A survey to assess patient and health care providers' knowledge, attitudes and perceptions of cancer-related fatigue and exercise

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DECLARATION

I, Erin Karam declare that this Dissertation is my own, unaided work. It is being submitted for the Degree of Master of Health Science in Biokinetics at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.

(Erin Karam)

26th day of August 2022

DEDICATION

Cancer has affected my family in many ways and by loving what I do and believing in the benefits of exercise I dedicate this study in memory of my late father, Christopher Michael Karam who lost his battle with cancer in 2012 and to my beautiful mother, Yvonne Karam who is in remission since 2020.

ABSTRACT

Background:

Cancer is a complex non-communicable disease which can occur almost anywhere in the human body. Cancer causes abnormal cells to divide uncontrollably and destroy body tissue. The Cancer Association of South Africa (CANSA) assists the National Cancer Registry (NCR) to provide statistics and confirms that there is an increasing cancer epidemic in South Africa. In South Africa the NRC reported a 31% increase in new cancer cases from 74577 in 2018 to 108168 new cancer cases in 2020. The continuous rise in cancer cases each year in South Africa is a cause of concern and therefore, more studies are needed in the area of cancer management.

Cancer related fatigue is multidimensional, and negatively affects patients' physical function, social and mental wellbeing, quality of life and may be a predictor for survival. It has been reported that over 80% of patients with cancer experienced cancer related fatigue. Exercise is a non-pharmacological treatment for cancer and the effects of cancer treatment, which is inexpensive and accessible. Structured multimodal individualised exercises can be used throughout the stages of cancer to reduce the effects of fatigue. Exercise assists in reducing cancer risk promoting health and may be used after recovery as secondary preventative cancer measure. In South Africa there is a need to determine the knowledge, attitudes and perceptions of cancer related fatigue as well as understand possible barriers people face in not leading an active healthy life.

AIM:

This study aimed to determine the knowledge, attitudes and perceptions of oncology health professionals and people who have cancer related fatigue as well as determine the use of exercise for treatment in these population groups.

OBJECTIVES:

To determine the extent of knowledge, current attitudes and perceptions of health professionals and individuals with cancer in Gauteng, regarding cancer related fatigue and exercise-based therapies to reduce cancer related fatigue using a survey. To

determine the extent that exercise is currently being prescribed by health care professionals for individuals with cancer related fatigue and the extent that individuals use exercise to treat cancer related fatigue in Gauteng, using a survey.

METHODS:

This cross-sectional descriptive study was employed to evaluate the knowledge, attitudes and perceptions health professionals and patients on Cancer related fatigue and exercise-based therapies. Two separate surveys were used. The first survey, "Survey for Health Professionals on cancer related fatigue and exercise" was a modified version of the survey from La Trobe University, "Clinical perspectives on cancer-related fatigue". The second survey, "Survey on cancer related fatigue and exercise for individuals who have been diagnosed with cancer" was modified from Macmillian et al. (2011) survey, "Cancer and physical activity standard evaluation framework baseline". This study was carried out over 3 months and allowed participants to complete the surveys via email through google forms and print copies.

The surveys were available in both print and online formats for participants to complete. The health professionals (oncologists, nurses, biokineticists, physiotherapists, dieticians, occupational therapists, and psychologists) survey took approximately 15 minutes to complete and comprised of 25 questions. The survey for patients who had been diagnosed with cancer took approximately 30 minutes to complete comprised of 22 questions. An information document was sent via email link and print copies were available at survey site. Consent was deemed to have been given/automatic as the participant agreed to complete the survey for the online and printed versions of the survey. This study used a sample of convenience for both, health professionals as well as patients diagnosed with cancer in the Gauteng region. Participants were excluded if their surveys were less than 90% completed.

RESULTS:

All participants included in the final analysis of this study met our inclusion criteria. **Biographical data:** Nighty-three health professionals participants comprising, of medical professional/oncologists; nurses; dieticians, biokineticists, physiotherapists and other. There ages ranged from 23 to 62 years and 12.35 mean years in practice. The health professionals comprised of 87 working in urban and 7 working in a rural

environment in Gauteng. Fifty-two individuals diagnosed with cancer took part in this study, this population group comprised of 37 female and 15 male participants. The ages ranged from 40 to 82 years, with the mean age of 65.38. In this study 15.4% of this sample population had a long term-illness or disability that limits their physical activity. The types of cancers participants had: 18 breast; 12 prostate; 6 bladder, 6 cervix, 5 skin, 4 uterus, 4 lymph; 2 kidney, 2 throat and 1 participant had head and neck cancer. **Knowledge of cancer related fatigue & Exercise:** Eighty-one percent of Health professionals stated that they had knowledge on cancer related fatigue and gained their knowledge from: 40 from self-knowledge (the knowledge gained through years of practice and working with cancer patients), 23 from information off the internet, 8 from courses on cancer related fatigue and exercise, and 6 participants gained their knowledge from the guidelines set out by ACSM. Fifteen percent of cancer patients in this study said they had heard of cancer related fatigue and 85% had not. Participants with cancer reported that the majority (n=44) did not know of non-medical treatments for cancer related fatigue and (n=8) reported that they did know of non-medical treatments to treat cancer related fatigue. **Current attitudes of cancer related fatigue & exercise:** Health professionals were asked if exercise-based therapies were made available to treat cancer related fatigue, would they use them. The majority of health professionals (96%) and individuals diagnosed with cancer (92%) stated that they would prescribe and use exercise to treat cancer related fatigue. **Current perception of cancer related fatigue and exercise:** Participants were asked how they felt cancer related fatigue would affect an individual's cancer treatment/ recovery. Health care professionals' majority (n=40) felt that cancer related fatigue would "very much" affect individuals cancer treatment/recovery. The individuals diagnosed with cancer in this study perceived that cancer related fatigue would affect their treatment/ recovery "quite a bit" (48%) and a "moderate" amount (46%). Health care professionals were also asked if they felt that their patients with cancer related fatigue symptoms were identified and managed. The results show that only 22% said yes and that 78% of health professionals felt that their patients cancer related fatigue symptoms weren't identified and managed.

Extent that exercise is prescribed to individuals with cancer related fatigue: Health care professionals were asked if they prescribe exercise to their patients with cancer related fatigue, only 17,4% selected "no" stating that they don't prescribe

exercise and 82,6% selected “yes”, they do prescribe exercise to patients with cancer related fatigue. Of the participants that do prescribe exercise to their patients the majority, 39,5% selected that they often prescribe exercise to their patients with cancer related fatigue. **The extent that exercise is being used by individuals to treat cancer related fatigue:** The participants in the study were asked if they felt fatigued in a 7-day cycle. Majority of participants in the study felt “a little bit” and “somewhat” fatigued the most at 28,9% each. Physically active participants: Individuals diagnosed with cancer were asked if they took part in any sport over the past 7 days. The results show that 50% did no sport last week, 11,5% took part in sport for 1 day, 13,5% participated twice last week, 15,4% of participants were active for 3 days and 9,6% did sport 6 days last week. The majority of participants (57,7%) stated that this was the typical amount of physical activity they usually do.

CONCLUSION:

In this study, there was no evidence of statistical significance for the knowledge, attitudes and perceptions of both health professionals and individuals with a cancer diagnosis in Gauteng on cancer related fatigue and exercise-based therapies for treatment.

Evidence of knowledge on cancer related fatigue was found to be higher in health professionals and less so in individuals with cancer diagnosis in Gauteng. However, with most of the knowledge gained by Health professionals was through their own experience in practice with patients, the extent of their knowledge on cancer related fatigue is unknown. Health professionals in this study (21.7%) mostly felt that they did not identify or manage their patients cancer related fatigue. However, 48% of cancer individuals in this study perceived that cancer related fatigue would “quite a bit” affect their treatment/recovery. Health professionals and cancer individuals in this study had a positive attitude towards using exercise-based therapy to treat cancer related fatigue. Evidence in this study show that majority of health professionals and cancer individuals would select exercise as a modality to treat cancer related fatigue.

With over 80% of clinicians of the sample using exercises for treatment of cancer related fatigue there are 34% said that the “rarely” prescribe exercise to their patients. The majority of cancer individuals in this study (96.2%) stated they felt fatigued and

50% took part in physical activity in the past week. The result of this study indicates that both health professionals and cancer patients would use exercise to treat cancer related fatigue and that individuals with cancer related fatigue feel that exercise would reduce their fatigue. An intervention study should be done for assessing the accuracy of fatigue and the use of structured exercise to effectively treat cancer related fatigue in cancer individuals pre and post cancer treatment.

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ABBREVIATIONS

ACSM: American College of Sports Medicine

CANSA: Cancer Association of South Africa

COVID-19: Coronavirus disease 2019

CRF: Cancer related fatigue

FITT: Frequency, intensity, time, and type

HCP: Health Care professionals

HPCSA: Health professions council of South Africa

NCD: Non-communicable disease

NCR: National Cancer Registry

WHO: World Health Organisation

DEFINITIONS

Cancer: A complex non-communicable disease caused by the uncontrollable division of abnormal cells which leads to the destruction of normal body tissue anywhere in the human body.

Cancer Related Fatigue: A persistent, distressing, subjective sense of emotional, cognitive, and physical tiredness or exhaustion related directly to cancer or its treatment that is disproportionate to recent activity, which impedes usual functioning.[22]

Exercise: Movement that is aimed to improve or maintain physical fitness through planned, structured, repetitive training.

Health Care Professionals: A provider of health care that can give treatment and advice based on their formal training and experience.

Knowledge: The theoretical or practical understanding of a subject acquired by an individual through facts, information, skills acquired, and education.

Attitude: The expression of a person towards the favour or disfavour towards a place, person, thing, or event.

Perception: The use of an individual's senses to see, hear, or become aware of something.

CHAPTER 1: INTRODUCTION

1.1 Background

Cancer is caused by the uncontrollable division of abnormal cells which lead to the destruction of normal body tissue. Cancer is a complex disease that is non-communicable and can occur almost anywhere in the human body. Information from the Cancer Association of South Africa (CANSA) sent to the National Cancer Registry (NCR) from 2018 to 2020 show that there has been a 31% increase of cancer in South Africa. With 74577 new cancer cases reported in 2018, increasing to 108 168 in 2020.[1] The increase of 33 591 new cancer cases in South Africa over a two-year period is a cause of concern and therefore, studies are needed to find improved interventions to lessen the burden of cases.

In cancer patients fatigue is caused by both the effect of cancer and the cancer treatment. Cancer related fatigue may be more severe the in the later stages of cancer and the type or amount of treatment a patient has. Cancer related fatigue has negative effects on the quality of life, physical function, social and mental wellbeing of patients, and may also be a predictor of survival. It was reported that over 80% of patients with cancer stated that they experienced cancer related fatigue[2]. Exercise is a non-pharmacological management for cancer and the effects of cancer treatment, exercise is inexpensive and can be easily accessible. Structured multimodal individualised exercises can be used throughout the stages of cancer to reduce the effects of fatigue.[3]

Furthermore, physical activity can aid in decreasing a patient's risk of getting certain cancers. Exercise should be promoted not only during cancer treatment but also when a patient is in remission or cancer free as a preventative measure. Due to the increased prevalence of new cancer cases in South Africa there is a need to determine the knowledge, attitudes, and perceptions of cancer related fatigue as well as to comprehend probable barriers people face causing them not to lead a physically active healthy life.

1.2 Research problem

The prevalence of cancer has increased over recent years, elevated levels of physical activity is known to decrease the risk of certain cancers.[2] The types of cancer

treatment by oncologists such as chemotherapy, radiation therapy, hormone therapy, bone marrow transplantation, and immunotherapy and the cancer itself has a side effect of fatigue. Cancer related fatigue is often undiagnosed and inadequately treated due to patients not reporting their fatigue, fatigue being misdiagnosed as depression or health professionals not identifying and treating an individual's fatigue.[2] Structured exercise has shown to aid in reducing fatigue and increasing health.[3]

There is an increased prevalence of cancer related fatigue (CRF) reported by patients during and after cancer treatment. The global cancer statistics from GLOBOCAN 2020 for South Africa shows that of a population of 59 308 690 there were 108 168 new cancer cases with 56 802 number of deaths and 262 455 number of prevalent cases (5-year).[4] Lancet medical journal published a study predicting that from 2008 to 2030 South Africa's cancer rate will increase by 78%.[5] With the increasing prevalence of cancer and its negative effect on biopsychosocial dimensions, namely, direct cancer burden, cancer treatment burden, cancer and treatment psychosocial burden and comorbid conditions burden, it is important to manage patients effectively as well as improve their quality of life where possible. Cancer related fatigue leads to reduced physical performance and a decrease in quality of life, which may further impair health.[6,7] Although numerous fatigue scales exist, there is no gold standard to date to assess CRF, hence information regarding the knowledge, attitude, and perceptions of CRF, as well as the barriers to physical activity is not often obtained. This therefore may hinder appropriate general management and more specifically exercise prescription in these patients.[6,7]

With there being a positive correlation between exercise and decreasing fatigue in cancer patients it is imperative to identify cancer patients and health professionals' attitudes and perceptions towards the use of physical activity as an effective treatment in Gauteng.[6,8]

Structured exercise including resistance and aerobic exercise has been used and proven to positively reduce the effects of fatigue in people undergoing cancer treatment[7] thus limiting barriers to participating in physical activity is paramount in managing these patients.

1.3 Research question

Do oncology health professionals and cancer diagnosed individuals have knowledge on cancer related fatigue? What attitudes and perceptions do oncology health professionals and cancer diagnosed individuals have towards cancer related fatigue? Do health professionals and individuals who have been diagnosed with cancer use exercise for treatment of cancer related fatigue?

1.4 Aim of Study

To determine the knowledge, attitudes and perceptions of oncology health professionals and people who have cancer related fatigue as well as determine the use of exercise for treatment in these population groups.

1.5 Objectives

1. To determine the extent of knowledge of health professionals and individuals with cancer in Gauteng, regarding cancer related fatigue and exercise-based therapies to reduce CRF using a survey.
2. To determine the current attitudes of health professionals and individuals with cancer in Gauteng, regarding cancer related fatigue and exercise-based therapies to reduce CRF using a survey.
3. To determine the current perceptions of health professionals and individuals with cancer in Gauteng, regarding cancer related fatigue and exercise-based therapies to reduce CRF using a survey.
4. To determine the extent that exercise is currently being prescribed in Gauteng, by health care professionals for individuals with cancer related fatigue using a survey.
5. To Determine the extent that individuals use exercises to treat cancer related fatigue using a survey.

