Measuring Adherence to Physical Activity Clinical Guidelines to Reduce Cancer-Related Fatigue in Post-Cancer Diagnosis Pediatric Patients: A Quality Improvement Project

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Submitted to: Sharon Norman - Chair

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Abstract

Background:

Cancer-Related Fatigue (CFR) can be a significantly debilitating side effect of cancer treatment. Clinical Practice Guidelines recommend physical activity as a means to reduce CRF in pediatric oncology patients. The challenge, however, is in translating this evidence into clinical care.

Methods and Intervention:

Patients and parents were encountered to discuss measuring adherence to physical activity Clinical Practice Guidelines. Patients aged 8-16 years old and who had been off treatment for 2 years were engaged to wear a wrist-worn fitness tracker to measure and collect physical activity metrics (duration of activity, heart rate, etc). Severity of CRF and parental perceived fatigue was assessed before and after a 6-week intervention period using the PedsQL Multidimensional Fatigue Scale.

Results:

Six patient/parent dyads were encountered. Four total participants completed the initial survey. Demographics included 2 male patients, 1 male parent, and 1 female parent. Reported ethnicities included 2 Hispanic parents, 1 Hispanic patient, and 1 Asian patient. Patient 1 and 2 reported their highest fatigue in the cognitive category. Parent 2 reported the highest perceived fatigue in the general category. Parent 1 perceived fatigue scores could not be calculated. There were no reports of physical activity or post-intervention CRF surveys from any of the 6 dyad participants.

Conclusion:

Parental reports of CRF were more severe and in different categories than the scores reported by patients. However, an interpretation of the impact of the intervention cannot be made due to the significant hole in physical activity metrics and post-intervention fatigue scale data collection.

Introduction

Problem Description

The American Cancer Society predicts approximately 11,000 children under the age of 15 will be diagnosed with cancer in 2021 (*Key Statistics for Childhood Cancers, 2021)*. In the 1970s, approximately 60% of children diagnosed with cancer between the ages of 0-19 years old survived at least five years. Today, the percentage of children surviving for at least five years has increased to 84% (*Key Statistics for Childhood Cancers*, 2021).

While increasingly potent cancer treatments have improved five-year survival rates, they have also been linked to significant, long-term morbidity. There are physical and psychosocial implications of oncology treatments that can impair a child's quality of life for years beyond their acute treatment. One of the most pervasive, but often overlooked and under-treated, ramifications of cancer treatments is Cancer-Related Fatigue (CRF) (Antill Keener, 2019).

CRF is defined by the National Comprehensive Cancer Network as "a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning" ("Cancer-Related Fatigue," 2020).

One area of research that has emerged as a possible solution to CRF in pediatric cancer populations is exercise oncology. The research of exercise oncology aims to assess the effect of including physical activity into either acute cancer treatments or during the survivorship phase of cancer care. Evidence of exercise oncology within adult populations has been promising thus far, so pediatric populations have recently been included in similar research. Current research results in pediatric populations indicate positive outcomes in reducing CRF, similarly to outcomes seen in adult populations. A pediatric hematology and oncology survivorship clinic at a local children's hospital in the Pacific Northwest includes physical activity Clinical Practice Guidelines into the care plan of their pediatric oncology survivors. However, this clinic has not yet measured adherence to physical activity Clinical Practice Guidelines and assessed reductions in the severity of a patient's CRF.

Available Knowledge

CRF is a significant issue within the pediatric cancer population because the effects impair physical, emotional, and mental wellbeing that can last for an extended period of time. In older children and young adults, CRF may manifest from emotional distress induced by worrying about family members, missing social milestones, and falling behind in school. In younger children, CRF may be described as more of physical heaviness and inability to move (Antill Keener, 2019; Kudubes et al., 2019). Studies suggest that children and adolescents who experience prolonged treatments effects, such as fatigue, report decreased feelings of wellbeing in their survivorship period (Sedmak, 2020). Other research articles have recommended that CRF be a priority in follow-up care because its negative association with a child's Health-Related Quality of Life (HRQol) has been noted independent of other neurocognitive impairments expected during treatment (van Erp et al., 2021).

CRF is a difficult symptom for patients to endure, but it also a difficult symptom for parents to recognize and classify in their children. Parents are advocates for their children and can often be in situations in which they are proxy communicators. Unfortunately, qualitative studies have illustrated that parents struggle to see CRF as the independent and manageable side-effect that it is. Parents report viewing fatigue as a normal result of cancer treatment or an anticipated behavior due to their child's age (Antill Keener, 2019; Loades et al., 2020).

Additionally, a prospective repeated-measure study found that parents have statistically significant overestimations of the prevalence and severity of cancer-related symptoms in their children (Montgomery et al., 2021). Because CRF can have such a profound effect on a patient's life, it is important to understand areas in which there could be inaccuracies in symptom reports so that patients can receive the mitigating interventions they need.

A benefit to incorporating exercise oncology into the survivorship plans of pediatric patients is that physical activity can often be completed as developmentally appropriate play. A randomized control trial discovered that just 4 days of adventure-based physical activity (shuttle runs, rock climbing, rope obstacles, etc.) greatly reduced the level of the participant's CRF (Li et al., 2018). In other studies, such as two randomized control trials and two prospective trials, CRF was evaluated in response to exercise interventions with differing activity intensity, exercise medium, length of study, and population of inclusion. The varying forms of activity intensity and exercise medium included daily walking, in-home exercise coaching, exercise and fatigue education, or computer-based exercise games. The participant populations across the four studies ranged from ages 6-18 years old and were either in active inpatient treatments, active outpatient treatments, or up to 12 months into survivorship. Trial lengths ranged from 12-week interventions to follow-up assessments at 12 months. Regardless of exercise modality, intensity, and duration, there was a reduction in CRF in response to physical activity across all studies (Kudubes et al., 2019; Lam et al., 2018; Platschek, 2017; Van Dijk-Lokkart et al., 2019)). Each study, in addition to a meta-analysis of observational studies, found that the reduction in CRF also correlated with improvements in rated Quality of Life (QoL) and Health-Related Quality of Life HRQoL Antwi et al., 2019; Kudubes et al., 2018; Lam et al., 2018; Platschek et al., 2017; Van Dijk-Lokkart et al., 2019). Additionally, according to the Clinical Practice Guidelines for managing CRF in pediatric oncology/hematopoietic stem cell transplants recipients, physical activity should be recommended in this population because the benefits of the intervention persist independent of the child's cancer diagnosis, phase of cancer treatment, level of fatigue prior to initiating physical activity, or the amount of time spent being physically active (Robinson et al., 2018).

