

Experiences of Physical Activity and Exercise in Cancer
Patients and Survivors using Te Whare Tapa Whā

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Abstract

AIMS: This project aimed to explore the experiences and perspectives of cancer patients and survivors engaging in a cancer exercise programme. The cancer exercise programme was an initiative undertaken by academic staff and post graduate students to increase exercise amongst a cancer community.

METHODS: Data were collected through a literature review, one-on-one interviews and observations. Interviews consisted of semi-structured questions related to experiences of cancer, physical activity (PA), a cancer exercise programme, and the subsequent impact on wellbeing. Observational data were gathered through field notes and informal conversations with the participants. The cornerstones of health described by Te Whare Tapa Whā provided a lens to analyse and interpret the data.

FINDINGS: Four participants from the cancer exercise programme, and a clinician from Otago, New Zealand (mean age 56.8 years) participated in the study. Participants reported that engagement in the cancer exercise programme resulted in peer support and psychological benefits, “...*It’s been marvellous. Not only physically, but mentally as well, getting to see people and getting out and socialising...*”, [the cancer exercise programme was] “...*fun because of everybody else there and being able to see everybody and ask how they’re doing...*”. The data demonstrated connections between PA and health across all aspects of wellbeing, described by Te Whare Tapa Whā. The findings demonstrated that Te Whare Tapa Whā principles can be useful when analysing experiences of a cancer exercise programme.

CONCLUSIONS: This study highlighted that cancer patients and survivors’ experiences of PA were more than physical and were exemplified in all aspects of Te Whare Tapa Whā. Their lived experiences describe how PA and exercise provides

opportunities for participants to gain peer and psychological support, a finding that is consistent with the literature.

KEY WORDS: physical activity, exercise, Te Whare Tapa Whā, cancer, well-being

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I would like to thank my family for this piece of work including my grandad Rouru Matapo, my aunties Deborah and Ngaupokoina Matapo, and my mother, Iriea Matapo.

Personal statement

[REDACTED]

In 2019, I began post-graduate study at the Institute of Sport, Exercise and Health. Primarily as I knew I was just scratching the surface with something I was

becoming increasingly passionate about which was health, cancer, and physical activity. With the idea from my academic lecturer, supervisor and mentor, Richard Humphrey, came the development and implementation of The Otago Polytechnic Cancer Exercise Programme. With extensive help, support, and ideas from Richard, the programme liaised with various health services in Dunedin to connect with potential clients. The exercise programme allowed me to explore some burning questions: if physical activity is beneficial, why is it not prescribed more often to patients? Why are cancer patients and survivors refraining from exercising during and post-treatment? What's the stigma around exercise and cancer? It didn't take long until I started to see some trends within the cohort I worked with.

The master's research project was secondary to the cancer exercise programme beginning and was more an afterthought. I wanted the research to be authentic and come from a place for the people. From researching, I discovered more and more evidence discussing the health gap between indigenous populations and their counterparts. Māori, alongside Pacific people, are heavily disadvantaged in a range of health indicators. I began to wonder whether the fusion of Māori health principles with the cancer exercise programme, could better explore the needs and impact of cancer groups, than traditional research methods. From conversations with clients, I knew the benefits of exercise was more than a physical and mental experience and supported a deeper connection for the clients, whether this is to themselves or their environment. I knew exercise played a bigger role than what the majority of the evidence was currently stating, so I decided I would try and find, and further explore, a small piece of a much larger puzzle.

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Chapter 1: Introduction

There is no doubt that cancer is a major pandemic immobilising the world (Blair, 2009; Bray et al., 2018; World Health Organisation, 2020; World Cancer Research Fund, 2018). Cancer may have a frightening stigma however this post-modern world is better equipped in diagnostics, treatment and rehabilitation than ever before (Ministry of Health, 2020b; World Health Organisation, 2020a). Governments, health agencies and policymakers have made major advances in the practice and regulation of healthcare services (Ministry of Health, 2020b; World Health Organisation, 2020a). Overall, more and more people are surviving cancer and continue to live with it until end of life (Ministry of Health, 2020b; World Health Organisation, 2020a). However, some scholars might suggest the world still has a long way to go regarding improvements in cancer outcomes and care (Pergolotti et al., 2019; Signal et al., 2020). The next important steps may be in addressing the long-term rehabilitation of cancer as a chronic condition.

The importance of cancer rehabilitation and recovery has been well-established, placing high demand on health professionals and hospital resources alike (Cheville et al., 2017; Fernandes, Richard, & Edelstein, 2019; Stubblefield et al., 2013). Cancer rehabilitation has been defined as an array of concepts, including the aim to reduce the disabling effects of cancer and its treatment (World Health Organisation, 2020a) and to improve psychological, physical and social functioning (Chasen & Jacobsen, 2010). Above all, rehabilitation is a key step for recovery in cancer patients and should not be overlooked (Cheville et al., 2017). Patient uptake of rehabilitative services varies and depends on clinician preference and exercise knowledge, availability and accessibility of local and national healthcare initiatives

and patient barriers/facilitators (Blaney et al., 2010; Schmitz et al., 2019). Further issues within healthcare such as being understaffed, lack of resources and poor pay, all contribute to cancer rehabilitation referrals and services. While cancer care can be complex, patients must be offered rehabilitative options for continuous recovery (Pergolotti et al., 2019).

Many cancer rehabilitation services have been explored to mitigate the effects of cancer and its treatment (Cheville et al., 2017; Fernandes et al., 2019; Pergolotti et al., 2019; Schmitz, DiSipio, Gordon, & Hayes, 2015; Stubblefield et al., 2013). Health education is popular which may incorporate how to keep well after treatment, physical activity (PA) recommendations and nutrition guidelines (Carlson, Ursuliak, Goodey, Angen, & Speca, 2001; Huang et al., 2020; Sheehan, Denieffe, Murphy, & Harrison, 2020). Health education can provide knowledge and address psychological needs, particularly in a peer support setting, however other research found this had little effect on the physical and functional issues the cancer survivors faced (Osborn, Demoncada, & Feuerstein, 2006; Sheehan et al., 2020). Cancer patients and survivors experience a range of side effects due to various therapies – resulting in diminished muscle and bone tissue, reduced strength and fitness and difficulty completing daily tasks, for example, getting dressed (Aredes, Garcez, & Chaves, 2018; Ax, Johansson, Carlsson, Nordin, & Börjeson, 2020; Treanor & Donnelly, 2016). These problems manifest as reduced quality of life (QOL), mental health conditions and poor social connection with others including family and friends (Cuypers et al., 2018; Schmitz et al., 2015).

PA and exercise have been central to cancer rehabilitation research (Ax et al., 2020; World Health Cancer Research Fund, 2018; Sheehan et al., 2020). In the past, the key messages for cancer survivors were to rest as much as possible and refrain

from exerting excessive energy. Today, there is a strong consensus that exercise is beneficial and safe for cancer patients and survivors (Ministry of Health, 2020b; World Health Organisation, 2020a). There is some evidence that suggests care must be taken when considering PA or exercise with immunosuppressant or palliative care patients (World Cancer Research Fund, 2018). Although exercise may not appeal to every patient or survivor, light stretching, and lower and upper body exercises can be useful in promoting movement for the body. PA and exercise recommendations have been set by several organisations, all indicating a similar premise – exercise can be beneficial; however, research has been limited for less common cancers (World Cancer Research Fund, 2018). Cancer and exercise research have been well-established with many studies adopting quantitative methods and biomedical health models (Mark & Lyons, 2010; Speck, Courneya, Mâsse, Duval, & Schmitz, 2010). Although less prominent, qualitative research using holistic health approaches are increasing (Adamsen et al., 2004; Aumann et al., 2016; Chang et al., 2020), which is a key attribute of this study.

The focus of this thesis is to explore the experiences of PA and wellbeing in people with cancer, and a cancer exercise programme, using Te Whare Tapa Whā health model (see figure 1). Te Whare Tapa Whā speaks to the four dimensions of health – taha tinana (physical wellbeing), taha hinengaro (mental and emotional wellbeing), taha whānau (family and social wellbeing) and taha wairua (spiritual wellbeing), which create the four walls of the wharenuī (Durie, 1998). The wharenuī symbolises harmony between the pillars of health, and if interrupted or imbalanced, can result in poor health and well-being (Durie, 1998).

Figure 1: Te Whare Tapa Whā model (Durie, 1998)
<https://www.health.govt.nz/our-work/populations/maori-health/maori-health-models/maori-health-models-te-whare-tapa-wha>



Other Māori health models including the Meihana model (Pitama et al., 2007) and Te Wheke (Pere, 1982; Pere & Nicholson, 1991) are adopted across the literature (Pere & Nicholson, 1991; Pitama, Huria, & Lacey, 2014), typically when researching Māori by Māori researchers. However, this research project focuses on using Te Whare Tapa Whā to analyse and interpret the data for a holistic perspective on health.

Cancer in Aotearoa New Zealand

Cancer in Aotearoa New Zealand is a reflection of the current status worldwide (Jackson, Bissett, Macfarlane, & Costello, 2020; Ministry of Health, 2020b; Sarfati & Jackson, 2020; Signal et al., 2020). In New Zealand, one in three people are affected by cancer during their lifetime, and between 2007 and 2016, there

was a 21 percent increase in incidence (Ministry of Health, 2018). Cancer in New Zealand is considered a treatable, long-term disease and commonly includes skin, breast, bowel, cervical, lung and prostate (Ministry of Health, 2020a). It is estimated that incidence rates are expected to double by 2040, placing major demand on health professionals and services (Bray et al., 2018). The rise in incidence is attributed to improved diagnostic tools, increased access to healthcare and more effective treatment regimens (Ministry of Health, 2020b). A range of government strategies set out by the Ministry of Health has also played a role in cancer prevention and management – including the New Zealand Cancer Control Strategy 2003 (Ministry of Health, 2003) and the New Zealand Cancer Action Plan 2019-2029 – Te Mahere mō te Mate Pukupuku o Aotearoa 2019-2029 (Ministry of Health, 2020b). The 2020 report includes a demand for healthcare services to ‘develop roles to better support a whānau-centred and holistic approach in cancer control’ (Ministry of Health, 2020b, p.16), which is a need that is woven throughout this thesis. The focus on modern equipment and treatments, screening programmes and managing cancer control activities in New Zealand resulted in reductions in cervical cancer (Smith et al., 2017) and improved survival rates for breast, melanoma and prostate cancers (Ministry of Health, 2020b). Cancer control activities such as the New Zealand Tobacco Control programme has seen reductions in smoking rates, which has led to progress in survival rates and quality of life in cancer patients and survivors (Ministry of Health, 2020b). Increased survival rates are having adverse effects on people and whānau socially, emotionally, economically and spiritually, which will continue to grow (Bloom et al., 2011; Gudenkauf et al., 2019). Increased survival rates mean people are living longer with the effects of treatment and disease. These effects include impaired physical strength and abilities, loss of identity and a reduced social and

emotional health. For people living with cancer and as survivors, everyday life can change drastically, particularly around work, income, daily activities, and relationships. This means health services must integrate holistic practices that reflect these needs (Ministry of Health, 2020b).