1.6 Hypothesis

Oncology health professionals and patients have limited knowledge, poor attitudes, and perceptions in terms of dealing with and treating cancer related fatigue. Furthermore, there is poor prescription of exercise by health professionals and poor use of exercise by patients who have CRF in Gauteng.

CHAPTER2: LITERATURE REVIEW

2.1 Introduction

Cancer rates are increasing in South Africa and fatigue is a common side effect of the disease and treatment that can negatively affect an individual's life both physically, psychologically, and socially. Exercise has been proven to reduce fatigue in cancer patients and assist in improving overall health. This study aimed to assess the knowledge of health professionals and individuals who have been diagnosed with cancer on-cancer related fatigue and the use of exercise as treatment. Individuals with knowledge of cancer related fatigue and exercise were assessed to see what their perceptions were towards how cancer related fatigue may affect their treatment/recovery and how they perceived the use of exercise as a modality for treatment.

This literature review will cover two main themes, the first is cancer. Cancer in general is reviewed to gain better understanding of the prevalence of cancer in South Africa and its burden on the country against global statistics. Furthermore, cancer related fatigue is reviewed to inform how it affects an individual, what assessment tools are generally used to identify it and what treatment modalities are available.

The second theme reviewed in this chapter is exercise/physical activity. Physical activity is reviewed to identify the different types of exercise, the recommended guidelines for taking part in physical activity and its benefits on the body. In addition, physical activity and its effects on cancer related fatigue in individuals diagnosed with cancer is reviewed.

2.2 Cancer

Cancer is defined by the National Cancer Institute as a genetic disease where abnormal cells uncontrollably divide and enter nearby tissues.[8] Cancer has both physical and psychological effects on patients which may reduce quality of life. During cancer treatment, cardiovascular toxicity can occur which leads to inflammatory responses in vessels, abnormalities in electrocardiograms, heart damage, and decreased blood perfusion in tissues.[9] There are several main forms of cancer

namely: carcinoma, sarcoma, leukaemia, lymphoma, multiple myelomas, melanoma, and central nervous system cancers, with each affecting the body differently as the gene chromosomes of a person's DNA are altered.[10]

South Africa is a third world country with its economy already strained and the increasing prevalence of cancer places a large burden on limited resources.[11] The World Health Organisation showed that in 2020, South Africa had 108 168 new cancer diagnoses and 56 802 people who died from cancer.[12] The South African health system is already strained, so it is important for individuals live a healthy and physically active life to reduce economical strain and premature death rates. By promoting exercise during cancer treatment and to get individuals more physically active the effects of cancer related fatigue will lessen, and active individuals are less likely to get cancer. Physically active individuals are better able to handle the tolerance of cancer treatment and recover. If South Africa places a bigger emphasis on getting individuals taking part in physical activity there will be less strain on the health system as physically active individuals are less likely to be diagnosed with chronic diseases.

i. Causes of Cancer

CANSA states that 90% of cancer is caused by environmental factors (infectious agents such as Human Papilloma Virus, Hepatitis B Virus and Hepatitis C Virus), lifestyle-related risk factors (poor diet, tobacco use, sun exposure and physical inactivity), environmental pollutants and carcinogens (benzene and formaldehyde).[13] Furthermore, Torre et al stated that with urbanisation and economic development there has been an increase in cancer incidence due to the growth of the population with the added cancer related risk factors.[14] Its important for individuals to know and understand that they are able to reduce their risk of getting cancer by improving their lifestyles especially through a nutrient correct diet, not using tobacco and to stay physically active as recommended by WHO[12]. Exercise can aid in strengthening an individual's immune system and regulate some hormones that contribute to the development of cancer.

ii. Types of cancer

In 2020 Globolcon released cancer statistics of South Africa showing that the 5 most common cancers in the country were; breast, cervix, prostate, lung and colorectum, illustrated in Figure 2.1.[15] In 2020 the cancers in South Africa that had the highest mortality rates were lung, cervix, breast, prostate and colorectal cancers.[15] The statistics show that South Africa had 1081682 new cancer diagnoses in 2020 and 56 802 deaths.[12] Research and interventions are needed to reduce premature death rates from cancer.

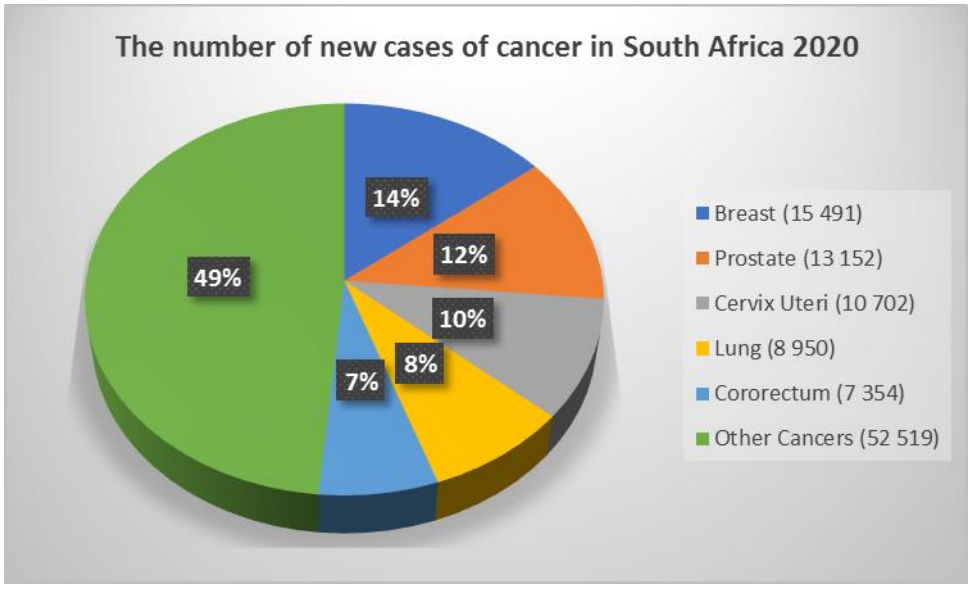

Figure 2. 1: Pie chart of the number of new diagnoses of cancer in South Africa 2020 of both sexes and ages [15]

iii. Treatment

There are many treatment modalities used to treat cancer in humans; these are chemotherapy, radiation, surgery, bone marrow transplant, immunotherapy, hormone therapy, targeted drug therapy, cryoablation. Hofman et al reported that fatigue is experienced by up to 90% of patients in radiation treatment and by 80% during chemotherapy treatment.[16] Fatigue

is often endured by patients before they are diagnosed with cancer, early detection in CRF and treatment is therefore imperative in the diagnosis and management of individuals with cancer.[17]

a. Chemotherapy

Chemotherapy is the use of cytotoxic drugs to kill dividing cancer cells and stop them from growing. Smith et al. stated that chemotherapy is used in complex and late-stage cancer and that chemotherapy agents are elected by the primary cancer stage and histological identification together with the genetic and molecular profile.[56] The study by Tierney et al on the side effects expected and experienced by women receiving chemotherapy for breast cancer and by Nerenz et al on the factors contributing to emotional distress during chemotherapy both show that 82-96% of individuals who receive chemotherapy to treat their cancer suffer from fatigue during treatment.[18,19]

b. Radiation Therapy

Radiation therapy is the use of intense ionized beams internally or externally to kill cancer cells by damaging the cancer DNA. When the cancer DNA is treated by radiation therapy the DNA then gets damaged beyond repair and therefore the cancer cell stops dividing or dies. Radiation therapy requires time to be effective and the therapy causes cancer cells to continue destroying cancer DNA cells for months after the therapy ends. External beam radiation therapy is done by use of a large machine that provides local treatment by targeting only a specific part of a body. Internal radiation therapy also known as brachytherapy is placed inside the body in solid or liquid form.[20] Reports of fatigue in patients undergoing radiation treatment range between 65–100% during treatment.[21]

iv. Cancer Related Fatigue

Cancer related fatigue (CRF) is defined by the National Comprehensive Cancer Network as a “persistent, distressing, subjective sense of emotional, cognitive and physical tiredness or exhaustion related directly to cancer or its treatment that is disproportionate to recent activity, which impedes usual functioning”. [22]

Saligan et al performed a literature review on the biology of cancer-related fatigue using 47 articles that used single and multi-item questionnaire surveys.[23] The studies show that cancer has a variety of biological effects that may cause fatigue, namely: impairment of mitochondrial/metabolic function and associated genes; immune response dysregulation and inflammation; dysregulation of the hypothalamic-pituitary axis with impairment of the neuroendocrine function; patient factors and biological markers (age, gender, socioeconomic status, comorbid conditions), and cancer treatment. Furthermore, cancer related fatigue may cause cognitive and behavioural symptoms such as anxiety, depression, cognitive impairment, and reduced quality of sleep, as well as the impairment of physical function, impairment of physical activity and anorexia-cachexia syndrome which causes fat and muscle loss.[24, 25] All of these factors may contribute to reduced quality of life within the population and thus the reduction in CRF may be paramount to the treatment of these individuals.

Joachim Weis did a study on CRF and found that 59 to 100% of cancer patients suffer from cancer related fatigue.[17] During the treatment of cancer, pain and nausea are more short-term side effects compared to CRF which is often affects a patient for longer, and negatively impacts their ability to perform activities of daily living and quality of life. Studies are needed to further understand the long- and short-term effects that CRF has on individuals and how CRF can be identified and treated.

v. Assessment and Management of Cancer Related Fatigue

Cancer related fatigue is a common symptom amongst patients with cancer. It is self-reported by patients both during and after cancer treatment. [26],[27] Pearson et al reported that there are inconsistencies in both the assessment and management of CRF and that many assessments do not take into account the psychosocial, cognitive and quality of life factors that are affected by it, and that this is due to the limited knowledge and expertise in treating fatigue.[28] To the researchers knowledge there are currently no gold standards to assess or treat CRF, however with the high prevalence of CRF more than 20 different tools have been designed so far.

Jean-Pierre et al assessed both unidimensional and multidimensional CRF screening and diagnostic tools and found that multidimensional assessments add relevance and texture considering CRF is a symptom that affects cognitive, emotional, and physical domains. Unidimensional assessment tools of CRF detect the absence or presence and severity of fatigue without considering other complexities of CRF such as the patients' symptoms.[27, 29]

Kessels et al[30] study found that aerobic exercise yielded the best results in reducing cancer related fatigue and that the best fatigue improvements were from high adherence of exercise. Kessels also found that exercise had a large effect size on improving CRF with no significant difference of the cancer type.[30] Mustian et al[31] states that CRF works in symptom clusters whereby two or more side effects of cancer with different pathopsychophysiology may strongly relate to each other. Examples of symptom clusters in cancer patients are: Firstly, muscle wasting and muscle weakness due to cancer treatment reduces the level of Adenosine triphosphate (ATP) which may contribute to CRF. Secondly, The immune system uses antibodies and cytokines to control infection and respond to injury, in cancer patients there are higher levels of cytokines in the serum of

individuals experiencing CRF. High levels of cytokines in the serum are linked to depression and cognitive impairment. Thirdly, Due to stress the neuroendocrine system that controls mood, sleep, energy expenditure, digestion and immune function releases the adrenocorticotropic hormone which stimulates the adrenal cortex to produce cortisol. Cancer patients with CRF also have upset cortisol levels, and then lastly, CRF is noted as a pre-clinical indicator and symptom of cardiotoxicity in cancer patients undergoing chemotherapy. CRF is increased by the cardiac dysfunction due to the increased cardiac work required and stress to the heart.[31]

Exercise is a treatment modality that is easily accessible for the treatment of fatigue and improvement of well-being (physical and mental).[32] Exercise interventions have been used to effectively treat cancer related fatigue. With an increased prevalence of CRF and knowledge of its negative effects on patients, there is a need to investigate the perceptions of oncologists and cancer patients with using exercise as a treatment modality.[25] It has been found that, aerobic endurance exercise improves aerobic function by continuously transporting oxygen through various systems in the body, aerobic endurance assists to a new lifestyle during and after cancer treatment.[33] Muscular strength exercises may improve body function and reduce the amount of muscle wasting and muscle weakness that occurs due to the musculoskeletal alteration from cancer.[34]

vi. Knowledge, perceptions, and attitudes of CRF in the health industry

Studies by Pearson et al[28] and another by Maqbali et al[35] both show there is a need to improve knowledge of health care professionals and assist the transition of CRF guidelines to clinical practice to improve the quality of life of patients.

Health professionals underestimate the symptom of fatigue in their cancer patients and often find the side effects of nausea and vomiting more

worrying.[37] Studies show that health care professionals perceive cancer related fatigue to be undertreated and overlooked and patients perceive CRF a symptom to be borne.[38] Cancer patients perceive fatigue to have a high impact on their daily living affecting both social and emotional aspects.[36] A study by Abdalrahim et al[39] revealed that the knowledge and attitude towards CRF is a barrier of fatigue management and that there is a need to improve knowledge to correctly manage CRF in patients to effectively improve quality of life.