Rationale

The Johns Hopkins Nursing Evidence-Based Practice model (JHNEBP) expedites the process of Evidence-based Practices being integrated into the clinical setting through an "Inquiry, Practice, and Learning" translational model (*Johns Hopkins Evidence-Based Practice for Nurses and Healthcare Professionals* 2022).

Inquiry, the first step in the model, acts a catalyst to change in evidence-based practice. Improvements or changes in patient care and patient-outcomes are often spurred from questions regarding if the most effective, safe, affordable, and/or up-to-date practices are being utilized (*Johns Hopkins Evidence-Based Practice for Nurses and Healthcare Professionals* 2022). The increased recognition of CRF, and the question of how it can be better managed, has led researchers and health-care practitioners to innovate traditional treatment regiments and incorporate a multi-modal approach to care. The inquiry shepherding this project is how adherence to physical activity Clinical Practice Guidelines reduces the severity of CRF in pediatric patients.

The "Practice" component of the JHNEBP model assess the who? what? when? where? why? how? how much? of the interventions related to implementing Evidence-based practices. Success in this step in the JHNEBP framework requires substantial interprofessional collaboration. Incorporating each interdisciplinary team in potential changes to clinical practice allows for the contribution of ideas/recommendations from varying levels of expertise. Institution-wide inclusion may also lead to greater application of the clinical changes within a facility (*Johns Hopkins Evidence-Based Practice for Nurses and Healthcare Professionals* 2022). The clinic facilitating this QI project has incorporated oncologists, nurse practitioners, physical therapists, psychologists, nurses, and other members of the patient-care team.

The “Learning” portion of the model is built upon the notion that learning provides an avenue to apply and integrate new knowledge after it is utilized in practice – learning is doing. This framework of learning may also extrapolate beyond the initial clinical area of interest and into other areas of practice (*Johns Hopkins Evidence-Based Practice for Nurses and Healthcare Professionals* 2022). This QI project may illuminate how encouraging adherence to the Evidence-based recommendations included in Clinical Practice Guidelines can improve patients’ symptoms. Under this model, blending physical activity into the clinical practice of the interdisciplinary team can lead to greater collaboration, improved patient outcomes, and an opportunity to use this new knowledge in other areas of care within this population.

Specific Aims

The goal of this project is to measure adherence to physical activity Clinical Practice Guidelines and evaluate the efficacy of physical activity in reducing CRF in pediatric oncology survivors at a local children’s hospital. Patient severity of CRF and parental perception of CRF severity will also be assessed to determine congruency between patient and parental reports.

Methods

Context

This local children's hospital in the Pacific Northwest is home to a children's Cancer and Blood Disorder Program that has a team of oncologists, neurosurgeons, neurologists, psychiatrists, endocrinologists, nurse practitioners, physical therapists, and many more team members. The hospital also has a survivorship clinic: the KITE clinic. The KITE clinic, which stands for Knowledge and Inspiration after Treatment Ends, offers guidance in navigating the physical and mental health components of life after acute cancer treatment. Each appointment with the KITE clinic offers patients an individualized plan of care that includes nutritional advice and how to engage in fitness activities. They also provide support in addressing new social issues for both children and patients, as well as ways in which school and work challenges can be mitigated (*Life After Cancer*). The KITE clinic and other specified hematology/oncology clinics related to the children's hospital largely interact with patients via face-to-face communication and appointments are usually covered by most insurance companies. There is one oncologist in the KITE clinic that oversees long-term outcomes who is supportive of this project. Additionally, the medical director and physical therapists are also supportive of this initiative.

This project included patients, aged 8-16 years old, who have been off cancer treatment for at least 24 months, and who are willing to wear a writs-worn fitness tracker.

The Clinical Practice Guideline followed by the pediatric oncology clinic and the gold standard from the Children's Oncology Group to which adherence was being measured was to recommend 60 minutes of physical activity each day (Landier, 2018; Robinson et al., 2018).

Intervention

Patient/parent dyads were encountered during annual clinic visits with their provider. These clinic visits were used to discuss the physical activity Clinical Practice Guideline, how physical activity is beneficial for reducing the severity of CRF, and how they related to this quality improvement project. It was discussed that participation in this project to measure adherence to Clinical Practice Guidelines would include data collection over a 6-week period from the time of the patient's initial clinic visit.

A wrist-worn fitness tracker was given to each participating child. The fitness tracker was given to patients to record steps taken, distance traveled, exercise duration, calories burned, and sleep patterns so that thorough physical activity data could be collected. Dyads were informed that the wrist-worn fitness tracker had the ability to be synched to a free phone application so that physical activity metrics could be reported via MyHealth messaging at convenient time intervals.

The physical therapy team at the Children's hospital was consulted regarding ideas for activity/play for participating patients. The physical therapist also provided insight into patients' typical guidance regarding physical activity, which helped conversations during the intervention period mirror the philosophies already established in their care plans.

Study of the Intervention

Pediatric participants and their guardian were both be provided with the PedsQL Multidimensional Fatigue Scale to complete voluntarily at the initial patient encounter and after a 6-week period. Time to complete the questionnaire could have ranged from approximately 20-30 minutes per family member. Qualtrics software was used as the landing page for the project and was optimized to create and supply the online questionnaires. A unique identification number/code was linked to each participating family so that data could be linked to the respective child and guardian.

The PedsQL Multidimensional Fatigue Scale was utilized to assess the severity of the patient's fatigue and the parent's perception of the severity of the patient's fatigue. This 18-question survey evaluates levels of general fatigue, sleep/rest fatigue, and cognitive fatigue. Each section was comprised of 6 questions scored from 0-4. Selections on the survey indicating levels of fatigue are as follows: '0' = never being a problem, '1' = almost never a problem, '2' = sometimes a problem, '3' = often a problem, and '4' = almost always a problem. The scores are reversed and transformed in a linear fashion from 0-100, meaning a selection of 0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0. Total fatigue severity was scored by calculating the mean of the scores. If over ½ of the scale questions were not answered, the score was not be calculated. Higher scores on this scale suggest a lower severity of fatigue ("PedsQL Multidimensional Fatigue Scale "; Varni, 2002).