Cancer outcomes vary within Aotearoa New Zealand, not only for Māori and Pasifika people but also for those who live in rural and deprived areas, people with mental illness and disabilities (Ellison-Loschmann et al., 2017; Lawrenson et al., 2016; Ministry of Health, 2020b). However, Māori are not only more likely to be diagnosed with cancer, they have worse survival rates for almost all cancers (Marriott & Sim, 2015; Ministry of Health, 2020b; Robson et al., 2010). Clear health inequities between Māori and non-Māori remain an issue (Gurney et al., 2019; Gurney et al., 2020; Harris et al., 2006; Marriott & Sim, 2015), and manifest as high hospital admission rates, high morbidity rates and delayed diagnoses and treatment (Cormack, Robson, Purdie, Ritama, & Brown, 2005). Health gaps between indigenous communities and their counterparts is global; where indigenous people are far more likely to contract diseases and die prematurely (King, Smith, & Gracey, 2009). The New Zealand Ministry of Health have developed strategies to address health inequities through policy and increasing Māori in the workforce (Ministry of Health, 2003, 2020b). Increasing Māori in the workforce, particularly healthcare, allows services to represent the New Zealand demographic (Ministry of Health, 2003, 2020b).

A range of factors contribute to health disparities within New Zealand including the lack of holistic health practices that speak to all aspects of well-being (Al-Busaidi, Huria, Pitama, & Lacey, 2018). A Māori health model, Te Whare Tapa Whā, is explored within this thesis to build upon previous work (Brown, 2018; Durie,

1999; Pitama et al., 2014) and promote the use of holistic health interventions for cancer patients and survivors. Cancer and exercise research may lack the use and understanding of holistic health frameworks, and recognition of other well-being facets such as spirituality, where this thesis attempts to give voice to these underrepresented aspects of health. With an increase in people living with and surviving cancer, long-term management and supportive care must be considered when working with cancer patients and survivors. This may include access to and quality of palliative care, and rehabilitative services which assist in mediating effects of diagnoses and treatment. Rehabilitative services are explored in the literature to mediate side effects in cancer patients and survivors; however, lack a holistic health approach of the individual and their whānau. Physical activity has been shown to improve the quality of life in cancer sufferers, even during treatment (Sweegers et al., 2018). The benefits of physical activity extend to the well-being of a person's family/relationships, spirituality and emotional and mental health, and is extremely beneficial for cancer communities (Farris, Courneya, O'Reilly, & Friedenreich, 2018; Irwin et al., 2017).

Cancer and well-being

Cancer diagnoses and subsequent treatments can have a detrimental impact on all aspects of health and well-being. Wellbeing is defined by a variety of terms, however, for this research project, well-being will be understood through the lens of Te Whare Tapa Whā. Treatments can cause a range of issues that affect and/or impair several dimensions of health, including our physical, mental, social and spiritual well-being. Treatments can cause reduced muscle strength and bone density,

increased fatigue and impaired physical and functional capability (Charles Shapiro & Recht, 2001) – affecting our taha tinana. These effects can then link to mental and emotional distress affecting taha hinengaro. Mental and emotional distress is established in research, as well as links between the physical body and mental/emotional health (Montazeri, 2008). Taha hinengaro in cancer patients and survivors can be severely affected by financial burdens, including costs from medical treatments, appointments and unemployment (Schmitz et al., 2015). This can leave people with a sense of hopelessness or existential crisis (Aredes et al., 2018; Brown et al., 2019; Jemal et al., 2019) – directly impacting taha wairua. Impaired taha wairua can manifest as reduced connectedness with the world and others, and an absence of fulfillment or feelings of satisfaction. For cancer patients and survivors, a diagnosis and its following therapies can produce a variety of emotions – while experiences are individual, the research suggests feelings such as loneliness, sadness and frustration can be common. Relationships between cancer and mental/emotional stress have been established since the 1980s (Love, Leventhal, Easterling, & Nerenz, 1989; Nerenz, Leventhal, & Love, 1982), and can extend beyond the individual and influence whānau, healthcare professionals, and the wider community. Taha whānau plays a key role in stabilising the four walls described by Te Whare Tapa Whā, where family and relationships with others are important for coping with diagnoses and treatments. A key difference described in Te Whare Tapa Whā, compared with other health models, is taha wairua. Spiritual well-being in cancer patients and survivors is an important component that can be often overlooked in healthcare. Spirituality can be interpreted differently between people and can often feel like a sensitive topic to discuss with patients. However, emerging research shows that patients and survivors are seeking increased spiritual support in healthcare policies and practice, particularly

to meet health and well-being needs (Egan, Graham-DeMello, Ramage, & Keane, 2018). Taha wairua (spiritual well-being) is an important part of Te Whare Tapa Whā and can speak to the connection people have with themselves, others and nature.

The wellbeing needs of cancer patients and survivors are diverse and practice may not be adequately addressing this, as reflected by (Egan et al., 2018). This research project attempts to give voice to exercise experiences in cancer patients and survivors, as well as address taha wairua. Te Whare Tapa Whā is an important part of analysing and interpreting the data captured within this thesis, as it provides a holistic outlook of the experiences of cancer and exercise. In a field where quantitative methods and biomedical health models override explorative studies, Te Whare Tapa Whā offers depth in addressing health interventions in cancer patients and survivors.

Rehabilitation

Over the past few decades, many interventions have been explored to reduce the negative impact of cancer diagnoses and treatments (Ax et al., 2020; Kerry S. Courneya, Keats, & Turner, 2000; Luoma et al., 2014; Speca, Carlson, Goodey, & Angen, 2000; Spiegel, Kraemer, Bloom, & Gottheil, 1989). It may take people months or years to fully adjust to a new life following diagnosis and treatments, and some people may never completely do so (Walker et al., 2015). Cancer patients and survivors, irrespective of disease status, have limited resources regarding exercise and cancer knowledge, post-treatment care and the time given by their caregivers/loved ones (Cheville et al., 2017). The Institute of Medicine created a report which highlighted the expansiveness of the cancer survivor's unmet health and

well-being needs post-treatment (Hewitt, Greenfield, & Stovall, 2005). The heavy meaning this report uncovered meant that cancer must be viewed as a chronic medical condition that requires extensive medical, rehabilitative and psychosocial support once treatment is complete (Hewitt et al., 2005). Cancer rehabilitation services may include, and are not restricted to, physical and occupational therapists, speech and language therapists, dieticians, counsellors, psychologists and peer support groups (Cheville et al., 2017; Stubblefield et al., 2013). The urgency for a holistic cancer rehabilitation model for practice and delivery, as well as multidisciplinary teams and an integrated approach, is evident (Cheville et al., 2017; Hewitt et al., 2005; Schmitz et al., 2019; Walker et al., 2015), however, the majority of people result in facing future challenges on their own, without cancer rehabilitation services.

There are many unanswered questions regarding cancer rehabilitation services and clinicians, including what makes a modern, effective and efficient cancer rehabilitation programme, where such programmes should reside, which skill sets are critical and how to train clinicians (Stubblefield et al., 2013). Moving forward, questions continue around successful cancer rehabilitation programmes and how to measure that success (Stubblefield et al., 2013). The majority of cancer rehabilitation programmes are not a part of routine care for cancer patients and survivors, during or post-treatment – and are usually subject to clinician prescription and preference or research-related programmes within hospitals or tertiary institutions. While this study does not answer these gaps in knowledge, it does hope to encourage and support the discussion regarding holistic and integrative exercise and health interventions for cancer patients and survivors.

Physical activity and exercise

PA and exercise are both widely used terms in today's world, especially when discussing exercise oncology research. Often PA and exercise are used interchangeably, however, their definitions help in separating them. PA is defined as any skeletal muscle movement that requires energy, for example, walking, vacuuming and gardening (McKenna & Riddoch, 2003). Exercise is defined as structured PA aimed at achieving specific goals relating to maintenance or improvement of health, for example, an exercise programme aimed at increasing muscular strength (McKenna & Riddoch, 2003). Both terms are similar and are often both used by the general population, which is reflected in the participant case studies in chapter three. To encourage a holistic lens of health and well-being when discussing exercise and cancer, PA and exercise are both used throughout this thesis interchangeably.

PA and exercise play a key role in the management and, in some cases, prevention, of cancer (Courneya et al., 2009; Farris et al., 2018; Mctiernan et al., 2019). Evidence surrounding the benefits of PA in cancer survivors is robust (Ax et al., 2020; World Cancer Research Fund/American Institute for Cancer Research, 2018; Penttinen et al., 2019; Roine et al., 2020; Sheehan et al., 2020), and demonstrates a clear relationship between PA, reduced cancer risk and improved side effects (World Cancer Research Fund/American Institute for Cancer Research, 2018). The World Cancer Research Fund/American Institute for Cancer Research (2018) estimated that within the rise of global cancer cases, at least a third of cases are preventable (World Cancer Research Fund/American Institute for Cancer Research, 2018), through reduced tobacco and alcohol use, and improved PA levels

and nutrition (World Cancer Research Fund/American Institute for Cancer Research, 2018). However, the majority of cancer patients typically reduce their PA levels during diagnosis and treatment, as some become unable to regain their previous PA tolerance (Courneya, Friedenreich, Arthur, & Bobick, 1999; Courneya & Friedenreich, 1997; Courneya et al., 2000).

Despite a strong case, the integration of PA and exercise knowledge, services, care and programmes, is still an ongoing issue. The use of other rehabilitation services, such as psychosocial interventions, are unable to truly address the physical and functional challenges cancer patients and survivors face (Courneya & Friedenreich, 1997; Osborn, Demoncada, & Feuerstein, 2006; Sheehan et al., 2020). The gap between evidence and practice is apparent in the field of exercise and cancer, leaving many people unsure of how to carry on with life post-diagnosis and treatment. In Aotearoa New Zealand, the options for community exercise rehabilitation services are scarce, delaying the process of mental, physical, and spiritual recovery. These reasons justify a qualitative study that attempts to explore the experiences and perspectives of PA, cancer, a cancer exercise programme and well-being in cancer patients and survivors.