2.3 Exercise

Exercise is the act of physical movement requiring the exertion of physical effort to maintain or improve health and fitness. Exercise is defined by Caspersen et al, as structured, planned, and repetitive bodily movement.[40] Exercise requires the increase of oxygen uptake from a resting level of approximately 0.25 litres.min^{-1} and energy expenditure of 5 kJ.min^{-1} to exercise levels up to and beyond 6 litres.min^{-1} oxygen uptake and 120 kJ.min^{-1} energy expenditure.[41] Exercise has multiple benefits, Elmagd et al states exercise and physical activity decrease stress and anxiety, improve brain power and mood, sharpen memory, increase bone, and muscle strength. It also aids in reducing and preventing obesity, diabetes, heart disease, cardiovascular disease, and cancer.[42] With the multiple benefits of physical activity and exercise it is important to assess why it is underutilised for CRF, prevention, mental well-being, and overall health.

i. Exercise prescription

The general guidelines for physical activity set out by the American College of Sports Medicine (ACSM) for healthy individuals aged between 18 and 65 years is to participate in 30 minutes of moderate aerobic intensity exercise 5 days of the week, or partake in 20 minutes of vigorous aerobic intensity exercise for 3 days of the week.[43] ACSM recommends that exercises that increase or maintain endurance and muscular strength for 2 days per

week.[43] ACSM guidelines for CRF recommend that individuals with cancer should take part in moderate intensity aerobic exercise 3 times a week and twice a week take part in moderate resistance training of 2 sets of 12-15 repetitions of large muscle groups.[43] The frequency, intensity, time and type (FITT) principal is used to prescribe individualised exercise programme prescription to oncology patients. Oncology patients are encouraged to take part in 150 minutes of moderate to vigorous exercise per week and to include resistance training twice weekly.[44]

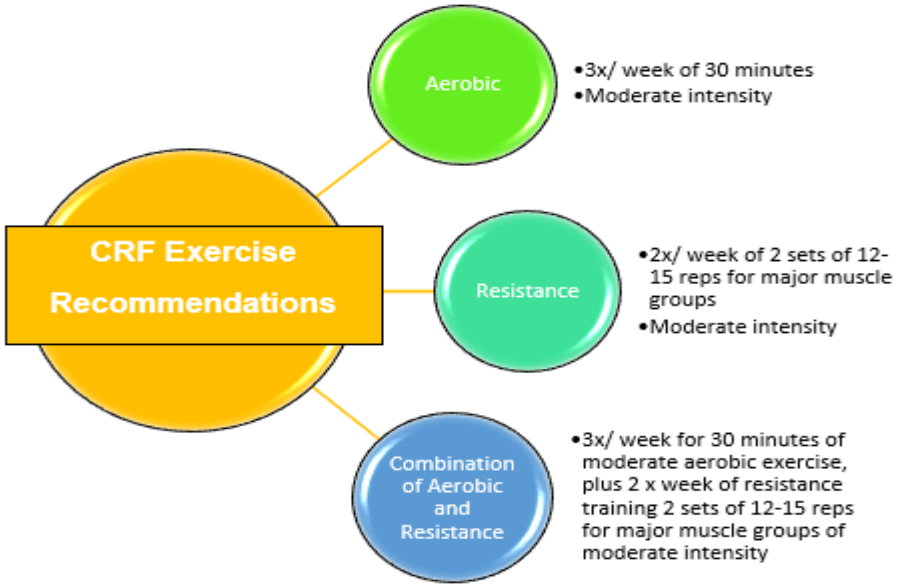

Figure 2. 2: Exercise recommendations for the treatment of cancer related fatigue[43]

Exercise has shown benefit in the treatment of cancer related fatigue comparison to sedentary oncology patients however, there is no set dose.[44; 45] The benefits of exercise can be maximised when the exercise prescribed for oncology patients is individualised. Many factors can play a role in individualising exercise and may include both physiology of the patient and their cancer, the stage of their cancer and the type of treatment they are receiving. Treatment stage and the side effects of treatment may influence the adherence and tolerance of exercise.[45] The study done by Koeppel et al found that integrating psycho-educational aspects in exercise

interventions are beneficial in increasing physical activity; not all survivors attain the physical activity level recommended in the guidelines, due to cancer related fatigue.[46]

ii. Types of Exercise

Aerobic Exercise:

Exercise that causes an increase in the cardiorespiratory response as more oxygen is required to supply the muscles is known as aerobic exercise. Aerobic exercise is known as endurance exercise lasting longer than 10 minutes in duration and can differ in frequency and intensity. Aerobic exercise optimises oxygen metabolic pathways to improve muscle supply with oxygenated blood through the cardiorespiratory system.[47] Intervention studies show that aerobic exercise performed for the recommended 3 times a week for 30 minutes of moderate intensity can significantly reduce fatigue, improve physical performance, and increase quality of life.[48]

Anaerobic Exercise:

Anaerobic exercise is more intense and often shorter in duration compared to aerobic exercise. Anaerobic exercise causes glucose to metabolise in the body without the use of oxygen, this leads to lactic acid production with the enzyme lactate dehydrogenase converting pyruvate to lactate. A study by P. Hofmann (2018) showed that high intensity anaerobic exercise can affect tumour host interaction and tumor metabolism.[49] Hofmann's' study states that high intensity exercise (anaerobic exercise) inhibiting glycolysis is safe in cancer patients as long as it is individually prescribed to suit each patient.[49]

Resistance exercise:

Resistance exercise is used to increase muscle strength and size and is a form of anaerobic training. Muscle fitness can be achieved by training regularly at a moderate to high intensity often against a resistive load or moving a weight.[50] Anaerobic training can increase muscular skeletal function and muscle strength.[50] The recommend dose of anaerobic training

is twice a week comprising of 2 sets with 8 to 15 repetitions of moderate intensity according to the ACSM guidelines.[43]

iii. Cancer Related Fatigue and Exercise

Meneses-Echávez et al studied the effects of supervised multimodal exercise interventions on CRF showing that physical activity was positively associated with physical functioning, physiological outcomes, body composition and fatigue.[50] The study however stated that there is a need to further research the effects of supervised multimodal exercise to decrease fatigue during cancer treatment. Hilfiker et al systematic review of exercise and other non-pharmaceutical interventions study for CRF showed that non-pharmaceutical interventions are effective in treating CRF during and after cancer treatment, however the rate of the effectiveness of these interventions are not known and further studies are required.[51] Cancer related fatigue can be reduced with exercise however studies are needed to identify the correct dose for patients.

i. Knowledge/ perceptions / attitudes of the health industry on exercise and its effect in cancer patients

A focus group study done by Smaradottir et al[52] found that both health care professionals and cancer patients have good perceptions and attitudes towards using physical activity during treatment. There is a lack of knowledge that exists between what exercises should be prescribed for CRF for the various types and stages of cancer and how these exercise programmes should be distributed and implemented.[52]

Lawson et al[53] study found that the perceptions that cancer patients have towards physical activity is strongly associated with physical activity levels, showing that a positive perception of physical activity may result in favourable physical activity levels. Health professionals should therefore educate cancer patients perceptions on physical activity to encourage improved physical activity levels.[53]

CHAPTER 3. METHODOLOGY

3.1. Introduction

A cross sectional descriptive study was used by gathering data from two surveys of health care professionals and individuals with cancer in Gauteng. The surveys were available through print and online copies via google forms. The data collected from participants in this study through the surveys was examined to assess knowledge, attitudes and perceptions of cancer related fatigue and exercise-based therapies in Gauteng.

3.2. Study Design

A cross sectional descriptive study design was used for this study. Two separate surveys were used. The first survey, Appendix C, “Survey for Health Professionals on cancer related fatigue and exercise” and the second survey, Appendix D, “Survey on cancer related fatigue and exercise for individuals who have been diagnosed with cancer”. The survey tool selected to gather information was comprised of modified versions of the “Clinical perspectives on cancer-related fatigue”[54] survey and the “cancer and physical activity standard evaluation framework baseline”[55]

The survey for health professions had questions to firstly identify whether have heard of the term “cancer related fatigue”, and if so, where did they gain their knowledge. It was also important to assess through the survey if health professionals identify if a patient has CRF; and if cancer patients are identified as having CRF do health professionals feel it affects their recovery? I assessed if health professionals prescribe certain exercise to patients with CRF.

The survey for cancer comprised of questions to identify if they knew of the term “caner related fatigue” and if so, how did they feel it affected their treatment/recovery. The survey for cancer individuals used a Likert scale to see if they felt fatigued and whether they took part in physical activity.

3.3 Site of Study

The online (emailed) version was from the Centre for Exercise Science and Sports Medicine (CESSM) at the University of the Witwatersrand and distributed via the world wide web to participants. The printed version was available on request and distributed to individuals at their offices or at Virgin Active Eastgate and Virgin Active Rosebank.

3.4. Study Population

The surveys (Appendix C and D) were distributed to two population groups as discussed below. Information sheets (Appendix A: Participant information sheet for Oncology Health Professionals & Appendix B: Participant information sheet for patients diagnosed with cancer) were provided with the online link to the study or as an appendix to the printed version of the study. Consent was deemed to have been given/automatic as the participant agreed to complete the survey for the online and printed versions of the survey.

i. Oncology health professionals: ICON is a network of oncology specialists who are committed to widening access to quality cancer care across South Africa. All oncologists were invited from the ICON-affiliated centres across Gauteng. Nurses practicing in Gauteng were invited to take part in the study through SANC (South African Nursing Council). Biokineticists practicing in Gauteng were invited to take part in the study through the BASA (Biokinetics Association of South Africa). Physiotherapists practicing in Gauteng were invited to take part in the study through the SASP (South African Society of Physiotherapy) and PASA (Physiotherapy Association of South Africa). Dieticians practicing in Gauteng were invited to take part in the study through ADSA (Association for Dieticians in South Africa). Occupational therapists practicing in Gauteng were invited to take part in the study through OTASA (Occupational Therapy Association of South Africa). Psychologists practicing in Gauteng were invited to take part in the study through PsySSA (Psychological Society of South Africa). All oncology health professionals who participated in the study, worked in a region of Gauteng, these sites included: Benoni, Johannesburg, Krugersdorp, Lenasia, Midrand, Parktown, Pretoria, Roodepoort, Sandton and Vereeniging.

ii. Individuals diagnosed with cancer: participants were invited to fill out a printed or an online survey. Printed copies of the survey were placed at two oncology centres, reception desks at Virgin Active Eastgate and Virgin Active Rosebank. An online link to the survey on Google forms was emailed to participants from data bases (DL Link, CANSA).

3.4.1. Recruitment and sample size

A sample of convenience was used for both, health professionals working in oncology as well as patients diagnosed with cancer in the Gauteng region. The sample size of health care professionals was 93 participants that comprised of oncologists, dieticians, nurses, occupational therapists, physiotherapists and biokineticists. The total sample size of individuals with cancer who met our inclusion criteria were 52 participants.

Health care professionals were recruited through their societies, associations, or networks via email. Oncology health professionals through the ICON network. Nurses were invited to participate through the South African Nursing Council. Biokineticists were invited to participate in the study through the Biokinetics Association of South Africa. Physiotherapists practicing in Gauteng were invited to take part in the study through both the South African Society of Physiotherapy and the Physiotherapy Association of South Africa. The Dieticians association were invited through the Association for Dieticians in South Africa and occupational therapists through the Occupational Therapy Association of South Africa. Psychologists practicing in Gauteng were invited to take part in the study through their society the, Psychological Society of South Africa. All oncology health professionals who participated in the study, worked in a region of Gauteng, these sites included: Benoni, Johannesburg, Krugersdorp, Lenasia, Midrand, Parktown, Pretoria, Roodepoort, Sandton and Vereeniging.

Individuals diagnosed with cancer were recruited by inviting through online and print versions at two oncology centres and the reception desks Virgin Active Eastgate and Virgin Active Rosebank and through the two organisations who deal with individuals with cancer, DL Link and CANSA.

3.4.2 Inclusion and exclusion criteria

Inclusion criteria

i. Oncology health professionals (oncologists, nurses, biokineticists, physiotherapists, dieticians, occupational therapists, and psychologists): 1. Must have had over 1 year of practice, 2. Obtained a health professional degree that was recognised by the Health Professions Council of South Africa. 3. Must have been working in Gauteng.
ii. Patients with cancer: 1. Resided in Gauteng and had been diagnosed with any type of cancer or were in remission, 2. Were older than 18 years. The inclusion criteria were chosen based on the low prevalence of cancer in youth and increased prevalence of cancer with age. (The NRC's 2014 stats revealed the highest prevalence of cancer in females was between the ages of 55 to 69 and males between the ages of 60 to 74 years old.)[12.] Must have received chemotherapy, targeted therapy or biologic therapy and completed their most recent therapy with in the last 0-12 months through intravenous, pill or tablet form.

Exclusion criteria: Surveys which were less than 90% complete

3.5. Procedures and measuring tools

Each participant in the study was invited (Appendix A: Oncology Health Professionals & Appendix B: Patients diagnosed with cancer) to complete an online or printed version of the survey. The survey selected was comprised of the "Clinical perspectives on cancer-related fatigue"[54] (Appendix C) was to be completed by health professionals. "Cancer and physical activity standard evaluation framework baseline questionnaire"[55], (Appendix D) was to be completed by participants who have been diagnosed with cancer. The surveys were chosen to assess the knowledge, attitudes and perceptions of cancer related fatigue and exercise-based therapies in Gauteng.

These surveys were sent out via an online link as well as self-administered and available via printed copies for by oncologists and people diagnosed with cancer in

the Gauteng region. The survey for Oncology Health Professionals took approximately 15 minutes to complete and the survey for patients who have been diagnosed with cancer and took approximately 30 minutes to complete.

3.4.1. Survey – This survey (Appendix C) for Oncology Healthcare Professionals was a modified version of the survey designed by La Trobe University, "Clinical perspectives on cancer-related fatigue".[54] The second survey (Appendix D) was for participants who have been diagnosed with cancer. Appendix D was a modified version of MacMillian's survey, "cancer and physical activity standard evaluation framework baseline".[55] The surveys from La Trobe university[54] and MacMillians[55] were chosen were based the ease of test re-test reliability and to ensure continued consistency from participants completing the survey.

The survey by La Trobe University on the "Clinical perspectives on cancer-related fatigue"[54] was found to be the most relevant for the research study due to it being related to assessing the knowledge, attitudes and perceptions of cancer related fatigue and exercise from the sample population of medical health professionals and people with cancer.

Participants were invited to take part in the survey online by email or print versions that were assessable at two oncology centres in Gauteng.

The online survey was emailed to participants. Appendix C was comprised of 25 questions, these questions were short closed ended questions that offered multiple choice answers, the participant were required to write a short answer. Appendix C took less than 15 minutes to complete. Appendix D comprised 22 questions, these questions were mostly short closed ended questions that offered multiple choice questions, there were 4 tables that used Likert scales to complete. Appendix D did not take longer than 30 minutes to complete.

Data collection was done over 3 months, every 2 weeks an email reminder was sent out inviting participants to take part in the survey.

The print copy of the survey took the same time to complete as the online version. Information relating to the research study inviting participants to take part was available at two oncology centres around Gauteng. Participants that would like to take part in the study were able to receive the print version of the survey from the

receptionist. All print surveys did not contain indemnifying information of participants to ensure no prejudice and full autonomy. Print surveys were collected at the end of each month for 3 months, all surveys collected were placed in one box so that data collected will not be traced back to a particular Oncology centre this ensured that the results are objective, valid, and reliable.

3.6. Data Collection Methods

Data were collected through an online survey host (Google forms) and printed copies. Online version: Data were automatically collected and collated via the google drive platform for the online version of the questionnaire. Data collected manually via printed versions were captured using excel. Data collection of the online survey commenced over 3 months, an invitation to take part in the survey was sent to participants twice a month for 3 consecutive months and printed surveys were given to oncology centres and of Virgin Active Eastgate and Virgin Active Rosebank to hand out willing participants, these surveys were collected at the end of each month for 3 months and completed surveys were placed in a box to ensure anonymity was maintained.