Reports of physical activity metrics collected via the wrist-worn fitness tracker were used to assess adherence to Clinical Practice Guidelines. Correlating outcomes with the intervention was based on whether the fatigue scale indicated less severe fatigue after the intervention period than before.

Measure

The Multidimensional Fatigue Scale, that was provided at the initial patient visit and again at the end of intervention period, has been validated for individual patient use in children aged 5-18 years old and has been validated for parent-proxy reports for children aged 2-18 years old. The internal consistency reliability score: α = 0.89 for child reports and α = 0.93 for parent reports

(Varni et al., 2002). Separate questionnaires were provided for children and their guardian via an online link at the initial visit in the survivorship clinic. Children received the questionnaire to report their baseline severity of CRF and parents received the same questionnaires to report the perception of their child's baseline CRF.

At the end of the intervention period, patients and parents/guardians were sent a link to the same questionnaire they completed at the initial clinic visit. Final reports of CRF severity were recorded, as well as the parent/guardian's perception of their child's symptoms. Paper questionnaires, envelopes, and return postage were offered for families who did not have technological resources. The severity of the patient's CRF and the parental perception of the patient's CRF was measured prior to and after the intervention period.

Analysis

Data was be analyzed via SPSS Version 27.0 in Windows 10. Descriptive statistics was used to describe both the child and guardian samples. Means/standard deviations were used to describe continuous variables and percentages/frequencies were used to describe categorical variables. Markers of physical activity (i.e., heart rate, steps taken, calories burned, and distanced traveled) were used to create a composite score for the physical activity variable. Correlations were used to assess bivariate relationships between the explanatory variables (child physical activity and sleep patterns), outcome variables (child CRF), and the covariates. Interclass correlations were utilized to determine the agreement between child and parent reports of CRF.

Ethical Considerations

All staff within the hematology/oncology clinic at Randall Children's Hospital were informed of this quality improvement project. Major stakeholders graciously provided support in this endeavor. Patient and family participation in this project included patients and families who wanted to participate voluntarily. Personal Health Identifiers of participating patients and families were not recorded. Safety parameters were discussed, mirrored the clinic's established safety protocols, and were approved by members of the patient's care team. This project was submitted to the Investigational Review Board at OHSU and Legacy system and both institutions deemed this a Quality Improvement project.

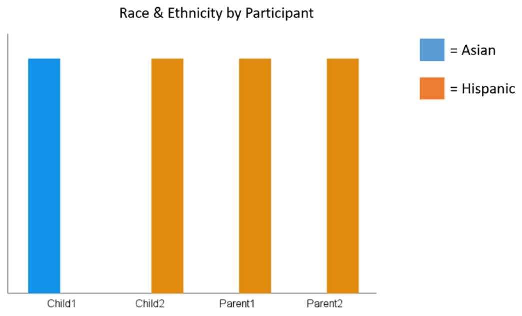
Results

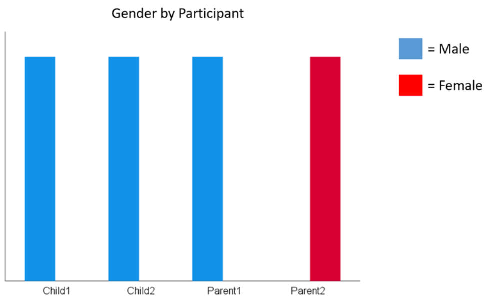
The intent of the project was to measure adherence to physical activity Clinical Practice Guidelines and the correlation between severity of CRF and assess parental perception of severity of CRF. There were 6 patient/parent interactions within the local children's hospital hematology/oncology clinic. Of the 6 dyads addressed, all 6 dyads agreed to participate in the QI project – there were 0 declinations to participate. Of the 12 total participants (6 patients and 6 parents – 1 parent per patient), 4 individuals completed the pre-intervention fatigue survey. There were 2 male pediatric participants and 2 parent participants who completed the survey. 0 of the 12 total participants completed the post-intervention fatigue survey. 0 patient/parent dyads reported physical activity data.

Demographically, the male patients reported themselves to be Hispanic/Latinx and Asian. Of the initial fatigue survey, one male patient participant reported a total fatigue score of 62.5 in general fatigue, 83.3 in sleep/rest fatigue, and 58.3 in cognitive fatigue' The highest severity of fatigue was reported in the cognitive fatigue category of the survey. The other male patient participant reported a total fatigue score of 100 in general fatigue, 87.5 in sleep/rest fatigue, and

66.6 in cognitive fatigue. The highest severity of fatigue was also reported in the cognitive fatigue category of the survey.

The parental demographic responses both reported themselves to be Hispanic/Latinx. Of their initial fatigue surveys, the male parent did not complete over 50% of the questions so that survey could not be calculated. The female parent reported their child's fatigue to represent a total score of 8.3 in general fatigue, 33.3 in sleep/rest fatigue, and 16.6 in cognitive fatigue. The highest perceived area of fatigue severity was reported in the general fatigue category.





As seen between the female parent report and both patient reports, there was a significant discrepancy between parental perception and patient reports of CRF severity. The most severe fatigue score between the two pale patient participants was 58.3. The most severe parental perception score of CRF was 8.3.

Discussion

Summary

Research in adult oncology populations has illustrated how physical activity is advantageous in reducing the severity of CRF. Like many areas of medicine, shifts in Evidence-based care trickle down from adult populations into pediatric populations after efficacy of a new intervention is observed. While emerging data in pediatric populations indicates physical activity is effective in reducing the severity of CRF, and thus why Clinical Practice Guidelines were created, it can be difficult to assess a patient's comfort in adapting/adhering to guidelines. There was a breakdown in communication from patient/parent dyads, which prevented physical activity and post-intervention CRF data to be collected. The gap in this area of data collection prevents the measurement of adherence to the Clinical Practice Guidelines and the patient/parent perception of fatigue severity to be assessed. While there was a significant hole in data collection, there is one particular area in which positive extrapolations from this project can be made. There were no declinations in the patient/parent dyad interactions, which may represent a positive outlook on physical activity integration/adherence within this population.