Methodology

There is a wealth of quantitative research investigating the effects of physical activity and exercise in cancer patients and survivors and demonstrate a clear relationship between PA and quality of life (QOL) (Courneya et al., 2007; Gaskin, Craike, Mohebbi, Courneya, & Livingston, 2017; Lewis et al., 2001; Ministry of Health, 2020a; Penttinen et al., 2019; Segal et al., 2001; Segal et al., 2009; Speck,

Courneya, Mâsse, Duval, & Schmitz, 2010). Quantitative research is popular whereas mixed methods and/or qualitative research make up a small percentage of cancer and PA studies (Haraldstad et al., 2019). A point of difference within this thesis is the adoption of a Māori health model, Te Whare Tapa Whā, which is used to analyse and interpret the data in chapter three. In New Zealand, various studies have used Te Whare Tapa Whā to either underpin the study or to analyse and report the findings (Glover, 2013; McGruer, Baldwin, Ruakere, & Larmer, 2019; Rix & Bernay, 2015). This research project uses qualitative methods to explore cancer patients and survivor's experiences of cancer, PA, a cancer exercise programme and wellbeing, using Te Whare Tapa Whā to analyse and report the findings.

Te Whare Tapa Whā

Durie (1985) pioneered the work of Te Whare Tapa Whā, a Māori health model that arose from a 1982 Hui regarding Māori health. Te Whare Tapa Whā uses the analogy of the wharenuī which represents four walls, or four dimensions of health (Durie, 1985, 1998), which include taha tinana, taha whānau, taha wairua and taha hinengaro. This model suggests that for optimal health, all four walls of the wharenuī must remain balanced (Durie, 1985, 1998; Rochford, 2004). If one wall is compromised, all others are affected, and a person or a collective can become 'unbalanced' and subsequently unwell (Durie, 1985, 1998; Rochford, 2004). The analogy of the wharenuī is the representation of the interrelatedness of each health dimension. Māori believed that the majority of health services in Aotearoa New Zealand applied a biomedical model based on a reductionist worldview, which lacked the recognition of things that are difficult to measure, such as taha wairua or spiritual

well-being (Rochford, 2004). This is also typically reflected in health services and research worldwide, where biomedical models are adopted to understand patients. In Te Whare Tapa Whā, the inclusion of wairua, the role of whānau, and the balance of hinengaro are as important as the physical manifestations of illness and/or injury (Durie, 1985, 1998; Rochford, 2004).

Te Whare Tapa Whā is a part of the research methods to provide a holistic worldview of cancer patients and survivor's experiences. While Te Whare Tapa Whā is a Māori health model, any person can identify and resonate with the concepts described in this model. Te Whare Tapa Whā may be native to New Zealand, but it has similarities with other health models such as the biopsychosocial model (George & Engel, 1980) and the World Health Organisation's 1947 definition of health which stated that "health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organisation, 2020b). The main difference between Te Whare Tapa Whā and other previously adopted health models is the importance of the spiritual dimension. Taha wairua speaks to the unseen and unspoken energies that connect to us and our environment and is considered an important aspect of living for Māori. This thesis focuses on exploring and understanding the experiences of cancer patients and survivors during a cancer exercise programme. These experiences are considered using Te Where Tapa Whā, the health model which underpins this thesis.

Research pathway

Aim

The purpose of this research project was to explore the experiences of cancer, PA, exercise and wellbeing in cancer patients and survivors engaging in an exercise programme, using Te Whare Tapa Whā to analyse and interpret the findings. These topics will be discussed through four chapters.

Thesis layout

Chapter one provides an overview of topics pivotal to this thesis and introduces the research rationale and methodology. Chapter two will review relevant literature on the prevalence of cancer within New Zealand and worldwide, the effects of a cancer diagnosis and treatments, quality of life (QOL) and wellbeing in cancer patients and survivors, cancer exercise rehabilitation programmes and Māori health models used to analyse health issues. Chapter three uses qualitative methods including semi-structured interviews and ethnographic analysis to explore the research question, supported by Te Whare Tapa Whā to analyse the findings. Chapter four includes a general discussion of the overall thesis.

Covid-19

This research project was affected by alert level four Covid-19 lockdown (25.3.2020-27.4.2020) in New Zealand, which affected how the data was collected.

Chapter 2: Literature review

This chapter reviews literature relating to cancer, worldwide and in New Zealand, how this connects to QOL and wellbeing in patients, survivors and loved ones, as well as the concepts of physical activity (PA) and cancer exercise rehabilitation programmes. Māori health theories, and other key health concepts, are considered within the contexts of cancer care practice and research

Cancer

Worldwide, one in six people die from cancer (World Health Organization, 2020) – a staggering statistic considered unacceptable by medical and health professionals (World Health Organisation, 2020a, p12, 13). Cancer has overtaken cardiovascular disease as the leading cause of death, as incidence and mortality rates continue to soar (Townsend et al., 2016). In New Zealand, cancer is the leading cause of death (Ministry of Health, 2020b). Prostate, breast, colorectal, lung, and skin have the highest incidence in New Zealand (Ministry of Health, 2020b). In 2016, 24,086 people were diagnosed with cancer, a 21% increase since 2007 (Ministry of Health, 2020b). With this trend expected to accelerate, Aotearoa New Zealand can expect increasing economic, social and emotional impact on communities, healthcare, hospitals and clinicians (Bray et al., 2018; Ministry of Health, 2020b). The projected increases will place immense pressure on healthcare services and workers, with many people lacking access to timely, quality diagnosis and comprehensive treatment – particularly in low and middle human development index (HDI) (World Health Organisation, 2020a, p12, 13). HDI was introduced to

emphasize that “people and their capabilities should be the ultimate criteria for assessing the development of a country, not economic growth alone” (United Nations Development Programme, 2021). HDI is a summary of key dimensions of human development including a long and healthy life, being knowledgeable and have a decent standard of living. Each dimension is assessed using specific measurements including life expectancy at birth, mean years of schooling for adults aged 25 years and more and expected years of schooling for children of school entering age. The standard of living dimension is assessed by gross national income per capita (United Nations Development Programme, 2021).

Cancer outcomes vary between different groups in New Zealand. For example, those from deprived areas or with a disability are more likely to develop cancer with increased mortality risk (McCarthy et al., 2007; Robson et al., 2010). Pacific people also have higher incidence and mortality than non-Pacific people (Ministry of Health, 2020b). Indigenous health inequities are a global issue posing great challenges for these groups (Lawrenson et al., 2016; Zambas & Wright, 2016), evident with the disparity between Māori and non-Māori within New Zealand.

Alongside increasing incidence, mortality rates are expected to rise markedly (International Agency for Research on Cancer, 2018; World Health Organisation, 2020a). Mortality rate trends are also a function of changes in incidence and survival, as a result of earlier diagnosis and access to effective treatment. This also means improved survivorship rates with many people living with and recovering from cancer (Jackson et al., 2020; Signal et al., 2020).

The increase in cancer survivors, and people living with cancer, is a direct result of improved therapeutics, advances in cancer screening and early detection, and improvements in supportive care. The health sector has become overwhelmed

with the impact of cancer in communities, with many services and treatments unavailable in low and middle HDI countries.

A cancer diagnosis and subsequent treatments can have severe adverse effects on individuals, their loved ones and carers (Hopkinson, 2014; Lim et al., 2018; Meeker et al., 2016). Treatments can cause adverse side effects including increased fatigue, muscle loss, mental and emotional decline and the questioning of spirituality and identity (Aumann et al., 2016; Blum-Barnett et al., 2019; Dennett, Peiris, Taylor, Reed, & Shields, 2019; Miller et al., 2016; Penttinen et al., 2019; Stuhlfauth, Melby, & Hellesø, 2018; Treanor & Donnelly, 2016; Williams & Jeanetta, 2016). More than half of cancer patients and survivors report depressive and/or anxiety symptoms as well as financial strain, ending of relationships, change in physical appearances and negative mental and emotional health (Blum-Barnett et al., 2019; Chambers et al., 2018; Iconomou, Mega, Koutras, Iconomou, & Kalofonos, 2004; Luoma et al., 2014). These can create difficulties for patients and survivors post-treatment to integrate back into normal life (Dennett et al., 2019; Institute of Medicine and National Research Council, 2006). These effects influence family, loved ones and carers and can severely impair QOL and wellbeing (Law, Levesque, Lambert, & Girgis, 2018; Roine et al., 2020).

Survivorship starts at the time of diagnosis and lasts throughout the lifespan (Office of Cancer Survivorship, 2021). The American Cancer Society (2020a) believes that people have the right to define their own experience with cancer and considers a cancer survivor anyone who describes themselves this way, from diagnosis to end of life. These definitions allow clinicians to consider cancer care for survivors as a critical part of the cancer continuum. Family, loved ones and caregivers are often included in the cancer survivorship definition (Office of Cancer

Survivorship, 2021), as in most cases, cancer is not experienced alone. Caregivers often provide integral physical and emotional support to the survivor and the recognition of the adverse emotional toll and health effects is part of the holistic definition (Shapiro, 2018; Office of Cancer Survivorship, 2021). While there is an increase in people surviving cancer, many patients become “lost in transition” from active to post-treatment care and do not receive appropriate care (Institute of Medicine and National Research Council, 2006; Jacobsen et al., 2018). Among the proposed solutions it was suggested that when active treatment ends, each patient should receive a survivorship care plan (SCP) that addresses topics including summary of treatment plans, how to manage secondary or new cancers, assessment, treatment or referral for side effects, assistance with prevention or management of late effects and support for accessing supportive care initiatives (Institute of Medicine and National Research Council, 2006; Jacobsen et al., 2018). SCP’s have yielded benefits such as improvements in patient health outcomes, however, research in this field have been limited to a small number of studies, with differences in the content and delivery of SCPs, and overestimating the long term effects of a one-time delivery (Institute of Medicine and National Research Council, 2006; Jacobsen et al., 2018). Although cancer morbidity and mortality has improved, patients and survivors ongoing well-being may be compromised.

Quality of Life

QOL is an important concept in the field of health and medicine. QOL is a complex concept that is interpreted differently across and between disciplines, including medicine and health. Traditionally, biomedical outcomes have been the

main endpoints in medicine and health research, rather than QOL. Over the past decades, more research has considered patients QOL and the use and adaptations of QOL measurements has increased (Haraldstad et al., 2019). Understanding QOL is important for improving symptom relief, late effects care and rehabilitation in patients (Haraldstad et al., 2019; McCaffrey, Bradley, Ratcliffe, & Currow, 2016). Challenges revealed through QOL research and self-reported measures can lead to changes and improvement in treatment and care or may show that some therapies offer little benefit (Haraldstad et al., 2019; McCaffrey et al., 2016). This information can then be communicated to future patients to better understand the side effects of their cancer and treatments. QOL is equally as important when considering the ongoing problems cancer patients and survivors may encounter. Without QOL assessment, these issues may be overlooked. QOL is also important for medical and economic decision making, and as a predictor of treatment success, therefore it is important for prognostic purposes (Haraldstad et al., 2019). For these reasons, there is a need for routine assessment of QOL in both qualitative and quantitative research.