3.7 Data Analysis

Data analysis was performed using Stata version 13.1. Descriptive data are expressed as percentage, means and standard deviations. Data were checked for normality by drawing graphs. Data were recorded on a data collection sheet. Statistical significance of 95% ($p< 0.05$) was accepted.

3.8 Ethics

Ethical clearance was applied for through the Human Research Ethics Committee (Medical) of the university of the Witwatersrand to conduct the study, and approval was granted on the 9th of June 2020 with certificate number M191174.

All participants were made aware of the purpose of study via an information sheet (Appendix A and B) and provided consent automatically upon completing the questionnaire online or print version of the survey. Participation was voluntary, all identifying formation was kept private and confidential. The results from the questionnaire were anonymous as no indemnifying information was obtained from participants. The survey results were analyzed by statistical software and therefore the margin of bias and error is minimized.

CHAPTER 4: RESULTS

4.1 Introduction

The biographical data of both health care professionals and individuals diagnosed with cancer was reported. Secondly, the results for the different types of cancers patients who took part in this study were diagnosed were reported. The results of this study is presented under each objective.

4.2 Biographical Data

i. Health Care Professionals:

There were 93 health care professionals that took part in this study and worked in Gauteng. The sample population of health professionals comprised of: Medical Professional/Oncologists (n=10); Nurses (n-6); Dieticians (n=8); Biokineticists (n=11); Physiotherapists (n=57) and Other (n=1). There were 93 respondents with ages 23 - 62 (38 ±1.88). The Health Care Professionals Mean of 12.35 years in practice and 92% participants (n=86) working in an urban environment and 8% respondents (n=7) in a rural environment. This population group had a minimum of 1 year of practice; maximum of 42 years in practice with a median of 8 years and a mean of 12,35 years of practice.

Individuals Diagnosed with Cancer

There were 52 participants of which 71% (n=37) were female and 29% (n=15) were male. This population group had a minimum age of 40 and a maximum age of 82 years, (65,38 ±5.1). In this sample,15,4% (n=8) of respondents said they had a disability or long term-illness that limits their physical activity.

ii. Cancer diagnosis per body site

Figure 4.1 shows the different body sites where cancer had been reported within the sample, including: breast, throat, prostate colorectal (bowel cancer), skin, lymph nodes, head and neck, bladder, kidney, uterus, cervix, and lung. The participants also

had an option to select “other” and “don’t know” as possible options. The most common body site in which cancer had been present in the participants was breast cancer - 29% of participants, followed by prostate cancer with 19.4% (n=12) of participants. There were 9.7% (n=6) of participants in this study had bladder and cervical cancer, and 8.1% (n=5) of participants were diagnosed with skin cancer, while 6.4% (n=4) of participants were diagnosed with uterine and lymph node cancer. Lastly, 3.2% (n=2) of participants presented with lung, kidney, and throat cancer and 1.6% (n=1) participant had head and neck cancer.

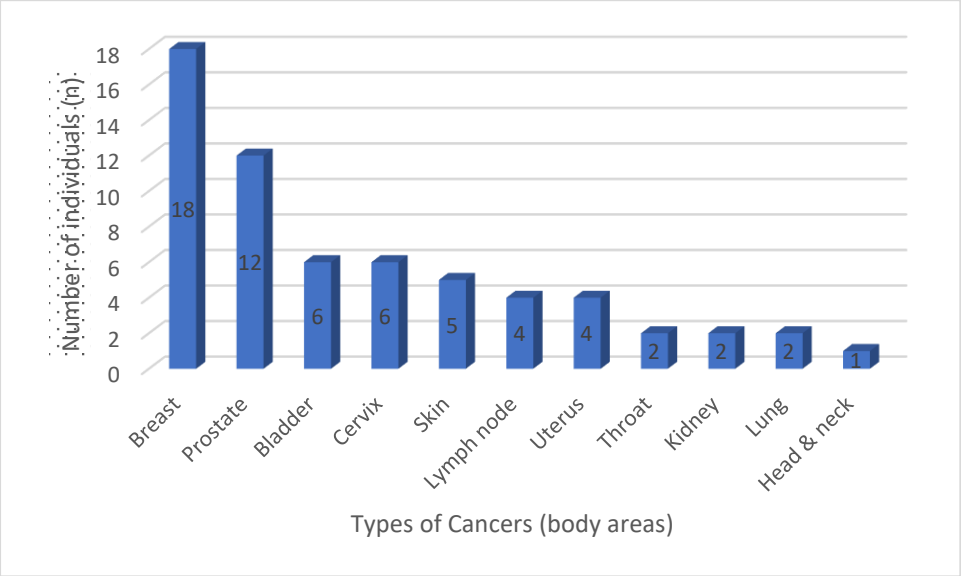

Figure 4. 1: The types of cancer individuals who took part in the survey presented with by body site (n=62)

4.3 Objective1: Knowledge of Cancer Related Fatigue and exercise

The difference in the knowledge of cancer related fatigue in healthcare professionals vs individuals diagnosed with cancer is shown in figure 4.2. Eighty one percent (n=75) of health care professionals reported that they had heard of cancer related fatigue while only 15 % (n=8) of individuals diagnosed with cancer where aware of the comorbid condition.

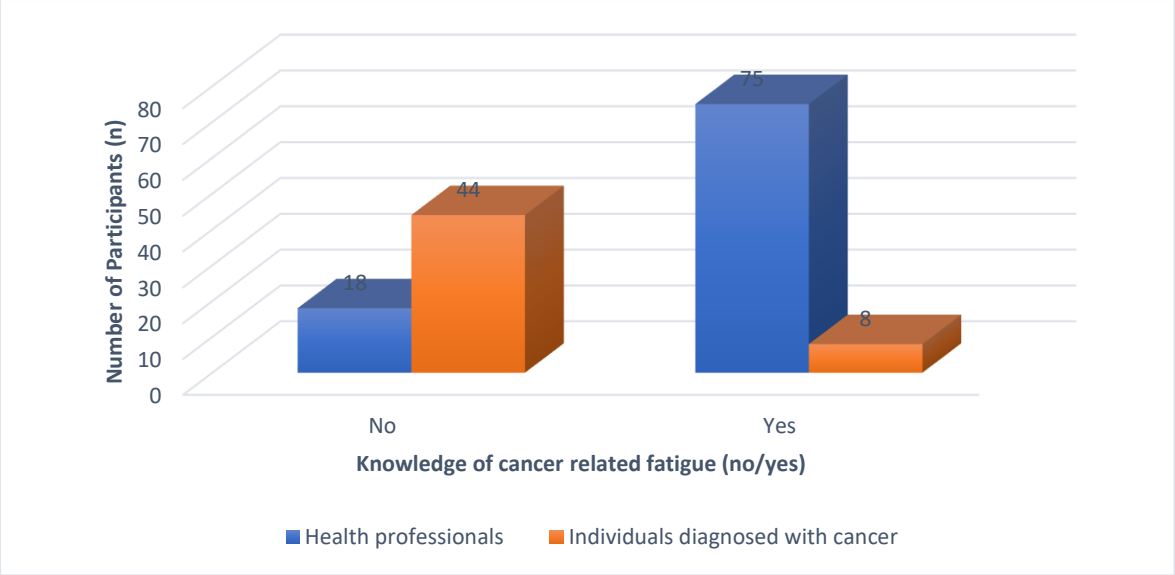

Figure 4. 2: Health Care Professionals(n=93) and individuals with cancer(n=52) knowledge of exercise-based therapies to treat CRF or not.

The health care professionals (n=75) stated that they had knowledge of cancer related fatigue and exercise, gained their knowledge through; self-knowledge; information off the internet, courses on CRF and exercise and guidelines set out by ACSM (Figure 4.3). Self-Knowledge was the majority source 53% (n=40) of information, followed by Information of the internet 28% (n=21) and courses on CRF and exercises 11% (n=8), compared to guidelines set out by ACSM which was the least common source selected 8% (n=6).

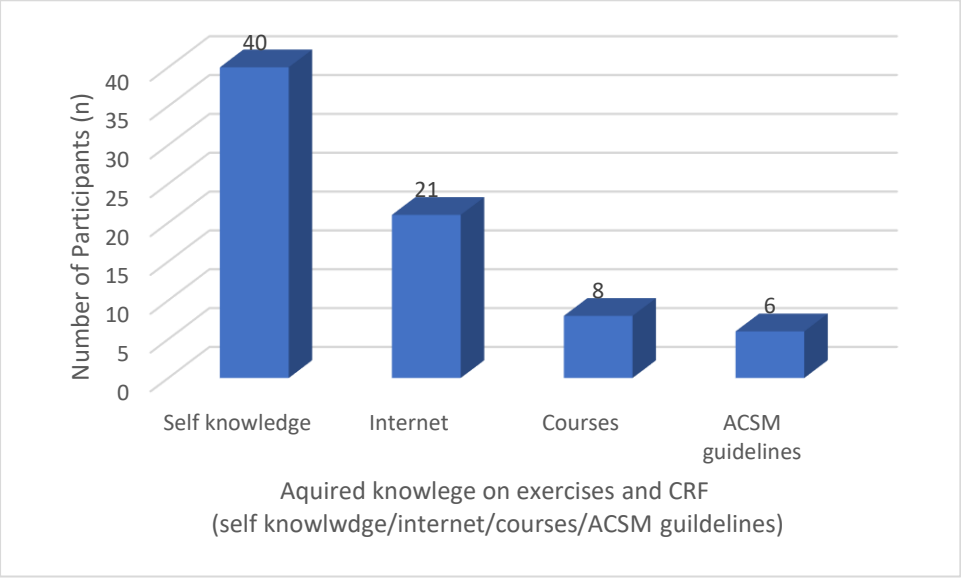

Figure 4. 3: Where Health Care Professionals (n=75) reportedly gained their knowledge on cancer related fatigue and exercise.

4.4. Objective 2: The current attitudes of Cancer Related Fatigue and Exercise

Figure 4.4 shows the attitudes of health care professionals and individuals with cancer towards using exercise-based therapies to treat cancer related fatigue. Participants were asked if exercise-based therapies were made available to treat cancer related fatigue, would they use them. Participants were asked to select "yes, no or unsure" as possible answers. The "no" response was reported by 4.3% (n=4) of healthcare professionals' and 1.9% (n=1) by individuals with cancer. Majority of healthcare professionals; 95.7% (n=89) and individuals with cancer; 92.3% (n=48) selected that they would make use of exercise-based therapies to treat cancer related fatigue. There were 5.8% (n=3) individuals with cancer reported that they were unsure if they would make use of exercise-based therapies to treat CRF.

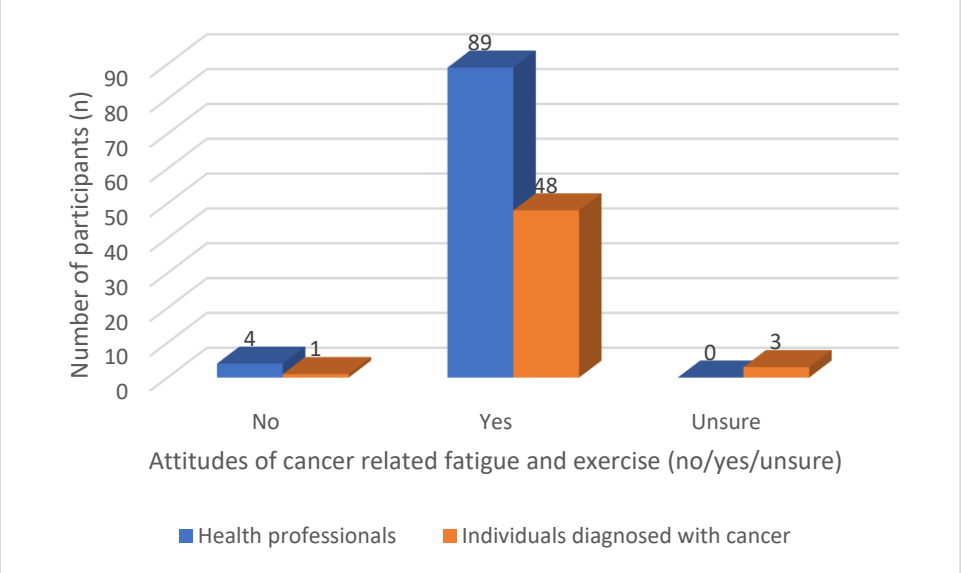

Figure 4. 4: The attitudes of Health Care Professionals (n=93) and individuals with cancer (n=52) towards using exercise-based therapies to treat cancer related fatigue

4.5 Objective 3: The current perception of cancer related fatigue and exercise

Figure 4.5 shows the difference in the current perceptions towards using exercise to treat cancer related fatigue in professionals vs individuals diagnosed with cancer. Participants were asked how they felt cancer related fatigue would affect an individual's cancer treatment/ recovery. The participants chose one of five options: not at all; a little bit; moderate, quite a bit and very much.

i. Healthcare Professionals:

Health care professionals (n=93) results show that majority, 43% (n=40) felt that cancer related fatigue would "very much" affect individuals cancer treatment/recovery this was followed by "quite a bit", 38% (n=35) and "moderate", 18% (n=17). The selection "a little bit" was only selected by 1% of participants (n=1).

iii. Individuals Diagnosed with Cancer

The cancer individuals' results showed in figure 4.5 that they perceived that cancer related fatigue would affect their treatment/ recovery in the following way: The majority, 48% (n=25) of individuals with cancer selected that they felt fatigue would "quite a bit" affect their treatment/ recovery. Forty-six percent% (n=24) selected that fatigue would affect their treatment/ recovery a "moderate" amount. The lesser chosen responses by individuals diagnosed with cancer was that fatigue would affect their treatment/recovery 3,8% (n=2) "Very much" and 1,9% (n=1) selected "a little bit". None of the individuals chose the option "not at all".