Interpretation

The communication from patient/parent dyads was not sufficiently established, which led to a significant hole in data collection. There was a marked difference between the initial report of the female parent's perception of fatigue severity and the patient reports of their fatigue severity. Had there been a more effective means of communication, there may have been more data to understand outcomes and impact of the intervention.

Limitations

There were many limitations within this project. COVID-19 pandemic played a massively influential role in healthcare across the globe. In the setting of this project, the Omicron variant was surging during the time of patient interactions. The presence of Omicron created an environment of even more brief and limited face-to-face communication, particularly in this susceptible population. A decreased amount of time with dyads may have contributed to the breakdown in communication due to insufficient explanations or misinterpretation of communication modality. The intended method of communication, MyHealth messaging, was utilized to reach-out to the dyads on a few occasions without response.

The time of the year in which patients were being engaged was another limitation of this project. The patients who are applicable for this project are traditionally seen in the summer months. As their distance from treatment increases, the urgency and frequency of clinic visits decreases. Because many of these children only have one clinic visit a year, they typically schedule an appointment during a time in which they do not have to miss school. Additionally, the winter months in the Pacific Northwest are notoriously cold and rainy. With the Omicron variant surging there is a decreased ability to be physically active indoors and the climate of the region makes physical activity in an outdoor setting uncomfortable and unideal.

Conclusions

In this Quality Improvement project, the intent to understand adherence to physical activity Clinical Practice Guidelines and correlations with Cancer-Related Fatigue were limited by communication breakdowns and the subsequently missing data. While the COVID-19 pandemic played a limiting role in this project, there were no declinations to participate in the project despite being a susceptible population. This is an important and useful piece of information as it could represent an openness to engage with physical activity interventions moving forward. Warmer weather, time off from school, and decreased community transmission rates may all optimize future endeavors similar to this project.

The willingness to participate experienced in this project indicates a potential for it to be implemented again when community and environmental conditions are more optimal. The intrinsic benefits of physical activity could be molded to fit pediatric patients in chronic and acute settings. The greatest levels of fatigue indicated by the two participants was in cognitive aspects of the survey. Future inquiry could focus more specifically on ways to maximize physical activity to reduce cognitive fatigue.

Progression from this project should be tailored to fit a time in which many applicable patients will be scheduling clinic visits – i.e., summer break from school and/when the weather is agreeable. Communication methods and expectations should be a greater topic of conversation in the initial interaction, as it is the lynchpin in collecting data. Also, as COVID-19 begins to become a more understood/controlled aspect of society, more interactions and broader expansion across pediatric populations can begin.

Other Information

Funding

Sigma Theta Tau Beta Psi chapter provided funding via the Naomi Ballard Research Award. This funding allowed for the purchase of wrist-worn fitness trackers for the participants, in addition to access to statistical data analysis and scholarship dissemination.

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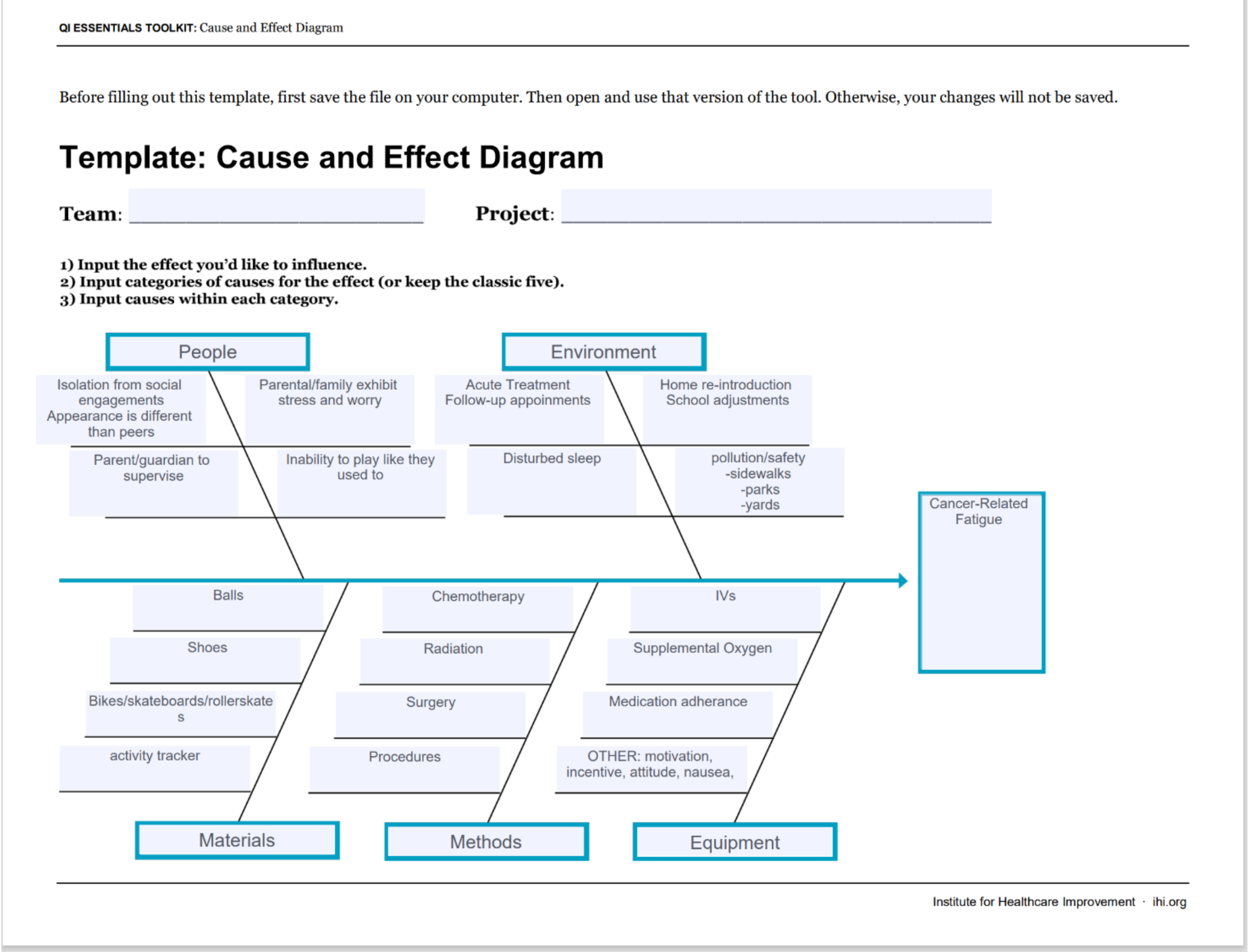
Appendices

Cause and Effect Diagram



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Template: Cause and Effect Diagram

Team: ______________________________ **Project:** ____

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2) Input categories of causes for the effect (or keep the classic five).
3) Input causes within each category.