Despite the importance of QOL in medicine and health, there is a debate about definitions of QOL, what should be measured and how it should be measured. The World Health Organisation defines QOL as “An individual’s perception of their position in the life in the context of their culture in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organization Quality of Life Group, 1995). The conceptual and methodological debate becomes more complex when considering health-related quality of life (HROL) and wellbeing.

Wellbeing as explored in medicine and health research, is concerned with people’s emotional responses, domain satisfactions and judgements of life satisfactions (Diener, Eunkook, Richard, & Heidi, 1999). The literature generally

classifies well-being as related to the concepts of happiness, positive experiences, life satisfaction and prosperity (Diener, Suh, Lucas, & Smith, 1999; Pinto et al., 2017). Usually when discussing well-being, people attribute it to things such as self-care, taking control of their lives and exploring how they can get more out of themselves or reach optimal health (Pinto et al., 2017; Salvador-Carulla, Lucas, Ayuso-Mateos, & Miret, 2014). Some researchers suggest that QOL and wellbeing overlap as constructs, and may need to be approached as integrated concepts (Medvedev & Landhuis, 2018; Pinto et al., 2017; Salvador-Carulla et al., 2014). Although ambiguity remains when defining and measuring QOL, it is a useful to explore social, mental, physical, spiritual and environmental factors in cancer patients, survivors and their loved ones (Pinto et al., 2017; Salvador-Carulla et al., 2014). Quantitative medicine and health research often lacks a holistic view of people and their experiences (Aredes et al., 2018; Courneya et al., 2003, 2009; Haraldstad et al., 2019; Irwin et al., 2017; Roine et al., 2020). Some research differentiates QOL from other measures including health-related quality of life (HRQOL) and wellbeing, which highlights a challenge for clinicians and researchers (Aaronson et al., 1991; Klassen, Creswell, Plano Clark, Smith, & Meissner, 2012). While QOL measurements can produce specific results on a particular topic, it may not illustrate the full impact of a phenomenon (Aaronson et al., 1991; R. I. Brown, 2017; McCaffrey et al., 2016).

Many instruments have been created to measure QOL (Irwin et al., 2017; Mayo, 2015; Theofilou, 2013). Some QOL instruments are for the general population and apply to several health conditions, while some are disease-specific, and relate to a particular pathology (Cella et al., 1993; Theofilou, 2013) . Common QOL instruments used in medicine and health research include the

- Short-form 36 (SF36) and short-form 12-item (SF-12) questionnaire (Ware, 2000),
- European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire for Cancer Patients (EORTC-QLQ-C30) (European Organisation for Research and Treatment of Cancer, 2020),
- World Health Organisation Quality of Life Brief (WHOQOL-BREF) (World Health Organization Quality of Life Group, 1995),
- Five level European Quality of Life Dimensions (EQ-5D-5L) (Herdman et al., 2011).

While quantifying QOL using rigorous instruments produces measurable outcomes these do not provide a holistic view of the individual, their experiences, and their health. Qualitative investigations of QOL allow for richer and deeper findings about the individuals and their experiences (Haraldstad et al., 2019).

Exercise

The benefits of exercise for cancer morbidity, mortality, late-effects management and rehabilitation has been researched extensively (Physical Activity Guidelines Advisory Committee, 2018; Ax et al., 2020; Dennett et al., 2019; Henke et al., 2014; Penttinen et al., 2019; World Cancer Research Fund, 2018; Roine et al., 2020; Sheehan et al., 2020; World Health Organisation, 2020a). Exercise has been found to improve QOL, alleviate treatment side effects and reduce the likelihood of future disease, including secondary cancers, in cancer patients (Physical Activity Guidelines Advisory Committee, 2018; Ax et al., 2020; Penttinen et al., 2019).

Qualitative research has demonstrated the scope of benefits received by the cancer survivors from exercise, emphasising themes such as regaining normalcy, taking control of their lives, improving psychologically and providing purpose (Ax et al., 2020; Dennett et al., 2019). Quantitative research supports these conclusions, citing the psychosocial, emotional and physical benefits of exercise in cancer survivors (Daley et al., 2007; Furzer et al., 2016; Henke et al., 2014; Porsrud, Sherif, & Tollbäck, 2014; Sheehan et al., 2020). It is clear that exercise is beneficial for cancer survivors before, during, and post-treatment, however during these periods exercise levels tend to reduce. The needs of cancer patients and survivors are diverse, meaning that supportive cancer care and rehabilitation services must reflect this in order to engage cancer patients and their loved ones.

Part of the global cancer prevention plan includes recommendations based on lifestyle changes and behaviours such as reducing tobacco and alcohol intake, eating a well-balanced diet, and participating in regular PA (World Health Organisation, 2020a). While the majority of these recommendations are reinforced in Aotearoa New Zealand by government policies (e.g., tobacco control), exercise initiatives are among the least supported and underfunded.

Cancer exercise rehabilitation programmes usually focus on exercise to improve one or more components of health and fitness, including strength, cardiorespiratory fitness, and balance (Irwin et al., 2017; Penttinen et al., 2019). These programmes are typically cancer-site specific (e.g., common cancers such as breast and prostate) which may exclude many cancer patients and explain some of the delay in community adoption of exercise programmes for cancer. Additionally, many programmes are research focused (e.g., pushing a quantitative agenda or seeking specific findings), tertiary based (e.g., student operated and unpaid), or in

commercial health settings (e.g., business owners, cancer trainers, physiotherapy, occupational therapy). Many cancer rehabilitation care services may not appeal or be accessible to people in low socioeconomic groups, living in rural areas and/or who have mobility limitations. Furthermore, many questions remain unanswered regarding an effective and efficient cancer rehabilitation programme, how to train clinicians in rehabilitative care, whose role it is to prescribe exercise and how this is achieved. These reasons and other factors mean that cancer exercise programmes are often inaccessible, unavailable in many places and usually adopt a biomedical approach. Given that integrative and holistic care models are a key component of rehabilitation services for cancer patients and survivors, this appears to be a major gap in the care continuum.

Te Whare Tapa Whā

This review has highlighted that cancer affects physical wellbeing, however it also takes a toll on mental, spiritual and social wellbeing. To explore a more integrative and holistic care model, the Te Whare Tapa Whā model (Durie, 1998) has been used within this research project. Te Whare Tapa Whā refers to the four cornerstones of health and wellbeing that directly impact an individual, including taha tinana (the physical body) taha hinengaro (the mental realm including thoughts and emotions), taha whānau (family and social context) and taha wairua (the spiritual realm). Taha tinana relates to the physical aspects of the body including how it feels, moves and how you care for it. Taha hinengaro is about the heart, mind conscience and thoughts, and how you feel and communicate what you're thinking. Taha whānau relates to who you feel you belong to, who you care about and who you share your

life with. Whānau is also about extended relationships and relates to colleagues, community, friends and the people you care about. Taha wairua is the spiritual essence of who you are, where you come from and where you are going. Wairua can be the capacity for faith, religion or having a belief in a higher power. Additionally, wairua can be an internal connection to ourselves, our environment, the universe and life itself (Durie, 1998).

Te Whare Tapa Whā was designed to understand and improve the health of Māori people by instilling Māori beliefs and values into the healthcare system (Durie, 1998). During the emergence of Te Whare Tapa Whā, it was believed that the current health services in New Zealand reflected a predominantly biomedical model, which responded to the taha tinana needs of Māori, but ignored other important factors (Cormack et al., 2005; Gurney et al., 2020; Ministry of Health New Zealand, 2019; Robson et al., 2010; Tin Tin et al., 2018). As the indigenous population of Aotearoa New Zealand, Māori have a deep connection to whānau, whakapapa, their environment, emotional health and spirituality (Durie, 1985, 1998, 2003, 2004). Te Whare Tapa Whā was created to combine the understanding of health at an individual and population level, and acknowledge the mind and body connection (Durie, 1998). Other Māori health models exist including Te Wheke (Pere, 1982; Pere & Nicholson, 1991), Te Pae Māhutonga (Durie, 1999) and the Meihana model (Pitama et al., 2007). Te Wheke uses an octopus metaphor to show the interdependence of various phenomena: the head represents the child/family, and each tentacle represents an intertwined dimension that provides sustenance to the individual/whānau (Pere, 1982; Pere & Nicholson, 1991). Te Wheke has been used as underlying frameworks to children's health, development and school curriculum (Jackson, 2009; Stebletsova & Scanlan, 2018). The Te Pae Māhutonga framework was created by Professor Sir

Masion Durie and is used by community and public health to address all the essential aspects of health promotion. Te Pae Māhutonga is the name for the constellation of stars usually referred to as the Southern Cross. The four central stars represent the four key tasks of health promotion and reflect specific objectives: Mauriora (cultural identity), Waiora (environmental protection), Toiora (healthy lifestyles) and Te Oranaga (participation in society). The two pointers are Ngā Manukura (leadership) and Te Mana Whakahaere (autonomy). Te Pae Māhutonga brings together important components of health promotion, as they apply to Māori health as well as all New Zealanders. The Te Pae Māhutonga framework has been used widely in New Zealand health promotion and community health (Russell & McBride-henry, 2017; Ryks, Kilgour, Whitehead, & Rarere, 2018). The Meihana model was created as a clinical assessment framework and incorporates the four dimensions of Te Whare Tapa Whā, as well as taiao (the physical external environment) and iwi katoa (societal impact). The work of Pitama et al (2007) and colleagues has provided a clear contextual framework for medical professionals to connect with Māori patients.

Te Whare Tapa Whā is a key model when considering how cancer exercise programmes are created, delivered, and studied. Exercise has predominantly been considered physical with clear connections to mental and emotional health. However, this Māori health model offers a spiritual dimension of exercise which can often be overlooked. This spiritual dimension can manifest as a connection to others or the way the exercise programme makes people feel – it can also play a large role in people's lives who are dealing with concepts such as life and death. PA and exercise can provide a sense of purpose, belonging within a group and a way of expression. Some cancer patients and survivors may not be able to do things they once could, therefore beginning an exercise programme becomes a way of connecting with things

that were once a part of their lives including socialising, movement and having regular things to do. The researcher strongly believes that spirituality means something different to everybody. Exercise may not seem to be a spiritual practice; however, it is a key driver in accessing other parts of our lives which could be having the energy and mobility to play with your children/grandchildren, the confidence to walk out to the mailbox or even down to the shop and it might even be the act of meeting new people through exercise. Exercising in a group rehabilitation programme can create a sense of belonging and togetherness that humans naturally desire.