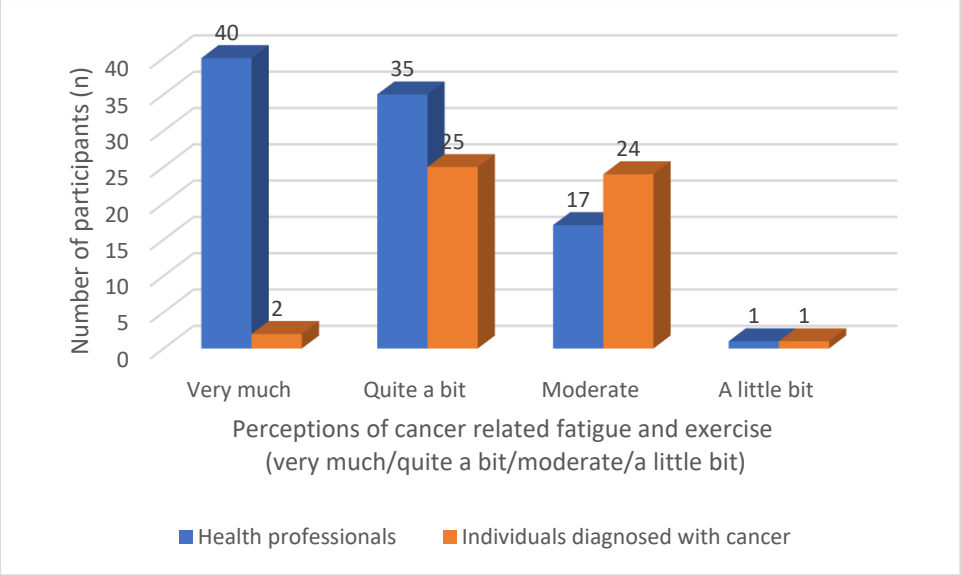

Figure 4. 5: The perceptions of Healthcare Professionals (n=93) and individuals with cancer (n=52) towards exercise-based therapies to treat cancer related fatigue

Healthcare professionals' response to how they felt their patients with cancer related fatigue symptoms were identified and managed is shown in figure 4.6. The health care professionals reported that 21.5% (n=20) selected "yes" that their patient's cancer related fatigue symptoms were identified and managed, and 78,5% (n=73) selected "no" that their patient's cancer related fatigue symptoms weren't identified and managed.

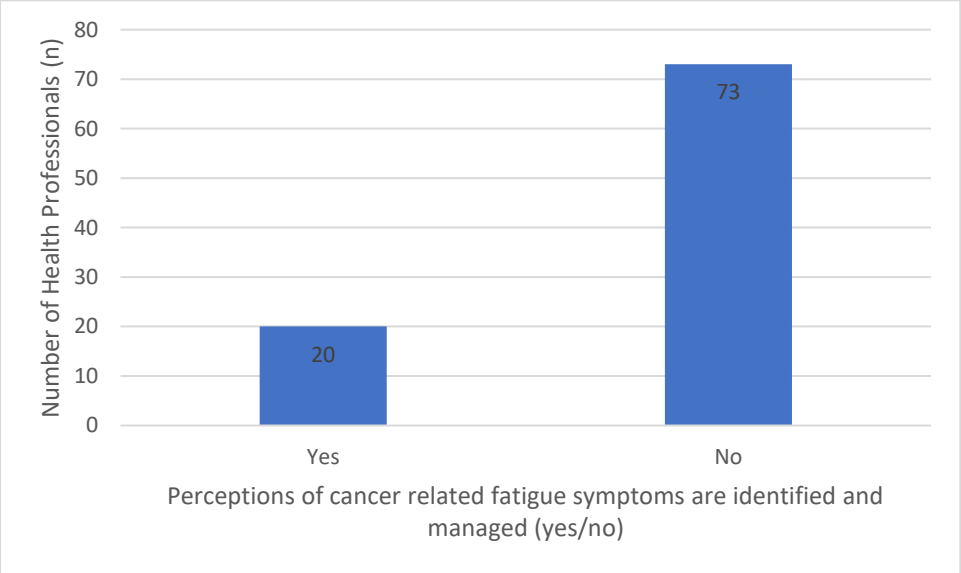

Figure 4. 6: The perceptions of Health Care Professionals (n=93) towards individuals diagnosed with cancer, symptoms of cancer related fatigue are identified and managed

4.6 Objective 4: The extent that exercise is prescribed to individuals with Cancer Related Fatigue

Figure 4.7 represents the number of health professionals in this study who prescribe exercise to treat cancer related fatigue. Seventeen percent (n=16) of health care professionals reported that they don't prescribe exercise to their patients with cancer related fatigue, and 83% (n=77) selected "yes", they do prescribe exercise to patients with cancer related fatigue.

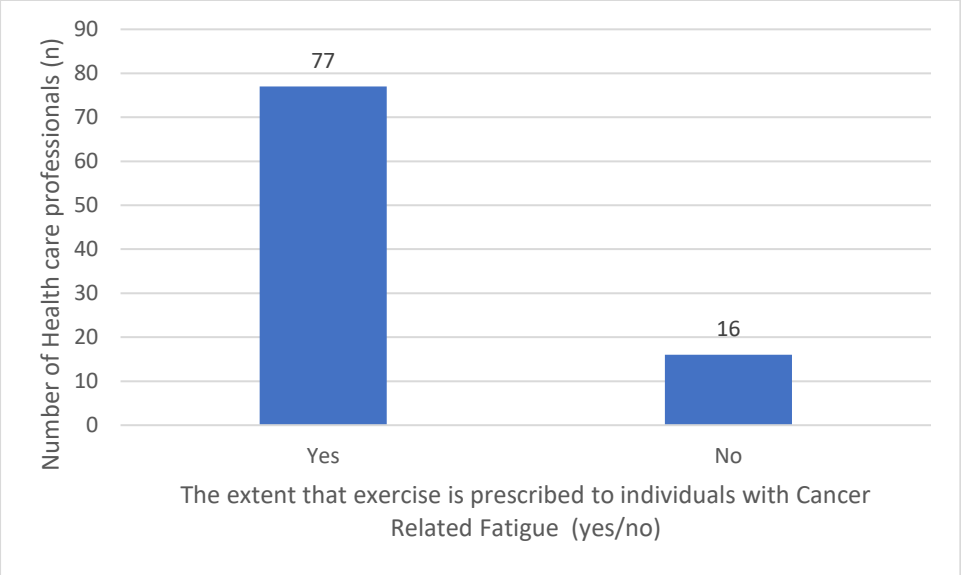

Figure 4. 7: The total sample of Health Care Professionals (n=93) who prescribe exercise to treat cancer related fatigue

Figure 4.8 represents the frequency that Health Care Professionals (n=77) prescribe exercise to treat cancer related fatigue. Of the participants that prescribe exercise (n=77) to their patients, 39% (n=30) selected that they often prescribe exercise to their patients with cancer related fatigue, 27% (n=21) selected moderate and 34% (n=26) selected that they rarely prescribe exercise to their patients with cancer related fatigue.

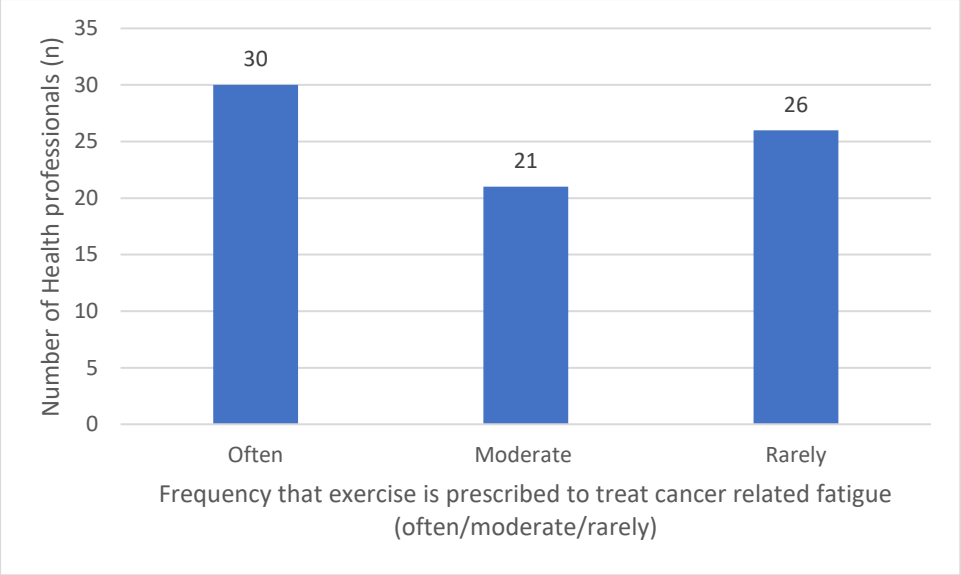

Figure 4. 8: The frequency that Health Care Professionals (n=77) prescribe exercise to treat cancer related fatigue

4.7 Objective 5: The extent that exercise is being used by individuals to treat Cancer Related Fatigue

i. Participants who feel fatigued

The level of fatigue that participants by individuals with cancer experienced in the past seven days is shown in figure 4.9. The participants in the study could select 1 of 5 options to respond from: not at all, a little bit, somewhat, quite a bit, very much. The results show that the majority of participants in the study felt “a little bit” (n=15) and “somewhat” (n=15) fatigued at 29% each. The results show 21% (n=11) of individuals in the study felt “quite a bit” of fatigue. Seventeen percent (n=9) of the sample study selected the option “very much” to describe their level of fatigue. The results show that 4% (n=2) of the participants in this study did not feel fatigued in the past 7 days.

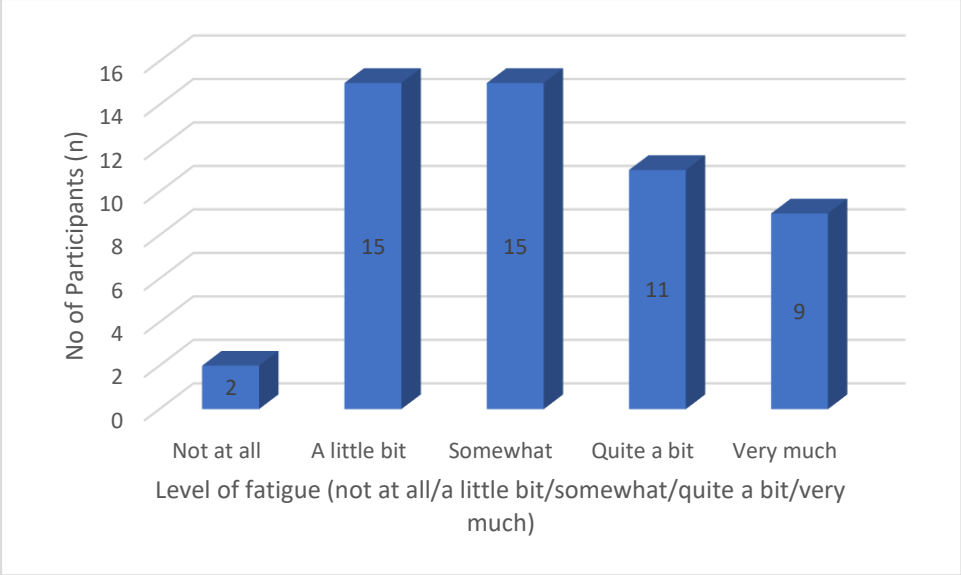

Figure 4. 9: The level of fatigue individuals diagnosed with cancer (n=52) felt within seven days

ii. Physically active participants

The number of days individuals diagnosed with cancer (n=52) took part in physical activity over the past week is shown in figure 4.10. They were asked if they took part in any physical activity over the past 7 days. The results show that 50% (n=26) did no physical activity last week, 12% (n=6) took part in physical activity for 1 day, 13% (n=7) participated twice last week, 15% (n=8) participants were active for 3 days and 10% (n=5) did physical activity 6 days last week.

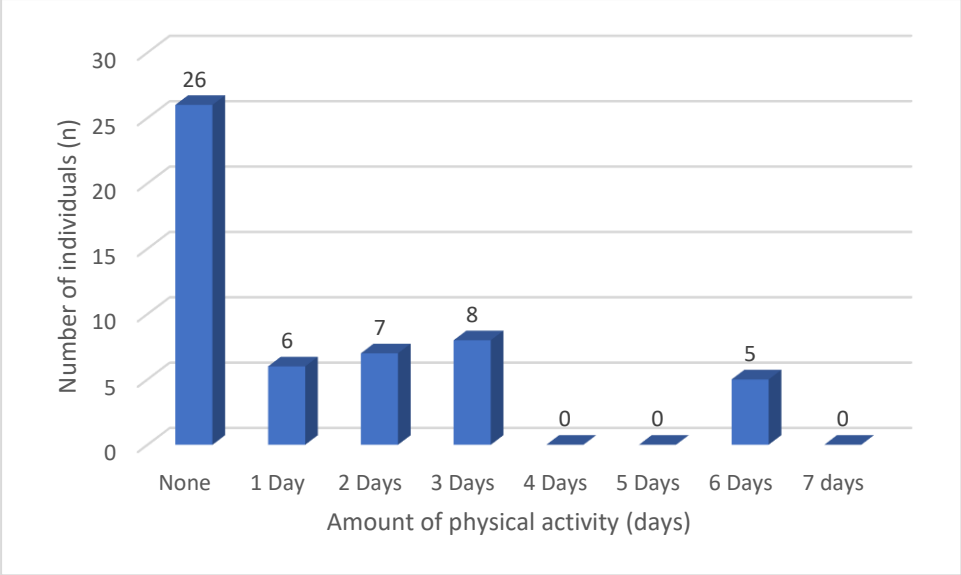

Figure 4. 10: The number of days individuals diagnosed with cancer (n=52) took part in physical activity over the past week

Figure 4.11 is a typical representation over seven days of physical activity by individuals diagnosed with cancer (n=52). Fifty eight percent (n=30) of participants reported that over the past seven days this amount of physical activity was a typical amount of physical activity that these participants usually take part in, and 42% (n=22) of participants reported that this was not the usual amount.