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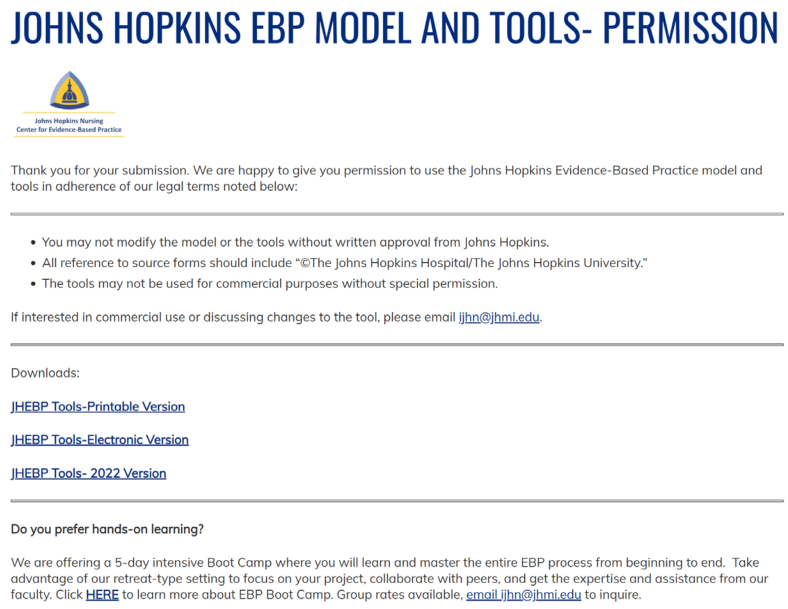

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The Johns Hopkins Evidence-Based Practice (JHEBP) Model for Nurses and HCPs—Essential Components: Inquiry, Practice, and Learning

The revised Johns Hopkins Evidence-Based Practice (JHEBP) Model for Nurses and HCPs (see Figure 3.1) is composed of three interrelated components—inquiry, practice, and learning—that take place in the context of interprofessional collaborative practice.

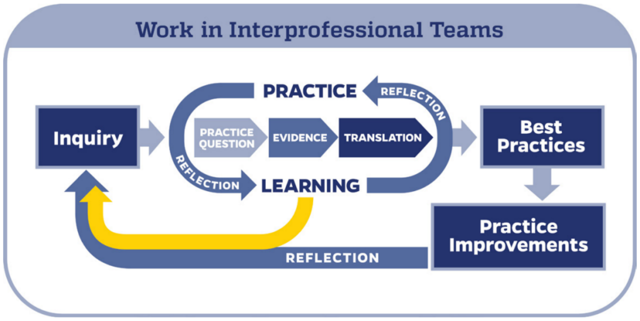

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Figure 3.1 The Johns Hopkins Evidence-Based Practice Model for Nurses and HCPs (2020).

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These Special Terms include the terms and conditions of the User License Agreement General Terms, which are hereby incorporated by this reference as though the same was set forth in its entirety and shall be effective as of the Special Terms Effective Date set forth herein.

All capitalized terms which are not defined herein shall have the same meanings as set forth in the User License Agreement General Terms.

These Special Terms, including all attachments and the User License Agreement General Terms contain the entire understanding of the Parties with respect to the subject matter herein and supersedes all previous agreements and undertakings with respect thereto. If the terms and conditions of these Special Terms or any attachment conflict with the terms and conditions of the User License Agreement General Terms, the terms and conditions of the User License Agreement General Terms will control, unless these Special Terms specifically acknowledge the conflict and expressly states that the conflicting term or provision found in these Special Terms control for these Special Terms only. These Special Terms may be modified only by written agreement signed by the Parties. 1. **User information**

User name	Elizabeth Brown
Category of User	Student
User address	3181 SW Sam Jackson Park Rd Portland 97239 OR United States of America
User VAT number	
User email	brelizab@ohsu.edu
User phone	3038682317
Billing Address	3181 SW Sam Jackson Park Rd Portland 97239 OR United States of America

2. **General information**

Effective Date	Date of acceptance of these Special Terms by the User
Expiration Date ("Term")	Upon completion of the Stated Purpose
Name of User's contact in charge of the request	Elizabeth Brown

3. **Identification of the COA**

Name of the COA	PedsQL™ - Pediatric Quality of Life Inventory™
Author	Varni JW
Copyright Holder	Varni James W, PhD
Copyright notice	Copyright © 1998 JW Varni, Ph.D. All rights reserved
Bibliographic reference	
Modules/versions needed	PedsQL™ Cancer module PedsQL™ Multidimensional Fatigue Scale™

4. Context of use of the COA

The User undertakes to use the COA solely in the context of the Stated Purpose as defined hereafter.

4.1 Stated Purpose

Other project

Title	Evaluating the Impact of Physical Activity on Cancer-Related Fatigue and Health-Related Quality of Life in Pediatric Oncology Survivors: A Quality Improvement Project
Disease or condition	Cancer-Related Fatigue
Planned Term*	Start: 07/2021; End: 05/2022
Description (including format or media)	This quality improvement project would use physical activity as an intervention to reduce Cancer-Related Fatigue and improve Health-Related Quality of Life in pediatric oncology survivors. Reports of Cancer-Related Fatigue and Health-Related Quality of Life would be measured via the PedsQL Cancer Module and the PedsQL Multidimensional Fatigue Scale in an online format or paper format for patients who do not have access to technology.

4.2 Country and languages

MRT grants the License to use the COA on the following countries and in the languages indicated in the table below:

Version/Module	**Language**	**For use in the following country**
PedsQL™ Cancer module	English	the USA
PedsQL™ Cancer module	Spanish	the USA
PedsQL™ Multidimensional Fatigue Scale™	English	the USA
PedsQL™ Multidimensional Fatigue Scale™	Spanish	the USA

The User understands that the countries indicated above are provided for information purposes. The User may use the COA in other countries than the ones indicated above.