Considering the context of other holistic health models, Te Whare Tapa Whā has been chosen as the primary framework to underpin this research project. It offers opportunities to understand cancer patient and survivor's experiences across a variety of dimensions and is a widely used model within health in New Zealand. Te Whare Tapa Whā was initially developed to improve the health of Māori people, however, the researcher believes it could be applicable to non-Māori, fits the purpose of exploring all dimensions of health at an individual and community level and is accessible for future research. Te Whare Tapa Whā draws on the Māori customs of storytelling which includes weaving, poems, stories and songs throughout research (Brown, 2018; Glover, 2013). This research hopes to include these customs by sharing people's stories on their personal experiences of cancer. Through Te Whare Tapa Whā, this research project attempts to demonstrate that the model offers a suitable framework for exploring the holistic impact of an exercise programme in cancer patients and survivors.

Summary

Cancer rehabilitation research is essential for future practice in order to improve QOL and wellbeing in future patients. The aim of this literature review was to explore cancer, cancer treatments and rehabilitation and how these connect to QOL and wellbeing in patients, survivors and loved ones. The effects of cancer on people and their loved ones are unarguable. These effects last long after treatment is complete and can continue until end of life. There are gaps evident in the literature, including how QOL is conceptualised and the ambiguity of exercise in a cancer care setting. In this chapter the concepts of PA and cancer exercise rehabilitation programmes have been discussed in relation to Te Whare Tapa Whā. While cancer and exercise research and literature are extensive, research exploring cancer care and Te Whare Tapa Whā is scarce, particularly in exercise settings.

Chapter 3: Main study

“Experiences of Physical Activity and Exercise in Cancer Patients and Survivors using Te Whare Tapa Whā”

Abstract

AIMS: This project aimed to explore the experiences and perspectives of cancer patients and survivors engaging in a cancer exercise programme. The cancer exercise programme was an initiative undertaken by academic staff and post graduate students to increase exercise amongst a cancer community.

METHODS: Data were collected through one-on-one interviews and observations. Interviews consisted of semi-structured questions related to experiences of cancer, physical activity (PA), a cancer exercise programme, and the subsequent impact on wellbeing. Observational data were gathered through field notes and informal conversations with the participants. The cornerstones of health described by Te Whare Tapa Whā provided a lens to analyse and interpret the data.

FINDINGS: Four participants from the cancer exercise programme, and a clinician from Otago, New Zealand (mean age 56.8 years) participated in the study. Participants reported that engagement in the cancer exercise programme resulted in peer support and psychological benefits, “...*It’s been marvellous. Not only physically, but mentally as well, getting to see people and getting out and socialising...*”, [the cancer exercise programme was] “...*fun because of everybody else there and being able to see everybody and ask how they’re doing...*”. The data demonstrated

connections between PA and health across all aspects of wellbeing, described by Te Whare Tapa Whā. The findings demonstrated that Te Whare Tapa Whā principles can be useful when analysing experiences of a cancer exercise programme.

CONCLUSIONS: This study highlighted that cancer patients and survivors' experiences of PA were more than physical and were exemplified in all aspects of Te Whare Tapa Whā. Their lived experiences describe how PA and exercise provides opportunities for participants to gain peer and psychological support, a finding that is consistent with the literature.

KEY WORDS: physical activity, exercise, Te Whare Tapa Whā, cancer, well-being

Introduction

Cancer is responsible for one in six deaths worldwide (World Health Organisation, 2020a), imposing major physical, emotional and mental strain on individuals, families, communities, health systems and countries (World Health Organisation, 2020a). In 2018, there were 18.1 million cancer cases worldwide (World Health Organisation, 2020a). With no evidence of diminishing, cancer incidence rates are estimated to nearly double by 2040 (World Health Organization, 2020), and are likely to overwhelm health providers in all countries – regardless of wealth or social status (World Health Organisation, 2020a).

In Aotearoa New Zealand, cancer incidence, mortality and survivorship mirrors global trends (Bray et al., 2018). In 2016, cancer incidence increased by 21 percent from 2007, with just over 24,000 diagnoses (Ministry of Health, 2018). Māori (the indigenous people of New Zealand) overrepresent cancer incidence and mortality rates in New Zealand, as a result of health inequities, racial and discrimination issues within Aotearoa and quality of healthcare – factors that have been widely explored in the literature (Ellison-Loschmann et al., 2017; Lao et al., 2016; Lawrenson et al., 2016; Marriott & Sim, 2015; Ministry of Health, 2019; Robson et al., 2010; Robson & Ellison-Loschmann, 2016; Walker et al., 2008). Commonly diagnosed cancers in New Zealand include skin, breast, bowel, cervical, lung and prostate (Ministry of Health, 2020a) – which all include a range of therapies (Ministry of Health, 2020b). While cancer rates continue to increase, survival rates are improving in New Zealand (Ministry of Health, 2020b; Smith et al., 2017). This is a direct result of better diagnostics, more effective treatments and improved health

strategies set out by New Zealand's Ministry of Health (Ministry of Health, 2003, 2020b).

Despite improved survival rates and life expectancies (International Agency for Research on Cancer, 2018; World Health Organisation, 2020a), cancer treatments can be difficult (Williams & Jeanetta, 2016). With the range of chronic side effects from the disease and/or treatment (World Health Organisation, 2020a), the concept of recovery, late-effects management and rehabilitation have emerged, alongside treatment and prevention, as prominent in cancer and exercise research. Emerging topics in cancer and exercise research include using exercise as an adjunct therapy, how exercise can be applied in a clinical setting and within a multidisciplinary team and exploring the many variables of cancer rehabilitation.

Cancer rehabilitation aims to reduce the disabling effects of diagnosis and treatment (World Health Organisation, 2020a), and to improve physical, psychological and social functioning (Chasen & Jacobsen, 2010). A variety of interventions have been explored to reduce the impact of cancer (Cheville et al., 2017; Dennett et al., 2019; Fernandes et al., 2019; Huang et al., 2020; Sheehan et al., 2020), however, there is strong evidence to suggest that exercise may be key for patient and survivor rehabilitation (Ax et al., 2020; Cummins et al., 2017; Schmitz et al., 2019, 2015).

Exercise produces a range of benefits including improved fitness and muscle strength, psychological benefits and peer support (Ax et al., 2020; Dennett et al., 2019; Fialka-Moser, Crevenna, Korpan, & Quittan, 2003; Midtgaard et al., 2015; Roine et al., 2020; Sheehan et al., 2020). However, most research that investigates exercise in cancer groups has used biomedical health frameworks and focused on quantitative endpoints (Mctiernan et al., 2019). As a result, cancer exercise

rehabilitation programmes rarely reflect holistic health approaches and the diverse needs of cancer communities. Exercise and cancer research could benefit from using indigenous holistic health concepts to understand and explore PA, exercise and cancer experiences in cancer patients and survivors.

Wellbeing

Cancer diagnoses and subsequent treatments can have a detrimental impact on all aspects of health and wellbeing. Definitions of wellbeing are well-researched and include descriptions such as life satisfaction, positive and negative emotions and its subjective nature (Diener et al., 1999). Wellbeing in a Māori worldview can be described through the constructs of Te Whare Tapa Whā – taha tinana (physical wellbeing), taha hinengaro (mental and emotional wellbeing), taha wairua (spiritual wellbeing) and taha whānau (family and social wellbeing). Treatments can cause reduced muscle strength and bone density, increased fatigue and impaired physical and functional capability (Charles Shapiro & Recht, 2001) – affecting our taha tinana. These effects can then link to mental and emotional distress affecting taha hinengaro. Mental and emotional distress is an established concept in cancer and exercise research, which has found links between the physical body and mental/emotional health (Montazeri, 2008). Taha hinengaro in cancer patients and survivors can be severely affected by financial burdens, including costs from medical treatments, appointments and unemployment (Schmitz et al., 2015). These can leave people with a sense of hopelessness or existential crisis (Aredes et al., 2018; Brown et al., 2019; Jemal et al., 2019) – directly impacting taha wairua. Impaired taha wairua can manifest as reduced connectedness with the world and others, and feelings of

unfulfillment or dissatisfaction. For cancer patients and survivors, a diagnosis and subsequent therapies can produce a variety of emotions; while experiences are individual, research suggests feelings such as loneliness, sadness and frustration can be common. Relationships between cancer and mental/emotional stress have been described (Love et al., 1989; Nerenz et al., 1982), and can extend beyond the individual to influence whānau, healthcare professionals, and the wider community. Taha whānau plays a key role in stabilising the four walls described by Te Whare Tapa Whā, where family and relationships with others are important for coping with diagnoses and treatments. A key difference of Te Whare Tapa Whā as a health model, is taha wairua. Spiritual wellbeing in cancer patients and survivors is an important component that can be often overlooked in healthcare. Spirituality can be interpreted differently and is not always discussed with patients. The researcher believes spirituality contains various components which include religion and faith, as well as a sense of connectedness and belonging either to a group, themselves or to life itself. In this study, spirituality was demonstrated in a variety of ways including people connecting with the group and the programme coordinator and also through religion and their families. Emerging research shows that cancer patients and survivors are seeking increased spiritual support in healthcare policies and practice, particularly to meet health and wellbeing needs (Egan et al., 2018). Taha wairua is an important part of Te Whare Tapa Whā and can speak to the connection people have with themselves, others and their environment.

The wellbeing needs of cancer patients and survivors are diverse and existing practices may not be adequately addressing this, as suggested in other work (Egan et al., 2018). The current research project attempts to give voice to exercise experiences of cancer patients and survivors, as well as address taha wairua. Te Whare Tapa Whā

was an important part of analysing and interpreting the data captured within this study, as it provided a holistic outlook of the experiences of cancer and exercise. In a field where quantitative methods and biomedical health models dominate explorative studies, Te Whare Tapa Whā offers depth in addressing health interventions in cancer patients and survivors.

Exercise

PA and exercise are both widely used terms, especially when discussing exercise oncology research. Often PA and exercise are used interchangeably, however, their definitions help in separating them. PA is defined as any skeletal muscle movement that requires energy, for example, walking, vacuuming and gardening (McKenna & Riddoch, 2003). Exercise is defined as structured PA aimed at achieving specific goals relating to maintenance or improvement of health, for example, an exercise programme aimed at increasing muscular strength (McKenna & Riddoch, 2003). Both terms are similar and are often both used by the general population, which is reflected in previous research (Sander, Wilson, Izzo, Mountford, & Hayes, 2011; Sweegers et al., 2018; Tsai, Robertson, Lyons, Swartz, & Basen-Engquist, 2018). To encourage a holistic lens of health and well-being when discussing exercise and cancer, PA and exercise are both used throughout this study.