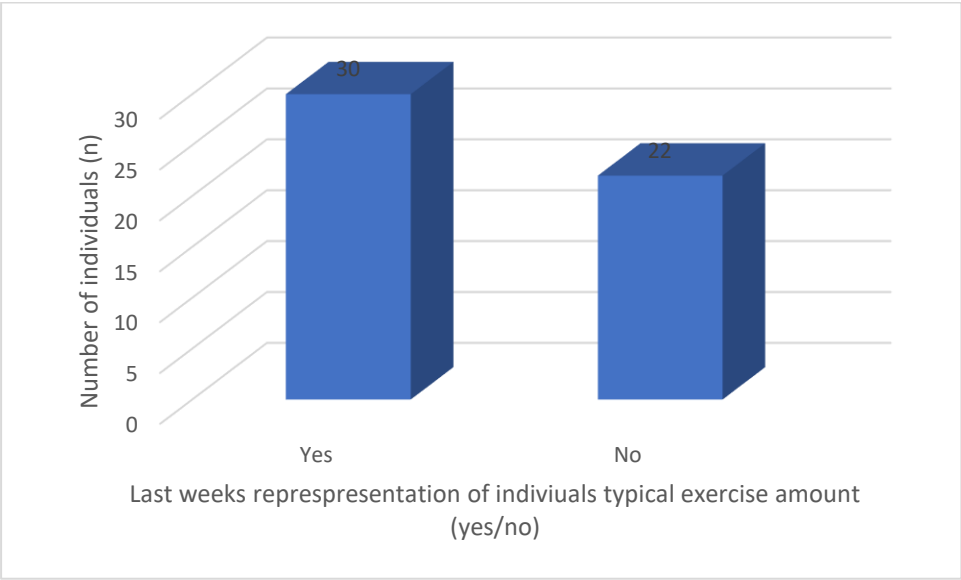

Figure 4. 11: The representation of cancer individuals' physical activity levels over the past 7 days being a typical representation of their regular physical activity levels (n=52)

CHAPTER 5: DISCUSSION

5.1 Introduction

Cancer is a non-communicable disease that destroys normal body tissue when abnormal cells form uncontrollably. The disease itself and its treatments cause fatigue. Fatigue may hinder a patient's progress and have long term effects on the quality of life both physically and psychologically. This study had 5 main objectives that will be discussed based on the study's results.

i. The extent of knowledge of health professionals and individuals with cancer in Gauteng, regarding cancer related fatigue and exercise-based therapies to reduce CRF

There is a disproportionate level of knowledge of cancer related fatigue and exercise-based therapies between health professionals and cancer individuals. Eighty one percent (n=75) of health professionals in this study showed to have knowledge of cancer related fatigue compared to only 15% (n=8) of cancer individuals who reported to have knowledge of cancer related fatigue. With high percentage levels of CRF noted in cancer patients and only 15% of individuals with cancer in this study have knowledge of CRF. There is a disproportion of the number of individuals diagnosed with cancer and knowing what CRF is, whereas 81% of health professionals in this study have knowledge on CRF.

The sample of health care professionals (n=75) in this study reportedly gained their knowledge on cancer related fatigue and exercise mostly through self-knowledge 53% (n=40) and through information off the internet 28% (n=21). Eleven percent (n=8) of health professionals gained their knowledge on CRF through courses and 8% (n=6) knowledge was gained through guidelines set out by ACSM. When comparing these findings to Pearson et. al. (2015) study who reported that there are inconsistencies in both the assessment and management of cancer related fatigue, and that

this is due to the limited knowledge and expertise in this field amongst health professionals, we can see that this study yielded similar results. [26] Studies by both AL Maqbali[35] and . Pearson[28] also found similar finding to this study showing that there is a need to further improve knowledge of health professionals.

Structured physical activity and reduce cancer related fatigue however there is a need for further studies to identify what exercise dose should be prescribed to patients based on the location, treatment, and stage of cancer. With South Africa's cancer statistics increasing each year it is important to bridge the gap between what clinicians and cancer patients know about CRF the benefits of exercise and to get more clinicians prescribing exercises for treatment and individual's actively taking part in structured physical activity.

ii. The current attitudes of health professionals and individuals with cancer in Gauteng, regarding cancer related fatigue and exercise-based therapies to reduce CRF.

The sample population yielded a similar response to the literature by Smaradottir et al[52] which also had a positive attitude towards using exercise in treating cancer related fatigue. The results of this study's sample population has mostly a positive response as 95.7% (n=89) of health professionals and 92.3% (n=48) cancer individuals reported that they would make use of exercise-based therapies to treat cancer related fatigue. There were 4.3% (n=4) health professionals and 1.9% (n=1) who reported that they would not use exercise-based therapies to treat cancer related fatigue.

iii. The current perceptions of health professionals and individuals with cancer in Gauteng, regarding cancer related fatigue and exercise-based therapies to reduce CRF.

There was a consensus in this study that both health professionals and individuals with cancer felt cancer related fatigue would affect treatment

and recovery. Forty three percent (n=40) of health care professionals in this study felt that fatigue would affect a patient's treatment/recovery "very much", and 38% (n=35) reported that fatigue would have "quite a bit" of an affect. The health professionals reported only 18% (n=17) of the sample selected that cancer related fatigue would "moderately" affect and individuals' treatment/ recovery and 1.1% (n=1) reported that fatigue would have "a little bit" of an affect. The health professionals' results and the cancer individuals result in this study were very similar showing that both population groups felt that fatigue with have a significant effect on the treatment and recovery of an individual with cancer. Most cancer individuals who participated in this study perceived that fatigue would affect their treatment and recovery "quite a bit" 48% (n=25) and 46% (n=24) selected that they perceived fatigue to have a "moderate" effect. With over 94% of individuals perceiving that their cancer treatment/recovery will be affected by CRF, it is important to further educate patients on how to identify CRF and reduce the affects it may have on them.

This study found that most health professionals perceived fatigue to have a negative impact on cancer patients' treatment and recovery however when they were asked if they felt that their own patient's cancer related fatigue was identified and managed the majority of 78.5% (n=73) reported "no", that their patients fatigued was not identified and managed. In this study a disproportionate finding was obtained by health professionals between the amount they perceive that CRF would affect cancer individuals' treatment/recovery to the management of a patients CRF.

The perceptions of both sample populations in this study on how fatigue has a negative effect on a cancer individuals' recovery and treatment was the same found in the literature by Diaz, N et al[36] This study and the study by Diaz et al[36] both show that cancer patients perceive fatigue to have a high impact on their daily living affecting both social and emotional aspects impacting their recovery and treatment. Williams, LA

et al[37] reported that health professionals underestimate the symptom of fatigue this is similar in our study knowing the amount of health professionals that know of cancer related fatigue, however only 21.5% identify and manage their patient's fatigue.

iv. The extent that exercise is currently being prescribed in Gauteng, by health care professionals for individuals with CRF.

The results of this sample populations identified that the majority, 83% (n=77) of health professionals in this study do prescribe exercise to their cancer patients who have fatigue. The health professionals in this study comprised of medical professional/oncologists, nurses, dieticians, biokineticists and physiotherapists. Some health professionals are more inclined to prescribe exercise to patients (biokineticists and physiotherapists) and less so with others (nurses and dieticians). When the health professionals were asked how often the prescribed exercise for patients with cancer related fatigue only 39% (n=30) reported that they "often" prescribe this was followed by 27% (n=21) reporting that they prescribe exercise to CRF patients a "moderate" amount. Of the 77 health professionals who prescribe exercise 34% (n=26) reported that they rarely prescribe exercise to their patients diagnosed with cancer related fatigue. Despite most health professionals (83%) in this study stating that they do prescribe exercise to their patients with cancer related fatigue only, 34% of these health professionals reported that they do so rarely. A further investigation is needed to understand why 34% of health professionals in this study only rarely prescribe exercise to their cancer patients with fatigue.

The Cancer Association of South Africa[13] states that lifestyle-related risk factors have a large effect on a person's chance on getting cancer and physical inactivity is cause, with this knowledge its alarming that there is a large amount (34%) of health professionals in Gauteng who only rarely

prescribe exercise and 17% who don't prescribe any form of exercise to their patients diagnosed with cancer. South Africa is a third world country considering the urbanisation and economic development this may also be causing the rise of cancer diagnosis in South Africa according to the study from Torre et al[14] these factors may further cause an increase in the number of new cancer cases in the years to come and therefore it is important to upsurge the extent that health professionals in Gauteng prescribe exercise to cancer individuals and to promote living a physically active life. Interventions for exercise improvement could be done by oncology centres having an exercise specialist on site where oncologists can refer cancer patients.

v. The extent that individuals use exercises to treat CRF.

The participants in this study expressed their fatigue over a 7-day period. The majority (96%) of cancer individuals in this study felt fatigued over the seven-day period. The finding in this study was similar to the findings of Mustian et al[26] and Jean-Pierre et al[27] who found CRF to be a common symptom in cancer patients.

The cancer patients in this study (n=52) reported on how many days in a 7-day cycle they were physically active. The cancer individuals reported that 50% (n=26) did not take part in any physical activity and that 11,5% (n=6) only took part in physical activity for 1 day. There were 13,5% (n=7) of cancer individuals who participated in physical activity twice last week. Cancer individuals reported that 15,4% (n=8) were active for 3 days and 9,6% (n=5) did sport 6 days in the 7-week cycle. When looking at the literature for Elmagd et al[42] whose study showed that exercise and physical activity aids in decreased stress and anxiety levels, improve brain power and mood, sharpen memory, increase muscle strength, and bone density, exercise aids in reducing and preventing obesity, diabetes, heart disease, cardiovascular disease, and cancer. Seeing these findings and knowing the benefits of exercise it is concerning that this study shows 50% of cancer individuals in Gauteng

don’t take part in physical activity and that majority 75% (n=39) are not following ACSM’s recommendations to physical activity.

Cancer individuals (n=52) reported on the representation of their 7-day cycle of physical activity was typical of them. The cancer participants in this study reported that 58% (n=30) was a typical refection of their usual physical activity level over 7 days, however 42% (n=22) reported that this was not their usual amount of physical activity. A further investigation is needed to evaluate why 42% did not take part in their usual physical activity and whether this level is higher or lower as reported in this study. The World Health Organisation[15] advocates that an individual should know and understand that they themselves are able to lessen their risk of getting cancer by living a physically active lifestyle, however 75% of this studies sample population is physically inactive. There is a need in Gauteng to improve the amount that individuals take part in physical activity and an intervention study should be proposed to assess what the barriers are that there is a low physically active sample population of cancer individuals in Gauteng and what interventions can be implemented to improve physical activity levels.

Studies from Brown et al[44] and Kirkham et al[45] have shown that there is benefit in taking part in physical activity both their studies compared their results to sedentary oncology patients however both their studies showed that there is no set amount of physical activity recommended. Kirkham et al[45] study further stated that there may be many barriers preventing individuals in adhering to exercise and that these factors may be the type of cancer treatment implemented and the physiology of the patient and their cancer. Both studies show that the best results were found when exercise-based therapies are individualised to a cancer patient. Considering the above-mentioned studies in Gauteng it is imperative to improve participation of cancer individuals taking part in physical activity and to further improve the benefit of exercise-based therapy for this population group, exercise should be individualised to

the physiology of an individual, the type and stage of cancer and their treatment.

One of the critical aspects that are often neglected in which these assessments/tools are questions regarding physical activity, physical well-being, and participation in exercise-based therapies. Therefore, current tools should be modified to include these variables so that patients are managed more holistically.

Cancer patients in Gauteng could benefit from using the findings from Koppel et al.[46] by integrating psycho-educational aspects in exercise interventions to increase physical activity related health competence. It may be beneficial to improve the quality of studies by dividing exercise dose for each patient specifically based on the current stage, location, treatment of cancer.

5.2.2 Clinical significance

While in the study there is no evidence of statistical significance, however there is clinical value. This study's population group was of various health professionals and individuals with multiple types of cancers at different stages and treatments. This study's results show that health professionals have knowledge of CRF. Both health professionals and cancer individuals in this study stated that they had a positive perception towards using exercise to treat CRF. If both health professionals and individuals with cancer know and understand CRF and the benefits exercise-based therapies have on their health and recovery we should further encourage both health professionals and individuals to prescribe/take-part-in exercise to assist with fatigue.

5.3 Strengths and limitations

This study covered both sides of knowledge, attitudes and perceptions of health professionals and individuals with cancer which gives more information to compare where gaps may be with prescribing exercise and utilising exercise-based therapies

to treat CRF. The inclusion criteria in this study of Gauteng health professionals were from various disciplines and of varying years of practice this shows that there was no bias and we could collect data from many sources. The inclusion criteria in this study for participants who were diagnosed with cancer in Gauteng strengthened the information collected on CRF and exercise due to their various ages, genders, and array of cancer diagnoses, however by only including participants from Gauteng this may be a limitation as it may not be representative of the whole country. The exclusion criteria of not assessing surveys that were less than 90% complete, meant that the data accepted and assessed was comprehensive and is a clear review of the complete study to draw conclusions.

The health professionals in this study all have voluntary membership through sub associations and so there may be numerous people who work in the area but may not professional registered by the health professions council of South Africa (HPCSA).

This study was conducted during the COVID-19 pandemic due to the restrictions by government and increased concern of health the study could not reach as many participants through print and online copies. The demographic of cancer individuals in this study are not known to be as computer literate as a younger more health demographic. With COVID-19 simple tasks like leaving pens and copies of the survey at oncology centres in Gauteng was no longer allowed as COVID-19 can be spread via touch surfaces and these cancer individuals' immune system is already compromised. Health professionals in this study may have been influenced/affected by the pandemic emotionally, financially, and physically making time to complete this survey less important to them. If this study was repeated at a time before COVID-19 it may have received a greater response.

CHAPTER 6: CONCLUSION

In this study the hypothesis was accepted stating that Oncology health professionals and patients had limited knowledge, poor attitudes, and perceptions in terms of dealing with and treating cancer related fatigue. Furthermore, there was poor prescription of exercise by health professionals and poor use of exercise by patients with CRF in Gauteng.

In this study on cancer related fatigue and exercise-based therapies in Gauteng, it was found that no evidence of statistical significance was found for the knowledge, attitudes and perceptions of both health professionals and individuals with cancer diagnosis in Gauteng on CRF and exercise-based therapies for treatment.

The level of knowledge on cancer related fatigue in Gauteng in this study reported that health professionals had a higher level of knowledge compared to individuals with cancer diagnosis. Most health professionals in Gauteng stated that their knowledge on cancer related fatigue was “self-knowledge”.

In this study the participants have an auspicious attitude towards treating CRF with exercise-based therapy. The results in this study show that most health professionals and cancer individuals would favorably select exercise as a modality to treat cancer related fatigue. In this study 21.7% of health professionals in Gauteng feel that their patient’s cancer related fatigue is identified and managed. Forty-eight percent of cancer patients in this study perceived that cancer related fatigue would have “quite a bit” of an effect on their treatment and recovery.

With over 80% of clinicians in Gauteng using exercises for treatment of CRF there are 34% said that the “rarely” prescribe it to their patients. Further assessment is needed to understand why 34% of health professionals stated that they prescribe exercise but at a rare frequency. The study showed that 96.2% cancer individuals in Gauteng felt fatigued, however the results show that of those only 50% took part in physical activity in the past week.