5. Specific requirements for the COA

- The Copyright Holder of the COA has granted ICON LS exclusive rights to translate the COA in the context of commercial studies or any project funded by for-profit entities. ICON LS is the only organization authorized to perform linguistic validation/translation work on the COA.

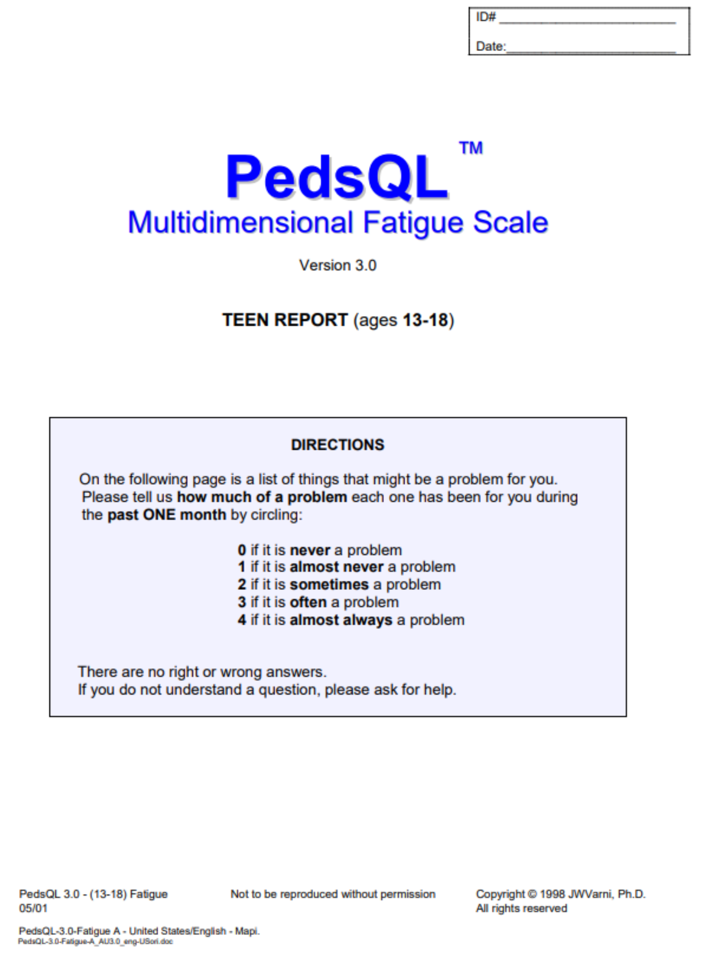
- In case the User wants to translate the COA in an academic context, the User shall send the back translations to the Copyright Holder for approval

- In case the User wants to use an e-Version of the COA, the User shall send the Screenshots of the original version of the COA to the Copyright Holder through MRT for approval. The Copyright Holder may request consulting fees for this review

- In case the User wants to use an e-Version of the COA, ICON LS shall update (if needed) and populate the COA translations into the User's or IT Company's system and the User shall send the Screenshots of the translations of the COA to ICON LS for approval. The update (if needed), population of translations and the Screenshots review may incur additional fees.

- By accepting these Special Terms, the User acknowledges and confirms that it has read and approves the User Agreement General Terms.

PedsQL Multidimensional Fatigue Scale and Scoring Tool



ID# ____________________

Date:____________________

PedsQL™

Multidimensional Fatigue Scale

Version 3.0

TEEN REPORT (ages **13-18**)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

PedsQL 3.0 - (13-18) Fatigue
05/01

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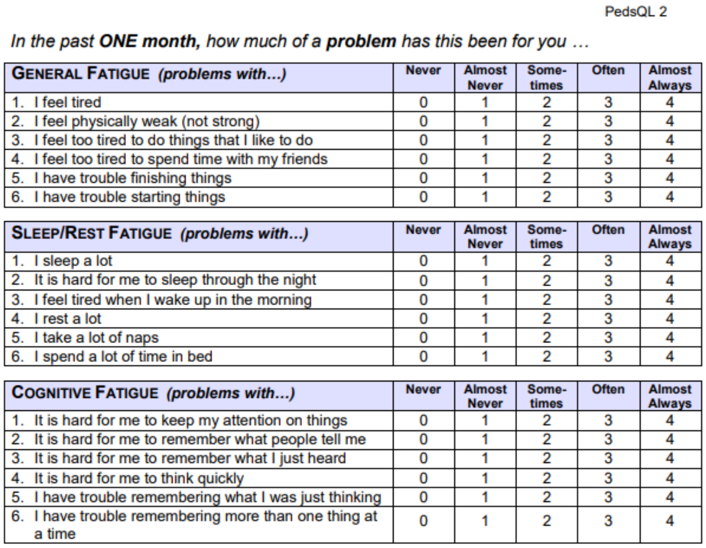
PedsQL-3.0-Fatigue A - United States/English - Mapi.
PedsQL-3.0-Fatigue-A_AU3.0_eng-USori.doc



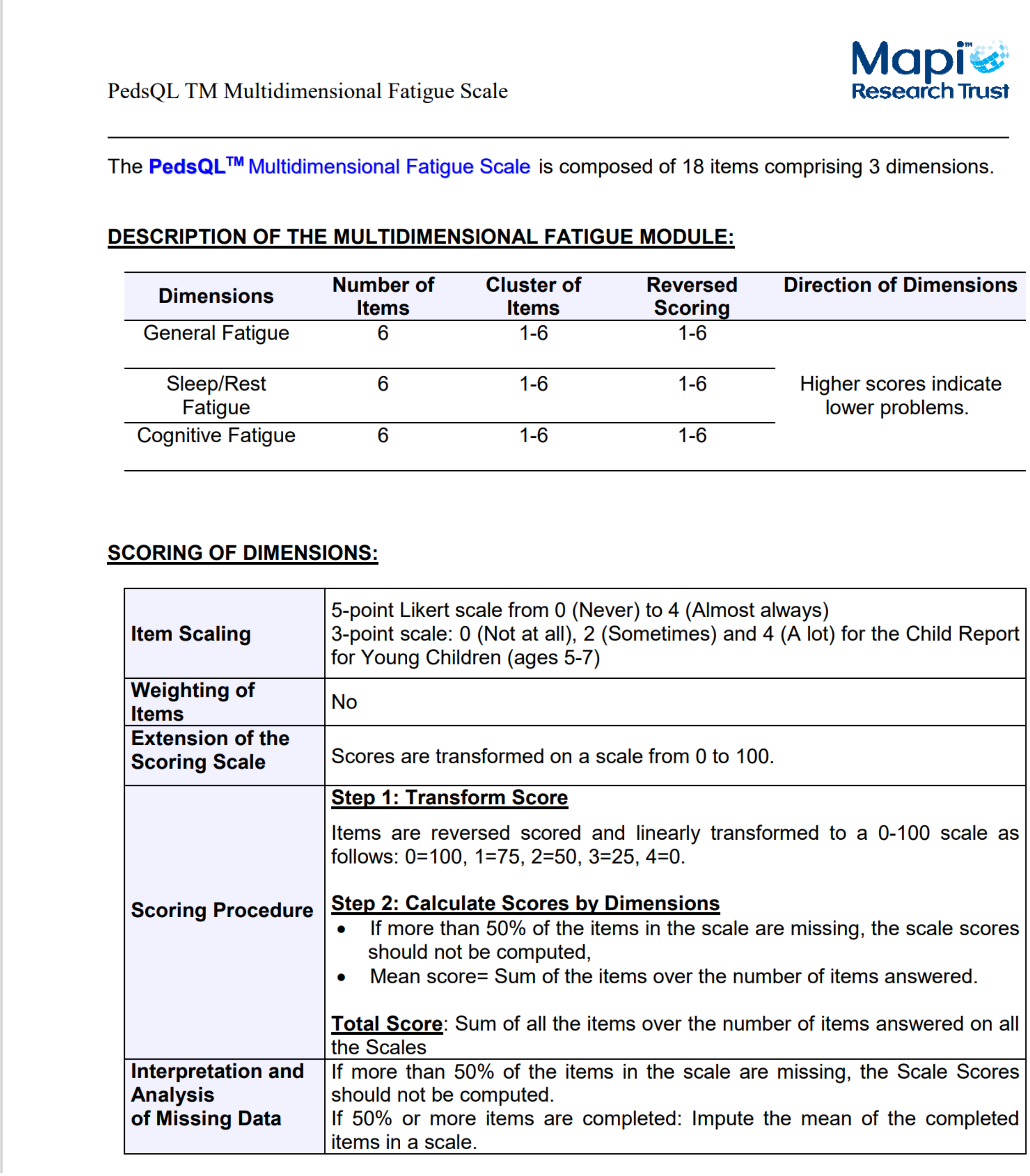
PedsQL 2

*In the past **ONE month**, how much of a **problem** has this been for you …*

GENERAL FATIGUE *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I feel tired	0	1	2	3	4
2. I feel physically weak (not strong)	0	1	2	3	4
3. I feel too tired to do things that I like to do	0	1	2	3	4
4. I feel too tired to spend time with my friends	0	1	2	3	4
5. I have trouble finishing things	0	1	2	3	4
6. I have trouble starting things	0	1	2	3	4

SLEEP/REST FATIGUE *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I sleep a lot	0	1	2	3	4
2. It is hard for me to sleep through the night	0	1	2	3	4
3. I feel tired when I wake up in the morning	0	1	2	3	4
4. I rest a lot	0	1	2	3	4
5. I take a lot of naps	0	1	2	3	4
6. I spend a lot of time in bed	0	1	2	3	4

COGNITIVE FATIGUE *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to keep my attention on things	0	1	2	3	4
2. It is hard for me to remember what people tell me	0	1	2	3	4
3. It is hard for me to remember what I just heard	0	1	2	3	4
4. It is hard for me to think quickly	0	1	2	3	4
5. I have trouble remembering what I was just thinking	0	1	2	3	4
6. I have trouble remembering more than one thing at a time	0	1	2	3	4



PedsQL TM Multidimensional Fatigue Scale

Mapi Research Trust

The **PedsQL^{TM}** Multidimensional Fatigue Scale is composed of 18 items comprising 3 dimensions.

DESCRIPTION OF THE MULTIDIMENSIONAL FATIGUE MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
General Fatigue	6	1-6	1-6	Higher scores indicate lower problems.
Sleep/Rest Fatigue	6	1-6	1-6	
Cognitive Fatigue	6	1-6	1-6	

SCORING OF DIMENSIONS:

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
Scoring Procedure	**Step 1: Transform Score** Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0. **Step 2: Calculate Scores by Dimensions** • If more than 50% of the items in the scale are missing, the scale scores should not be computed, • Mean score= Sum of the items over the number of items answered. **Total Score**: Sum of all the items over the number of items answered on all the Scales
Interpretation and Analysis of Missing Data	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed. If 50% or more items are completed: Impute the mean of the completed items in a scale.

OHSU IRB Approval

Dear Investigator:

On 9/15/2021, the IRB reviewed the following submission:

Title of Study:	Implementing Physical Activity Clinical Guidelines to Reduce Cancer-Related Fatigue in Post-Cancer Diagnosis Pediatric Patients
Investigator:	Sharon Norman
IRB ID:	STUDY00023305
Funding:	Name: Sigma Theta Tau International, Beta Psi Chapter, PPQ #: Unfunded

The IRB determined that the proposed activity is not research involving human subjects. IRB review and approval is not required.

Certain changes to the research plan may affect this determination. Contact the IRB Office if your project changes and you have questions regarding the need for IRB oversight.

If this project involves the collection, use, or disclosure of Protected Health Information (PHI), you must comply with all applicable requirements under HIPAA. See the HIPAA and Research website and the Information Privacy and Security website for more information.

Sincerely,

The OHSU IRB Office

Legacy IRB Approval

LEGACY HEALTH INSTITUTIONAL REVIEW BOARD

NOTICE OF IRB ACTION

Protocol Title: Reducing Cancer-Related Fatigue in Pediatric Oncology Survivors Through Physical Interventions	
Principal Investigator: Elizabeth Brown	Board Action: EXEMPT/QI DETERMINATION
Submission: NEW STUDY QI EXEMPTION: submitted 8-9-21	Date of Board Action: 8-26-21
Version Date of Protocol:	Level of Review: Exempt
Site: RCH	Expedited Reviewer: P. Newton
Legacy Site Manager: Tricia Mickle	Study Risk Level: QI/Exempt
Study Contact: Elizabeth Brown	Continuing Review Frequency: None
IRB Tracking Number: 1558	

SUBMITTED DOCUMENTS REVIEWED

- ☐ Legacy Guidelines for Graduate Student RN Project Approval Form 7-20-21
- ☐ Investigator's CV: E. Brown
- ☐ Study Staff Training Information: CITI Documents
- ☐ Subject Materials: PedsQL
- ☐ Other: C. Bianchini Questions

REVIEW

REVIEW TYPE	IRB ACTION
☐ Initial Review ☐ Exemption Review ☐ QI Review	☐ Exempt/QI from IRB Review determination

ADDITIONAL FINDINGS AND REQUIREMENTS FOR THIS STUDY

Exempt/QI determination 8-25-21

- ☐ The study is not greater than minimal risk.
- ☐ Legacy site management must be apprised of the study and the Board’s action.

APPROVAL IS GRANTED SUBJECT TO THE FOLLOWING

1. Conduct the research in accordance with the protocol, applicable laws and regulations, Legacy policies, and the principles of research ethics as set forth in the Belmont Report.
2. Unless consent has been waived, conduct the informed consent process without coercion or undue influence, and provide the potential subject sufficient opportunity to consider whether or not to participate.
3. Use only the most current consent form bearing the Legacy Health IRB "APPROVED" stamp.
4. Provide non-English speaking subjects with a certified translation of the approved consent form in the subject's first language. The translation must be approved by Legacy Health IRB.
5. Obtain pre-approval from Legacy IRB for changes in research.
6. Obtain pre-approval from Legacy IRB for planned deviations and changes in research activity.
7. Report all deviations, violations, adverse events in a timely manner and submit corrective actions.
8. Report all unanticipated problems in a timely manner and submit plans to resolve such problems.
9. Provide reports to Legacy IRB concerning the progress of the research, when requested.
10. Ensure that prior to performing study-related duties, each member of the research study team has had training in the protection of human subjects appropriate to the processes required in the approved protocol.
11. Retain all IRB documentation at study site.

IRB ACTION SIGNATURE

APPROVED BY LEGACY IRB – EXPEDITED REVIEW – DATE: 8-26-21

Paul Newton JD CIP – LEGACY IRB ADMINISTRATOR

8-26-21

Paul Newton JD CIP
Legacy IRB Administrator

DATE

IRB CONTACT

If you have questions or concerns or wish to ask the IRB to reconsider its action, please contact Paul Newton, JD, CIP, Research Regulatory Specialist Sr. at 503-413-5355, pwnewton@lhs.org.

If you have questions regarding the administrative procedures for your study, please contact Valerie Stallings, IRB Administrative Assistant at 503-413-2916, vstallin@lhs.org.

IRB INFORMATION

Joe Frascella, PhD, VP of Research, Legacy Institutional Official, Legacy Research Institute

Legacy IRB: FWA00001280

REG: #1 (Good Sam): 00000677

REG: #2 (Emanuel): 00000678 LRI IRB (LRI): 00011999 Cc: Study contact:

Legacy Site Manager:

Ms. Valerie Stallings:

END OF IRB ACTION DOCUMENT

Letter of Support from Clinical Agency

Date: *[06/02/2021]*

Dear *[Elizabeth Brown]*,

This letter confirms that I, *[Dr. Sharon Norman]*, allow *[Elizabeth Brown]* (OHSU Doctor of Nursing Practice Student) access to complete his/her DNP Final Project at our clinical site. The project will take place from approximately *[06/29/2021]* to *[09/30/2021]*.

This letter summarizes the core elements of the project proposal, already reviewed by the DNP Project Preceptor and clinical liaison (if applicable):

- **Project Site(s)**: *[Randall Children's Hospital Cancer and Blood Disorders Program - 2801 N Gantenbein Ave 3rd floor, Portland, OR 97227]*
- **Project Plan: Use the following guidance to describe your project in a brief paragraph.**
    - Identified Clinical Problem: *[Cancer-Related Fatigue (CRF) is a significant side-effect of cancer treatment in pediatric populations that is present from acute treatment through survivorship. This intervention has not yet been utilized in the population at Randall Children's Hospital.]*
    - Rationale: *[Physical activity as a method to reduce CRF has shown to be very effective in adult populations. Immerging evidence in pediatric populations shows similar efficacy in reducing CRF. Importantly, research also indicates that it is a safe intervention in children.]*
    - Specific Aims: *[1) Reduce Cancer-Related Fatigue 2) Improve Health-Related Quality of Life.]*
    - Methods/Interventions/Measures: *[Participants will be given a broad guide for physical activity ideas that was outlined by a staff physical therapist (Dr. Greg Sjostrand). Heart rate, steps taken, calories burned, duration of exercise, and sleeping patterns will be monitored via a wrist-worn fitness tracker. Fatigue will be measured via the PedsQL 3.0 Multidimensional Fatigue Scale. Health-Related Quality of Life will be measured using the PedsQL Fatigue Scale. Reports will be collected by the participant, and then a guardian proxy report will be recorded as well.]*
    - Data Management: *[Patient demographics, physical activity metrics, CRF severity, and Health-Related Quality of Life scores will be collected. Data will not be identifiable. Qaultrics applications will be used for both its data collection and privacy protection capabilities.]*
    - Site(s) Support: *[The pediatric oncology/hematology clinic will be utilized for direct patient interaction so that the goals of QI project can be outlined, patient/family questions can be answered, and baseline data regarding physical activity levels can be collected.]*
    - Other: *[As part of the QI project, I will be supplementing the ongoing COG study with the data that I collect]*

During the project implementation and evaluation, *[Elizabeth Brown]* will provide regular updates and communicate any necessary changes to the DNP Project Preceptor.

Our organization looks forward to working with this student to complete their DNP project. If we have any concerns related to this project, we will contact *[Elizabeth Brown]* and *[Dr. Sharon Norman]* (student's DNP Project Chairperson).