<b>Age at diagnosis</b>		
15	1	14.3
16	4	57.1
17	1	14.3
18	0	0
19	1	14.3
<b>Age at time of study</b>		
18	1	14.3
19	1	14.3
20	2	28.6
22	2	28.6
24	1	14.3
<b>Diagnosis</b>		
Acute Lymphoblastic Leukemia	1	14.3
Hodgkin's Lymphoma	1	14.3
NonHodgkin's Lymphoma	2	28.6
Osteogenic Sarcoma	1	14.3
Other	2	28.6
<b>Ethnicity/Race</b>		
Caucasian	4	57.1
Hispanic	3	42.9
<b>Education</b>		
High school graduate	2	28.6
College or technical school	4	57.1
Graduate school	1	14.3
<b>Income</b>		
0-\$10,000	5	71.4
\$10,001-20,000	1	14.3
\$20,001-40,000	1	14.3

Table 2

*Total scores for IPAQ, PSQI, and FSS*

Participant Identifier	IPAQ Activity Level	Global PSQI	FSS Average
Participant A	Moderate	6	2.3
Participant B	Moderate	6	3.7
Participant C	Moderate	10	3.33
Participant D	Moderate	0	0.64
Participant E	High	1	2.25
Participant F	Moderate	6	2
Participant G	High	9	4.88
Total Participant Average	Moderate	5.4	2.7

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