The evidence of this study shows that both health professionals and cancer patients would use exercise to treat cancer related fatigue. The study results show that

individuals with CRF felt that exercise would positively reduce their fatigue. There is a need for an intervention study of both the accuracy of fatigue assessment and identification and the use of structured exercise to treat CRF in cancer individuals during and after cancer treatment.

6.2: RECOMMENDATIONS

6.2.1 Recommendations to practice

The same study may yield results that show greater insight to CRF and exercise-based therapies if done at a time of no pandemic. A further intervention study to stratify types of cancer and their rate of fatigue during and after treatment/diagnosis together with structured exercise intervention.

Tools to assess cancer related fatigue currently neglect information to assess an individual's physical activity, physical well-being, and their participation in exercise-based therapies. There should be modifications of current tools assessing CRF to include physical activity information to assess, treat and manage CRF better.

6.2.2 Recommendations for further research

This study found that health professionals were more aware of CRF than individuals diagnosed with cancer. Further studies should be done to assess the quality and level of professionals and individuals' knowledge in this field of cancer related fatigue and exercise-based therapies to further improve knowledge through targeted education or within medical curricula. Increased knowledge of cancer related fatigue and treatment will have a positive impact for improving patients' quality of life. A study to see if there in an increased amount of information given from health professionals to cancer patients on CRF and exercise what cancer patients response to exercise would be and assess its effect on CRF.

A further investigation is needed to understand why there are some people who would not make use of exercise to reduce the effect of fatigue on a person with a cancer diagnosis. With this study and previous literature showing that both health

professionals and individuals with cancer have a positive attitude for employing exercise-based therapies to treat cancer related fatigue, it is imperative to analyse what barriers hold these individuals back from what they know can assist them and what they choose to use to treat CRF, if any. Studies should assess why certain individuals and health professionals are not in favour to use exercise to treat CRF and if they have other modalities of treatment or to understand why they feel negatively towards exercise-based therapies and CRF. If this study and previous studies show a high favourable mindset to exercise-based therapies further studies should be done to assess how these therapies can be implemented constructively.

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APPENDICES

APPENDIX A: STUDY INFORMATION DOCUMENT FOR ONCOLOGY HEALTH CARE PROFESSIONALS

STUDY INFORMATION DOCUMENT UNIVERSITY OF THE WITWATERSRAND
CENTRE FOR EXERCISE SCIENCE AND SPORTS MEDICINE
PARTICIPANT INFORMATION SHEET

Thank-you for taking the time to read this information sheet. This document is to explain what the research study is about and how this research may aid in gaining information on cancer related fatigue and exercise.

Hello,
My name is Erin Karam, and I am completing my Master's degree in Biokinetics at the University of the Witwatersrand. As part of my degree I am conducting a study to assess patient and healthcare providers knowledge, attitudes and perceptions, of cancer related fatigue and exercise-based therapies. Research is a process used in seeking new knowledge. In this study a survey will be used to determine if cancer related fatigue is seen as a factor affecting cancer patients and their treatment and to determine how cancer related fatigue is currently assessed and treated by health care professionals.

TITLE:
A survey to assess patients and health care providers knowledge, attitudes and perceptions, of cancer-related fatigue and exercise

PURPOSE OF THE RESEARCH:
The research aims to determine the knowledge, attitudes and perceptions of oncology health professionals and people who have cancer related fatigue as well as determine the use of exercise for treatment in these population groups.

Invitation to Participate: We are asking / inviting you to take part in a research study

What is involved in the study? This could include but would not necessarily be limited to such features as:

1. A cross sectional descriptive study design will be employed for this study
2. Participants who wish to take part in the study will need to complete a survey.
3. Participants may complete the survey online or print version
4. Data collection will be over three months from 1 May 2020 to 31 July 2020
5. The survey should take approximately 15 minutes to complete

6. The survey questions are short in nature and require either one-word answers; multiple choice selection and tables.
7. The print surveys can be left with the receptionist at the clinic and will be collected every 2 weeks.
8. The online survey can be emailed to you

Risks of being involved in the study: There are no known risks for participants involved in the study

Benefits of being in the study: There is no direct benefit for participants taking part in the study, however all knowledge gained through the study may aid in assisting patients and health care professionals in assessing and treating cancer related fatigue.

Participation is voluntary, refusal to participate will involve no penalty or loss of benefits to which the Participant is otherwise entitled, as, for example, a hospital patient; that the Participant may discontinue participation at any time without penalty, or loss of benefits to which the Participant is otherwise entitled; that there is no requirement to provide a reason for withdrawing and any data collected on such a person will in default be destroyed, unless the Participant specifically consents to its retention.

Confidentiality:
The information obtained throughout this study will be treated as privileged and confidential. Researches and supervisors of this study will have access to the information. The study will have no mention of any identifying information in order to protect every participants anonymity. Normally personal information will be treated in the strictest confidence and will only be available to the Principal Investigator (PI) and his/her Supervisor. The only exceptions - and all of them are rare - would normally be:

1. personal information may be disclosed if required by law
2. the Human Research Ethics Committees of the University may exceptionally require personal data to respond to a formal complaint, or for a compliance audit
3. the South African Health Products Regulatory Authority (SAHPRA), which is the successor body to the South African Medicines Control Council (SAMCC), might conceivably require access to personal data, if conducting an investigation into a drug trial

If results are published, this may, exceptionally, lead to cohort, or more rarely, individual identification. All data collected in the course of the study will be securely retained for two (2) years, if a scientific publication arises from the study and six (6) years, if there is no publication. Thereafter it will be destroyed accordingly.

PARTICIPATION AND WITHDRAWL
All participants who choose to participate in this research study may choose to withdraw from the study at any time without reason and without prejudice.

Anonymity can usually only be guaranteed in questionnaires, whether in hard copy or online

Enquiries

If you would like to receive further information, or have any questions or concerns regards the research, please contact:

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Outputs
The results from this study will assist in further understanding Oncology Health Professionals and patients' knowledge, attitudes and perceptions in terms of dealing with and treating cancer related fatigue. Furthermore, this study will give insight to determine whether exercise is prescribed to patients with cancer related fatigue and if so what type of exercise and its effect on these patients.

Contact details of HREC administrator and chair – for reporting of complaints / problems. The following text is recommended:

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for reading this Participant Information Sheet.
Erin Karam
Clinical Biokineticist, BHSc (Hons) Biokinetics (Wits)

Date: January 2020
All participants may have a copy of this information sheet for their own records

APPENDIX B: STUDY INFORMATION DOCUMENT FOR PARTICIPANTS WHO HAVE BEEN DIAGNOSED WITH CANCER

STUDY INFORMATION DOCUMENT UNIVERSITY OF THE WITWATERSRAND
CENTRE FOR EXERCISE SCIENCE AND SPORTS MEDICINE
PARTICIPANT INFORMATION SHEET

Thank-you for taking the time to read this information sheet. This document is to explain what the research study is about and how this research may aid in gaining information on cancer related fatigue and exercise.

Hello,
My name is Erin Karam, and I am completing my Master's degree in Biokinetics at the university of the Witwatersrand. As part of my degree, I am conducting a study to assess patient and health care providers knowledge, attitudes and perceptions, of cancer related fatigue and exercise-based therapies. Research is a process used in seeking new knowledge. In this study a survey will be used to determine if cancer related fatigue is seen as a factor affecting cancer patients and their treatment and to determine how cancer related fatigue is currently assessed and treated by health care professionals.

TITLE:
A survey to assess patients and health care providers knowledge, attitudes and perceptions, of cancer-related fatigue and exercise

PURPOSE OF THE RESEARCH
The research aims to determine the knowledge, attitudes and perceptions of oncology health professionals and people who have cancer related fatigue as well as determine the use of exercise for treatment in these population groups.

Invitation to Participate: We are asking / inviting you to take part in a research study

What is involved in the study? This could include but would not necessarily be limited to such features as:

1. A cross sectional descriptive study design will be employed for this study
2. Participants who wish to take part in the study will need to complete a survey.
3. Participants may complete the survey online or print version
4. Data collection will be over three months from 1 May 2020 to 31 July 2020
5. The survey should take approximately 30 minutes to complete

6. The survey questions are short in nature and require either one-word answers; multiple choice selection and tables.
7. The print surveys can be left with the receptionist at the clinic and will be collected every 2 weeks.
8. The online survey can be emailed to you

Risks of being involved in the study: There are no known risks for participants involved in the study

Benefits of being in the study: There is no direct benefit for participants taking part in the study, however all knowledge gained through the study may aid in assisting patients and health care professionals in assessing and treating cancer related fatigue.

Participation is voluntary, refusal to participate will involve no penalty or loss of benefits to which the Participant is otherwise entitled, as, for example, a hospital patient; that the Participant may discontinue participation at any time without penalty, or loss of benefits to which the Participant is otherwise entitled; that there is no requirement to provide a reason for withdrawing and any data collected on such a person will in default be destroyed, unless the Participant specifically consents to its retention.

Confidentiality:
The information obtained throughout this study will be treated as privileged and confidential. Researches and supervisors of this study will have access to the information. The study will have no mention of any identifying information in order to protect every participants anonymity. Normally personal information will be treated in the strictest confidence and will only be available to the Principal Investigator (PI) and his/her Supervisor. The only exceptions - and all of them are rare - would normally be:

1. Personal information may be disclosed if required by law
2. The Human Research Ethics Committees of the University may exceptionally require personal data to respond to a formal complaint, or for a compliance audit
3. The South African Health Products Regulatory Authority (SAHPRA), which is the successor body to the South African Medicines Control Council (SAMCC), might conceivably require access to personal data, if conducting an investigation into a drug trial

If results are published, this may, exceptionally, lead to cohort, or more rarely, individual identification. All data collected in the course of the study will be securely retained for two (2) years, if a scientific publication arises from the study and six (6) years, if there is no publication. Thereafter it will be destroyed accordingly.

PARTICIPATION AND WITHDRAWL
All participants who choose to participate in this research study may choose to withdraw from the study at any time without reason and without prejudice.

Anonymity can usually only be guaranteed in questionnaires, whether in hard copy or online

Enquiries

If you would like to receive further information, or have any questions or concerns regards the research, please contact:

Principle Investigator:
Erin Karam
Email bio.erink@gmail.com
Contact number: 072 299 7156

Co-supervisors:
Prof Demitri Constantinou
Email: Demitri.Constantinou@wits.ac.za
Contact number: (011) 717 3372
Centre for Exercise Science and Sports Medicine, University of the Witwatersrand

Miss Natalia Neophytou
Email: Natalia.Neophytou@wits.ac.za
Contact number: (011) 717 3368
Centre for Exercise Science and Sports Medicine, University of the Witwatersrand

Outputs

The results from this study will assist in further understanding Oncology health professionals and patients' knowledge, attitudes and perceptions in terms of dealing with and treating cancer related fatigue. Furthermore, this study will give insight to determine whether exercise is prescribed to patients with cancer related fatigue and if so what type of exercise and its effect on these patients.

Contact details of HREC administrator and chair – for reporting of complaints / problems. The following text is recommended:

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for reading this Participant Information Sheet.
Erin Karam
Clinical Biokineticist, BHSc (Hons) Biokinetics (Wits)

Date: January 2020
All participants may have a copy of this information sheet for their own records

APPENDIX C: SURVEY FOR HEALTH PROFESSIONALS ON CANCER RELATED FATIGUE AND EXERCISE

Survey for Health Professionals on Cancer Related Fatigue and Exercise

1. What is your age in years? _____

2. Your gender
    a. Male
    b. Female

3. To which professional discipline do you belong?
    a. Medical Practitioner/oncologist
    b. Nurse
    c. Dietician
    d. Biokineticist
    e. Occupational Therapist
    f. Physiotherapist
    g. Psychologist
    h. Other _____

4. Approximately how many years have you practised either part time or full time in your profession? _____
    [Please do not count periods not practising or on family or other special leave]

5. In which Gauteng city your current practice?
    a. Benoni
    b. Johannesburg
    c. Krugersdorp
    d. Lenasia
    e. Midrand
    f. Parktown
    g. Pretoria
    h. Roodepoort
    i. Sandton
    j. Vereeniging
    k. Other , please state: _____

6. Do you describe your location as?
    a. Urban
    b. Rural
    c. Remote
    d. Other (please specify_____)

The questions in this section refer to your practice setting.

7. How would you best describe your practice setting?
    a. Acute hospital
    b. Community health
    c. Domiciliary service
    d. Palliative care centre
    e. Primary health care
    f. Private practice
    g. Rehabilitation centre
    h. Specialist oncology unit or centre
    i. Other _____

8. How often do you see patients with a cancer diagnosis in your own practice?
    a. Daily
    b. Weekly
    c. Monthly
    d. Occasionally (e.g. once every 2-6 months)
    e. Rarely (e.g. once a year)
    f. Never

9. Have you heard of the term Cancer Related Fatigue?
    a. Yes
    b. No

Cancer related fatigue Cancer-related fatigue (CRF) has been defined as a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer and/or cancer treatment that is not proportional to recent activity and interferes with usual functioning

10. Are you aware of any non-pharmacological treatments for Cancer related fatigue?
    a. Yes
        1. Please specify_____
    b. No

11. If exercise-based therapies were made available to treat Cancer related fatigue would you make use of them?
    a. Yes
    b. No
    c. Unsure

12. Please select how you feel that Cancer Related Fatigue would affect cancer treatment/recovery?
    a. Not at all
    b. A little bit

c. Moderate
d. Quite a bit
e. Very much

13. Do you prescribe exercise to your patients with cancer related fatigue?
    a. Yes
        ii. How often do you prescribe exercise to you patients?
            1. rarely (only when a patient requests)
            2. Moderate
            3. Often

        iii. What type of exercise do you prescribe? (Please select all options that apply)
            1. Flexibility exercises (stretching)
            2. Aerobic exercise (brisk walking, jogging, and swimming)
            3. Resistance training (lifting weights or isometric exercise)
            4. Other (please specify_____)

        iv. Where did you gain your knowledge of exercise for CRF?
            1. Self-knowledge
            2. Information off the Internet
            3. Courses on CRF and exercise
            4. Guidelines set out by ACSM
            5. Other (please specify _____)

    b. No

14. Your professional discipline receives a referral for 'Brad', a 54-year-old man who completed surgery and chemotherapy for cancer about 4 months ago. He is able to walk at a slow pace for about 5 minutes before needing to sit down. 'Brad' is independent in self-care but has low mood and limited energy for other tasks and needs to return soon to his job as a salesman. He identifies his usual fatigue as 6/10.

    a. Would this sort of referral (including self-referral) be made in your setting?
        i. Yes
        ii. No

    b. What services would be offered to this client? Mark all that apply.

i. Reassurance and/or education
ii. Medical certificate
iii. Screening for needs
iv. In-depth CRF assessment
v. Initial assessment
vi. Referral on to other service/s
vii. Individual therapy
viii. Group program
ix. Other _____
x. No services

15. Does your professional discipline have a priority system in place for client referrals where you currently practise?

a. No – what is your current waiting time for first appointment?
_____ weeks
b. Yes - What priority is given to referrals like 'Brad'?
i. Not accepted – Reason _____
ii. Low
iii. Medium
iv. High

16. What is the target waiting time for that priority level?

i. No set time ii ____ weeks

This section concerns your knowledge and practice about cancer-related fatigue (CRF).