PA and exercise play a key role in the management and, in some cases, prevention, of cancer (Courneya et al., 2009; Farris et al., 2018; Mctiernan et al., 2019). Evidence surrounding the benefits of PA in cancer survivors is robust (Ax et al., 2020; World Cancer Research Fund/American Institute for Cancer Research, 2018; Penttinen et al., 2019; Roine et al., 2020; Sheehan et al., 2020), and

demonstrates a clear relationship between PA, reduced cancer risk and improved side effects management (World Cancer Research Fund/American Institute for Cancer Research, 2018). The World Cancer Research Fund/American Institute for Cancer Research (2018) estimated that within the rise of global cancer cases, at least a third of cases are preventable (World Cancer Research Fund/American Institute for Cancer Research, 2018), through reduced tobacco and alcohol use, and improved PA levels and nutrition (World Cancer Research Fund/American Institute for Cancer Research, 2018). Many cancer patients reduce their PA levels during diagnosis and treatment, as some become unable to regain their previous PA capability (Courneya, Friedenreich, Arthur, & Bobick, 1999; Courneya & Friedenreich, 1997; Courneya et al., 2000).

Despite a strong case, the integration of PA and exercise knowledge, services, care and programmes, remains an ongoing issue. The use of other rehabilitation services, such as psychosocial interventions, are unable to truly address the physical and functional challenges cancer patients and survivors face (Courneya & Friedenreich, 1997; Osborn, Demoncada, & Feuerstein, 2006; Sheehan et al., 2020). The gap between evidence and practice is apparent in the field of exercise and cancer, leaving many people unsure of how to carry on with life post-diagnosis and treatment. In Aotearoa New Zealand, the options for community exercise rehabilitation services are limited, delaying the process of mental, physical, and spiritual recovery. These reasons justify a qualitative study that attempts to explore the experiences and perspectives of PA, cancer, a cancer exercise programme and well-being in cancer patients and survivors.

Summary

It is clear that cancer is a major and ongoing issue not only within New Zealand, but also globally. The impact is extreme and often the patients wellbeing is considered secondary to the diagnosis and treatment. Cancer rehabilitation and recovery is a relevant research topic and requires further exploration to impose community change. Exercise and PA play a key role in health and medicine and is a component of cancer rehabilitation. However, the major gap in research is the lack of understanding the holistic nature of exercise and how medical practices can reflect this when engaging patients in exercise programmes. Te Whare Tapa Whā is used to analyse the data and guide the understanding of health in cancer patients and survivors.

Methods

This study used semi-structured interviews and observational notes to explore the experiences of PA and exercise in cancer patients and survivors, engaging in a exercise programme. Interviews and analyses were guided by key principles from Te Whare Tapa Whā (Durie, 1998) and were further analysed using elements of Grounded Theory methods (Glasser & Strauss,1967). Ethical approval was granted for this study from the Otago Polytechnic Research Ethics Committee and through Māori consultation with a Kaitohutohu office representative.

Purposive sampling (Etikan, 2017) was used to recruit participants from a cancer exercise programme. A gatekeeper made initial approaches to potential participants, with four participants expressing interest and providing written

informed consent. A clinician working with the cancer patients also volunteered for interview.

All interviews were conducted by the primary researcher, a female post-graduate student with a background in exercise and health, who had also guided the participants in a cancer exercise programme. Interviews were interrupted by New Zealand's Covid-19 alert level four lockdown and were conducted face-to-face (n=1), by telephone (n=2) and by audio-visual meetings (Microsoft Teams, n=2). Interviews lasted between 20 and 60 minutes. All interviews were audio-recorded and transcribed verbatim. Transcripts were returned to participants for member checking.

Researcher field notes were made during exercise sessions (four sessions per week for nine months) and following all interviews and were included as appropriate in case studies. Two researchers coded the data (MM and RH). Interview transcripts were read multiple times to become familiar with the content, analysed and arranged into a data coding tree. Similar text segments from the raw data were grouped and given a descriptive label (e.g., psychological benefits). Descriptive labels were then categorised under each of the Te Whare Tapa Whā health domains. Themes were generally identified in advance, however, some themes emerged from the data. For reporting purposes, participants were assigned pseudonyms and narratives were altered to protect the participants' identities. Data saturation was reached when no new themes emerged after two consecutive interviews. This was reached after the fifth interview.

Findings

Three women and two men participated in interviews (Table 1). All participants were New Zealand European. At the time of the interviews, one participant was undergoing treatment and the others had concluded treatments. The clinician was able to provide anecdotal accounts and observations of cancer patient experiences. All participants experienced a range of benefits from the cancer exercise programme (Table 2).

Participant one: Charlie

Charlie was extremely excited from the beginning to be a part of the cancer exercise programme. On the first day we met, Charlie had difficulty breathing due to Chronic Obstructive Pulmonary Disorder (COPD) and his physical capabilities were limited after treatment, which was consistent with the research (Aumann et al., 2016; Williams & Jeanetta, 2016). Charlie had only ever thought of exercise in terms of his working life, valuing the “...*importance of being well enough to go to work...*”. Charlie found that the effects of cancer and treatment had “...*physically wiped me out and were really full on and non-stop...*”. After going through his treatment plan, Charlie said he was “*A lot more on the slow side. As soon as I developed my taste buds back is when things started to become more on the normal side*”.

Table 1: Participant Demographics

ID	Participant Type	Time since diagnosis	Sex	Age (years)	Cancer
Lesley	Clinician	N/A	F	53	N/A
Charlie	Cancer survivor	2 yrs 2 mnths	M	49	Head and Neck
Alex	Cancer survivor	2 yrs 8 mnths	F	75	Myeloma
Jordan	Cancer survivor	1 yr 9 mnths	M	72	Non-Hodgkin's Lymphoma
Mackenzie	Cancer survivor	2 yrs 4 mnths	F	31	Myeloma

Table 2: Themes

Theme	Subtheme	Description
Taha tinana	Exercise programme	Physical, mental, spiritual and social benefits
	Cancer and treatment	Physical, psychosocial and functional decline
Taha wairua	Connectedness/interrelatedness	Relationships with other people and the environment Religion
Taha whānau	Family	Importance of family throughout the cancer journey
	Societal roles	How health interventions must meet needs of people's societal roles
Taha hinengaro	Depression/anxiety	Impact of diagnosis and treatment
		Use of exercise for rehabilitation

On joining the programme, Charlie's exercise goals were to increase his weight and improve fitness. During exercise sessions, it was important for Charlie to perform low impact exercises and take regular breaks. Due to pain in the neck and back, exercises were scaled to how Charlie felt on arrival,

"...it's about feeling fit enough and mentally and emotionally stable enough to get out of bed and get through the day. I might lift my weights now and then and do a few stretches. Other than coming to the exercise programme, I'm doing things around the house like hanging out the laundry, moving firewood or being out in the garden..."

During lockdown, Charlie's primary form of exercise was gardening – moving and replanting pots,

"...It's good to see the progress of what you've achieved and your progress. It's definitely helped with my fitness, and because of that, it's opened everything else up. I've actually got the energy to and well enough to go for a walk down the road, I enjoy going for a walk down the road and you just notice the little things, A cat down the road came up to me and wanted a pat, it's just the little things in life that you notice, and you feel pretty good. You can notice those things rather than just walking past the cat and not thinking anything of it..."

Before diagnosis, Charlie suffered from mental health issues, sharing that he was once suicidal. Charlie's cancer diagnosis had completely changed his perspective on life,

[it was] *"...silly of me to even think of ending my life when now I have cancer and bigger things to deal with..."*. Charlie used physical activity and the exercise programme to improve his psychological well-being and quality of life. He gained peer support from the programme that enabled him to socialise, connect with others

and discuss topics such as medications, treatments and appointments. Other research has highlighted the importance of peer support as a direct result of rehabilitative exercise programmes (Cormie, Turner, Kaczmarek, Drake, & Chambers, 2015; Luoma et al., 2014). For Charlie, the exercise programme provided a sense of responsibility, where he treated sessions as important appointments.

Charlie's experience of cancer had the largest impact on his Mother, and said she really struggled. When seeing the oncologist, and getting the results back from the x-ray, "*...mum was there at the time and mum just collapsed, she was taken out by one of the other nurses...*". Charlie felt that the exercise programme improved his mood and health which positively changed his relationship with his mother, and how she perceived the impact of his cancer.

Charlie shared more on his mental health, "*...I was quite suicidal. And then I was starting to become better, and I thought maybe I could cut back on my meds. I went to see my doctor to tell her I was feeling better, but then I developed a swelling under my ear and that was the cancer. At the lowest end of the scale, passed a little anxiety and moved into depression, knowing in yourself that you're headed in the wrong direction and now is the time to reach out for help. If not, sleep, food and personal hygiene suffers, and thoughts of suicide enter your mind and never leave. Family and friends should be appreciated but are unrecognised in your mind...*".

A cancer diagnosis changed Charlie's perspective on life, where he thought it was "*...stupid to think I was once suicidal. And then you get over that because you have cancer...*". Charlie found that he had to accept his diagnosis and treatment plan and it became an opportunity to improve his health and life.

When asked about his experience of the cancer exercise programme, Charlie replied “...*It’s been marvellous. Not only physically, but mentally as well, getting to see people and getting out and socialising...*”, which intersects with taha whānau. Charlie felt a sense of responsibility towards the cancer exercise programme and described the sessions as similar to doctor, dentist or counselling appointments.

Charlie’s experiences of cancer, physical activity and the exercise programme were mainly related to taha tinana and taha hinengaro. These findings were consistent with other clinical evidence, where physical and psychological benefits were central to experiences of exercise (Cormie et al., 2015). The physical benefits and peer support Charlie gained from the exercise programme improved other aspects of his life, including his mental health. Charlie noted that during Covid alert level four lockdown in New Zealand he used exercise skills he learned from the cancer exercise programme to continue enjoying daily life,

“...exercise has helped with my fitness, and because of that, it’s opened everything else up. I’ve got the energy, and feel well enough, to go for a walk down the road...”

Participant two: Mackenzie

Mackenzie was a young mum when she became involved with the cancer exercise programme. She had been through a recent traumatic birth and was struggling mentally and emotionally to cope with the impact of her diagnosis and treatment. Mackenzie had previously coped with life events well, however, her diagnosis and treatment produced an array of adverse effects,

“...I think it hit me harder than I thought it would. A lot of people said if it’s going to happen to anybody it’ll happen to you, it’ll be okay because you’re a really strong person. I always used to boast that I was pretty strong and independent – but nothing prepares you for how hard it’s going to be, and how much it hits you mentally and physically. I had no stamina; it was all gone. Mentally, I was scared every day. I woke up scared and fearful if something had happened to my body. And I was emotionally drained”.

Mackenzie was advised to reduce her PA and refrain from overstressing herself. This left Mackenzie feeling helpless and being unable to control her body. Mackenzie spoke about the difficulties of having a newborn and going through chemotherapy,

“...That was just so tiring. Getting up every three hours to feed her while going through chemo, I was just tired all the time...”.

Mackenzie had lived an active life prior to and during her diagnosis,

“...I was pretty active during the diagnosis time because I was up in Christchurch and I had to walk to the hospital every day to see [her daughter], so I was moving a lot up until chemotherapy...”.

It was important to support Mackenzie’s taha whānau by encouraging her to bring her toddler along to sessions. This meant Mackenzie was able to begin exercising by reducing other stressors such as finding a babysitter. The relationship between taha whānau and health is important and has been highlighted in previous research (Glover, 2013; McGruer et al., 2019).

Mackenzie spoke about “positive pain” when participating in the cancer exercise programme, where she was previously used to experiencing negative pain from treatment,

“...I feel like my muscles are actually working. Knowing my muscles are actually getting used again, and you feel them, and they’re sore, but I know why they’re sore. They’re sore for a reason, they’re not sore because there’s something wrong with them. It’s a good sore. Knowing that I’m getting tougher, stronger and the muscles are growing...”

Through exercise, Mackenzie had improved her self-confidence and self-esteem. The way she felt about her body “*...had been negative for so long...*” and now she was creating a positive relationship with herself. Exercise gave Mackenzie a sense of autonomy and control over her body,

“...during exercise, I had more control over my body and what it was doing. I started to feel stronger. I was so out of control of my own body for so long. When you’ve been pumped full of chemicals, you can’t control the pain and side effects. But when you’re exercising and you have muscle pain, that’s pain you can control...”

Mackenzie explained that the diagnosis and treatment “*...messed me up...*” which resulted in a psychological breakdown in 2019 “*...I couldn’t handle it...*”. Mackenzie said the cancer exercise programme gave her something positive to focus on “*...if I knew what I know now, I would have started exercising sooner. The main positive is regaining control over your body again...*”.

Mackenzie’s main barriers to returning to exercise included the advice received from health professionals to reduce physical activity, and fears of worsening the disease and returning to the hospital. Cancer patients have reported similar barriers, demonstrating the influence clinicians can have on patient physical activity levels (Clifford et al., 2018; Eng et al., 2018). Returning to exercise had a significant impact on Mackenzie’s taha whānau, taha tinana, and taha hinengaro, similar to Charlie’s experiences with exercise. Since beginning the cancer exercise programme,

Mackenzie reported increased muscle definition, dropping a dress size and the satisfaction of reaching her goals.

Participant three: Alex

Since childhood, exercise and being physically active had always been a part of Alex's lifestyle. Alex fondly remembers going camping and adventuring with her family, which had a major influence on her enjoyment of physical activity,

"...it's my way of life. I've always been an active person. We've always walked the dog, done some gardening, and gone for bush walks and tramps. It's reassuring to keep going with what you like doing. I wanted to keep up with what I was already doing [being active] and I have managed to do that..."

Alex spoke of the way treatment affected her physically and functionally, which included being unable to tend to her garden or lift heavy loads. She was happy to be able to do things around the house and outside, and treatment had taken that away from her. The ability to do these things was key to maintaining a sense of positive well-being in her life. Alex discussed her taha wairua and taha tinana as being closely connected, where one directly influenced the other (e.g., tramping and walking outside was a spiritual practice for Alex). Alex's spiritual wonder was with nature, as she was able to walk outside and witness the abundance around her, including the fruits and vegetables from her garden, the birds and walking through the trees.

The cancer exercise programme provided Alex with a sense of social connection [it was] *"...fun because of everybody else there and being able to see everybody and ask how they're doing..."*. Alex's taha whānau (family and social

well-being) continued to expand through exercise by walking and cycling with her husband. Alex said exercising and being physically active with her husband was a great way to connect and create “...*togetherness*...”. Alex discussed quality of life and how it related to her physical activity,

“...everything’s about quality of life. It’s to do as much as you can that makes your life happy. I am most happy when I have done a physical project for the day...”

Participant four: Jordan

Before cancer, Jordan lived an active life which included daily walks to and from work, tramping with friends, raising his family and helping in various community projects. For Jordan, exercising was a way of life and a daily habit. During his treatment, Jordan was grateful for the support of his family and felt these relationships were key in rehabilitation. Jordan also received extensive peer support from his local church, where people would cook him meals and check in on him. When Jordan was diagnosed with Non-Hodgkin’s Lymphoma, he became acutely aware of his physical and functional decline. For example, he noticed activities he would previously do, had become difficult. This became the main reason why Jordan expressed interest in the cancer exercise programme.

He experienced many side effects from treatment, which resulted in reduced muscular strength and fitness. This was emphasised when Jordan first attended the cancer exercise programme “...*I was aware of how physically unwell I was. You gave me some exercises that suddenly I realized I couldn’t do...*”. Jordan was enthusiastic about participating in the cancer exercise programme, as he wanted to do things that could improve his health and well-being. When Jordan initially became a part of the

cancer exercise programme, his self-confidence was low. However, Jordan created key goals with the programme coordinator, including to improve his fitness and have the ability to continue doing things he enjoyed. Jordan worked towards these goals through the cancer exercise programme, which started with a weekly outdoor walk. This improved his base fitness, increased his exercise tolerance and confidence. By the end of the programme Jordan was able to walk for over 45 minutes and had gained confidence in going up and down hills. Jordan's results were consistent with other research that demonstrate improvements in taha tinana through regular exercise (Ax et al., 2020). Jordan enjoyed the programme as it "...helped move things along...". He spoke of the spiritual connection he had with the programme coordinator "...you were a part of a bigger puzzle for me and I appreciated your support. It was also a physical and mental thing for me...". As with other participants, the cancer exercise programme provided Jordan with a social connection, as he mainly enjoyed the company and feeling welcome.

Participant five: the clinician

The clinician believed in using exercise to enhance patients' well-being throughout the stages of a cancer diagnosis and treatment, including the four pillars of Te Whare Tapa Whā. She lived an active life growing up and spoke about using her past experiences with exercise and PA to educate patients about how important PA was for their recovery. This was consistent with other research that demonstrates the influence of clinicians' preferences when counselling patients (Schmitz et al., 2019). She discussed the decline of muscle strength and functional abilities due to

diagnosis and treatment which is similar to the experiences of the participants noted in this chapter.

“...their muscle strength is going to be affected by the steroids, and this is true whether you’re 20 or 80 years old...”

This clinician believed in the many benefits patients gained from regular PA and encouraged exercise from the beginning of the treatment care plan. The clinician had seen many patients recover, survive and benefit from increasing PA levels. The clinician recalls noticing improvements in patients taha tinana, even if the patients had not noticed yet. Research has shown that exercise is a valuable rehabilitation option for cancer patients and survivors, particularly in improving physical deterioration in the patients (Ax et al., 2020; Dennett et al., 2019; Roine et al., 2020; Sheehan et al., 2020). For example, the clinician had worked with a patient in his 70s whose main goal after treatment was to be strong and healthy enough to take his grandson fishing. Cancer treatment had made him weak and he was unsure if he could care for his grandson. After working with a physical therapist and engaging in daily exercise, the patient built up his strength and self-confidence to be able to go fishing with his grandson. This anecdote reflects the importance of taha wairua and how it intersects with other dimensions such as taha whānau,

“...it was a social, spiritual, cultural and environmental thing to be physically well enough to be with his grandson – exercise played a part to achieve this goal...”

The clinician described another patient whose pelvis had partially disintegrated from cancer. The exercises used for this patient’s recovery included chair-based exercises to improve upper body strength. It was about *“...people maintaining some sort of strength so that when it does come time to do more stuff, they’re not starting right back at zero...”*. Another of her patients had started having

difficulty moving around the house and performing his usual activities. After three weeks of brief face-to-face physiotherapy and completing exercises at home, the patient required his walking frame less and could get up and off the toilet more easily. Although these were simple improvements, the clinician said they were major factor in the patient's ability to do things post-treatment.

The clinician's experiences of working with cancer patients reinforces the importance of exercise and PA along the cancer continuum. These anecdotes reflect all dimensions of Te Whare Tapa Whā and links with an aspect of other Māori health models such as the Meihana model. The Meihana model includes environmental aspects which is reflected in the patient who felt an environmental connection when fishing with his grandson. The clinician was able to link the Te Whare Tapa Whā model with experiences she had seen in patients which relates to the diverse needs within this group.

Summary

This study explored individual experiences of cancer, PA, well-being and a cancer exercise programme, using the lens of Te Whare Tapa Whā. Mason Durie's (1998) explanation of Te Whare Tapa Whā emphasises the relatedness between well-being dimensions. In the current study, the benefits of PA and a cancer exercise programme were found to extend beyond physical wellbeing, and provided benefits across spiritual, psychological and social health dimensions. The findings from this study are similar to those from previous clinical research (Ax et al., 2020; Dennett et al., 2019; Roine et al., 2020; Sheehan et al., 2020). However, this study differed by adopting the holistic health lens offered by Te Whare Tapa Whā, to

interpret data in holistically. This study highlighted the range of health benefits experienced by cancer patients and survivors that extended beyond the physical and included taha wairua. The experiences of PA and exercise can be spiritual and invoke spiritual feelings. For example, Alex discussed how her physical and spiritual well-being were closely connected, and the account of the grandfather who wanted to fish with his grandson. These examples show that PA may influence an individual's life socially, physically and mentally. The findings from the current study suggest both positive and negative experiences produced a ripple effect on other health domains. For example, Charlie reported improving all aspects of his life by engaging in the cancer exercise programme, and Mackenzie found that the impact of treatment that had left her emotionally, mentally and physically depleted. Other New Zealand research has used Te Whare Tapa Whā to interpret data, highlighting how the model can better inform holistic health interventions (Glover, 2013; McGruer et al., 2019). While Te Whare Tapa Whā offers a Māori worldview, it highlights the often-overlooked spiritual dimension of health. In our postmodern world, spirituality has become more than a religious belief and points to our interrelatedness to ourselves, others, whānau, communities and the environment (Egan, 2019; Egan et al., 2018).

The current study adds to existing literature by exploring spirituality through the use of Te Whare Tapa Whā (Egan, 2019), demonstrating the extensive benefits from exercise and utilising indigenous health concepts to frame and interpret cancer and exercise research. Understanding holistic well-being in cancer patients and survivors may be an important consideration for future healthcare interventions.

Some limitations of this study warrant consideration. Firstly, this study was undertaken during the Covid alert level-four lockdown in New Zealand. As a result, the sample size and method of data collection were affected.

Strengths of the research include the researcher's established relationships with participants which aided in whanaungatanga. This study used a holistic Māori health model, Te Whare Tapa Whā, to analyse and interpret the data, which is a strength for this qualitative study attempting to explore holistic experiences.

Conclusion

The results obtained in this study highlight that a cancer exercise programme can have psychosocial and spiritual benefits, which a biomedical model may overlook. This study indicated that cancer patients and survivors' experiences of PA can be meaningfully interpreted using a holistic view of wellbeing – Te Whare Tapa Whā. This study adds to existing literature using indigenous health frameworks to understand the impact of PA on health and wellbeing (Demark-Wahnefried et al., 2018; Moore et al., 2021). Future research in this area might explore how cancer exercise programmes could be developed and delivered to cancer patients and survivors using holistic health models.

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Chapter 4: Discussion

The purpose of this research project was to explore the experiences of cancer, physical activity (PA) wellbeing and a cancer exercise programme in cancer patients and survivors. This analysis was guided by the Te Whare Tapa Whā model to address broader elements of health. This research project found that there were a variety of benefits of exercise for cancer patients and survivors that span across the Te Whare Tapa Whā dimensions – taha tinana (physical wellbeing), taha hinengaro (mental and emotional wellbeing), taha whānau (family and social wellbeing) and taha wairua (spiritual wellbeing). These benefits included physical and psychological benefits, the value of peer support, and identification with spirituality. The experiences of the cancer exercise programme related to the four components of health described in Te Whare Tapa Whā which demonstrated the value in employing a holistic approach to cancer research.

The study findings agree with previous clinical research that suggests cancer rehabilitation should take a holistic and integrated approach if services are ever going to meet the demands of current cancer trends (Ax et al., 2020; Dennett et al., 2019; Roine et al., 2020; Sheehan et al., 2020). An important difference between earlier investigations and the present study was the use of a Māori health model as a lens to interpret and analyse the data. The present study allowed for the investigation of taha wairua (spiritual wellbeing) which is typically seldom considered in exercise and cancer research. Previous research have adopted biomedical frameworks to investigate exercise in cancer groups (Dieli-Conwright et al., 2018; Penttinen et al., 2019; Roine et al., 2020), however, studies are increasingly exploring the use of holistic health models. It may be argued that the present study allowed for a greater

exploration of wellbeing experiences of cancer patients and survivors. A greater exploration was established by using the Māori health model, Te Whare Tapa Whā, which created a deeper understanding and a holistic conversation with participants. This study also laid the foundation for people within the Otago region with a variety of cancers to discuss their wellbeing regarding their cancer and exercise. The holistic nature of this study allowed people to discuss their life and experiences with few restrictions. Taha whānau being an important aspect of Te Whare Tapa Whā meant that building and establishing rapport, respect and care between the researcher and the participants was key in fostering openness and trust in these relationships. This study also agreed with qualitative evidence which highlighted the important work of writing about and investigating the intricacies of cancer care and peoples experiences (Appleton et al., 2015; Blaney et al., 2010; Dennett et al., 2019; Egan et al., 2018). Quantitative research reflects similar findings of improvements in quality of life (QOL) dimensions (Brown & Schmitz, 2015; Clifford et al., 2018; Courneya et al., 2012; Roine et al., 2020; Speck et al., 2010). These quantitative studies were able to sample larger populations including work by Roine et al (2020), which demonstrated findings from 537 breast cancer survivors. However, through qualitative methods, Dennett et al (2019) was able to explore cancer survivors' experiences of an exercise-based rehabilitation programme and found that exercise provided a 'good stepping stone to normality' (Dennett et al., 2019, p1729.). This is consistent with findings from this research project, which found PA was used to regain control of the survivor's lives. The sample size of Dennett et al's (2019) study was 26 – considerably more participants than the current research project. Many studies typically refrain from describing the theoretical frameworks which make it difficult to understand the contexts of how the researchers explore their data. Previous New

Zealand research has explored health issues focusing on Māori worldview frameworks (Glover, 2013; McGruer et al., 2019; Robson & Ellison-Loschmann, 2016), however, none of these have focused on the experiences of cancer patients and survivors engaging in a rehabilitation exercise programme in New Zealand.

Te Whare Tapa Whā proved useful in understanding the full experiences of study participants, however, other aspects also need to be considered in future. These include the physical environment which someone occupies, their societal roles, and any historical contexts. This study found that some aspects, such as environment, social roles and culture, were unable to be drawn out. Exploring environment, social roles and culture may have provided context in this study's participants. In this study, some participants were parents, sons, cousins, grandparents, friends – and the societal roles they played also had an impact on their experiences, uptake and maintenance of the cancer exercise programme.

This also extended to the societal impact on the participants which explore how their current societal perceptions, beliefs and services impacted on the wellbeing of clients. In this study, participants had never engaged with a cancer exercise programme before, however, all had engaged with the state healthcare system, which may have affected their experiences of the programme studied. This could be considered using the Meihana model (see figure 2) which specifically seeks to understand the impact of societal beliefs and values, which can act both as barriers and enablers when engaging in health behaviours.

Figure 2: The Meihana Model (Pitama et al., 2007)

<https://www.semanticscholar.org/paper/A-proposed-hauora-M%C4%81ori-clinical-guide-for-Using-in-Pitama-Bennett/0f81851dc751415e70c69b596bd06ba4f72b483a>

Although exercise programmes are not considered to be within the realm of medical practice, they remain services that work with patients who have previously engaged with healthcare providers. While this may help exercise professionals understand the context of the participants, it does not address the need for a more holistic framework for exercise professionals to use.

Using Te Whare Tapa Whā in health practices promotes understanding and empathy in comprehending others' lives and contexts. Research exploring how exercise professionals engage with cancer care services using Te Whare Tapa Whā is required to understand this further. Potential solutions could be by encouraging te reo Māori in programme marketing, promotions and conversations when working with Māori and non- Māori. This may impact on multiple dimensions including taha wairua, taha hinengaro (mental and emotional wellbeing) and taha whānau (social wellbeing). Additionally, taha wairua could be embraced by having new people introducing themselves before an exercise session begins, or rituals such as closing sessions with moments of gratitude and/or karakia. In future, the key may be to ask clients how they might like to connect with components of Te Whare Tapa Whā, which could in turn inform practice for exercise professionals. This study also highlighted that it may be beneficial for exercise and health professionals, counsellors, oncologists and haematologists to work in a multidisciplinary team to

better support the diverse needs of cancer patients. It must also be acknowledged that while exercise is integral to health and wellbeing, exercise professionals cannot expect to understand the broader needs of clients alone.

Frameworks used to discuss the cancer care continuum generally start with a diagnosis and finish with an individual's long-term survival and survivor health (Courneya & Friedenreich, 2001; Hudson, 2005). Most exercise interventions are focused on long-term survival with an emphasis on rehabilitation and late-effects management. However, this phase of the cancer continuum may be too late as some individuals pass away, develop secondary cancers, other diseases or suffer injuries. A solution may be to introduce exercise professionals and services in the beginning of the cancer care continuum, which may be completed in stages. For example, a referral could be made to an exercise professional who creates a wellbeing plan with the client that coincides with their treatment. While there are various unanswered questions, this discussion can continue to be explored.

The findings from this study contribute to the need for exercise as part of treatment and care in cancer. Several studies indicate that exercise is safe and effective as a programme on the cancer continuum (Haas, Kimmel, Hermanns, & Deal, 2012; Leach, Danyluk, Nishimura, & Culos-Reed, 2015; Schmitz et al., 2019). Further research is required to understand how to incorporate Te Whare Tapa Whā in practice and what this means for exercise professionals.

Strengths and limitations

This research project had a number of strengths and limitations. A strength was that the researcher (MM) had established relationships with all participants

which increased the trust and care during data collection. These established relationships allowed the researcher to explore sensitive topics with participants. This research project used qualitative methods and Te Whare Tapa Whā to explore the research question, which provided data on the full impact of the participant's experiences. The sample size was small (n=5) which meant the researcher could focus closely on each participant and explore the breadth and depth of their stories.

While it is important to acknowledge the strengths of a research project, limitations must also be noted. This research project was limited by being a non-funded Master's project, which restricted the potential scope of the study. Data collection was directly affected by the 2020 covid-19 alert level four lockdown in New Zealand, which meant interviews could not be completed in person. The participants in this study identified as New Zealand Europeans, with no representation of Māori, or other ethnicities. As a result, the findings within this research cannot be generalised across various ethnic groups.

Implications and future research

This research project highlights the psychological, social and spiritual benefits a cancer exercise rehabilitation programme can offer cancer patients and survivors. These findings demonstrate the urgent need for healthcare services to incorporate and practice holistic health interventions for this vulnerable population. Unfortunately, within New Zealand, few services are available to tend to the spiritual wellbeing of cancer communities. This may be due to the gap of cancer rehabilitation services in New Zealand; however, this should not deter clinicians from exploring avenues for change. Future research should attempt to bridge the gap between the

evidence of the benefits of exercise on well-being in cancer patients and survivors, and professional practice, using holistic frameworks. Understanding the full impact of cancer and exercise in patients and survivors is pivotal for health professionals to reflect the needs of cancer communities. Further, Māori communities cannot be expected to improve their health with services that fail to recognise a Māori worldview. Future cancer exercise rehabilitation programmes should attempt to adopt holistic health approaches to better understand client needs.

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Appendices

Appendix 1

Ethics Committee Approval

28 February 2020



Tēnā koe 

Ethics: Exploring the experiences and perspectives of cancer survivors engaging in physical activity

Thank you for your application.

We agree that you have addressed all of the issues we had concerns around and have approval to proceed with your research.

We wish you well with your study and remind you that at the conclusion of your research you should send a brief report with findings/conclusions to the Research Ethics Committee.

Nāku noa, nā



Appendix 2

Evidence of Kaitohutohu consultation

 Re: Kaitohutohu consultation




Friday, 25 October 2019 at 7:01 PM


[Show Details](#)

Hi 

This is an email to confirm that you have completed Maori consultation and have fulfilled the requirements.

Regards,



Sent from my iPhone 