17. Are patients routinely asked specifically about their experience of CRF in your setting?

a. No
b. Yes ...by
i. Medical staff – direct question
ii. Nursing staff – direct question
iii. Nursing staff – screening tool (specify_____)
iv. Responding to client/family-initiated concern
v. Other staff (specify direct question, part of a quality of life screening tool, etc. _____)

18. Which of the following best describes your level of knowledge about cancer-related fatigue?

a. I don't know anything about CRF
b. I have heard of CRF
c. I have read about CRF
d. I have limited clinical experience with people with CRF
e. I have moderate expertise in CRF in my own discipline
f. I have a high level of expertise in CRF in my own discipline

19. Do you use any guidelines for assessment and management of CRF in your practice?

a. No
b. Yes
    i. Facility specific guidelines
    ii. Discipline guidelines
    iii. National Cancer Action Team
    iv. National Comprehensive Cancer Network
    v. Other _____

20. How do you screen for or assess CRF in your role? (Mark all that apply)
    a. I do not screen for or assess CRF [go to question #17]
    b. I do not screen for or assess CRF but others in my organisation do
    c. Informal interview (no specific assessment)
    d. Standardised patient reported outcome or validated instrument
    e. Discipline pro-forma – generic initial assessment
    f. Discipline pro-forma – specific for CRF
    g. Functional assessment
    h. Exercise test
    i. Work or home assessment
    j. Other (comment) _____

21. What outcome measure/s or standardised assessments do you use for CRF? (Mark all that apply)
    a. Numeric rating scale (e.g. 0 to 10)
    b. Brief Fatigue Inventory
    c. Multi-symptom inventory
    d. Quality of life questionnaire
    e. Visual Analogue Scale
    f. Other (please specify) _____
    g. Not applicable

22. What **interventions** are you aware of for CRF and which of these do you implement? Please list up to 5.

	Intervention	**Implemented**
1		
2		
3		
4		
5		

23. What do you think are the barriers in your workplace to assessment and management of CRF? Mark all that apply.
    a. Patient expectations that doctor will raise important issues
    b. Lack of routine screening for fatigue
    c. Lack of documentation about fatigue

d. Referrals are not made
e. Lack of knowledge about possible interventions (referrers)
f. Lack of expertise in assessment or interventions (disciplines)
g. CRF is not considered a priority
h. Please add your comments (Free text) _____

24. Do you think that most clients with CRF within your facility have this symptom identified and managed?

a. Yes
b. No

Comment _____

25. Do you have any suggestions about how to improve assessment or management of CRF? Please share your opinions. (_____)

Thank you for taking time to complete the survey, your participation is greatly appreciated

APPENDIX D: SURVEY ON CANCER RELATED FATIGUE AND EXERCISE FOR INDIVIDUALS WHO HAVE BEEN DIAGNOSED WITH CANCER

Survey on cancer related fatigue and exercise for individuals who have been diagnosed with cancer

1. What is your age in years? _____

2. Your gender
    a. Male
    b. Female

3. Have you heard of the term Cancer Related Fatigue?
    a. Yes
    b. No

Cancer related fatigue Cancer-related fatigue (CRF) has been defined as a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer and/or cancer treatment that is not proportional to recent activity and interferes with usual functioning

4. Are you aware of any non-medical treatments for Cancer related fatigue
    a. Yes
        i. Please specify_____
    b. No

5. If exercise-based therapies were made available to treat Cancer related fatigue would you make use of them?
    a. Yes
    b. No
    c. Unsure

6. Please rank how you feel that Cancer Related Fatigue would affect cancer treatment/recovery?
    a. Not at all
    b. A little bit
    c. Moderate
    d. Quite a bit
    e. Very much

7. Do you have a disability or a long-standing illness, or infirmity that limits your activity in any way? (By long standing, we mean anything excluding your cancer that has troubled you over a long period of time or that is likely to affect you over a long period of time.)

a. Yes
b. No
c. Prefer not to say

Under the Equality Act 2010 a person is classified as disabled if they have a physical or mental impairment which has a substantial and long-term effect on their ability to carry out normal day-to-day activities.

8. Please state which of the following apply to you? (Please select all options that apply)

a. Deafness or severe hearing impairment
b. Blindness or partially sighted A
c. long-standing physical condition
d. A learning disability
e. A mental health condition
f. A long-standing illness, such as HIV, diabetes, chronic heart disease, or epilepsy
g. Prefer not to say
h. Other, describe your disability, eg physical/sensory/learning disability?

9. What type of cancer are/ have you been affected by? (Select all that apply)

a. Breast Lung
b. Throat
c. Prostate Colorectal (Bowel cancer)
d. Melanoma
e. Non-Hodgkin lymphoma
f. Head & Neck
g. Bladder
h. Kidney
i. Uterus
j. Cervical
k. Lung
l. Other (Specify_____)
m. Don't know

10. Thinking specifically about the location of your cancer, what is the status of your cancer?

a. I am undergoing testing for diagnosis/the status of my cancer is not known
b. My cancer is stable (the cancer is neither decreasing nor increasing)
c. I am living with advanced or progressive cancer (cancer that is getting worse or cannot be cured)
d. My cancer has come back in the same part of my body.
e. I am in remission or am cancer-free (cured)
f. Other (please specify _____)

11. How has your current cancer responded to treatment? (Treatment refers to any chemotherapy, radiotherapy, or surgery for your cancer. Please tick ONE option that is closest to your situation)

a. Treatment has not yet started

b. I am not in active treatment but I am on "Watch and Wait"
c. I have had treatment, which has been effective and I have no signs or symptoms of cancer
e. I have finished treatment but my cancer is still present (https://www.cancercounsellingsa.com/)
f. I finished treatment, but am being treated again because the cancer has not responded fully to treatment
g. My cancer has not been/will not be treated at all
h. Don't know

12. When you were aged 20 to 24 (current age if less) how much sport or exercise did you take part in? Would you say... (Please select one option only)

a. … a lot
b. … a moderate amount
c. … very little
d. … none at all

13. Thinking about the five years leading up to your cancer diagnosis how much sport and exercise did you take part in then? Would you say... (Please select one option only)

a. … a lot
b. … a moderate amount
c. … very little
d. … none at all

14. Please complete the questionnaire on the following page regarding your current physical activity.

The following questions relate to your physical activity over the previous week. Please mark in the appropriate box the number of minutes spent doing a particular activity. Please try and think carefully and be as accurate as possible with your answers and only include activities of either moderate or vigorous intensity. Examples are given of what should and should not be included.

i. x **Light intensity** – Your heart rate and breathing rate are no different from what they are when you are standing, sitting, etc.
ii. **Moderate intensity** – Your heart rate and breathing rate are faster than normal. You may also sweat a little. Brisk walking or sweeping and mopping are good examples of how you might feel.
iii. **Vigorous intensity** – Your heart rate is much faster and you have to breathe deeper and faster than normal. You will probably sweat. Playing football or squash are good examples of how you might feel.

Leisure time physical activity – Remember, do not include light intensity activities In the past week how many minutes did you spend each day:								
	Mon	Tues	Wed	Thurs	Fri	Sat	Sun	Total
Walking outside of work? DO include: eg walking to the shops, walking to work, walking the dog, stair walking								

DO NOT include: eg standing, sitting, driving, walking whilst at work								
Manual labour outside of work? DO include: eg cutting grass, decorating, washing car, DIY, digging DO NOT include: eg weeding, planting, pruning								
Active Housework DO include: eg vacuuming, scrubbing floors, bed making, hanging out washing DO NOT include: eg sewing, dusting, washing dishes, preparing food								
Dancing? DO include: eg only include time actually spent dancing; disco, line, country DO NOT include: eg time spent not actually dancing								
Participating in a sport, leisure activity or training? DO include: eg exercise classes, cycling, football, swimming, golf, jogging, athletics DO NOT include: eg darts, snooker/ pool, fishing, playing a musical instrument								
Other Physical Activity if not already covered (please specify:_____)								
							Total	

15. Physical activity at work – Please complete this section if you are in regular employment, remember not to include light intensity activities.

In the past week how many minutes did you spend each day:	Mon	Tues	Wed	Thurs	Fri	Sat	Sun	Total
Walking whilst at work? DO include: eg walking up or down stairs, to and from your desk, 'doing the rounds' DO NOT include: eg standing, sitting at desk etc – ie time spent not actually walking 8								
Manual labour whilst at work? DO include: eg lifting, stacking shelves, climbing ladders, building work, cleaning DO NOT include: eg sitting at desk, answering telephone, driving, check-out operation								
							Total	

16. Was last week typical of the amount of physical activity you usually do?

a. Yes
b. NO – I usually do more Normally,
    i. how much more?
    ii. Of which activity?
c. NO – I usually do less
    i. Normally, how much less?
    ii. Of which activity?

17. Quality of life Health Questionnaire. Under each of the following headings, please select the option which best describes your health today

a. Mobile (please select one option only)
   i. I have no problems walking about
   ii. I have some problems walking about
   iii. I am confined to bed
b. Self-care (please select one option only)
   i. I have no problems with self-care
   ii I have some problems washing or dressing myself
   iii. I am unable to wash or dress myself
c. Usual activities – eg work, study, housework, family or leisure activities (please select one option only)
   i. I have no problems with performing my usual activities
   ii. I have some problems with performing my usual activities
   iii. I am unable to perform my usual activities
d. Pain/discomfort (please select one option only)
   i. I have no pain or discomfort
   ii. I have moderate pain or discomfort
   iii. I have extreme pain for discomfort
e. Anxiety/depression (please select one option only)
   i. I am not anxious or depressed
   ii. I am moderately anxious or depressed
   iii. I am extremely anxious or depressed

18. To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.
We would like you to indicate on this scale how good or bad your own health is today, in your own opinion. Please do this by drawing a line below at the point on the scale that indicates how good or bad your health state is. Your own health state today:

Best imaginable health state
100
90
80
70
60
50
40
30
20
10
0
Worst imaginable health state

19. Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	Not at all	A little bit	somewhat	Quite a bit	Very much
I feel fatigued	0	1	2	3	4
I feel weak all over	0	1	2	3	4
I feel listless ('washed out')	0	1	2	3	4
I feel tired	0	1	2	3	4
I have trouble starting things because I am tired	0	1	2	3	4
I have trouble finishing things because I am tired	0	1	2	3	4
I have energy	0	1	2	3	4
I am able to do my usual activities	0	1	2	3	4
I need sleep during the day	0	1	2	3	4
I am too tired to eat	0	1	2	3	4
I need help doing my usual activities	0	1	2	3	4
I am frustrated by being too tired to do the things I want to do	0	1	2	3	4
I have to limit my social activity because I am tired	0	1	2	3	4

20. For each of the following statements, please circle or mark one number per line to indicate how true you think each statement is for you. The questions ask about your opinion. There are no right or wrong answers.

	Not at all	Hardly true	Moderately true	Exactly True
I can always manage to solve difficult problems if I try hard enough	1	2	3	4
If someone opposes me, I find the means and wats to get what I want	1	2	3	4
I am certain that I can accomplish my goals	1	2	3	4
I am confident that I could deal efficiently with unexpected events	1	2	3	4
Thanks to my resourcefulness, I can handle unforeseen situations	1	2	3	4
I can solve most problems if I invest the necessary effort	1	2	3	4
I can remain calm when facing difficulties because I can rely on my coping abilities	1	2	3	4
When I am confronted with a problem, I can find several solutions	1	2	3	4
If I am in trouble, I can think of a good solution	1	2	3	4
I can handle whatever comes my way	1	2	3	4

Next, I'd like you to think about any sport that you have done in the last 7 days. By sport we mean any competitive or non-competitive sporting activity, including sessions of deliberate exercise such

as running or jogging. Think only about those sports or exercises that you did for at least 10 minutes at a time.

21. During the last 7 days, on how many days did you take part in any sport? Please state your answer in days per week in the box below.

a. Days per week… (___)
b. I did no sport

22. How much time did you usually spend doing sport on one of those days?
Please provide the number of hours and minutes in the corresponding box below; if you don't know please tick this box.

a. Hours per week… (____)
b. Minutes per day…(____)
c. Don't know/Not sure

Thank you for taking time to complete the survey, your participation is greatly appreciated

APPENDIX E: ETHICS TRAINING CERTIFICATE

TRREE

Zertifikat
Certificat
Certificado
Certificate

Promouvoir les plus hauts standards éthiques dans la protection des participants à la recherche biomédicale
Promoting the highest ethical standards in the protection of biomedical research participants

Clinical Trials Centre
The University of Hong Kong

Certificat de formation - Training Certificate

Ce document atteste que - this document certifies that

Erin Karam

a complété avec succès - has successfully completed

Introduction to Research Ethics

du programme de formation TRREE en évaluation éthique de la recherche
of the TRREE training programme in research ethics evaluation

Release Date: 2020/01/21

Professeur Dominique Sprumont
Coordinateur TRREE Coordinator

FMH Continuing Education Program (5 Credits)
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[REV : 20170310]

APPENDIX F: ETHICS CLEARANCE CERTIFICATE

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Mrs Erin Karam

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M191174

NAME: (Principal Investigator)	Mrs Erin Karam
DEPARTMENT:	Centre of Exercise Science and Sports Medicine
PROJECT TITLE:	A survey to assess patient and health care providers' knowledge, attitudes and perceptions of cancer-related fatigue and exercise
DATE CONSIDERED:	29/11/2019
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Prof Demitri Constantinou and Miss Natalia Neophytou
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	09/06/2020

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.** The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in **November** and will therefore be due in the month of **November** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES