How does the metaphorical conversation Te Awa assist young people to traverse their cancer journey?

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Abstract

Cancer is an overwhelming experience for anyone to deal with and understand no matter the age; yet young adults diagnosed with cancer are also faced with this alongside achieving normal development. The purpose of this research was to answer the question, ‘How does the metaphorical conversation Te Awa assist young people to traverse their cancer journey?’ The primary aim was to answer this question via young peoples shared experiences of Te Awa. The secondary aims were to enhance Te Awa, and health professionals’ practice by informing them of participants’ experiences. While there has been extensive international literature documenting adults’ experiences of metaphor while diagnosed with cancer, there is little within the context of young people. Semi-structured face-to-face interviews with five young people aged between 16 – 24 years with a cancer diagnosis, were conducted. Additionally, one written reflection and one palliative diary reflection were provided. The interviews and reflections were transcribed and analysed utilising thematic narrative analysis. Two themes captured the overall experiences of participants, Te Awa assisted them and in turn, the participants assisted Te Awa. The research findings clearly indicated young people found Te Awa useful, by gaining understanding and control in various forms. Participants’ experiences also provided comprehensive feedback to enhance Te Awa going forward. The dissertation provides recommendations for health professionals and challenges them to go with the flow, to use metaphor, and listen to the metaphors people bring.

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Ko Hikurangi toku maunga

Ko Waiapu toku awa

Ko Rahui me Rauru toku marae

Ko Ngati Porou toku iwi

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I would like to honour my parents, the late Frank and Lottie Proffit for laying a strong foundation for me. Thank you, Mum, for setting this challenge for me 22 years ago, as I received my official letter from New Zealand Nursing Council informing me of my registered nurse status. I know you both continue to walk beside me to this day.

I give thanks to my ‘Bosses’ aka the young people I support in my day to day practise. Thank you for letting me swim alongside you and be one of your many fish in your awa (river) supporting you as you navigate your cancer journey. Thank you for the privilege and honour to help you during vulnerable, challenging and life defining moments. Especially, a huge thanks to the Bosses who took part in this research, gave of your valuable time, energy and experiences. I am truly honoured.

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Ko te wai te ora o ngā mea katoa

Water is the life giver of all things

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Chapter One: Introduction

This chapter introduces the research and provides context to the research question, ‘How does the metaphorical conversation Te Awa assist young people to traverse their cancer journey?’ In my nursing role, I discovered that the metaphor of a river, when shared with young people facing a cancer diagnosis, assisted them to describe and understand the complexities they experienced. I learnt this time and time again when sharing Te Awa with the young person and their whānau (family); I would often hear “that is exactly how it feels!” This awareness fueled the desire to explore the effectiveness of using the metaphor more rigorously through conducting this research.

In this first chapter the effects of cancer on young people between the ages of 12-24 are discussed, along with key aspects of the use of metaphor before providing an overview of Te Awa, the metaphorical conversation, and the way it is used. I position myself as the key health professional involved with young people diagnosed with cancer, the person who developed Te Awa and also the researcher conducting the research. The chapter concludes with an overview of the structure of the dissertation.

Cancer in young people

In the international oncology world young people are called ‘Adolescents and Young Adults’, using the acronym ‘AYA’. According to the Adolescent and Young Adult Cancer Network Aotearoa (2016) there are a number of terms to describe 10 – 25 year-olds: ‘young people’, ‘adolescents’, ‘youth’, ’teenagers’ and ‘rangatahi’. The World Health Organisation [WHO] (2014) uses the term ‘young people’ for this age group and will be the term used throughout this dissertation to describe those between 12 – 24 years of age.

It is globally recognised within the present healthcare system that adolescents and young adults diagnosed with cancer are disadvantaged (Barling, Stevens & Davis, 2013), and have distinct and unmet needs (AYA Cancer Network Aotearoa, 2016). Historically, some unmet needs of young people were due to where they received health care, as there were only two services either ‘child or adult’. Within these services, specific young people’s needs were not advanced due to the vast amount of needs for the general population. A myriad of other complex factors have contributed to their unmet needs; access to care, coordination of treatment, limited availability of clinical trials, minimal clinical trials being offered due to health professionals assumptions of young people’s inability to comply, exclusion due to age ranges or no actual available trials (Barr, 2011; Bleyer & Birch, 2006). Low funding and research of young people's specific cancers also impacts on survival improvements (Ballantine & Sullivan, 2013; Palmer, Mitchell, Thompson & Sexton, 2007; Patterson, Millar & Desille, 2008).

This situation is highlighted globally through the lack of improvement in survival rates for young people over the last 20 years, in contrast to paediatric and adult cancers (AYA Cancer Network Aotearoa, 2016). A report undertaken by the National Child Cancer Network in 2013 supported this by detailing the incidence and survival rates of the 185 12 – 24 year olds diagnosed with cancer annually in New Zealand (Ballantine & Sullivan, 2013). The report stated the five-year survival rate for this age group in New Zealand lagged behind that of the EUROCARE group by 6.8%. Survival for Māori youth sat at 69.5% versus non-Māori youth at 84.2%, highlighting a 14.7% difference of survival between the two groups. From this local comparison it was evident that it is important to address these gaps and improve the healthcare of New Zealand's young people.

The New Zealand Ministry of Health (2009) acknowledged the inequity by introducing the Adolescent and Young Adult Cancer Service to coordinate care directed to the specific needs of adolescent and young adult cancer patients. While these inequities exist, it is even more crucial to ensure young people are able to understand the complex treatment plans and clinical decisions required to be made while navigating their way through a cancer journey. This prompted me to develop the tool Te Awa (The River) to help 12 –24 year-olds diagnosed with cancer understand and make sense of their cancer diagnosis and treatment plan/s to enable them to be active participants in their healthcare journey.

Impact of cancer on normal development

When a young person is diagnosed with cancer the impact on them and their whānau (family) is extremely challenging as it disrupts their life trajectory at a vulnerable time (Wicks & Mitchell, 2010). Without full cognitive development of the prefrontal cortex of the young person's brain, they can find it hard to understand the long-term consequences of decision-making, as normally what is important to young people is the here and now. Therefore, trying to rationalise with an immunocompromised young person (e.g. "Sit this party out, there'll be other parties") is not always successful. Without the ability to see long term benefits from lengthy treatment regimes, young people may find it hard to adhere, especially when wanting to exercise their newly found independence.

Cancer and required treatments can impact young people financially. Particularly when a previously independent young person is now reliant on others for basic needs such as accommodation, as they may no longer be able to afford to live on their own while having treatment. As well as moving away from friends, accessing cancer treatment can also decrease young people's access to their usual social support networks such as sports groups, work colleagues and school friends, especially if they have to travel great distances away from family and partners. Support from such social groups can help young people cope with the cancer experience (Barling, Stevens & Davies, 2013; Miedema, Hamilton & Easley, 2007), but the absence of these supports at such a vulnerable time can take a heavy toll emotionally on them.

During a cancer journey, a young person may cling emotionally to their support systems, either whānau (family) or partners, especially if they are reliant physically and financially. On the other hand, some young people may pull away to avoid becoming a hindrance. Relationships can be a very emotional experience without also facing a cancer diagnosis. If a young person is in an intimate relationship during treatment, they may feel their partner is remaining with them solely out of pity which can cause tension. On the other hand, 'single' young people may experience a dilemma about when is the right time to tell a potential love interest that they are or maybe infertile due to chemotherapy. Research has shown that one of the biggest unmet needs for a young person navigating a cancer diagnosis is the unmet emotional and psychological needs (Miedema, et al., 2007).

A cancer can affect normal physical functioning, such as mobility. Restricted mobility, together with the added assault and impact of the treatment regime, can leave a young person extremely reliant on others. This sudden dependence/loss of independence can be very hard to deal with as some young people may not have been in this position since childhood. Required treatments may leave young people with ongoing issues such as surgical removal of limbs and painful nerve damage, requiring them to learn to live with prolonged physical and psychological side-effects long after treatment has finished (Hokkanen, Eriksson, Ahonen, & Salantera, 2004).

A cancer diagnosis can also impact on the young person's sexual development and sexuality depending on the type of cancer they have and/or the treatment/s they require (Whyte & Smith, 1997). Some cancers can impact on hormone levels, requiring the young person to permanently take hormone replacement therapy. Required surgery may impact on their body image leaving them feeling less feminine such as surgery for breast cancer, or less masculine due to surgical removal of a testicular cancer. Cancer treatment may also impact on the young person's fertility reducing their ability to become a parent in the future (Evans, 2015).

Spiritually, healthy adolescents and young adults can find themselves questioning the meaning of life during this stage of life. However for those young people who have to contend with a life-threatening diagnosis such as cancer, it can ultimately shake their spiritual and religious foundations. Cancer regimes can alter young people's developing personal identity. This can occur both negatively due to the physical side effects of treatment that may cause nausea and hair loss (Whyte & Smith, 1997) but can positively leave young people feeling more mature (Hokkanen et al., 2004). Cancer treatment can also cause frustration towards social constraints placed upon them due to adverse side effects for example, lowered immunity can prohibit young people's activities (McCaffrey, 2006).

Cancer is a very scary experience for anyone to deal with no matter the age. People still assume 'the worst' and immediately think it is a death sentence when hearing the word 'cancer'. Sitting in that doctor's office it is hard to take anything in after initially hearing the word 'cancer' and then the thoughts begin to swirl. Will I survive? How will I cope? How will this diagnosis impact my life? Will I have the ability to function normally?

As a nurse who has supported young people between the ages of 12 – 24 with cancer over the last eleven years, I have sat in that doctor's room numerous times while young people experienced being told they have cancer. Prior to their appointment, these young people were just like their peers; embarking on study, working, forming relationships, travelling and figuring out what they wanted to do with their lives. However, once that word was spoken, young people have described to me feeling stuck in time, as if suspended in a glass bauble, as they watch their peers go forth achieving similar milestones they had set for themselves. As a nurse working closely with these young people, I developed a way of supporting them through their cancer diagnosis using a metaphorical tool Te Awa (the River).

Using metaphor

A metaphor is a figure of speech used to compare the common similarities between two different things. They have been used throughout time to communicate and share meanings to those who have not experienced what the 'other person' is trying to explain (Skott, 2002;

Stott, Mansell, Salkovskis, Levender and Cartwright-Hatton, 2010). In essence, this is what I try to do every day I meet with young people who are diagnosed with a cancer. The various uses of metaphor are further discussed in Chapter Two.

I have wondered if using metaphor was already innately within me. Growing up, I was often told I had a gift for using metaphor, because I found it easier when learning new things to compare them to something I had already come to understand. I am Māori and historically, Māori have had an oral tradition, and storytelling using metaphors was a predominant way to educate and pass on knowledge. Acknowledging my awa (river) is important to me, not only as part of my pepeha when introducing myself, but also to acknowledge my tipuna (ancestors) who came before me, and how they settled within the tribal regions we have today. Within our introductions we pay tribute to our iwi (tribe), maunga (mountain), waka (canoe) marae (meeting house) <u>and</u> awa (river).

For Māori, like many other cultures, water has healing elements both spiritually and physically. In order to survive, water is an essential element that all living things require (Durie, 2000; Royal, 2006 and Yu, 1999). Without water, mankind could not exist. Water makes up to eighty percent of our anatomy and seventy percent of the Earth’s surface. Many cultures, religions and spiritual practices have been, and continue to be, captivated by the utilisation of water. The Wai Māori discussion held in Wellington in 2007 reflected the significance of freshwater to Māori. It was clearly identified at this discussion that in an historical context, the health of the water reflected the health of the people; they are one and the same (Wai Māori, 2008). According to Durie (2000) Māori understood that water and health were inter-linked. They still do to this day.

Internationally, indigenous people share the belief in the value of water and our dependence on it. During 2016 in the United States of America, the largest gathering of Native American tribes called ‘Water Protectors’, gathered for the first time in a hundred years to stand up for the rights to safe water supplies because of growing concern that the proposed gas pipeline will negatively impact water quality. The tribes stood united chanting, “water is life”. For the Aboriginal people of Australia water has both physical and cultural significance, the term being ‘Ngapa Kunangkul’ or ‘Living water’ (Yu, 1999). In India, water is also acknowledged for sustaining life and is of special significance in Hinduism, as there are seven sacred rivers, one being the Ganges River. These rivers are used to wash away sins, and to assist their loved ones to reach nirvana by spreading their ashes into the river (Heart of Hinduism, n.d.). For many religious denominations, baptism by total immersion under water assists the renewal of the soul, while holy water is used by Catholics to provide blessings (Hamilton, n.d.). In biblical times, water played a symbolic part in spiritual realms. For example, Noah and the great flood depict water destroying but cleansing the world of disobedience (Gen. 7:6, NIV). Moses' ability to part the sea and lead the people to new lands while the evil was washed away is another example of the cleansing properties water has in religious contexts (Exo. 14:21, NIV).

For Māori, water not only assists the human body physically, increasing cognition, function, and physical healing, but also spiritual healing and cleansing of negative forces (Durie, 2000; Royal, 2006). Water is also used for ritual purposes (Royal, 2006). As a young person I was taught to cleanse and remove the tapu (sacredness) when leaving the urupa (cemetery) or the presence of tūpāpaku (deceased) by sprinkling water over me. This is a practice I continue to this today and will pass this on to the next generation.

Marsden (2003, p.68) likens Papatuanuku (also known as Mother Earth) and her rivers and streams to the arteries and veins of a human being, giving sustenance and nutrients via water to wildlife, flora and fauna: *"the streams of water are her arteries, bringing the life giving waters for her to imbibe and share with her offspring. Those same streams act as alimentary canals and help in the disposal of waste."*

Using the idea of water and its ability to provide sustenance seems consistent with notions of healing and support not only for the earth, but also for us as humans. Therefore, the thought of the young people who I support going through their cancer journey basking in these healing waters of Papatuanuku metaphorically seemed an important concept.

Introduction to Te Awa

Te Awa (the river) is a therapeutic metaphor I created at the end of 2009 by using the idea of navigating a river and comparing it to a cancer journey. I use Te Awa almost every day to assist and support the 12-24 year-old patients I work with to talk about and try to understand their cancer journey. It is incorporated into conversations I have with young people over the phone, face to face at clinic appointments and during hospitalisation. The metaphor can help illustrate to young people the various issues and complexities that may arise for them and their whānau during treatment. In this way Te Awa aids in creating a language for the young people to discuss concerns and/or issues in a safe format. It is a tool that young people can engage in at any time and stage of their treatment and use because it gives them a non-frightening way to talk about a frightening thing. Laranjeira (2013) confirms this in saying "metaphor can bridge the gap between the cancer experience and the world of technology and treatment, helping patients to symbolically control their illness" (p. 469). Te Awa is introduced as close to diagnosis as appropriate, then re-addressed along the different stages of the cancer control continuum or whenever the young person wants to talk about and relate to where they are at on their cancer journey.

The 'cancer control continuum' is a framework created in the mid-1970s to assist planning, assess progress and prioritise resources. The sections within the continuum framework range from cancer prevention, early detection, diagnosis, treatment and palliative care and are utilised by health services and professionals (National Cancer Institute, 2016). The National Cancer Institute acknowledges that the cancer control continuum has transformed since inception of the original framework due to advancements and new understandings of cancer care. The Midland Adolescent and Young Adult Cancer Service demonstrate adaptation of the continuum by comparing the initial more linear format found in Figure 1. to a more cyclic layout demonstrated in Figure 2. The adaptation has occurred over the last eleven years and demonstrates a young person's potential experience and journey through a cancer diagnosis. As Te Awa was being formed it became clear to me that various parts of the river metaphor aligned to the continuum, for example diagnosis and treatment equated to the 'waterfall' and 'rapids' while prevention is demonstrated in Te Awa by the construction and or reinforcement of existing dams, (see appendix A for a full description of Te Awa).

Te Awa is flexible enough to allow for individuality within the metaphorical conversation. Personalising aspects of a health journey can enable a greater understanding of not only complex medical terms and treatments but also the social, emotional and psychological stressors a cancer diagnosis can bring with it. I believe through my clinical experience of using Te Awa and from feedback received it does help young people to talk about and make sense of their cancer journey. This dissertation invited young people aged between 16 and 24 years who have had a cancer diagnosis and experienced Te Awa to become research participants to formally explore how Te Awa does assist young people to navigate and understand the flow of the river, their cancer journey; a journey they have never traversed before.

Figure.1 Midland Adolescent and Young Adult Cancer Service initial adaption of the Cancer Control Continuum 2008

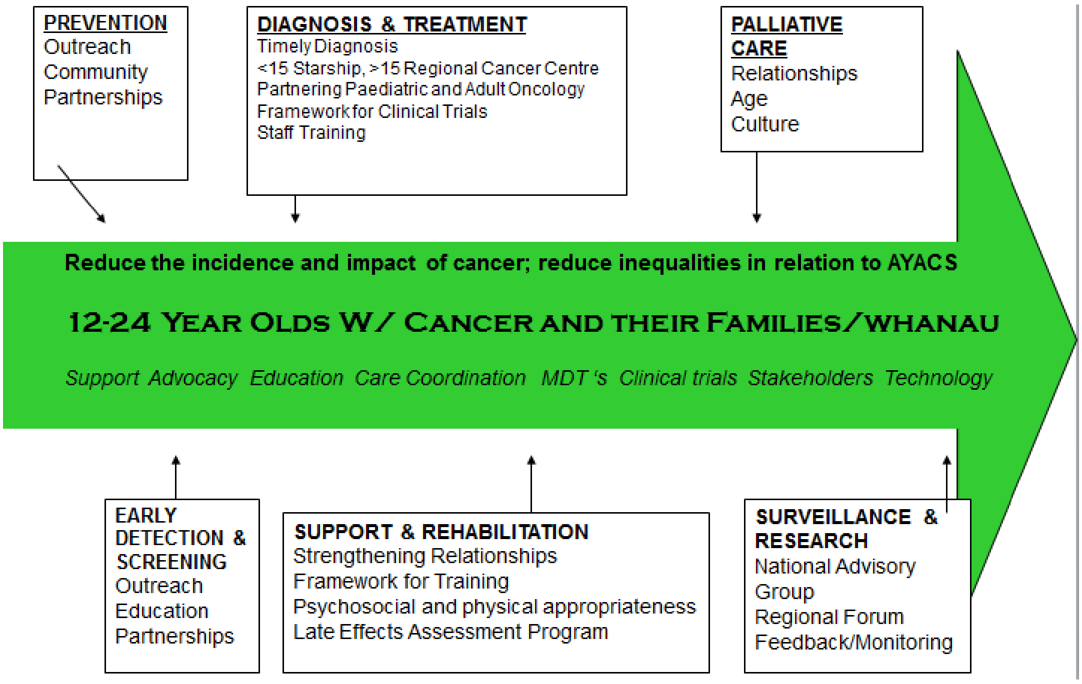
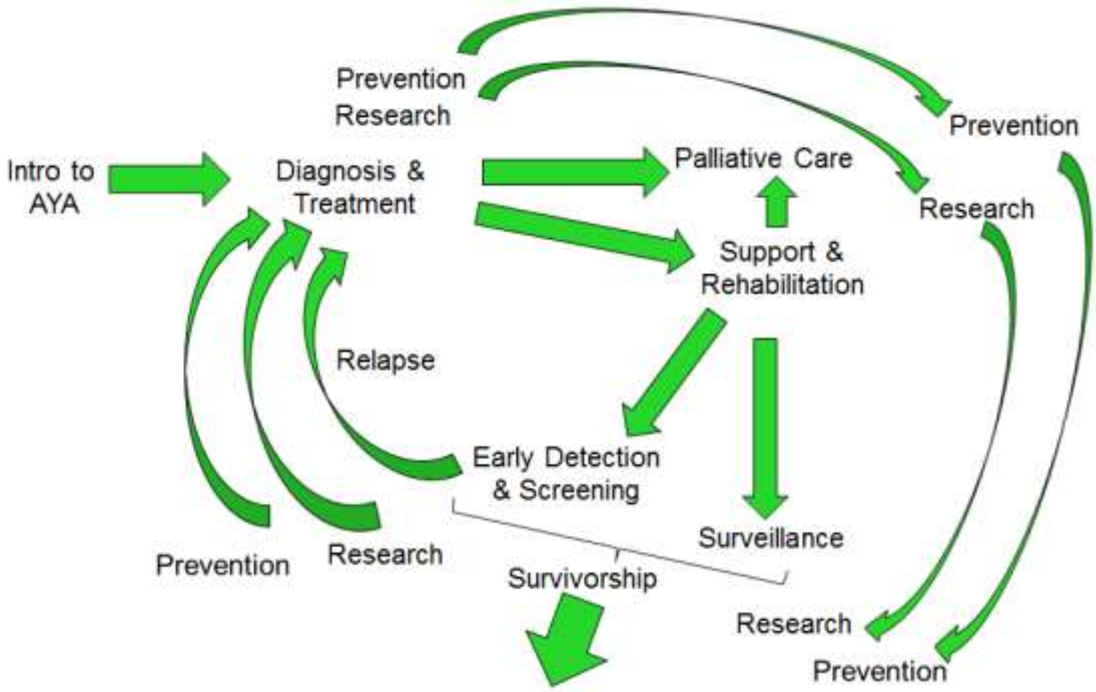


Figure.2 Midland Adolescent and Young Adult Cancer Service current adaption of the Cancer Control Continuum 2016



The process of introducing and using Te Awa with young people

When Te Awa is introduced, time is spent with the young person explaining the likeness between a ‘river’ and a ‘cancer diagnosis’. Here I briefly summarise the stages in Te Awa.

Falling over the edge of the waterfall and being hurtled out of their kayak symbolises the young person being told they have a cancer diagnosis, with the force of the water hitting them at the bottom signifying feeling overwhelmed and overloaded with information and wondering how it will impact on their life.

The river is paused just before they go over the edge as fish are introduced to the story and represent their support people i.e. whānau, friends and sporting mates, who can react with various responses. For example, some fish might be over protective while other fish might be draining; giving unnecessary advice. Some fish might go over the waterfall with them, while others back away and disappear. At the bottom of the waterfall they are informed that fish who may not have been involved in their lives recently can rejoin them. For example, high school friends who hear about their illness might start trying to make contact, along with a myriad of health services and professionals. This can be overwhelming, especially since most young people are still coming to terms with the severity of the diagnosis. Advice is given on how to manage the extra support.

Once past the cascading flow of the waterfall the current starts to settle into the flow or pattern of treatment, and each treatment cycle is seen as a patch of river they can see before it goes around a bend, which represents entering the next cycle of treatment. As the current settles I invite the young person to be the main narrator, by matching their emotions and experiences to the rivers environmental cues they begin to tell their story, and by doing this gain understanding of their cancer. Once settled into treatment and the flow of their river, they are also asked to visualise and voice what they choose to navigate the rest of their river on; their responses have been varied and at times comical.
Attending clinic appointments are seen as forks in the river, as they learn which way the current takes them depending on test results and responses to treatment. Anxiety is common here, as well as dealing with the unsettling physical aspects of treatment the entire length of the river such as hitting rocks when infection sets in or slipping down caves if depression sets in. If such things occur support is given, such as counselling or the use of coping strategies that have helped in the past, or installation of new ones.

The young people are continually supported wherever their river flows and if cure is no longer achievable they are assisted to metaphorically ascend skywards to their chosen beliefs, with the support of their whānau, palliative services, and hospital and community teams. If treatment response occurs, Te Awa continues with the added implementation of support and rehabilitation for the young person to acclimatise into the 'new normal' life after treatment. This can be achieved with the support of various fish in their river or referring them to new fish for example a physiotherapist.

Prevention education is represented as dams in the river, which can either be newly erected cancer preventing strategies such as smoking cessation programmes or reinforced strategies already practiced by the young person to stop other cancers occurring such as sun smart care i.e. sunscreen. Research participation may be offered if eligible trials or studies are available at the time of diagnosis, when they begin descending the waterfall, and is incorporated in the strengthening of dams.

Surveillance signifies the estuary, with treatment finishing and the start of monitoring for cancer recurrence and treatment related side effects. The river they have been accustomed to navigating spits them out into the flow of the estuary, a stage that can be just as daunting as the waterfall as young people can lose reassurance as they are not seen as regularly as they were in the river. Post-treatment follow-up begins with 3 monthly appointments and slowly spreads out to yearly appointments. However the young people are educated and reminded to seek advice if any issues arise between visits. Education also starts from diagnosis around screening and early detection of other cancers, such as testicular and breast checks, as well as monitoring for relapse and knowledge where to seek follow-up.

Finally, they finish their post-treatment follow-up and are encouraged to set sail and adventure the seven seas once officially in the survivorship phase. Encouraged to access their GP for concerns just as the rest of the healthy population do; nevertheless, they know our support or advice is only a call away.

Anecdotal evidence of the value of Te Awa and changes to the tool

Much like a river, Te Awa itself has naturally evolved and developed over the last nine years, thanks to the constructive feedback received from young people and their whānau to constantly assist this tool to change and adapt to fit their specific needs. For example, pre-diagnosis young people are navigating the river on a kayak, once over the waterfall and through the rapids I would initially instruct them to climb on board an outrigger. However, I was working with a young person who told me that they wanted to climb on board a jet ski instead of the outrigger. Although I was surprised with this response I realised this was positive as young people could personalise their story. So, ever since I have asked young people to visualise what *they* would like to float on to navigate the rest of their journey on. Another adaptation is the 'fish', which initially were viewed as 'positive' support people/groups that assisted young people during their cancer journey, however some young people voiced some of their fish became piranha-like in nature, very negative and opinionated. Discussion was had regarding how to capture and remove the piranha; solutions involved casting a fishing rod or setting out a fishing net to eliminate the unnecessary negativity. When appropriate these experiences and various ways of coping are shared with other young people. Other feedback young people and their whānau experienced while using Te Awa was how the river metaphor became integrated as an everyday part of their cancer vocabulary. For example, meeting up with young people before their follow-up appointment they voiced how they were eagerly anticipating no further formal oncology follow up by saying "I can't wait to smell the salt sea air". Anecdotal feedback from young people (see appendix B) has been collated since Te Awa's 2009 inception, which inspired the timeliness of this research to gain current feedback from young people experiencing Te Awa.

While educating and using Te Awa with young people I too have reflected on various aspects of the tool and incorporated changes, such as the palliative care phase as discussed earlier. However, I have also incorporated whare/houses or pit stops along the river where we engage in holistic conversations to assess how things are going for them and if any extra supports or interventions need to be put in place.

Positioning myself

Positioning myself as the nurse

I am employed as the key worker coordinating care for adolescents and young adults diagnosed with cancer within four district health boards in New Zealand. I have had this role since its inception by the Ministry of Health in 2007. During my eleven years of supporting 12-24 year-olds with cancer I have been a representative on the AYA Cancer Service Governance Board and am currently on the AYA Cancer Network Aotearoa Governance Group. Also, I am a new member of the local Cancer Society Governance Board. Prior to working in adult oncology services I nursed within a paediatric surgical and oncology ward, with the added role of 'Shared Care Nurse' where I supported children and young people aged 0 – 16 years of age, and their whānau (family). I coordinated their care in partnership with the tertiary paediatric hospital, organising chemotherapy treatment, local outpatient clinics, certifying fellow colleagues on chemotherapy administration and providing them with education regarding care for the acutely unwell child/young person with cancer.

While working in the paediatric ward I volunteered as a nurse for Camp Quality, which holds summer and winter camps for 5-16 year-olds with cancer. I have continued to volunteer for 19 years and have also volunteered for CanTeen which supports 13-24 year-olds with cancer since starting in my key worker role. During my nursing career I have had the honour of hearing patients and families stories of how a cancer diagnosis has impacted their lives - physically, emotionally, socially and as a whānau (family). The power of young people's stories, lead my imagination down the twists and turns of their experiences, like a river or 'awa' as known in (Te reo) Māori language.

Positioning myself as the educator

Because of the correlation I saw between this metaphor and young people's experiences, I began to use it to educate adolescents and young adults about the impact a cancer diagnosis can have on them. I then used this river metaphor to educate my fellow nursing colleagues during paediatric oncology study days, to teach them about the strain a cancer journey can have financially, physically, emotionally and spiritually on a young person and their whānau. From there I was encouraged to present Te Awa at the 2011 Psychosocial Oncology Conference in Hamilton. Prior to presenting, I sought guidance from a colleague who suggested a term to describe the discussions I was having with young people I nursed as 'metaphorical conversations'. This was an unfamiliar term, so I was motivated to conduct a literature search to review whether there was anything similar already being used in practice. The process was enlightening and humbling to learn I had innately been using metaphor, which historically has been incorporated in both the health field and Te Ao Māori (the Māori world) for many years.

Positioning myself as the researcher

I started my post-graduate education pathway by completing a child health certificate through Waikato Institute of Technology (Wintec), followed by a post-graduate diploma commenced one year into my current role. The feedback I received from young people, their whānau and colleagues about Te Awa over the years has resulted in me needing to conduct this research; I wanted to formally learn what young people's experiences were of using the metaphorical tool Te Awa while facing a cancer diagnosis and treatment. I am positioned in this dissertation as the researcher who developed Te Awa as I work towards achieving my Master's in Nursing at Waikato Institute of Technology.

Structure of dissertation

This chapter introduced the context of this study, being, the experience of cancer for young people, the use of metaphor and introduction of the research question. Finally, this chapter positioned the researcher also as the nurse who developed and disseminated the model. Chapter Two explores the literature pertaining to the origin of metaphor, the general use of metaphor, the general use of metaphor in health care and then more specifically literature pertaining to young people diagnosed with cancer. Chapter Three outlines the general methodology and methods used in this thesis. It explains a narrative approach and the data collection methods used. The research participants and the process for thematic analysis of the data are described. Chapter Four presents the research findings, presented within two key themes: *Assistance* ***'of'*** *Te Awa* and *Assistance* ***'to'*** *Te Awa*. Within these themes there are several sub themes. The two key themes are described first, followed by a discussion of the specific sub themes which emerged. Chapter Five discusses the research findings in correlation to the literature. Chapter Six finally concludes the dissertation with the the strengths and limitations of the study, implications for practice, and recommendations for further research and for health professionals.

Chapter Two: Literature Review

Do metaphorical conversations assist young people to traverse their cancer journey?

This chapter explores literature related to the use of metaphor, in health care and specifically any used by or with young people throughout a cancer journey. Holge-Hazelton (2011) suggests young people traversing a cancer journey are regarded as an emerging field for research. This may explain why literature relating to young people's experiences using metaphorical conversations to traverse cancer journeys is noticeably limited here in New Zealand and worldwide. However, there are large quantities of literature relating to the numerous aspects of metaphorical conversations for the 'general population' when receiving cancer care and treatment (Woodgate & Busolo, 2017).

The first section of the literature review looks broadly at what metaphor is, and identifies the various disciplines and cultural contexts in which metaphors are used. The next section highlights metaphors used in health, the positives, the negatives and whether its use is best initiated by clinician or patient. The third section delves more intricately into specific cancer metaphors, with the final section of this review revealing literature discussing cancer metaphors and young people.

Metaphor

The word 'Metaphor' originates from the Greek root 'metapheiren' (Czechmeister, 1994; Arroliga, Newman and Longworth, 2002). Arroliga et al. define metaphor to mean 'willing to transfer' while Rosenman's (2008) definition is 'transfer' and Laranjeira's (2013) is to 'carry over/across'. Czechmeister defines the complexities of describing the emotions of illness as being 'beyond words', coincidentally for her the word 'metaphor' means 'going beyond' in Greek (p.1232). Throughout history there has been great debate regarding the usefulness of metaphor, some state it is only required to pretty up languages (Ortony, 1975), while others regard it as a pivotal aspect of everyday communication and understanding (Arroliga et al., 2002; Lakoff & Johnson, 2003; Southall, 2012; Yu, 2012).

The Merriam-Webster dictionary (n.d.) describes metaphor as "a figure of speech in which a word or phrase literally denotes one kind of object or idea being used in place of another to suggest a likeness or analogy between them”. For example, the word ‘cancer’ itself is a metaphor meaning ‘crab’ in Latin and in health, this metaphor helps to visually demonstrate the intrusiveness of the ‘actual’ disease (Penson, Schapira, Daniels, Chabner & Lynch, 2004). Like the behaviour of a crab within its environment cancer slowly deteriorates the lives of people and bodies (Skott, 2002). Nicholas (2013) simply says metaphors are the building blocks for literature when trying to describe how A is B.

Nevertheless, Nicholas (2013) goes on to state, in agreeance with Lakoff and Johnson (2003), the ‘A is B’ definition does not describe the importance of metaphors in assisting people to understand their surroundings. Metaphors are used to assist a person to understand something they have never previously experienced by using an example of something they have experienced (Arroliga et al., 2002; Skott, 2002; Stott, Mansell, Salkovskis, Levender and Cartwright-Hatton, 2010). Therefore, metaphors are used to increase understanding (Scherer, Scherer, & Fagerlin, 2014). Lakoff and Johnson’s seminal work, *Metaphors We Live By* adds purpose to metaphors’ in regards to assisting expression of emotion, as well as understanding.

‘Hope’ and ‘positivity’ are emotions Reisfield and Wilson (2004) found prominently used in adult cancer, unlike Mooney-Somers, Lewis and Kerridge (2015) who found ‘hope’ along with ‘optimism’ featured less when discussing cancer with healthy young people. This is in opposition to young people diagnosed with cancer, whose advice for health professionals is to “follow their lead, and adopt an attitude of hope, where the hope is no longer focused on cure but on other wishes” (Wiener, Weaver, Bell & Sansom-Daly, 2015, p. 9).

Additionally, Chan (2011) and Nicholas (2013) state metaphors are essential elements to express and to communicate and Arroliga et al. (2002) agree voicing metaphors support communication. Metaphors are variations of tropes; tropes assist meaning and understanding of the topic being discussed (Berendt, 2008). According to the literature there are many types of metaphor, such as conceptual, extended, primary and complex (Kovecses, 2010, Nordquist, 2018).

Historically, metaphors helped humans to make sense of things which at first were not understood (Nicholas, 2013). For example, weather was understood as gods expressing how they felt about things mankind were doing. However, the use of this metaphor has been made redundant as science has provided scientific reasons for how and why weather patterns occur. But this is not the case with cancer, excluding a few environmental factors, humans still remain uncertain of cancer’s root cause (Nicholas).

Metaphors have been used for thousands of years within numerous disciplines; the humanities: religion (Costello, 1993) and philosophy (Yu, 2003 & Rosenblatt, 2008); the arts: plays (Shakespeare Online, 2018), poems (Rosenman, 2008); music, literature (Steen, 2009), language and history (Moje, Luke, Davies & Street, 2009) with the seeds sown by Aristotle (Ortony, 1993; Woodgate & Busolo, 2017). Metaphors have also long been woven into politics (Mio, Riggio, Levin & Reese, 2005; Thibodeau & Boroditsky, 2013) and education (McCandless, 2012), and have played a fundamental part in shaping how we make sense of many things today (Yu, 2012).

Over the ages, metaphors have been woven intrinsically through cultures. For example, Chan (2011) argues that a diverse ethnic cohort of people can understand some of the same metaphors, while Rosenblatt (2008) says some metaphors can only be understood if people have shared a similar background. Stott et al. (2010) agree, stating when working with other cultures the meaning of metaphors can be lost in translation, so it would be best to study, comprehend, and accustom one-self to the culturally based metaphors they use. Kangas, Warren and Byrne (1998) also argue that metaphors can be lost travelling from one culture to another. For example, Panoho (1995) describes how Māori use the metaphor of the harakeke (flax plant) when referring to cultural sustainability; if one does not understand how the outer leaves affect the inner leaves they won’t understand the full meaning of the metaphor.

Skott (2002) however suggests metaphors can be shared between cultures, and Stott et al. (2010) states it just depends on how relatable the metaphor is. For example, the relatable metaphor of a ‘house’ is used in the conceptual framework ‘Te Whare Tapa Whā’, developed by Mason Durie, post Rapuora research findings, highlighting barriers within health for Māori (Tāne Ora Alliance, 2018). Each of the four walls represent various dimensions of health; Taha Tinana (Physical health), Taha Wairua (Spiritual health), Taha Hinengaro (mental health) and Taha Whānau (family health). It is widely used between various ‘cultures’ within New Zealand such as; health services (Ministry of Health, 18 May 2017), social services (Ministry of Social Development, 2009), education services (Edgecombe & Bennett, 2003) and career services (CareersNZ, 11 Sep 2018).

Cultures can also incorporate their own metaphors, whether they are dominant cultures or sub-cultures within a dominant culture, for example a dominant culture being the ‘general health field’ and sub-cultures within this being ‘cardiac’, ‘renal’ and ‘cancer’ health care. The ‘cancer’ sub-culture may also have their own metaphors woven within their foundations. Even within the cancer sub-culture, there are sub-cultures such as ‘paediatric, young people and adult cancer care’. People going through a cancer diagnosis can find themselves having metaphors thrust upon them like ‘stay strong’, ‘keep fighting’, ‘be positive’ (Frank, 2012; Perusek, 2012).

Metaphors in Health

In numerous areas of the health arena there has been a time and place for metaphor. Metaphors have found their way into medicine, nursing and allied health. For example; psychology (Landau, Zhong & Swanson, 2017), cognitive behavioural therapy (Stott et al. 2010), counselling (Lyddon, Clay & Sparks, 2001), mental health (Rosenman, 2008), neonatology, paediatrics (Hodgkin, 1985; Penson et al, 2004), gerontology, and oncology (Appleton & Flynn, 2014; Harrington, 2012).

The literature highlights how long metaphors have been associated with health, for example in 1398 “consumption” was the metaphorical word John of Trevisa gave to tuberculosis (Sontag, 1989), and this metaphor persisted into the late 1800s and early 1900s. Sontag demonstrated numerous examples of health metaphors throughout the ages, the most prominent being tuberculosis, cancer and later AIDS. Sontag advised not to use metaphors alongside illness, as she believed it can portray negative connotations about the disease and prevent people from seeking timely medical advice.

There are hundreds of metaphors used in health to help the person understand and make sense of specific illnesses, treatments and pathways. For example, to explain how treatments work the term magic bullets or Pac Man metaphor can be used (Penson et al, 2004). Treatment pathways can be described using the metaphor of a journey or roller coaster, while the sports team metaphor can be used to increase patients understanding of how the medical team is part of their health team (Campbell, 2011). Penson et al argue the team metaphor is more useful when working with young people, children and parents as this metaphor highlights working together.

In medicine there is an extensive history of the military metaphor, as defined by Hodgkin (1985, p.1820) “medicine is war”. The military metaphor has dominated for many years, as Penson et al. (2004) states in 1627 John Donne used war to voice experiences of his ill health. According to Wurzbach (1999) in the late 18th century the military metaphor would become the foundation to the structure and organisation of nursing i.e. nurses had ‘ranks’, wore uniforms and took ‘orders’. Politically, in the United States of America (USA), this metaphor was adopted in 1971 when President Nixon signed the National Cancer Act; this was viewed as the start of war on cancer and the momentum avalanched from there (National Institutes of Health, 1997; Hanahan, 2013).

Teucher’s (2000) doctoral thesis found hundreds of autobiographical titles declaring their martial stance on cancer. Leading on from the military metaphor Hodgkin (1985) and Penson et al. (2004) found in some health fields such as geriatrics, psychiatry and paediatrics the ‘fight’ metaphor was not helpful at all. In paediatrics, children are developmentally still concrete thinkers and when told to fight they literally start kicking and punching. Even for adults – both patient and health professional, the ‘fight’ metaphor can be confusing as there are different versions of ‘fight’ and each person has to be clear about what the other person’s version is. ‘Clearly fight all the way’ or ‘fight to die with dignity’ have different meanings. Penson et al. highlights the need to re-check the definition of the metaphor being used when the treatment goals change for patients, as shown in a study of cancer narratives used by five palliative patients. Keim-Malpass, Adelstein and Kavalieratos (2015, p.210) also found palliative cancer patients’ metaphors can change as they move physically and psychologically along the cancer continuum. For example, one patient initially used “fight” and “battle” metaphors but as she became accepting of the change in her prognosis, so too did her metaphors change.

While reviewing the literature a Japanese health metaphor was found called ‘The Kawa Model’, with similarities to Te Awa, not only with the meaning of the name as kawa means river in Japanese, but aspects of its intent. It was developed by a group of occupational therapists, educators and students in Western Japan who had taken two years to develop the model and establish it (Iwama, n.d.). The Kawa model uses a river metaphor as a medium to translate subjective views of self, life, wellbeing and the meanings of occupations (http://kawamodel.com/).

Te Awa and Kawa Model share similarities, they both use the metaphor of a river as the mode to discuss key issues for the patient. Both are free frameworks to assist health professionals to work with patients and their creators are keen for people to use them. Te Awa and Kawa Model share a similarity regarding ‘rocks’ in the river symbolising difficulties however Kawa talks about removing obstacles or decreasing issues by breaking the rocks, while Te Awa talks about climbing over or navigating around rocks. Both models look at the patient’s environmental, social, psychological, physical and financial issues.

There are differences between these two tools; the Kawa Model's river represents a person's life ascertaining changes needing to be made to improve wellbeing from birth to death, while Te Awa the river represents a person's cancer diagnosis from pre-diagnosis to survivorship or palliation, ascertaining how to navigate the smoothest current. For the Kawa Model, upstream represents the past and downstream the future. In comparison to Te Awa the stretch of river prior to the waterfall represents signs and symptoms of the cancer emerging, the waterfall symbolising learning of the cancer diagnosis and downstream how to navigate the complexities of cancer. The walls and base of Kawa's river depicts the patient's environment and driftwood is the patient's values, personality and personal resources. While the spaces between the rocks and driftwood represent the patient's overall satisfaction with life; the more spaces the more wellbeing a person feels.

The flow of the river for Te Awa depicts the emotion or psychological wellbeing of the person, for example if the patient voiced their river was flowing smoothly it would be understood that things are going well, however, if they voiced they were hitting the rapids an obvious issue is at hand. Rocks, caves and whirlpools also denote issues, while rays of sunshine or smooth currents highlight periods of calm. Fish represent social supports. Kawa Model assists occupational therapists to gain pertinent information and understanding of what the current issues are for a patient. Te Awa assists discussion and understanding of current issues for patients, while also being able to deal with potential up and coming issues. The occupational therapist and patient draw the river together using the Kawa model, Te Awa is mostly a verbal exercise. Yet, drawing the river has been part of the strategy for some young people.

Impact of using metaphors in health

Over the decades there has been ongoing debate regarding the beneficial use of metaphor. There has been extensive literature regarding how metaphors have contributed positively and/or negatively to communication and understanding in health. The rationale for using metaphor is to find that common language which will strengthen the patient-health professional bond, reassuring the patient that they are an active part of the team. Metaphors offer all parties involved the ability to connect and simplify a journey that can be extremely complicated; they can also help shine a light on aspects that people are having trouble coming to grips with understanding (Penson et al., 2004). Toombs (1993) agrees with this but argues there is a risk to the ability of the patient to understand if their doctor does not share a common language. This is illustrated in the research Arroliga et al. (2002) conducted with twenty-two pulmonary and critical care health professionals; ten staff expressed communication improved when using metaphor, while one staff member thought it confusing for patients. It is clear that “metaphors can have different meanings for different people, or even different meanings for the same person at different times.” (Teucher, 2003, p.13). Nevertheless, Reisfield and Wilson (2004) insist, “No metaphor is inherently good or bad…Each has its strengths and weaknesses” (p.4027).

Metaphors can be counterproductive, for example the ‘Pac Man’ metaphor encourages the patient to boost their immunity through visualisation, by imagining the cancer cells being gobbled up by the white cells. However, if the patient’s health worsens they can be left feeling doubly responsible for not ‘fighting’ hard enough and not boosting their immunity well enough (Penson et al., 2004). Casarett et al. (2010) and Czechmeister (1994) also highlights metaphors can add meaning and aide understanding however they do not convey facts which they argue can give false hope and obscure information.

Scherer et al.’s (2014) research found using metaphors helped describe health conditions such as the flu virus, which assisted decision-making, enhanced participation with medical interventions and was cost effective. A cross-sectional observation study of ninety-four patients and fifty-two doctors conducted by Casarett et al. (2010) found doctor’s communication skills improved when using metaphors, doctor’s ensured patient’s understood discussions and patients also reported increased understanding.

The literature also shows discrepancies around whether metaphors are best coming from the patient or the health professional (Semino et al., 2017, Woodgate & Busolo, 2017). As stated earlier, metaphors can become part of a common language, which simplifies the journey (Penson et al., 2004; Toombs, 1993). Penson et al., stressed that the metaphor the patient likes is best because it will strengthen communication and alliance and it is not unusual for patients to exchange the clinician’s metaphor for their own. This should be supported as it “already has the client’s attention…represents the client’s attempts to make sense…[and] may reveal important meanings…” (Stott et al., 2010, p.45). Periyakoil (2008) explains that when working with ‘patient initiated metaphors’ there is a ‘basic response’ which involves ‘naming, mirroring, validating and exploring’ their metaphor, and an ‘advance response’ where the clinician uses the patients metaphor to add to and redirect decision making. The latter requires greater communication skills.

There can also be issues if a patient brings a metaphor into the therapeutic relationship such as football for example that the health professional doesn’t understand and this gap in knowledge can stress communication lines. Alternatively, if the health professional tries to use a metaphor the patient doesn't relate to, it too can impact on the communication. Both parties need a common understanding behind the metaphors used or they risk not having the same understanding (Penson et al., 2004). In contrast, when both parties can understand the metaphor being used such as "beat it", but either of them feels uncomfortable working with it, then a mismatch can still occur. When this happens Penson et al. assert that there is a professional obligation to find common ground. There are two main uses for clinician-initiated metaphors, the first when introducing something unfamiliar, and the second when attempting to change former perceptions (Periyakoil, 2008).

Metaphors can assist patients to talk more openly about difficult and sensitive topics, as metaphor can create distance between the topic of discussion and what is happening in reality (Southall, 2012). For example, a central venous line infection that delays chemotherapy can be described using Te Awa as 'hitting a rock', or experiencing psychological difficulties as 'heading into a cave'.

Metaphors relating to cancer experience

According to Laranjeira (2013) metaphors can bridge gaps between the cancer experience and coming to grips with technology and treatment. Nicholas (2013) states there are six types of cancer metaphors, the first being combat, such as fight/military, which is deeply ingrained and almost innate for medical professionals. The second refers to human personality metaphors such as 'cancer is naughty', which has negative connotations. There are physical incarnation metaphors such as 'living in negative environments' or 'lifestyle choices'. Examples might be 'he lived near a power station' or 'he smoked' which also have negative connotations because they appear to blame the person for their condition. Another type of metaphor which has negative connotations, are the conspiracy metaphors such as 'just a money making scheme for drug companies'. Finally Nicholas (p.609) cites a more technical type of metaphor used by researchers; teleologic metaphors which are foreign to nature and imply for example, cancer working towards a goal by "acquiring resistance". While Nicholas cites six metaphors used to talk about cancer, Periyakoil (2008) found three dominant cancer metaphors which were war, sports and machine. An interdisciplinary and cross-cultural doctoral thesis (Teucher, 2000) on the importance of metaphors in cancer found eight hundred and ninety four individual descriptions for cancer. His study interviewed people eighteen years and older, so represents some of the cohort of interest to this thesis. However, the study was undertaken from a northern hemisphere perspective and did not represent a New Zealand context. Nevertheless, the study overall found metaphors helped a person to contextualise an experience. Teucher found that for one patient 'a metaphor' can be helpful and beneficial but for others that ‘same metaphor’ may be negative and distressing. A hypothesis which questioned whether genders have ‘specific metaphors’ was not substantiated.

As this review has shown there are vast amounts of literature reporting the various aspects of metaphor use in the general health field, as well as the adult cancer health field. Positively, for young people there has been a huge surge of literature in the last few decades, reporting on almost every angle of the cancer journey covering; treatment (Spraker-Perlman, Smits-Seeman, Li & Kirchhoff, 2018), side effects (Rugbjerg & Olsen, 2018), psychosocial issues (Leuteritz et al., 2018), education (Warner et al., 2016), developmental stages (Wiener et al., 2015), effect on fertility (Lindsay, 2017; Roche, Mazanec, Boebel Toly & Pateva, 2018), and relationship concerns (Mobley, Foster & Terry, 2018). Yet, there is limited documentation regarding metaphors specifically involving young people making sense of their cancer experience (Woodgate & Busolo, 2017), this may be due to young people’s cancer being the ‘latest trend’ in the health field (Thomas, Albritton & Ferrari, 2010). Health professionals voice young people’s cancer as the last ‘cancer lands’ to be pioneered in what has been ironically named metaphorically as ‘no man’s land’ (Hollis & Morgan, 2001; MacFarlane, 2010; National Cancer Institute, 2018). There were a number of articles found using metaphor with young people, predominantly when it comes to education (Lahelma, 2009), communication and decision making. Within health there is a reduced amount of literature using metaphor within this age group, and what exists is mainly found in psychology (Woodgate & Busolo), sexual health and education (Undie, Crichton & Zulu, 2007), mental health, and occupational health, where metaphor can assist therapeutic communication (Fazio, 1992).

Naar-King and Suarez (2011) point out metaphors and similes are a powerful way to get information and messages across to young people. Only five pieces of research were found, and included as they specifically discussed ‘young people, cancer and metaphor.’ Within this literature, two items discussed healthy young people’s perceptions of cancer and the remaining three actually involved young people with a cancer diagnosis. I will firstly give an overview of the healthy young people’s perceptions, followed by those who had a cancer diagnosis.

The research with healthy young people’s cancer perceptions (Mooney-Somers et al., 2015) involved three Australian high school drama classes, using creative activities and focus group discussions to generate data. The two overarching themes shared by the groups were, ‘youth cancer is an inescapable slope to demise’ and ‘cancer leaves their peer a ‘cancer victim’. The metaphors used to describe the physical effects were ‘thin, pale and fragile’ and cancer described as ‘doomed thing’ which left the young person ‘completely broken’ (p. 430), as well as the well-known battle metaphor ‘fight’ (p.431). The findings are deemed important for young people who have had cancer to know, as it can assist them when socially integrating to be aware of the cancer constructs their peers may have. The second research (Woodgate & Busolo, 2017) involved the perspectives of seventy-five healthy high school aged Canadians. Four metaphors emerged; ‘loss, military, living thing and faith’ and were influenced by their families’ experiences with cancer and social media. Overall this study recommended that care needs to be taken when communicating cancer messages to youth in the public and healthcare arenas.

Research involving young people who have had cancer came from Penson et al. (2004) who highlighted that the team metaphor is beneficial when working with young people, children and parents as it highlights working together. An example is the team having a ‘game plan’; a ‘treatment plan’ which all members have agreed with. Penson et al. caution that if a cure is no longer achievable, the child/young person and or their family can be left feeling they did not try hard enough. A second article (Subbiah, 2012) insists that communication is the key to keeping the doctor-patient relationship intact, and one way is having metaphorical cancer conversations using “movie therapy”. This reflective narration gives anecdotal evidence of how effective communication can be with young people when using media forms. Unfortunately there is currently no scientific base to this and the findings have not been replicated, trialled or tested for validity. Love et al. (2012) conducted a ‘content analysis’, with the initial purpose to assess how young people’s psychosocial needs were met by their fellow online community. A substantial three hundred and fifty posts were analysed but cultural affiliations by ethnicity or geographical location were not identified. Apart from saying the forum was ‘open to any young adult affected by cancer across the cancer continuum’ a definition of what the age range was for a ‘young adult’ was not identified. Also, consent was not gained from the participants, but approval for the research was gained from the Institutional Review Board and managers. The study found the online community provided a forum for young people to share supports they found of value, an outlet to express emotions, develop a sense of connection with others who had similar experiences and continued to have similar experiences such as coping with life after cancer. Finally, the investigation found young people used metaphors to talk about themselves and their experiences of cancer.

Summary

The findings from this literature review have many implications for clinical practice. The health professional–patient relationship can be enhanced if there is an awareness of the fitting language for a young person using metaphor during their cancer treatment. Appropriate language can improve communication, understanding and also decision making. Communication in health situations can be a complicated process, but so too is comprehending metaphors, and interpreting the various contexts they could be used in, especially from one patient to another. However, the health profession must remember that there can also be negative effects of using metaphors for example, misinterpretations. The key requirement to reduce misinterpretation is for health professionals to be educated on the use of metaphorical conversations. Further research on this is required to ensure an evidence base underpinning this approach. Evidence remains a core element of nursing and a practicable way to improve health outcomes and provide quality health care. There is currently a lack of research regarding young people with cancer's use of metaphorical conversations (Woodgate & Busolo, 2017) therefore it is timely and appropriate for this research to be conducted.

Chapter Three: Methodology

Introduction

This research set out to explore and analyse the ways in which the metaphorical conversation Te Awa assists young people to traverse their cancer journey. Te Awa was developed to help young cancer patients make sense of something they had never personally experienced – cancer. In essence it is a therapeutic conversation tool with a basic storyline, a common natural water feature, a river that most young people would be familiar with. It was developed with dual intent to support and enhance young people's understanding, while providing them with a language to verbalise their cancer treatment experiences. Te Awa has been utilised for over nine years, therefore it is time to critique, reflect and potentially enhance this tool by listening to research participants. As Skott (2002, p. 230) states "much of our knowledge about sickness is gathered through verbally conveyed stories. The intention of the teller is often to relate the story in a manner that stimulates a meaningful response and understanding from the listener", it is time to listen to young cancer patients' stories.

The research was designed to answer the question 'How does the metaphorical conversation Te Awa assist young people to traverse their cancer journey?' and the design and methodology are presented in this chapter. Ethical considerations are discussed, particularly in relation to the issues faced when recruiting young people as research participants; and for whom the researcher is also their support nurse. A description of the sampling criteria and participant characteristics are provided.

The metaphorical conversation Te Awa was developed by the researcher, while in the role of the Adolescent and Young Adult Cancer Service key worker. The primary aim of the research was to explore and analyse if, and how Te Awa assists young people to traverse their cancer journey. The secondary aims were to enhance the metaphorical tool by incorporating changes/feedback from participants and inform health professionals who work with young people of the research outcomes to enhance their practice when working with young people. The objectives of the research were to interview a group of young people who have been diagnosed with cancer and met the inclusion criteria, to describe their experiences and perceptions of utilising Te Awa.

Research Design

Burns and Grove (2003, p.3) report that ‘research’ means “to search again” or “to examine carefully”. The Cambridge Dictionary (2016) defines ‘research’ as studying something in-depth so that new information and/or knowledge are generated. Tuhiwai (1999) adds that “research is important because it is the process for knowledge production; it is the way we constantly expand knowledge” (p. 214). Research is an integral component of nursing. The new knowledge that nursing research produces assists in enhancing best nursing practice, education, health policy, and adds to the body of nursing knowledge (Burns & Grove, 2003; Roberts & Taylor, 2002). Knowledge in relation to using metaphorical conversations to support young people experiencing a cancer journey is currently extremely limited (Woodgate & Busolo, 2017). An initial literature review found sparse information regarding how young people with cancer use metaphors during their health journey. This research endeavours to expand understanding around this unique area of practice.

All research approaches can, and do, potentially increase nursing knowledge. Whilst a positivist approach is concise and objective, an interpretive approach focuses on broad, subjective and holistic topics (Burns & Grove, 2003). Streubert and Carpenter (2011) propose that to have a better understanding of health for people, both approaches are required. For this research, an interpretive approach can be justified by trying to understand the meaning Te Awa has had for young people through their experiences of cancer.

Qualitative research

Qualitative research seeks viewpoints, personal feelings, and experiences from its participants (Burns & Grove, 2003; Green, 2000; Streubert & Carpenter, 2011). As Holloway (2005) contends, such research is pertinent to understanding emotions, perceptions and actions of people who undergo a medical condition. “‘Understanding is what interests’ qualitative researchers, ‘not prediction’” (Pinnegar & Daynes, 2007, p. 4). Munhall (2007) informs nurses taking up research that qualitative methods are “known for giving voice to people, hearing people’s own personal narrative and using the language of our participants in research” (p. 4). A qualitative approach was chosen for this research as it values and is interested in (young) people’s voices being heard. The research wants to understand their experiences of using Te Awa by listening and collating their stories through the language they use.

Narrative

Narrative is one of the many methodologies that fit under the umbrella of qualitative or interpretive research (Duffy, 2007; Wang & Geale, 2015). Narrative uses stories of people’s experiences as data; these stories can be told by participants themselves or by others. As

DePoy and Gitlin (2016, p.166) express “The storytelling may be autobiographical, biographical, testimonial or in another form”. Most methodologies utilising narrative inquiry involve a ‘process and a product’ (Kramp, 2004). The process requires the narrator to tell an experience, which in turn produces a product – the story told. Narrative methodology is much more than just informing the reader of an experience had by one person, it tells us a number of elements that are internally and externally at play during the act of storytelling. Narrative reveals meanings that experiences have had for people (Wang & Geale, 2015). The storyteller can relay the sequence of events, people involved, time and place differently depending on the audience at hand. According to Birch they can tell and retell their stories in different ways to emphasise different parts depending on the audience (L. J. Birch, personal communication, June 13, 2017). For example, what a young person tells their friend about cancer treatment side effects can be very different to when they talk to a health professional. Hence, the objective truth of the story may then be questioned. While this concerns some researchers, others are more interested in the subjective truth; the meaning an experience holds for the individual (Wang & Geale, 2015). ‘Truth’ fluctuates in storytelling, as it is dependent on ‘memory’ and ‘experience’; perceptions can change over time (Bochner & Riggs, 2014). This research is interested in the various subjective truths of the participants, as the purpose is to seek the young people’s meanings of their experiences of using Te Awa through the use of narrative research.

There are a number of terms for narrative methodology used in the literature, which can be confusing for the beginning researcher, for example ‘narrative methodology’, ‘narrative research’ and ‘narrative inquiry’. The latter two, according to Clandin (2007) “are used almost interchangeably” (p. xiii). Similarly, Taylor (2002), Feldman, Skoldberg, Brown and Horner (2004), and Duffy (2007) found the words ‘narrative’ and ‘story’ were used interchangeably by researchers. Riley and Hawe (2005) agree but also note ‘they are analytically different in regard to where the primary data ends and the analysis of the data begins’ (p. 227); the meaning/voice needs to be drawn out of the story by the researcher. Likewise, Frank (2010) says narratives arise by the analysis of stories people tell. In this research, the term ‘story’ has been used as it fits best from the researcher’s perspective; this being a Māori worldview and the term is also young people friendly.

Stories

Story derive from humans; we use it to describe the meanings that events and experiences have for a person or people. Bochner and Riggs (2014, p.202) suggest “stories are social performances” as “storytelling is a relational activity” which involves a teller and a listener, a performer and an audience (Riessman, 2000). Bell (2006, p.69) explains, “The sharing of stories helps us to know where we have come from and to understand who we are”. Storying can also help people gain understanding and assist them to make sense by attaching meanings to their experiences (Bochner & Riggs; Brunner, 1990; Duffy, 2007). The meanings storytellers construct are used to inform, warn, guide and share through experiences a person has had. Bochner and Riggs voice “whether we like it or not, our lives are rooted in narratives and narrative practices” (p. 196). Similarly, Victor (2009) explains her personal views on the value of being able to engage with story:

> …reading others’ stories allows you to enter their life and understand their life experiences and viewpoints. It is through the written and spoken word that you can transcend your own experience to understand someone else’s. Through stories, you learn how others differ from you but also how they are the same - sharing similar feelings, beliefs, and attitudes. People want to listen to others’ stories - are they similar to their own story, are they different, are they different but the same? ... (p. 172).

Toma, Bacioiu, Dascalu and Trausan-Matu (2018) found storytelling to be a powerful tool in the education arena to assist teachers and students with difficult subjects, and in the health arena Talley (2016, p. 116) states it is “a powerful health communication tool”. For example, facilitating paediatric oncology nursing education days with complex topics taught throughout the day, the most robust feedback nurses gave, and rated the most valuable learning, was listening to the patient and their whānau (family) share their story. I believe this is because nurses are hearing firsthand what the person and their whānau had to endure, hearing their truths and experiences. Bochner and Riggs (2014) point out, “we depend on stories almost as much as we depend on the air we breathe. Air keeps us alive; stories give meaning to our lives, they become our equipment for living.” (p. 196).

Brunner (1990) says we make sense of our experiences by creating stories of our lives and selves in a particular sequence in which it occurs, and also argues that we seek understanding of the unexpected by creating stories. In turn, “we live our lives according to the stories we tell ourselves and are told by others” (Portnoy, Girling & Fredman, 2016, p.4). This can be extremely powerful for young people traversing cancer journeys, as DePoy and Gitlin (2016) acknowledge the powerful link between story and healing. Through storying young people have the opportunity to reflect and learn from their own experiences and the experiences and stories shared by other cancer patients. With this combined knowledge, it could enable the young people to ready themselves for what may lie ahead, for example by enhancing decision making and being better prepared psychologically for side effects.

Purakau (story) in Māori culture

Prior to colonisation Māori were an oral people, therefore such things as historical events, legends and genealogy would be passed down to each generation via metaphorical conversations in the way of purakau (stories) and whakatauki (proverbs) (McRae, 2000). Māori were learned people, in touch with their surroundings and the natural world. They navigated the oceans, trading with other cultures and sourcing ample fish and planting bountiful crops, all achieved through the ability to read the stars (Best, 1959).

Through whaikorero (formal speech making) articulation of metaphor and narrative was mastered and art used to relay messages and to educate (Salmond, 1990). The ability to recount genealogical ties through whakapapa was, and is, a specific skill and considered a gift to be able to memorise such vast amounts of detail (Best, 1959). It was noted by Best that early European settlers found this skill incomprehensible.

Māori also incorporated stories into Moteatea (traditional songs) and waiata oriori (lullabies) and were able to conjure up images and build understanding and pass down cultural knowledge (Benton, 2006; Jenkins, Harte, & Ririki, 2011). Benton also states historical accounts and transfer of knowledge were captured using visual imagery/symbolism such as artwork on and within Marae (meeting house), in the form of kowhaiwhai (weaved panels) and intricate carvings. Even the tokotoko (walking stick) relays stories such as legends or genealogical connections (J. Lambert, personal communication, 23 June, 2016). It can also signify the person holding it has mana (authority) to speak (Smith & Smith, 2007).

Method

Managing multiple positions of the researcher

As already stated, in this research I occupied several roles in relation to this research as the researcher, the key worker supporting the young person during their treatment, and the health professional who developed the metaphorical tool Te Awa being discussed by the participants. The multi-positioning I held in this research both served and limited me. I was privy to hearing firsthand what participants found of value and what worked for them. However other times there were challenges when hearing that other metaphors worked best for some participants.

Researchers can uncover the meanings health professionals give to their work by observing their interaction with clients and assessing their experiences (Holloway, 2005). Prior to the research I had already observed and participated in patients' responses as they occurred naturally while in the key worker role when the metaphor was first introduced making me an ‘insider’. The intent of this research assisted discovery of experiences and meanings the young people developed when using Te Awa during the interview while being the researcher and therefore positioned more as an ‘outsider’. I was also invested in the research as the health professional that created the tool being reviewed. The research process allowed me to further reflect on the experiences shared by the participants during the process of interviewing, transcribing and analysing.

Occupying each position could mean that I would lose the ability to see things from other perspectives and be selective in the details that I attended to. In order to ensure that I was open to a range of responses from the participants I needed to ensure that I remained reflexive. One way to be reflexive during the research process is to keep a study journal (Arber, 2006). I did this by recording my reflections via a dictaphone; this helped me to record what I was thinking and my emotional responses during the interview. As part of the reflexive process I tried to consider each role separately and how I might be viewing the research from each position.

The researcher as nurse

It is important to acknowledge that there are significant ethical issues associated with research being undertaken where the researcher has a current nurse-patient relationship with the participants (Nursing Council of New Zealand, 2012). For this research, I was currently or had been the participant’s nurse. This relationship may have impacted the participants’ ability to give honest feedback. Nevertheless, I believed that I had developed an open relationship with the young people during the course of their treatment that would allow them to be honest about their experiences with the metaphorical tool. This was confirmed through the interviews, particularly with one participant who offered constructive criticism about the stage in her journey that I had introduced Te Awa. I felt this critique demonstrated how comfortable and open the participant was with me the researcher and her ability to say what she honestly felt. I also had concerns that the research may have jeopardised the nurse-patient relationship when they attended follow-up due to potentially feeling like they had not performed well enough or not provided vital information. This has not been the case as they still attend their follow-up and are invested in the research asking how the research is progressing.

The researcher - as researcher

The participants may have also have seen me in a position of authority as a researcher and this may have affected what they chose to say, perhaps only saying what they thought I wanted to hear. Alternatively, having developed a rapport with the participants as part of the nurse-patient relationship over a long period of time, there was potential for participants to feel more at ease during the interview and say what they really think (Rice & Ezzy, 1999). Conversely, if I as the researcher knew their cancer experience wasn't positive, having been their support nurse, they or I may not have felt comfortable sharing or seeking their feelings or thoughts on Te Awa.

The researcher as developer of the model Te Awa

This was a challenging and interesting position to be in due to a sense of ownership of the metaphorical tool conflicting with my desire to hear what the young people had experienced while using it. At times it was hard to separate researcher from developer and not take too much to heart or get too excited about various feedback. I worked harder to remember what role I was in during interviewing, as I tried to maintain consistent body language throughout the interviews worried that enthusiasm or lack of enthusiasm might influence the conversation and encourage or discourage the participant from saying things they thought the researcher might or might not like to hear. I was conscious at times of starting to feel excited when hearing the positive comments about Te Awa that participants had experienced, especially learning of outcomes that had not been preconceived as the developer. When hearing about the critiques initially I was let down, but on reflection found these positive as they will assist when introducing Te Awa to other young people. Additionally, what I thought was negative feedback ended up being positive and exciting, as it supported findings in the international literature, such as using the metaphor that aligns with the patient. Receiving formal feedback that the tool was beneficial to a number of the participants, made the investment in developing the tool worthwhile.

In this research, the potential challenges of occupying and managing the roles of the health professional who developed the metaphorical tool, while being the nurse who introduced the tool to the young people, as well as being the researcher conducting the research had numerous ethical considerations. This is considered in more detail below.

Inclusion Criteria

- Have had a cancer diagnosis when aged between 12 – 25 years of age (but are currently older than 16 years of age).
- Were treated in the Regional Cancer Service, DHB.
- Have completed active treatment.
- Are current CanTeen Branch members.
- Have been supported by the Adolescent & Young Adult Cancer Service Clinical Nurse Specialist.

Initially, 20 young people met the inclusion criteria from the adolescent and young adult cancer service database and were identified as potential research participants, and six participants agreed to participate. Due to the scope of the research it was intended that four participants would take part in the research. However, due to a higher than expected response rate in the initial recruitment phase, a decision was made to honour their time and contribution and include all participants in the research either through an interview or through their personal written reflections.

A number of the participants had kept personal diaries through their cancer journey and some examples of these were offered to me to show how they had incorporated Te Awa into their experience, as did the mother of one young person who had passed away. These personal snapshots have contributed to the richness of the data collected regarding the experience of using Te Awa to understand their cancer journey.

To reduce further risk to the participants the inclusion criteria stipulated it was for young people who were off ‘active treatment’ as I did not want to create extra stress for them by being interviewed as well as tolerating and navigating treatment.

Exclusion Criteria

- No participants under the age of 16.
- No participants who were treated on clinical trials.
- No participants who are currently undergoing palliative care will be included.

Young people who were actively still engaged in some type of cancer treatment or intervention – whether it was for cure, prolonging of life, palliation or end of life cares, were excluded from the research. The excerpt of the young person who had passed away was able to be added as she was no longer undergoing palliative care and consent was gained by her mother to add to the data.

Younger adolescents were not recruited to minimise consent issues for minors as per the ‘Consent in child and youth health: information for practitioners’ published by the Ministry of Health (1998) of New Zealand. Older young adults were not recruited, as they would have ‘aged out’ a term coined by CanTeen when a member reaches 25 years of age, no longer a current CanTeen member and therefore not eligible.

Recruitment

For this research only participants who had experienced the tool Te Awa and were aged between 16-24 years were recruited for this research; therefore recruitment was purposeful (Patton, 2002). Young people were recruited via formal networks, a District Health Board’s AYA cancer service and CanTeen, which were intermediaries for this research. All participants had to be treated through a Regional Cancer Centre via one of the District Health Boards. I did not approach participants from outside the chosen District Health Board due to time constraints and the challenges of acquiring ethics approval from the three other district health boards the AYA key worker covers.

The young people’s cancer service works with patients aged twelve to twenty four, however if young people over 24 years are still receiving treatment and/or undergoing follow up they can still remain in the AYA Cancer Service. Potential participants were identified using the adolescent and young adult cancer service database, which is maintained by myself as the AYA Cancer Service Clinical Nurse Specialist.

CanTeen is a New Zealand non-government organisation that supports 13-24 year olds diagnosed with cancer by supporting them and ensuring they do not journey alone. The staff at CanTeen endeavour to help young people with the physical, emotional and practical issues of living with cancer. Their primary principle is to invite young cancer patients to meet, talk and share their experiences with other young people as this can assist them on their cancer journey (CanTeen, n.d., para. 2). A prerequisite to participating in this research was ensuring participants were current members of CanTeen as they could access extra support such as counselling and peer support if required during the research process. This was done by comparing the list of potential participants to the database held by the CanTeen Youth Worker. Ethically, this was an added safeguard for participants in the research as CanTeen have systems in place to facilitate smooth referrals to counsellors as needed.

I approached the CanTeen Branch Youth Worker to discuss the potential opportunity to talk about this research at their next board meeting. It was accepted and put on their agenda. I attended the Canteen Board meeting to introduce the research and gain their buy in. The Board was invited to be involved in the research by encouraging members to consider becoming research participants and allowing access to the branch meeting rooms for interviews if needed. The CanTeen Board accepted the invitation (appendix F).

Although the CanTeen Youth Worker informed me that candidates were more likely to respond/participate if contacted via email, text or Facebook, candidates were first contacted via post. This ensured the potential candidates received all the necessary information to be able to make an informed decision. It also allowed them to share the research information with their significant others to aid in decision-making around becoming a participant. Candidates were sent a cover letter (appendix G) via CanTeen, along with the information sheet (appendix H) and a prepaid self-addressed envelope to return their acceptance form/letter to the researcher. Candidates also had the option to contact the CanTeen youth worker or researcher directly to communicate their response and ask any further questions. A time frame of two weeks was allowed for individuals to respond. Following this period, all of the young people who had agreed to participate were then contacted and interview dates were arranged.

Participant Characteristics

Narrative methodology does not require large numbers of participants to shed light on experiences and their meanings (DePoy & Gitlin, 2016). Six young people aged between 16-24 years of age participated in the research - three young men and three young women. A young woman’s reflection from her diary was also offered for inclusion to this research from her bereaved parents. The participants were from New Zealand and overseas. Those from New Zealand identified as either Māori (indigenous) or Pakeha (European New Zealander) (see appendix L).

The cancer diagnoses among the participants included both oncological and haematological cancers. Each of the young people had undergone one or more types of treatment: surgery, chemotherapy or radiation. At the commencement of the present research, all of the participants had finished treatment, were symptom free, and participating in their recommended follow-up regime.

Data collection

Process

Once participants confirmed their interest in being included in the research, a suitable time and place was arranged to conduct the interview. The interviews were conducted at a location where the participants felt comfortable. Richer data is gained when the interview is conducted in an optimal environment with no interruptions, and which is felt to be safe and comfortable (Taylor, 2002; Wuest, 2007). The time and place for the interviews was negotiated with the participants. They all chose different places; some areas were more conducive to interviewing than others and this may have influenced the quality of the data. Three interviews took place in office spaces within the Regional Cancer Centre which the participants were familiar with and the remaining three took place at the participants' homes. Three of the interviews, two in offices and one in the patients' home included various interruptions. This could potentially have changed the mood and direction of the conversations but did not appear to have an adverse effect. The remaining three interviews were uninterrupted and free from distractions. All of the participants were given the option of having a whānau/family and support person/s of their choice present during the interview. All of the young people chose to be interviewed alone, demonstrating again perhaps the rapport developed between interviewees and myself.

With the participants' permission (see appendix I), the face-to-face interviews were recorded using a digital audio recorder and a back-up recording device to prepare for potential technical issues. The recordings were transcribed verbatim, some by the researcher and some by a qualified transcriber. The decision to use a transcriber was made to save time.

A koha (donation or offering) of $20 was given to each participant after the interview as a token of appreciation for the time and energy they expended to be a part of the research and for sharing their valuable knowledge and experience. They were not informed of this prior to the interview purposefully, as I wanted them to enroll without coercion.

Semi-structured face-to-face interviews

The method used to collect data was semi-structured face to face interviews. As DePoy and Gitlin (2016) suggest interviews assist in hearing the participant's voice while Mishler (1986) sees interviews as a way of empowering the participant's voice. The primary aim of the narrative interview is to gain stories of specific experiences from participants (Rangahau, 2016). At the beginning of the interview, each participant was given time to read over the consent form and information sheet, and informed that their experiences would support further development of the model, Te Awa. This process was essential in order to assist interviewees to feel comfortable to say whatever came to mind throughout the interview. It also helped to reduce the power differential that is often experienced between interviewer and participant during interviews (Gwyn, 1999).

The interviews lasted between 20 and 65 minutes. The researcher asked questions (see appendix J) to prompt the participants to share their experiences of using Te Awa. As each of the young people were at different post treatment stages of their cancer journey, initial conversations within the interview involved reflecting upon/discussing/recapping/re-visiting the Te Awa model in order to assist the participant to recall their personal experience(s). Although the initial questions were formulated, participants were encouraged to speak freely about their experiences. Further questions were asked if more clarification was needed. As the interview progressed, questions were asked to follow the young people's leads. Over time the researcher became more confident in the interviewing process, for example 'awkward silences' were understood as 'time to reflect and collect thoughts' for the participant.

Additional data

One participant provided a sample of their reflective writing rather than participating in an interview. I wanted to include all the young people who volunteered but owing to time constraints was unable to interview them all. Rather than limit the number of young people who wished to participate it was decided that if the participant felt able to provide their reflections in written form this would be a valuable contribution to the richness of the data. I met with the young person reviewing informed consent and the contribution their reflections would make to the research. The participant agreed to provide their reflections within the following two weeks. Another participant offered a copy of the drawing of their personal 'river' and the reflections they had late one night in hospital (Figure 3). As mentioned previously a bereaved mother offered the diary excerpt of her young person's reflections and experiences of using Te Awa. Their contributions are included in the research as another form of information other than the spoken word and as a rich contribution.

Ethical considerations

The core of ethics it is to ensure minimal harm comes to those participating, while respecting them and their privacy. Streubert and Carpenter (2011, p.20) declare, "all research affects the study participants in some way." Narrative inquiry involves a relationship between the researcher and participants where both are affected by the process. Ethical considerations are thus an important part of the research process to keep each party as safe as possible. Ethics approval for the research was sought through the following organisations:

- The District Health Board's approval was required as the participants interviewed received treatment through the Regional Cancer Centre located at a specific hospital, and to ensure confidentiality of the participants. (see appendix C)
- The District Health Board's Māori Consultation Research Review Committee's approval was sought also, to ensure I consulted with and included Māori in the research to improve health outcomes for Māori and to reduce inequalities. The hospital research reference number is: RDO15066. (see appendix D)
- Approval from the Waikato Institute of Technology ethics committee was also sought as I have undertaken the dissertation under this educational facility and the research involved conducting interviews with human participants, which requires ethics approval. (see appendix E)

The geographical area the AYA key worker covers is across four district health boards within the North Island, due to time constraints this research was conducted in only one of the four district health boards. It is important to acknowledge commitment to the principles of the Treaty of Waitangi/Te Tiriti o Waitangi when conducting research in New Zealand, especially if it involves or impacts Māori (Health Research Council, 2010). All research conducted in New Zealand is of interest to Māori. According to the AYA Advisory Group 2013 CTAG report Māori and Pacific youth have a higher prevalence of death following their cancer diagnosis than their non-Māori counterparts, even though Māori and Pacific youth make up only one third of young people diagnosed each year in New Zealand. The participant group included Māori and the knowledge gained from the research may have an impact on young Māori people and their whānau/family going forward. It was important to consult with Māori as to the appropriateness and cultural safety of the proposed research project. As stated previously the District Health Board's Māori Health Unit was consulted to assess the cultural suitability of the research for Māori families in the region and to advise on any requirements for this research.

Maintaining privacy and confidentiality

Participants were informed that all steps would be taken to protect their privacy, by removing all names and identifying information from interview transcripts and the research report. Also pseudonyms will not start with the same letter of the alphabet or have any resemblance to their actual names. For this reason, the site for data collection has not been named nor the key worker location. Researching a topic within a small country where potential participants are few makes it difficult to completely maintain participants' anonymity. This was explained to the participants in writing and verbally at the time of interview. All information related to the participants and the research was locked and stored securely.

Ensuring informed consent

All potential participants were sent the Information Sheet (see appendix H) where it informed them they could withdraw from the research at any time, with information regarding the process to go about this. For those that went on to become research participants they were given the Participant Consent Form (see appendix I) at the time of the interview. At this point again, they were informed that they could withdraw from the project at any time without any penalties. No participants chose to withdraw once they had agreed to participate.

Minimisation of harm

In discussing and re-living their experiences, young people could potentially have experienced distress and/or emotional discomfort during the interview. White (2005) describes this as potentially 're-traumatising' people. The consent form highlighted this possibility, as well as a continued right to withdraw from the research at any time. I am an experienced nurse who is used to working with young people in times of stress and trauma, therefore time was taken to listen openly and allow participants to express their feelings and thoughts on the interview, either during or after the process. I was also able to refer participants on to counselling services via CanTeen if required. Whilst conducting the interviews no distress was observed or articulated by the participants, they were informed at the onset of the interviews if they required time and/or support during or following the interview it would be provided.

Clarification of 'initial transcripts' was sought from participants via email. Further clarification of the 'analysis' was not pursued as I had not informed the participants of this step and did not want to burden them. There is the potential to harm participants if interpretations of meanings have been misconstrued. Elliot (2009) explains that the interview itself may not be the only thing that can affect a participant but also the interpretation and analysis can have positive and/or negative effects. Depending on the analysis of the meanings within the participant's experiences, some stories could be misinterpreted or perceived as being storied incorrectly by the researcher.

Data Analysis

The aim of narrative interviews is to gain ‘the story’ of something a person has experienced (Rangahau, 2016), and narrative analysis aims to analyse the ‘story’ to gain ‘understanding’ from experiences shared (Floersch, Longhofer & Kranke, 2010). The researcher needs to investigate ‘the story’ in order to collate the themes within the stories to interpret the meaning people have gained from the experience (Riessman, 2000). Consequently, the purpose and outcome of narrative data analysis is to reveal to others through fresh insights what has been observed and discovered about the human condition (Leavy, 2014). Victor (2009, p. 174) reiterates ‘in thematic narrative analysis, answering the question “what” is most important’. This dissertation used thematic narrative analysis to review the stories the participants shared regarding their experiences of using Te Awa; this enabled me to hear their voices and learn from ‘what’ they were saying about Te Awa by analysing their narratives.

Riessman (2008) and Victor (2009) suggest that thematic narrative analysis is the more common approach used in narrative analysis, and according to Riessman this is because it is ‘…most straightforward and appealing…’ (p.53). At the same time, analysing narratives is also ‘methodical, focused and detailed, while still retaining a sense of the “whole” story’ (Birch, 2011, p.38).

The thematic analysis is guided by theory and research (Birch, 2011). For example, as part of this research I undertook a literature search seeking young people’s experience of metaphors during a cancer diagnosis. While the literature referring specifically to this topic was limited, the general literature regarding metaphor provided important information about the potential influences metaphor/s can have. Some participants in this research did confirm what some of the literature also revealed. Although it was initially disheartening to hear that other metaphors appealed more than Te Awa to some participants, it was also encouraging to learn this research reflected similar findings to other international research around the perceived appropriateness of the specific metaphor.

Narratives can be gathered in a number of ways and can also be analysed in a number of ways (Birch, 2011), which the literature repeatedly acknowledges can be confusing for the beginning researcher. For example, there is ‘analysis of narratives’, ‘narrative analysis’ (Polkinghorne, 1995), ‘structural narrative analysis’ (Labov, 1982), ‘dialogic/performance analysis’ and thematic narrative analysis (Riessman, 2008). Riessman states there are four main ways to conduct analysis and reiterates that thematic narrative analysis focuses on “what” the story is saying, structural analysis looks at “how” the story is being told while dialogic analysis critiques how the story is performed between two storytellers and visual analysis looks at how people use images to tell a story or tell a story through use of images.

To assist the process of thematic narrative analysis in this research I used Braun and Clarke's (2006) step by step guide (Table 1). I used it in conjunction with Owen's (1984) criteria for thematic analysis which uses recurrence, repetition and forcefulness to identify themes.

Table 3. Phases of thematic analysis (Braun & Clarke, 2006)

Phase	Description of the process
1. Familiarising yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Transcribing was the first step in the analysis process as it required the recorded audio to be typed up into a written record. Wuest (2007) suggests that if the researcher undertakes the transcribing themselves they will get to know the data very well, however she cautions it can be time consuming. I transcribed the first interviews verbatim with utterances included by participants and I did pick up things not initially heard while conducting the interviews and noting down ideas coming out of the data. However due to time constraints the remaining interviews were transcribed by qualified transcribers.

There are various approaches to transcribing narrative interviews (Elliot, 2009; Jovchelovitch & Bauer, 2000), it just depends on what the research is required for, as wording may only be the initial step of analysis. Some analyses require noting features such as tone of voice, pauses, and/or a change of subject, and according to Riessman (2008) these features can play an important role in analysis, as this is what determines the story. Once the interviews were transcribed I reviewed the typed transcripts by repeatedly listening to the interviews, while reading the transcripts. This also assisted in familiarisation of data and uptake and allowed me to take note of the emotional expression in the narratives through the tone and pitch of voice. This completed the first step in the analysis process.

The transcript was then emailed back to each participant asking them to verify and make changes if required and email back within two weeks, otherwise I would assume no changes were required. Two participants emailed with no changes required. The plan then, was to develop a revised transcript from the initial version, preserving the participants' sequencing of events while removing any utterances of the interview.

For this research a combined approach was utilised, firstly an inductive approach was used as the main aim of this research was to hear and learn from the voices of experience, the young people using Te Awa. Reading and subjecting the data to an inductive bottom up analysis revealed interesting points brought up by the participants and initial codes were highlighted in specific colours. Then, systematically working my way through all the interviews I used the same highlighting colours to collate relevant data to each code. During this process it was encouraging to learn and hear new ways Te Awa was assisting young people during their cancer journey. A deductive approach was also incorporated, as key themes revealed in the interview data, such as the helpful and adverse effects of metaphor, which were also identified in the literature (Gale et al, 2013). This completed the second step in regard to generating initial codes.

Two methods were used to identify potential themes. I combined Owen's (1984) method alongside Braun and Clarke's (2006) to highlight potential themes. I also mixed Braun and Clarke's step four alongside step three, as I drew thematic maps for each interview using the codes that were identified from each transcript (see appendix K). This assisted me to quickly see the commonalities and unique differences of each interview. I also looked for recurrences, repetition and forcefulness to assist in identifying themes as per Owen's (1984) method. Each transcript was then given a different colour font, so that when themes were cut out and collated together I knew which participant to reference the quote back to. Step five involved analysing and collating the themes continually from the data to refine and ensure each theme was specific and defined clearly. The last step involved the final opportunity to analyse the data and to relay the findings in relation to the research question and literature.

Trustworthiness

Trustworthiness in research is sought from participants and readers and can be done in a number of ways. For participants, establishing trust and rapport are important aspects of the interview process (Rice & Ezzy, 1999); this step was expedited due to the pre-existing nurse-patient relationship confirmed by the young people's willingness to be interviewed. Trust in the researcher was demonstrated as participants had the ability to tell the researcher how they felt. For example, interviewee's said: "interview felt therapeutic" or "introduce Te Awa at a better time" and "ask what metaphor fits best for the participant". Participants can also be involved in the verification of the data, for example, transcripts were emailed, and participants asked to reply to the researcher within a two-week time frame if corrections or alterations needed to be made. Taylor (2002) reveals validation from participants is sought this way and the researcher felt it was important that each participant was given the opportunity to certify their interview. Two out of the five participants communicated to the researcher via email saying: '… read through the transcript and it looks good to me. Hopefully you can get some good stuff out of it??' and '… yup that interviews fine! Pretty cool reading it!'. No changes or concerns were identified. Detailing the processes undertaken in the research and being transparent in the analysis are also ways of achieving credibility and trustworthiness for the research (Saldana, 2014).

Summary

This chapter has discussed the research design using a qualitative method, with an overview of narrative, story and purakau (story). Managing the multiple positions of the researcher was discussed, along with inclusion and exclusion criteria. The ethical considerations were outlined in regard to working with a cohort of this age, along with recruitment strategies and the characteristics of the research participants. The process of data collection, maintaining privacy and confidentiality along with informed consent were discussed. Lastly, minimisation of harm, data analysis and trustworthiness of the research have been highlighted. The next chapter discusses the findings of the stories shared by the young people and the meanings discovered via their experiences of using Te Awa.

Chapter 4: Findings

Introduction

This dissertation endeavoured to answer the initial question ‘How does the metaphorical conversation Te Awa assist young people to traverse their cancer journey?’ Young people with a cancer diagnosis who have used the metaphorical tool Te Awa, found it helpful in a variety of different and unique ways. The secondary aims of the research were to develop the metaphorical tool by incorporating changes and feedback from participants, and to provide information for health professionals who work with adolescents and young adults of the research outcomes to inform their practice. The last chapter discussed the methodology and the utilisation of Braun and Clarke’s (2006) six phases of thematic analysis and the three key elements by Owen (1984). This chapter introduces the themes from the participant interviews. Quotes from participant interviews are presented and identified using pseudonyms to maintain their anonymity and of the people they discussed. The findings show that as well as providing support, using Te Awa enhanced other aspects of the young people’s lives, as well as those people they shared it with. The findings are presented within two key themes: *Assistance **‘of’** Te Awa for young people with cancer* and *Assistance **‘to’** Te Awa by young people who have experienced it*. Within these themes there are a number of sub themes. Several of the themes overlap demonstrating the complexity of the experiences of this group of participants. The two key themes are described first, followed by a discussion of the specific sub themes that emerged.

- Assistance **‘of’** Te Awa to young people.
  These were the reflections that participants shared during the interviews about the ways that Te Awa helped them during their cancer diagnosis, treatment and how it enhanced other parts of their lives. The interviews reflected various themes for the participants, for them personally and for supports close to them. The specific themes that emerged were *understanding and control.*

- Assistance **‘to’** Te Awa by young people.
  These were reflections that participants shared during interviews which led to further development of Te Awa, by helping it to become more diverse and flexible. The participants’ constructive feedback demonstrated how this tool can be adapted and tailored by the individual.

Assistance ‘of’ Te Awa to young people

Understanding their cancer journey

Te Awa’s ability to assist understanding was a theme that came across strongly, in a number of ways. Some participants recognised that even though they had not experienced a personal cancer journey before, once that they were on one, Te Awa could assist them to gain understanding. By using Te Awa, participants voiced that they gained understanding through the simplicity of the model, the ability to use it for reflection and its sense of hopefulness. Additionally, they discussed the value of metaphor, and the ability it gave them to understand how their cancer diagnosis impacted them holistically. Finally, the transferability across cultures and across personal situations was highlighted.

Simplicity

The simplicity of this metaphorical tool supported young people to try and understand their cancer journey in a way that words and medical consultations could not accomplish. As Ava shares, Te Awa’s simplicity was a way to reassure herself where she was in the journey at any one time:

> *… even though it’s something simple I think the beauty is in the simplicity of it and the fact that people can see a picture of it and go ‘OK I’m at this point in the river now’...* (Ava)

Ava also reiterates how she found it hard describing to others the complexities of traversing a cancer journey, so she used Te Awa for self-reflection, which helped assess where things were at for her and supported her everyday life.

> *…so I feel like it’s quite hard to put into words how you are feeling in that period of time. And I remember so many times during my cancer journey I was just absolutely hopeless. And I had no way of really kind of telling people how shit it was and how to like really explain it. It was those little things that were what got me through on those nights that I couldn’t sleep, the nights when I just wanted to give up and um it’s full of symbols like that, that really kinda push you through in those dark times so I think I really appreciate that about Te Awa…* (Ava)

Hope

While Ava talks about feeling hopeless at times she and other participants also voiced that Te Awa gave them hope at various times and in various forms along the cancer pathway. For Ava hope came via the metaphorical ‘flow’ of her river, whether calm, swift or choppy;

the ability to visualise ‘flow’ helped her to know she was continuously evolving and progressing, helping her to physically go forward in life.

> *… it was something that was constantly moving, never standing still and I think that knowing that there was always going to be constant change and knowing that things are always going to move forward, even if they move backwards a little bit…it was always going to keep going and the river always flows… having that vision in my head and constantly going back to that picture and knowing that my journey wasn’t going to end necessarily…was really important to me… it kinda gave me a little bit of hope.* (Ava)

Anihera, initially writes in her diary about trying to steer herself using a rudder, but on reflection while relapsing, she lets go; for her path to be decided upon by her faith in God, which she describes as the ‘flow’ of her river. Reading her reflection you get an immediate sense of the freedom and hope she feels as she allows the weight to be lifted off her shoulders by trusting the flow of her river.

> *…I’m trusting God to keep my umbrella afloat and letting Him take me where He wants me to go. And I should just sit back, relax and enjoy the sun when it shines.* (Anihera)

Claire also shared two metaphorical experiences of hope, the first her trying to ‘hold on to hope’ when things got tough by visualising ‘light’, and the second reaching the ‘ocean’ (survivorship, end of treatment follow-up) which gave her hope to make plans for the future.

Metaphor as a language form

Participants talked about their thoughts when asked directly about the metaphor of the river; they responded to the idea of metaphor in different ways. Dylan talked about the unknown being the hardest aspect of his cancer journey but that that he found that by using the metaphor he could prepare himself “for the next ‘rock’ and the next ‘rock’”. While Dylan’s comment was about solid objects Ava’s was about ‘flow’ the feeling of movement and not being stuck.

> *Yeah and I still refer to my cancer as a journey like it hasn’t ended, it will never end. I’m just not necessarily in the same part of the river as I used to be which is good. But yeah, so I think having that analogy to really know the flow and know that things*

> *weren't concrete, was really helpful and I think that's definitely my favourite part.* (Ava)

For Claire reflecting on the potential use of other natural elements, to emulate a cancer journey concluded that for her a river was the best choice. Claire also preferred movement to solid objects.

> *…I was also thinking how else would you… instead of using a river… and you couldn't really…. and the movement of it, cos that's what it 'IS'… it's the movement of… feeling and getting it…and you know…and emotions…and physical and yeah…and just like a river moves …cos yeah I was like…you can't use mountains and you can't… use valleys because you know… it's perfect... and like the ocean is that big world* (Claire)

Claire voiced having something real such as a river that she could picture and use when going through physically difficult times, gave her another way to think about what was happening to her. Using language of natural elements moved her experience away from medical discourse

> *…it [Te Awa] just made it easier to understand what I was going through. Giving it… something physical… instead of going 'ah yeah you're sick'… it helped a lot.* (Claire)

Transferability

Crosses streams

While the cancer journey was a dominant theme in the young people's lives, they also continued to experience the normal challenges that young people face in their relationships. Te Awa also helped them to navigate these other challenges. Most of the participants shared how they benefitted by transferring the concepts of Te Awa to other aspects of their lives than their cancer experience. As Ryan *said "[I] use it for lots of different situations which is good…"*

Another participant shared her experiences of using Te Awa to talk about challenges related to her marriage and fertility issues that arose while navigating her cancer treatment:

> *I definitely use… the Te Awa metaphor in other aspects of my life, not just the journey I was on with the chemo* (Claire)

In addition to using Te Awa to support them with their own challenges, participants used the language to support other people in their lives. For example,

> *I actually used it on one of my friends who was going through a really, really hard time with some family stuff and relationship break ups and things. …cause it helped me through a really tough time and it's like, look at it, like a river - you'll work through it, you'll get there in the end, but there's just some really shitty parts on the way, and I think it helped her.* (Ava)

Ava believed "*it could be cut and pasted into any traumatic experience in anyone's life"* and encouraged others to draw their river as she found that tangible form of reflection helped give her perspective and understanding to problem solve. Similarly, Anna thought she could use Te Awa in a programme that she was running for young people facing bereavement. Another participant, a young man found the metaphor useful for supporting a friend who was facing some personal problems.

Cross-cultural

New Zealand rivers are part of the cultural as well as the geographical landscape and may not be relevant to people from other parts of the world. However, in the research participants felt that Te Awa would translate across cultures. This included a young person from another country. Claire, when asked about the metaphor's relevance for her experience, voiced she could relate to the river metaphor as there where rivers where she grew up:

> *… you could, you could. …where we're from… you've got the river and the dam, so um definitely… in that sense. …So yeah people will totally get… get what you're going on about.* (Claire)

Ava voiced that she could use Te Awa to assist her daily work, as she worked with cultural groups who had a strong affinity to water.

> *… it's really easy to understand, and with the cultural… community I work in… such a huge Pacific Island, Māori population and their connection to the water and their connection to their culture is huge. So, having that connection with people could be really powerful.* (Ava)

Dylan, who was New Zealand born, found Te Awa of value as he could connect directly to this metaphor, as he uses and relates this tool to his local river.

> *Yeah, at work they did karakia (prayer) for me…which was nice, being at home, good using 'my local river' as well. It did help being at home, I guess heaps, heaps.* (Dylan)

Supporting holistic wellbeing

Te Awa makes space for young people with cancer to consider all aspects of their wellbeing. Metaphorical structures in Te Awa represent these aspects providing a language to think about each one.

Taha Whānau (Family/Social wellbeing)

The young people in this research experienced their supports in various ways; some found their presence important while others wanted to go it alone. Some found friends fell away, while others felt responsible for their friends and whānau. Young people can choose who swims along and supports them, as Claire emphasised by wanting her fish (supports) in the river with her the entire way as this gave her strength to cope with her cancer diagnosis no matter where it was leading. Others choose to go it alone, such as Ava who voiced that Te Awa was something she preferred to use for herself. However, she liked the river concept when it came to assessing her supports, as knew she if they swam away, they could also return.

Dylan said that he didn't necessarily mean to cull the numbers of fish swimming beside him, he just could not relate to some anymore. As young people like him are made to face their own mortality and the challenges of a cancer journey it can propel the rate of their maturity beyond their peers. As Dylan noticed he was less tolerant with trivial issues and found it hard to have his fish (supports) around

> *…my thinking towards life changed and I didn't want any dramas and I just said "get over it", but it was more they didn't talk to me about it [dramas], they didn't go away but they just…went quiet.* (Dylan)

Initially, fish in the context of Te Awa was a visual metaphor of supports young people had during their cancer treatment. However young people have shared their experiences of some of their supports turning into 'piranha's' and we learnt to discuss how to manage those supports. Anna experienced changes with her supports and found that using Te Awa she could understand how they might react.

> *…I think I liked it [Te Awa] and that the fact that I remember the fish part was quite a good way to explain it cause…your friends might go away, just bugger off, if you know what I mean, so it was a good way to say like that they might find you again. Definitely, looking at it, that happened. …I think just with the fish side of things…um, cause it definitely was interesting who stuck by you and, and you do understand that it's not like their fault that they didn't…* (Anna)

Taha Wairua (Spiritual wellbeing)

Spiritual wellbeing is a broad term open to the young people's interpretation as to what they acknowledge nourishes their spirituality. For example, they may use yoga, meditation, music therapy, beach walking and religious practices, such as prayer. Anihera enhanced Te Awa by turning the original supports of 'fish' into 'rapids'. For her, rapids metaphorically represented the spiritual support she gained from 'God' to help her through hard times. Claire too shared her spiritual supports and how this assisted her to navigate the river. For her, God helped to take stock of how she was tracking and make changes to improve her wellbeing.

> *I ask God to give me a picture… to show me where I should be …not to see the future but…you know… that's the only way I would see it. …You ask him for the signs, yea and I think that's why the river helps so much, cos I can visually see it… just even the kayaking, being in that kayak….* (Claire)

Taha Tinana (Physical wellbeing)

Physical wellbeing is a major area of focus during a cancer diagnosis, not only from a medical point of view but also holistically. Claire uses Te Awa to explain how hard it was for her when her body was not physically responding to treatment.

> *…physically my body wasn't doing what they [health team] wanted it to do, so yeah that's where the rapids come in the river – doh doh doh doh [making motions of bumping down a rapid]. But… that happened quite a bit… haha* (Claire)

Despite being consciously focused on ridding her body of cancer, Claire describes the impact of being questioned on her every day decisions by her support team. While she was being scrutinised about her choices, they were making lifestyle choices that increased their cancer incidence which she found disconcerting.

Anna says when it came to dealing with the physical side effects of chemotherapy she found addressing the river one section at a time beneficial. She didn't want to be told the whole pathway all at once, as she did not want to worry about physical side effects that she would not necessarily experience.

> *I just remember those three sheets of side effects of chemo and you think you are going to get every single one of them and you're like 'ohhh what!!' But I only got three kind of thing, so I think it's good with the whole river when it comes along, then you explain it, cos there's no point in worrying about something that might not happen, so yeah I think that's a good part, that it's in parts…stages, cos I'm really a structured person as well, that's why I like stages yeah.* (Anna)

Taha Hinengaro (Mental/Psychological wellbeing)

Psychological wellbeing was a strong theme that participants voiced while using Te Awa. Some of them took the metaphor of the river and used their own metaphors within this natural element to describe and explain how things were going for them emotionally and mentally. For example, rocks, caves and rapids depicted difficult experiences, while the flow of the river…constantly moving, never stuck depicted times of ease. Ava, discussed earlier, found the river was psychologically freeing as there was a flow, a current demonstrating she was not stuck with cancer forever. Te Awa gave her the ability to see that cancer was just 'one section' of her life and not the 'total sum'.

Anna shares how she psychologically found the section of river, even before the waterfall, overwhelming while learning of the diagnosis. Using Te Awa Anna shares her emotional experience of follow-up, heading out into the estuary and the emotions she felt during this time.

> *…cause you get bombarded with all this information…cause I pictured that the rapids were before the waterfall… And then the estuary, I remember that part cos I was like 'Yusss like I'm out', and you're like – 'Don't freak out cos a lot of people like freak out and just let go' … But yeah the estuary part was a good part cos you're like 'Yeeyaah!!'* (Anna)

The impact on Claire's psychological wellbeing was intense due to a diagnostic biopsy leaving her acutely unwell. As a result, it affected Claire's ability to process her initial cancer diagnosis and subsequently spent time and energy worrying about relapsing.

> *…I think it was therapeutic to mentally tell myself "ok, it will be ok if it comes back", the waiting time was forever but …I think mentally I could prepare myself going 'if its cancer we've done this before we will be ok'.* (Claire)

Claire highlights the psychological turmoil a person can experience hearing over and again how effective or ineffective their cancer treatments have been. She uses her own metaphorical aspects of the river to explain this impact on her.

> *...cos we were on a river and that chemo stopped working so we had to take this river, and then we hit a sand bank and we didn't know what was happening and it was taking its time so we like nah nah… other way… let's try this side of the river…. Yeah.* (Claire)

Claire and Anihera were two of three participants who relapsed after their first treatment, requiring them to go over a second waterfall and they voiced this experience was different compared to their first waterfall. For Claire she could reflect back on her initial river and take stock of where she was, so Te Awa assisted her to navigate and gage where she was second time around.

> *Cause the river for me in both cancers were completely different, so I think meeting you for the very first time in my first journey and having that vision of the river going smoothly and the rapids... having that vision was really good, you could put your journey… into something that you could see…-and then having that conversation again when relapsing… made total sense when you think 'Ok now we at this different river, we still on the river, but now you are back on the rapids again'* (Claire)

For Anihera the relapse was more emotionally and mentally freeing.

> *But this time feels different. I am quite happy to completely let go and let God [the rapids] take me where I need to go…* (Anihera)

Control

Control emerged as a prominent theme for participants while using Te Awa, as they frequently talked about their various experiences of either taking control, letting go, or losing it. ‘Control’ was described in a number of psychological or metaphorical forms within the river. Being able to visualise the course of the river for them and their whānau also assisted in their ability to have or gain some control during their cancer treatment.

Taking control

The ability for the participants to visualise and voice what mode of transport they navigate their river on is a way of taking control that seems important to them. It is insightful, as their ‘choice of transport’ can demonstrate the level of control they want to have during their cancer treatment. For example, ‘jet ski’ equals the ability to try and control the speed and direction, versus a ‘rubber tyre’ which is more open to going in the direction and flow of the river’s current. Anihera describes these two variations of control vividly:

> *…kayak meant control – to some degree. It was something I could use to sort of guide my way through the rapids. Last time, I had chosen a kayak. But this time [relapse] I had the image of me being a frog, lazing in the sun, on a deck chair, on this upside down rainbow umbrella with a drink in my hand.* (Anihera)

In this last reflection Anihera allows the reader to see how things were for her emotionally and psychologically; through the pictures she painted of what she wanted to float on to navigate her river. The first reflection seeking control in a strong and sturdy kayak, versus her second reflection, a beautiful and powerful image painted in amongst the chaos of palliative rapids, choosing to go with the flow in a flimsy, fragile umbrella.

For Ryan it was powerful to hear him wanting to remain in the same mode of transport along the entire river journey; he chose to do this as it allowed him to acknowledge his cancer journey and the experiences gained along the way.

> *… if I chose a jet ski I would want to get through it quickly? …if I just stayed in the kayak … cause you know if you are getting into something else, it’s kind of like you are almost leaving it behind. So if I stayed; it’s kind of like… it’s always going to be with me… definitely acknowledging it, yeah rather than trying to… distance myself from it and forget about it in a sense. Cause it’s an achievement in the loosest sense; it’s you know something to be proud of…* (Ryan)

Young people can understandably feel a loss of control with psychosocial and other aspects while navigating a cancer diagnosis, due to adhering to treatment regimens and dealing with treatment side effects. Te Awa can help young people take back some control by making decisions, such as deciding what to navigate the rest of their river on.

Claire experienced loss of control through her first experience of cancer because her initial waterfall (diagnosis) arrived swiftly, giving her little time to psychologically prepare for the impact of a cancer diagnosis This resulted in her developing a 'fear of relapse' towards the end of treatment. This fear controlled her ability to enjoy life and make plans for the future, but when she actually did relapse, because of understanding the journey, Claire felt more psychologically prepared and in control than when she had her initial diagnosis, allowing her to make future plans and enjoy life.

> *So the second time the fear went away and it was more like, "Ok I've got to live for myself" and "I've got to live for my husband and I've got to have a family, and I've got to start really just…yes we can beat this and we'll be fine; let's just move on and live".* (Claire)

Letting go of control

Claire mentions 'letting go of control' in two different ways, the first being able to trust her fish (whānau/family) to steer her boat and help make cancer treatment decisions. The second, allowing herself to let go of the psychological baggage she was carrying from her initial diagnosis.

Anihera's diary excerpt cited earlier shows she initially spent her cancer diagnosis trying to gain control via the use of her kayak's rudder to steer her path. However, when she relapsed she decided to let go and voiced how psychologically freeing this was for her. For her whānau being able to read her reflection and know she was open to going wherever the flow of her river was to take her must have been extremely comforting during her passing.

Dylan shared similarities with Anihera in regards to letting go of control on his river and how freeing this was:

> *…think I'm going good so far, just floating there, yeah no jet boats, no where I want to get fast. It's pretty good just chilling out. Crack a beer… sit down, and take in the sun. …I won't be paddling anywhere I'll just let the river take me yeah… wherever I*

> *end up, is where I end up, and hopefully no more waterfalls [cancer progression], well; if there are they are fun, its more the thrill and not the crash...* (Dylan)

Losing control and going with the flow

For three participants the experience of ‘losing control’ had differing effects on them. As Anihera discovered, a loss of control was not as psychologically off-putting as she thought it was going to be. Rather it appeared to ease her journey. Claire states she lost control two ways, at two different parts of her river. The first time she lost physical control at the beginning of her river, as she required a general anaesthetic to conduct a diagnostic biopsy, during this procedure her airway blocked as a result of the cancer mass, requiring time in the intensive care unit. While incapacitated, treatment decisions needed to be made, so her family consented for chemotherapy to be initiated. The second time she experienced a psychological loss of control was while waiting for results to learn if she had relapsed, people have voiced ‘waiting’ for results as one of the hardest parts of cancer treatment.

Te Awa and visualisation

Visualisation can be understood in two ways, as a mental image or a tangible pictorial image from the young people’s narratives. The first and most commonly used by all participants was as an imaginal process, linking what was being experienced at the time or what might happen in the future with a mental image. Ava described this process vividly:

> *I think because I’m quite visual it really worked for me to picture it…I think it really helped me through it [cancer] …kinda have a visual picture of how it could get better…* (Ava)

The second way of using visualisation occurred for Ava during a hard night in hospital when she had the chance to reflect on her cancer journey by drawing her river. Through drawing and being able to see it on paper, this process of reflection helped her to find the positive aspects in the quiet of a stark night.

> *…and then I kinda got my river opening up at the end once I’ve recovered, and at the end I’ve put ‘Who knows?’ Which was kind of like my open-ended question to myself of ‘what I could do post treatment’ and that the possibilities are there, and who knows where the river might lead kind of thing.* (Ava)

Different aspects of the river resonated more strongly for different participants. For example, Claire expressed that the river metaphor was beneficial for her as she was aware of the various natural river formations, such as rocks and caves; with this knowledge she could visualise and psychologically steady herself when heading into tough periods of cancer treatment. This enabled her to anticipate what to expect and therefore she was able to prepare herself for bigger things, such as rapids or potential complications from treatment.

> *Having that vision of the river going smoothly and the rapids... having that vision was really good, you could put your journey… into something that you could see* … (Claire)

For John a positive aspect was being able to visualise his fish (supports) helping him resurface from the pounding waterfall (diagnosis), assisting him to deal with the aftermath and shock of falling over it. "*It helped to visualise all the support I was receiving from various sources".*

The second way that visualisation became important to these young people was being able to engage with the images in a more tangible form by drawing them. This was evident for Ava discussed previously who, during a difficult hospital admission, found herself lying awake in the middle of the night and began to draw her river (Fig. 3). She found Te Awa assisted her to process her feelings and visualise beyond the current challenges she was facing. Ava saw her river as freeing, as there was a flow, a current that showed her she was not stuck with cancer forever.

> *I think it was a lot easier for me to write things down and have them on paper to process them for myself; and I think the way it [Te Awa] worked for me, to be able to draw the river and see there was shitty parts, waterfalls and stuff.* (Ava)

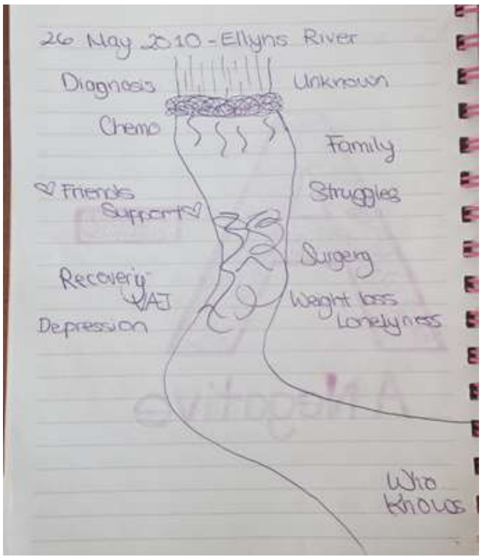


Figure 3. Ava's River Drawing

Although seeing was important to most participants, ironically Te Awa provided one participant with the ability to visualise ‘not seeing’ at times on her river. When using Te Awa, impending treatment appointments are relayed to young people as ‘forks in the river’. As young people approach appointments, they can experience anxiety due to the anticipation of learning the results of their scans and/or blood tests. The river left of the fork represents continuing with the current recommended treatment regimen, as there has been a positive response. The river to the right of the fork represents needing to change course, change treatment regimens due to a lack of response or no response at all. A change of course, and steering down a new river can be scary for young people and their whānau, as they may still be trying to come to terms with the news while learning to navigate a new and unfamiliar treatment river.

This occurred a few times for Claire, when treatment plans needed to be abruptly changed due to the cancer not responding appropriately. Despite Claire losing sight while relapsing, her narrative comes across positively as she puts trust in her doctor to lead her blindly down new rivers/new treatment paths.

> *…definitely not seeing…. but having hope and having the trust in the Dr’s…I was very blinded on my rapid…. I had a lot more courage in terms of ‘yeah we can fight this’ but very blinded...*(Claire)

Visualisation for others

The participants recognised that friends and family who had not experienced cancer personally found it difficult to understand what they were going through. However, being able to share their story through Te Awa enabled their support people to have insight and a visual account of their cancer experience. It provided a common language to communicate. Participants shared the language of Te Awa with whānau and friends.

> *…I think it [Te Awa] helped me to explain to people that it was just a shitty time and it will get better cause it gave me that picture in my head so I could explain it to others.* (Ava)

Anna who also voiced that Te Awa’s visual images helped her understand the cancer pathway was more cautious when sharing Te Awa with others. When people sought her counsel, instead of immediately sharing Te Awa she would ascertain where they were on the cancer continuum and then use the corresponding image to know what support to offer.

> *… people now that come to me, that message me, now who have just been diagnosed or something like that… now I explain that to them almost, but I don't use that exact analogy,* (Anna)

Assistance 'to' Te Awa:

The metaphorical tool Te Awa was created using a river to help young people face their cancer diagnosis and understand in a very quick way the impact it can have on them physically, spiritually, socially and psychologically. While conducting this research, participants taught me things about Te Awa I had not anticipated, for example how they processed Te Awa and gained their own understanding by taking it and making it their own. They also made suggestions related to the timing of information and being careful about the kind of metaphor that patients might relate to.

Patient centered metaphor

Anna's feedback during her interview reflected the importance of finding the specific metaphor that works for the relationship. For Anna the 'road bump' metaphor shared with her by her oncologist aligned better with her than Te Awa. She articulated clearly the benefits for her.

> *if you could find something specific to the person I know *Dr Jones [oncologist] for me, the first thing he said was it's just a speed bump in the road and so that was like 'boom' like that. So that if you are going to get real literal about it, cause I'm not like a water person… in terms of the analogy I liked it that idea… Yeah, yea and whether you use a different one for different people, like for sporty kids you could use a sports one… (Anna)*

Timing

When conducting Anna's interview she informed me the timing of the introduction of Te Awa was not opportune. This was the first time I had received this feedback and was grateful to have been given insight on the timing of teaching Te Awa. With this feedback I am now more mindful of the time and place I teach young people this tool.

> *I remember the first day you introduced it to me and it was in the 8th hour of my first chemo … yeah cos I was there for eight hours and I remember you came in just before I left and I was a little bit just gone by this stage… so yeah I probably would just say do it before, or after… I was like I want out of here! But then the next time you spoke to me it made more sense, and I could actually like focus…* (Anna)

A number of participants shared the fact that Te Awa did not initially sink in or require utilisation until later down the river when the current became rough. Ava shares her experiences of Te Awa and when she found it of use.

> *I took it in and I acknowledged it but I think I didn't really use it until, I think about 4-5 months later…cause that was my first lot of chemo, obviously was shit. …my second lot was just absolutely hell and I hated it and I was losing all the weight and I had a lot of issues with friends and stuff so it [Te Awa] came kinda at a low point, it kinda came back to me and I started thinking about it and what my journey was and how I could kinda put it on paper in a really easy way.* (Ava)

Anna also shares how she did not relate to Te Awa initially, but on reflection she was able to implement it during later stages of the cancer trajectory.

> *…now that I look back on it… I can be like 'oh that's what you meant' kinda thing. But when I was there I was like 'what do you mean?' kinda thing…but now it's happened or once I've been through it I'm like 'oh yeah, that's...' I can relate, I can now put the two together.* (Anna)

Anna, along with Ryan voiced their rivers were relatively smooth with no real issues experienced and may have implemented Te Awa more frequently if more issues had arisen.

> *…compared to a lot of people I had a really straight forward journey, so I probably didn't like need it, if you know what I mean, cause it was pretty smooth sailing most of the way, so... I think maybe if I'd had more things pop up I probably would have used it more…* (Anna)

> *…I kinda couldn't really relate to it cause I didn't really have any problems… I can more probably relate to the end, about how… you had a routine - going to chemo, going to radiation and then kinda got nothing… I could relate to that probably more than the actual start of it being rough through the journey for me.* (Ryan)

Owning Te Awa

Participants' interviews confirmed that young people saw Te Awa's worth by implementing it into their lives. Their feedback demonstrated how they chose to use Te Awa to assist understanding and sense-making during their cancer journey by making it their own. Personal ownership was demonstrated when participants took initial aspects of Te Awa which were shared with them and added their own metaphors which seemed to increase their understanding and ability to communicate what they were experiencing. John enhanced Te Awa through the addition of a metaphor to explain the side effect he experienced with his cancer treatment:

> *I guess during treatment there was, perhaps, a fog that had settled over the river. I say this as some of the drugs I was on during treatment affected my mood and memory.* (John)

Claire also enhanced her Te Awa experience through the addition of a 'sand bank' metaphor to explain relapse issues:

> *…the rivers finished there - we've gotta get back on to it, we hit a sand bank… yeah many a time we hit a sand bank, we stood there for a little while, but then we got back on the boat and went somewhere else.* (Claire)

Anna rearranged the primary stages of Te Awa to fit the experience of her cancer path, as when I first created Te Awa the 'rapids' (shock of diagnosis and information overload) usually follows after the 'waterfall' (diagnosis). However, she was tentatively informed by her General Practitioner that she may have a cancer before her biopsy results were confirmed. Hence, she hit the rapids before the waterfall.

Participants also changed the length of the river which represents the time treatment takes to complete. Although Ryan voiced his river was quite smooth it was the length of the river that impacted on him; the time the cancer journey took from his life. While Ryan felt that treatment took a big period of time out of his life he still managed to do other things while he received chemotherapy for one day every two weeks in an outpatients department. Because of this he felt that the cancer didn't have such a big impact on him thus describing it as 'smooth'.

A number of participants voiced they liked the visual aide Te Awa provided, therefore I asked some participants if I should provide actual 'pictures' when introducing and talking about Te Awa in future? The young people I asked said provision of pictures could help, as Ava voiced, she would have appreciated visual aids to avoid unnecessary pressure of trying to visualise aspects of Te Awa while talking to her.

> *I was just like 'What a boat? What? I don't know what a boat is? What boat am I supposed to do with it? I don't know?' And so I think I was a bit like stuck on just the practicality of it. So, and because I am quite a visual person, I think having maybe options of different things* (Ava)

Summary

This chapter has presented the findings of the study. The key findings were, Te Awa assists young people to have an understanding of the various aspects of a cancer diagnosis, and with this newly acquired understanding it helps them to have some control during an extremely chaotic part of their life. This control begins metaphorically within the tool but splashes out into their experiences of life. The contribution to Te Awa will enhance the tool. The next chapter will discuss these key findings in relation to the literature.

Chapter 5: Discussion

Introduction

The previous chapter looked at participants' personal stories and experiences of using Te Awa while navigating a cancer journey. Utilising a thematic narrative analysis, the study explored ways in which the metaphorical conversation of Te Awa assisted young people to traverse their cancer journey. After nine years of implementing Te Awa in my clinical practice, receiving positive anecdotes from young people and whānau, as well as constructive feedback from health professionals, it was time to formally learn from the voices of the young people. To accomplish this, the following question was asked, 'How does the metaphorical conversation Te Awa assist young people to traverse their cancer journey?' Semi-structured face-to-face interviews with five young people were conducted, and analysed along with one participant's reflective writing and a palliative reflection from a young woman, gifted by her parents.

This chapter will discuss the study's findings in conjunction with the reviewed literature. Some of the previous anecdotal findings are included in the discussion, in places where the findings of the research are confirmed and where they might challenge previous understandings. The two main themes that flowed from the narratives were: Ways in which Te Awa assisted participants' in their cancer journey, and ways in which the Participants' assist the development of Te Awa. The discussion is structured under the two headings: Assistance of Te Awa and Assistance to Te Awa.

Assistance 'of' Te Awa

From the findings, it is clear that the metaphorical conversation Te Awa assisted young people to traverse their cancer journey in multiple ways. Te Awa achieved this initially by enabling young people to gain a better understanding of their journey. This finding reflects earlier research (Berendt, 2008; Casarett et al., 2010; Czechmeister, 1994) that suggested the use of metaphor assists peoples' understanding of their experience. While Casarett et al. and Czechmeister concluded that metaphors do not convey facts which can therefore result in giving false hope and obscuring information, the findings in this study show that Te Awa helped participants to gain meaning around the complexities of a cancer diagnosis and offered a means of hope for some participants.

Te Awa helped participants gain understanding of an event in their lives they were unprepared for and which they had never previously experienced by using simple metaphors. Navigating and understanding the complexities and multifaceted nature of the cancer journey which can include arduous treatment strategies, unpleasant side effects, intrusive tests, endless scans and assessments required to monitor treatment progress, can be demanding and overwhelming. Metaphor can play a fundamental part in shaping how we make sense of things (Yu, 2012). Using a metaphor provided these participants with a language and images that were simple and familiar. The characteristics of a river on its journey to the ocean are familiar to most New Zealanders and form an essential part of the fabric of Māori life in this country. As such they are understood in different ways by all New Zealanders.

In addition to understanding the medical jargon, young people and their families have to come to terms with how cancer impacts a person's life plans, their relationships with whānau and friends, study, work, financial security, suitability of living environments, and life choices. This is immensely challenging and the simplicity of Te Awa offered participants a strategy to understand the cancer journey and the accompanying emotions in a way that words, assessments and medical conversations could not easily accomplish. As previous research (Penson et al., 2004; Subbiah, 2012; Toombs, 1993) has concluded, metaphors can provide a common language, which can assist in simplifying the patient's journey. Te Awa provided a vision the young people could immediately implement and allowed them to align their experience to the river at any point and time.

The cancer journey for young people is emotional, as well as physical. Both are equally difficult to articulate, yet the participants in this research found ways of expressing what they were feeling using the language of Te Awa. For example, one participant voiced they were coming to the end of a hard section of their river and emerging from a cave they were able to see the light. Czechmeister (1994) refers to experience as often being beyond words, but this participant, like others in the study, could reflect through the metaphorical expressions.

Reflection

Through reflection, Te Awa guided participants' understanding by providing time and space to re-evaluate and assess aspects of their lives, goals, and future directions. Ultimately, the use of the metaphor aided reflection for young people with cancer, which in turn assisted improved decision making and treatment choices (Subbiah, 2012).

The complex experiences associated with a cancer diagnosis can be physically, emotionally, socially and spiritually taxing. Consequently, the ability to reflect on existing skills, previous coping strategies, and what is important to them enabled young people in this research to prioritise and focus energy on things that mattered to them, as one participant found while drawing their river during particularly challenging times. The ability to reflect while drawing, allowed the participant to acknowledge the positive and challenging learnings experienced, and use this knowledge to navigate future situations.

In addition, two of three participants who relapsed after their first treatment, voiced that their second experience differed, on reflection, to their initial diagnosis. Reflection allowed these young people to ‘take stock,’ and ascertain their position the second time around and implement initial learnings and experiences to assist going forward with the relapse. The metaphor Te Awa provided them with hope that they could navigate the relapse journey by reflecting on learnings from their previous journey.

Hope

Te Awa’s ability to encourage ‘hope’ was a surprising finding. Prior to conducting this research, I was not aware that metaphorical conversations could instill such hope. One young person I cared for several years ago expressed the following thoughts using Te Awa, *“I can’t wait to smell the salt sea air,”* which metaphorically represented heading out into the ocean, equating to finishing their cancer follow up. Subsequently, through this I realised the potential power of the metaphor for some young people, although it was unanticipated that it could offer significant hope.

Hope was found at various times and forms in the research, such as the metaphorical ‘flow’ of a river, reminding young people they are continuously evolving and voyaging, never static. For one participant, the flow of her river demonstrated her faith, providing hope and trust. Another participant mentioned previously revealed hope through the use of metaphor, by comparing the light at the end of a cave to overcoming a difficult section of their cancer treatment.

The importance of hope was reinforced by a conversation with one participant’s parents as they articulated: *“At the end of the day, all some have left is hope, and who has the right to take hope away?”* Wiener et al. (2015) conveyed similar results with young people, advising oncology health professionals to continue the practise of hope, despite changes to prognosis. Conversely, Mooney-Somers et al. (2015) found that there was less association of hope with cancer among healthy young people. Nevertheless, the findings from this research suggest that hope should be discussed, encouraged and re-evaluated with young people when aspects of treatment change along the continuum.

Appropriateness

I held some initial reservations whether the river metaphor was appropriate to use in supporting all young people on their cancer journey. Teucher (2000) found that for one patient, ‘a metaphor’ can be helpful and beneficial, but for others, that ‘same metaphor’ may be negative and distressing. While some writers (Chan, 2011; Iwama, n.d.) agree, that a diverse ethnic cohort understand some metaphors; others argue that metaphors are only relatable and transferable if a common background or culture is shared (Kangas et al, 1998; Panoho, 1995; Rosenblatt, 2008; and Stott et al., 2010). A question was whether Te Awa would be considered too culturally specific when working with multiple ethnicities. However, participants felt Te Awa could transfer easily to other cultures inside and outside New Zealand. Te Awa is consistent with the New Zealand context due to the strong Māori and Pacific Island links with water bodies, making it relatable, familiar and easy to identify with. Within this research most non-Māori participants also found Te Awa easy to relate to, as 'rivers' are a well-known water feature globally. From this research Te Awa could be considered universal in terms of cultural appropriateness, although any metaphor can be experienced as a poor fit based on personal interests and experiences.

My experience of using Te Awa as a cancer metaphor has been that it is transferable and easily utilised by other cultures. I have experienced a number of young people and their whānau being comfortable with the metaphor, and how the natural elements of a river can mirror the turmoil and distress one experiences during diagnosis and treatment. In a similar manner, research participants noted that Te Awa was an appropriate fit and suitably captured the complexities of their cancer experience from a physical, relational, emotional and spiritual perspective.

Several of the young people appreciated the visual imagery that the rivers' *flow* provided, assisting them to not feel confined to their situation. Te Awa helps individuals develop their ability to consider in detail their journey, providing both a 'snap shot' of the treatment section they are currently navigating, while also providing an aerial view of the whole treatment regime; of the entire length of their river. Young people expressed that it is useful to know the overall treatment regime, but psychologically easier to deal with the cancer treatment in sections. Nevertheless, not all participants found every aspect of the metaphor ideal, which will be discussed in terms of timing and specific metaphors.

Timing the introduction of Te Awa is another aspect of the theme 'appropriateness.' I have observed that Te Awa was more efficacious as a tool when introduced as soon as possible following diagnosis. However, there is a 'fine line' between provision of tools to assist navigation, and information overload. Reading cues and body language, as well as asking if they are open to discussion at that time is important. As one participant identified, the timing for discussing Te Awa was not opportune because it was at the end of her first eight-hour chemotherapy. Understandably she was still sleepy from anti-nausea medicines and desperately wanting to go home. Consequently, I am now more mindful of the timing and location when introducing Te Awa. The importance of timing is discussed again in the second section 'assistance to Te Awa'.

When presenting Te Awa at conferences, the importance of 'transferability' was another key feature expressed by other health professionals who voiced how easily transferable this tool could be to other health conditions such as diabetes. Such a view is reflected further in this study. One participant said that Te Awa could be useful with clients in her professional role. Other participants stated that they used Te Awa during their cancer journey, and when facing other challenges, such as infertility. Participants also voiced Te Awa was useful in assisting their whānau and friends to manage future challenges, such as relationship breakups. As said earlier Te Awa can capture the physical, relational, emotional and spiritual aspects of an issue making it a holistic model.

Holistic view

Te Awa assists with the provision of holistic health care, as it promotes discussion and assessment to be articulated along the cancer continuum. Including Te Whare Tapa Wha model of health (Durie, 1984) in Te Awa, allows all the impacts that a cancer diagnosis can have on a person to be discussed from the very start of their river. Ascertaining young people's psychological wellbeing is made possible using Te Awa, as it provides clear descriptions or metaphors to signal the experience of their journey. Participant feedback highlighted this finding, when some described turbulent currents, hitting rocks, cascading over waterfalls or floating down caves. Comments like this immediately signal that further discussion is required to ascertain issues or concerns being experienced. Once problems are identified and reflected upon, implementation of previous coping strategies are discussed and actively encouraged, along with referrals to relevant services for support.

This finding was similar for the physical implications the participants experienced, as river metaphors were also used to communicate concerns participants had with their body, such as hitting a rock when sustaining an infection or going over a second waterfall when relapsing. One participant shared the benefits of focusing on the current section of their river being psychologically easier to cope with, opposed to the entire river course, as it prevented unnecessary worry of side effects which they may never experience. Overall these findings are in accordance with outcomes reported by Southall (2012), whereby metaphors assist in the discussion of difficult and sensitive topics. Using metaphor creates a distance from the reality which allows the person to engage with the issue without being overwhelmed by it.

The physical side effects of cancer and cancer treatment affect both genders, such as the physical impact of chemotherapy on the body. Sometimes a young person needs to take a break between treatments; a few days off to recover and continue once recuperated. This is achieved by swimming to the side of the bank to regroup and breathe. One young man said it was helpful to have this time, as ‘if he had been forced to continue in the current he would have just climbed out’ and would have chosen not to continue with treatment.

Social supports such as whānau and friends are metaphorically described to young people as ‘fish’ in their river. Te Awa also provides a way for young people to understand both the negative and positive impacts a cancer diagnosis can have on their social supports. A participant voiced that having to face their mortality left some friends less relatable, when hearing them complain about trivial issues. Navigating their cancer experience gave them a different perspective than that of their friends. This is not an isolated experience, as young people over the years have voiced similar challenges, as the impact of a cancer diagnosis can often force them to develop a mature outlook on life sooner in comparison to their peers (Laranjeira, 2013). To cope with this, some have expressed a sense of relief in culling their social circles, allowing some fish to drift away, while others tolerate their peers, and let them swim alongside knowing one day they too will mature.

One of the major themes coming through the data was the social versatility Te Awa provided young people. Participants’ voiced they could choose whether to swim alone or be selective in who, and when supports accompanied them in their journey. One participant demonstrated this by navigating rough patches mostly on their own, involving whānau only if needed, as not wanting to trouble them. The ‘cancer pathway’ is more often navigated collectively by young people and their whānau. In contrast this participant chose to face the majority of their cancer journey independently, viewing it to be not a ‘big thing’. On the other hand the participant may have felt they were protecting and caring for their family by not involving them, without thinking their family would be wanting to support them. Versatility is important to the research as it demonstrates the flexibility of the tool, and how socially and psychologically this tool can be adapted to suit people’s individual needs. This versatility offers them some control in an experience that may feel out of control.

Control

The findings show strong indications that the metaphorical conversation Te Awa supported young people to achieve a sense of control in a situation which is largely out of their control. While it is said ‘where there is knowledge there is power’, this research suggests ‘where there is understanding there is control’. Understanding the various twists and turns a cancer diagnosis can impact on a person’s emotional, psychological, physical and social wellbeing can assist a person to have some control. They can anticipate certain experiences and prepare psychologically for them. This view aligns with studies conducted by Scherer, Scherer and Fagerlin (2014) and Yu (2012). It is interesting to note, Laranjeira (2013) claimed that metaphor can assist patients to '*symbolically control their illness'*. Perhaps a sense of control is also about having greater understanding and improved meaning making capacity, as Berendt (2008) has argued.

The correlation of control with Te Awa was not expected when initially creating this tool in 2009. Although I had not initially anticipated this, in the years that followed I was taught by the young people themselves how they strived to take back control where and when they could. As the decisions young people make when utilising Te Awa can symbolically illustrate how they choose to control and navigate their river. For example, a young woman I was supporting demonstrated the way she wanted to take control just after making her way through the initial chaos of diagnosis, as I gave my usual advice, '*to navigate the rest of her river by climbing onboard an outrigger'*. She promptly told me *'she wanted a jet-ski'* and voiced the rationale for this was to have the ability to speed up parts of the treatment process as needed. Since learning this lesson, I always ask young people to visualise what they choose to stay afloat on to navigate their river. The ability to have choice is important as it contributes to a sense of control, especially when the day to day aspects of cancer treatment are predetermined. Participants in this study also demonstrated that what they chose to stay afloat on, correlated with the degree of control and/or speed they required along their cancer path. As one participant wanted to float on an upside-down umbrella and go with the flow, while others wanted to paddle and steer their canoe, giving them the ability to try and control their speed and path. Again, this is important to the research as it demonstrates how psychologically flexible and empowering Te Awa can be.

Within the theme of 'control', a number of subthemes emerged such as 'taking control' psychologically by overcoming fear, 'letting go of control' by allowing fate to take its course, 'losing control' due to the stress of awaiting test results, or gaining control by visualising the many stages of the cancer journey and matching them to the various faces of a river.

The research highlighted numerous ways participants' 'let go of control', and ironically in doing so, at times enables them to have more control. For example, one participant found themselves unnecessarily spending time and energy worrying about relapsing, so much so it became all-encompassing. Once they psychologically allowed themselves to let go of the baggage they had carried since being diagnosed, they found they were able to emotionally and psychologically move on with things in their lives and be actively present.

For another participant, the change in their cancer prognosis symbolically mirrored a change in the metaphors they utilised within Te Awa. For example, as they gained acceptance of their changing prognosis, the metaphors they used also changed. Initially, steering to have control, but once accepting of a palliative path was able to metaphorically let go into the rivers flow. This result ties well with a previous study where palliative cancer patients also changed their metaphors as their path along the cancer continuum changed (Keim-Malpass et al., 2015). In the case of this young person whose diary excerpt was shared by her whānau, I imagined that it must have been comforting for her parents to know that in letting go their daughter had accepted her path.

Losing control was revealed throughout the data through various experiences for participants. For example, one participant experienced 'physically losing control' during a routine diagnostic procedure, leaving them acutely unwell and cascading down their waterfall to be admitted into intensive care. Upon waking, the participant discovered they literally had lost control, as chemotherapy had been initiated after whānau were asked to make treatment decisions on their behalf. However, the participant voiced, having whānau steer their boat and make treatment decisions for them, psychologically freed them up to concentrate on healing.

It has been commonly voiced to me over the years, that young people experiencing cancer find 'waiting for results' the hardest part of the journey. The emotional and psychological stress can be taxing, as they wait to learn which of the rivers in the fork they will be traversing, as these sections of the cancer journey are represented as forks in Te Awa. The research data also highlighted this; with one participant struggling at times with the 'psychological loss of control' they experienced leading up to hospital appointments, so much so, their partner could tell just by their body language when appointments were due.

Understandably, there are times when young people experience 'loss of emotional control', especially since they are at a stage in their lives where they are developmentally gaining independence and learning to take control of their lives. In this age group, just as they are starting to take charge, some are diagnosed with cancer and lose all that newly acquired control in the blink of an eye, as one word is spoken - cancer. One of the ways participants regained control was by visualising their river.

Visualisation

The impact of visualisation for young people came through positively numerous times throughout the data in two main ways; imaginal processes and tangible processes. To be able to see in their mind's eye or to draw and see on paper proved beneficial. To have the ability to visually imagine and compare their cancer treatment experiences alongside a river, helped some participants realise and understand they are not stuck with cancer forever. Just as a river flows through calm and rough patches, so too will they. Therefore, this visual image that Te Awa provides can also assist 'movement'. Te Awa is an active engaging process which can potentially help to increase and/or maintain young people's activity, whether this is psychologically or physically during a time in their lives when they could be feeling debilitated from the side effects of treatment such as fatigue.

They also used imaginal processes to ready themselves for more complicated treatment regimes, which assisted their ability to cope better during difficult times. This is similar to the practice of professional river guides, looking ahead to see if there are impending rapids approaching, setting their course to position themselves and their equipment in the most opportune place to navigate the rapids easier.

Tangibly drawing their rivers opened up another therapeutic strategy, as young people were able to process and reflect while drawing what they had been through and were currently experiencing, while also being able to look ahead and process things in the future. So much so, one participant shared a confronting night in hospital where they were compelled to draw their river and reflect on the impact cancer already had and could have on them. They voiced they found the drawing process beneficial to them, as starting this process they were feeling weighed down by everything going on for them. By the end of their drawing they were feeling better and able to see positive outcomes in amongst the challenges.

Since Te Awa's implementation nine years ago, young people have reported sharing it with whānau who found it insightful to know what they were experiencing, alongside understanding aspects occurring for them. For example, a young lady many years ago voiced "*I used my river journey to explain to my Mum why we've had some of the reactions we've had from people we knew – and why they acted the way they did*". Participants in this research also shared Te Awa with their whānau and friends, and as the data showed they also benefitted. Te Awa aided communication amongst participants and their whānau who gained understanding and insight into the impacts a cancer experience had on their young person. Therefore, this aspect of the metaphorical conversation is really important, as most people have experienced the changeable climates of rivers, its twists and turns, caves and rapids but thankfully will never personally experience cancer. It can be generally hard talking about cancer with people, let alone discussing this with your own child, but Te Awa gives young people a 'shared language' to use with their whānau, giving them a 'shared understanding' to express emotions and experiences they are dealing with, which in turn can ease discussion for both the parent and young person. As demonstrated recently within a bereaved Mum's card I received, *'Thank you for being in your waka and allowing *John to paddle his own… Lastly, thank you for coming over the waterfall with us.'* This Mum was able to use the language of Te Awa to relay her thoughts and emotions. The ability to visualise, using the metaphor of a river, has assisted young people and their whānau to psychologically better understand various aspects and impacts cancer treatment can cause, enabling them to ready themselves physically, socially, psychologically and emotionally.

It is clear that using Te Awa through a cancer journey has benefits for the young person and their whānau and friends. Participants also provided feedback on aspects of Te Awa that they thought could be enhanced. Their feedback has been gratefully received and merged with feedback previously gained from other young people over the years to guide the development of this tool.

Assistance ‘to’ Te Awa

Within the theme Assistance to Te Awa there are a number of aspects to be discussed which are, ensuring a patient centered metaphor, considering the timing of its introduction, and taking ownership of Te Awa.

Patient centered metaphor

One participant’s feedback reflected what the literature revealed (Penson et al., 2004; Stott et al., 2010), that metaphors can be patient specific. Initially I was disheartened to learn Te Awa did not work for this participant, but on reflection was thankful they felt comfortable to give me honest feedback. For this participant, while not dismissing the utility of Te Awa found another metaphor better fitted her experience. Nevertheless, she did use Te Awa to support other people with cancer, while noting to explore what the specific interests of the young person are such as sporting metaphors.

Over the years I have wondered if Te Awa could have a negative effect for young people with water fears, such as a near drowning experience or the loss of a loved one to drowning. While this has not occurred, I am mindful that it could be a possibility. However, when talking about Te Awa several years ago with one young man, he did say “*I used to like waterfalls*”. Therefore, when introducing this tool, I am learning to ask if people have any previous concerns or fear of water, so I can be sensitive to their needs and experiences.

Timing

Several participants voiced Te Awa did not sink in for them initially, not until later down the river when the current became rough. I recall hearing this and originally feeling dismayed; but after some reflection realised this was a strength as these young people had Te Awa at the ready and able to use as needed. For example, if they were approaching a difficult section in their cancer journey by metaphorically ‘hitting a rock’ and acquiring an infection, they may not have managed to navigate this as well without psychologically knowing that Te Awa’s current is always flowing and they will get passed this. Nevertheless, it reminds me to not to assume that the metaphor is making sense at the initial time of relating it to the young person. One of the participants also talked about being introduced to Te Awa at a time when she was exhausted from chemotherapy and therefore unable to take the ideas on board. This is similar to the stress that people are experiencing when first given their diagnosis and may also be a limitation to understanding.

Some participants thought that having pictures of different things to float on could be helpful when people were unable to imagine one themselves either because they were too tired or overwhelmed, or because they were unfamiliar. This may also be useful for other aspects of the river though correspondingly it seems important that people use their own imagination to develop their story and to own it.

Owning Te Awa

When I listened to the participants’ interviews and heard how they were using and sharing Te Awa this demonstrated to me that young people saw value in using Te Awa. They chose to pick Te Awa up and use it to assist them to make sense of their cancer journey. To formally learn that I had provided young people with a useful tool, in which they took the opportunity to use and assist them to navigate a cancer journey, was awe-inspiring. Not only this, they found it of such value they willingly shared it with others, who also found it beneficial.

Summary

This chapter has discussed the findings of the research, in conjunction with the literature reviewed and previous anecdotal findings. The following chapter discusses the strengths and limitations of the research, and the implications for practice and recommendations for health professionals of using Te Awa.

Chapter 6: Conclusion

This research set out to answer the question, ‘How does the metaphorical conversation Te Awa assist young people to traverse their cancer journey?’ The primary aim of the research was to find the answer, by analysing if and how young peoples experiences of Te Awa assisted them to traverse their cancer journey. The secondary aims were to incorporate participants’ experiences into the tool to enhance Te Awa and inform health professionals of the research outcomes so they may enhance their practice when working with young people diagnosed with cancer.

The study was conducted by utilising thematic narrative analysis using Braun and Clarke’s (2006) step by step guide (Table 1) in conjunction with Owen’s (1984) thematic analysis criteria. Semi-structured face-to-face interviews with five young people were conducted, along with obtaining one written reflection and one palliative diary reflection. The research findings clearly indicated that the young people in this research found Te Awa useful in unique and various ways, particularly by gaining understanding of their journey and by finding and relinquishing control.

This study is a small qualitative study conducted in one geographical area and as such cannot be generalised to other populations of young people diagnosed with cancer or other life-threatening illness. Research using a different methodology may have determined other findings. However, this research has contributed to the limited body of knowledge that currently exists for young people with a cancer diagnosis when using metaphorical strategies. It has done this by confirming some of the available literature for this population and by developing new insights. Further research may uncover other as yet unknown aspects of using metaphorical conversations.

The research contributes to the extremely limited pool of research by showing that metaphors can be a valuable adjunct to working with young people diagnosed with cancer. Te Awa does this by providing a succinct way for young people to process information and finding ways to make sense of cancer. This research also confirmed the literature by highlighting the benefits of the team metaphor, as fish were the participants’ metaphorical supports. Using Te Awa provides strategies for young people to cope with the ways their peers construct cancer and the effects this can have on the young person experiencing cancer.

Te Awa assisted participants' ability to gain an understanding of how cancer can holistically impact their lives. Within the chaos of cancer Te Awa also provided a simple, succinct and user-friendly vision helping participants navigate and understand complex treatment paths. The metaphorical conversation provided a tool to reflect, which also helped participants understand what was important to them in their lives. Reflection is a key quality of Te Awa, as navigating a cancer diagnosis is physically and psychologically draining, therefore being aware of priorities can help channel limited energy sources.

A valuable and surprising finding, which helped highlight the power of metaphor, was the importance of hope for young people, and the way that Te Awa supported hopefulness along the entire cancer continuum. The literature around hope is somewhat contradictory but as Wiener et al. (2015) advised oncology health professionals need to continue the practice of hope. The research findings also emphasised Te Awa's ability to provide social and psychological versatility and flexibility to suit people's individual needs, allowing young people to tailor their river to match their unique cancer journey. No two rivers are the same and likewise no two cancer journeys are the same.

The ability for participants to have some form of 'control' proved to be a pivotal aspect of Te Awa. Potentially this may be the one place young people feel they can have control or can take back control in their lives some way. The ability to have choice which Te Awa provides is important to this sense of control, especially when the day to day aspects of cancer treatment are predetermined. Again, this is an important finding as it reinforces how psychologically flexible and empowering the metaphorical conversation of Te Awa can be.

Participants also have assisted the ongoing development of Te Awa with their feedback such as being open to using young people's metaphors. It is also important to understand that metaphors may not immediately be of value, but the tool once shared is always available when needed. Finally, once shared, the story is no longer exclusively yours, it is theirs to adapt, change and enhance.

The research based on the general cancer population regarding the use of metaphors suggests that they support communication between the patient and health professional and therefore aids decision making. The findings of this research support that view as being relevant for young people with cancer as well. From my experience of using Te Awa it has supported me to have open conversations about aspects of cancer care the young person may have normally avoided.

Over time I have learnt that Te Awa has assisted young people's lives in a variety of ways, ways I could never have imagined. I told a story using the metaphor of a river to try and assist young people facing a very serious and life threatening disease how to understand the cancer journey in a very quick and succinct way, as time normally is of the essence. Te Awa was shared to give young people an idea of what they were about to experience and deal with physically, spiritually, socially and psychologically during their cancer treatment. I shared a story with young people not realising how Te Awa would impact and assist them to get through one of the hardest times of their lives.

My challenge for fellow colleagues and researchers to come is to be receptive and listen to the metaphors people bring to their health journeys. Try to integrate them into discussions to assist understanding, find a mutual metaphor if the initial metaphor is not conducive to both parties. Seek metaphor/s to incorporate and enhance your clinical practice, experiment with them and actively take notice of the way it opens up conversations. Lastly, be ready to enhance people's ability to take more control and understanding of their health care.

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Appendix A Overview of Te Awa

Beginning the journey on 'Te Awa'

Young people are introduced to me, the Adolescent and Young Adult Cancer Service Clinical Nurse Specialist as close to diagnosis as possible, this may be through a variety of pathways. The pre-existing hospital pathways include young people presenting acutely to an emergency department, needing scans and tests before being referred to a cancer specialist, or being referred to the District Health Board (DHB) via their general practitioner for specialist input, after presenting over various lengths of time with concerning symptoms. Young people have even come through the not so conventional paths such as the young person's optometrist or osteopath when seeking relief from concerning symptoms. I have also initiated referral pathways through partnerships with Child Cancer Foundation, CanTeen, Leukaemia and Blood Cancer Foundation, as well as other senior cancer nurses, health professionals and specialty wards. By the time young people are introduced to me they may have been navigating a turbulent river for a substantial period of time and living with waves of emotions including fear and uncertainty. Ironically for some, to be told of their cancer diagnosis can come as a relief as they now have something to focus and work on. A therapeutic relationship is developed through engaging, connecting with and educating the young person and spending time with them in person or via the phone, finding out their interests and what makes them the young person they are. At this time 'Te Awa' is introduced and time is spent explaining the storyline of how 'a river' is likened to 'a cancer diagnosis'.

The Waterfall/diagnosis

The young person is then asked what signs and symptoms their body displayed prior to their diagnosis. For example, frequency of bruises, stubbed toe that wouldn't heal, the gradual decline in ability to finish their usual run in the timeframe they normally do or a neck swelling rationalised as a rugby injury.

They are also asked how and from whom they came to learn about their cancer diagnosis, for example their general practitioner or physiotherapist. The young person's information is then incorporated into a story and I narrate back to them how their river started (aka life before illness). The story may begin like this: the young person was travelling along their smooth flowing river, the sun was shining and the birds were chirping when their river started to get rough (due to the signs and physical symptoms they were experiencing). During this period the young person may have sought various therapeutic supports such as their physiotherapist or visited their general practitioner for symptom relief, which may have caused their river to flow more softly, but an increase in symptoms may have led them to seek support again. Eventually as symptoms exacerbate and/or tests results return, the forceful flow of the river leads them over the side of the waterfall, symbolising the young person being told of their cancer diagnosis.

The Fish/supports

The conversation is paused just before they go over the edge of the waterfall and the metaphor of fish in the river is introduced into the storyline. The fish represent the support systems the young person has around them such as whānau, friends, church groups, and sports teams. At this time young people are educated and given advice around coping with different reactions their supports may display. For instance:

- Some fish will go over the waterfall with the young person giving them their full support.
- Some fish can do a U-turn never to be seen again. This can be explained to the young person that the support person may have had previous experiences of someone close to them having a difficult time with cancer/illness and for some people it may just be too challenging for them to provide support, so they make a U-turn and back away.

- Other fish may follow at a later time, once they have come to terms with what is happening to the young person, their diagnosis and how they are personally going to react when they next see the young person.

A number of young people have already gone over the waterfall (learnt of their cancer diagnosis) by the time I meet with them, and if willing share their experiences of the fish (support people) in the river, and if they have had any fish fade away. If whānau are present during this part of the discussion they too often share their experiences of fish who have supported them and experiences of those who have chosen to swim away. From my experience, this section of the story can be more emotional for support people to discuss and time is taken to offer support.

The storyline is then restarted and acknowledgement is given to the psychological and emotional impact that can occur for young people and their fish when going over the edge of the waterfall (receiving the cancer diagnosis). At this point it is reiterated that it can be normal for people to find it difficult to take in information once given their cancer diagnosis. The importance of having a support person to attend clinics with them is encouraged as information retention can be difficult. I also inform young people that I am available to support them and their whānau during appointments.

Some young people reflect on the time they were told of their cancer diagnosis and how it was a very scary and life changing moment. I relate this feeling to the pressure of the water pushing them under at the bottom of the waterfall, and despite this being overwhelming at times assure them of how they re-surface with the assistance of their fish (their whānau and supports).

At the bottom of the waterfall we discuss how upon emerging to the surface they will find other fish waiting to support them, such as extended family and distant friends who want to be more present after learning about the young person’s illness. Acknowledgment is given as to how all this new support can be overwhelming, physically draining and emotionally exhausting as the young person is still coming to terms with their cancer diagnosis. Constantly repeating and updating support people and dealing with their emotions can become an additional burden for young people. At this time I share ideas and tips that have been passed on to me from previous young people in regards to managing this extra support and attention, such as: communicating and updating people via face book, or by enlisting the support of close whānau to be their ‘personal assistant’ to take phone calls or texts.

Education is given around other fish (supports) that are in the community. These can range from CanTeen, Child Cancer Foundation, Leukaemia and Blood Cancer Foundation and various counselling services, with prioritisation of referral to these supports in partnership with the young person. Numerous services making contact all at once can be overwhelming. Hospital services from clinic/ward nurses, doctors, dietitians, social workers, Kaitiaki (cultural support workers) and physiotherapists are also at the bottom of the waterfall to give support.

Once brought to the surface by their supports, attention is given to the fierce flow of the river and how the sides can appear to be so steep and seemingly impossible to climb out. This phase can be known as the ‘I don’t want to have cancer!’ phase. It is also where ‘information overload’ occurs when they are learning of their cancer diagnosis, the baseline tests required, what treatment they will need, the side effects and the duration of the treatment. The young person is educated and advised about the best flow and direction (treatment path) to take. At times young people like to investigate other river flows, for example; complementary or alternative medications such as Māori medicine - rongoa or herbal medicines and are supported during this process.

Settling into the flow of the river

From here I invite the young person to take over the process of being the main narrator, whilst I remain in the background as a co-narrator/navigator. All the while the young person is experiencing and living their cancer journey, they are producing their story of their cancer experiences using the metaphor of 'Te Awa' to assist understanding.

I support the young person for the entire time they are navigating the river, no matter which way their river flows. The river can start to ease once they have been tossed out of the rapids; this is in regards to the young person becoming accustomed to their treatment, timetables, appointment dates, having bloods and scans taken, chemotherapy/radiotherapy and the many other aspects of treatment.

We acknowledge that clinic appointments can be daunting due to the uncertainty of how their cancer is responding to treatment and which way their river will flow. They may be responding well and continuing on the initial treatment plan (staying on the same river) or not responding and needing to change the treatment plan (veering down another river). Strategies are worked through with the young person to assist them in recognising and coping with stress, and dealing with anxiety.

During this time emphasis is placed on assisting the young person to equip himself or herself with the right boat or waka that suits them to navigate the rest of their journey. Time is taken here for the young person to choose some type of floatation device, and they are encouraged to go with what feels right no matter the size or form. This process can be fun and enlightening with laughter shared when reflecting on the choices made. This places them in a position of having some control, in an otherwise out of control journey.

Depending on which route their river takes them, they are continually supported, whether they travel through to the palliative phase or onto the support and rehabilitation phase.

Ascending/Palliative phase

If the treatment pathway for the young person is **palliative** I continue to support them and their whānau, alongside palliative care services, Hospice, district nurses, GP and various non-government organisations involved to ensure their individual needs are catered to. Initially in having introduced Te Awa to young people, flowing out into the ocean metaphorically represented palliation however, after some reflection this was changed to the young person ascending upwards, enabling them to elevate to wherever or whatever they believe occurs after passing away.

Reminder of other fish available/Support, Rehabilitation and Prevention

In the **support and rehabilitation** phase the focus is on getting the young person back to their 'new normal' life which may be back into school, university studies, or work. Sometimes a side effect of navigating a river has young people reflecting on their previous career pathway and considering a new line of work or study. After treatment young people may have to contend with acclimatising back into social networks with those who have not had to face a life threatening disease, whilst the young person's perspective on life may have changed significantly as a result of facing their own mortality. Some young people find it too cumbersome and find a whole new group of friends. Fatigue is also a very common concern for young cancer patients to deal with. This part of their journey may be represented by caves where experienced cavers (health professionals, counsellors, support groups) assist young people to navigate their river out into the open air.

Reinforcing dams /Prevention

Prevention education is incorporated from the beginning of treatment (see Fig.2), unlike the initial cancer continuum (see Fig.1), as young people are educated how to assist themselves to prevent or reduce the likelihood of other cancers such as lung cancer; young people are provided with smoking cessation education, or melanoma; sun smart education is given. These prevention strategies are represented as dams in the young person's rivers, some dams may only need reinforcing, whilst others may need to be erected.

Strengthening dams/Research

Likewise **research** is incorporated from the beginning of treatment (see Fig.2) and the young person is educated about how research is an integral part of the entire river (cancer journey), and informed of relevant clinical trials available for them. For example, clinical trials, health promotion and, fatigue management.

Estuary/Surveillance

From here the river flows onto **surveillance** which is known as the 'estuary'. The narrow river the young person has been used to traversing now opens up and they are pushed out into the wider estuary, signifying the frequent clinics, blood tests and scans they had become accustomed to will now be less frequent and spaced out every three or more months. At this stage where clinics are further apart, it can be just as daunting as the waterfall for some people, as they may have become accustomed to and reassured by frequent visits and monitoring by their health team. Emotions that have been suppressed have time to catch up with them as the river flow slows and they are able to reflect and look back up stream to review the waterfall/s, the rocks, the swift river flow and caves they have overcome. Counselling is re-offered and reflection on which coping strategies they found helpful earlier on in their journey are re-engaged, enhanced and added to.
For **surveillance** the young person is educated around the specific requirements they need to do post treatment; scans, blood tests and appointments for a recommended period of time to monitor for relapse and treatment side effects.

Erecting dams/Screening and early detection

In terms of **screening and early detection** the young person is educated right from the start about the importance of screening and early detection for other cancers. For example, young people are encouraged to have cervical smears or testicular checks, breast self-examinations and mammograms at an earlier age as opposed to their non-cancerous counterparts, especially if they have had radiation near breast tissue, as this tissue can become more prone to developing another cancer.
Anxiety at this stage is common, and the young person is educated on how to access services if they have any concerns. If relapse occurs whilst they are under 24 years of age the young person's clinical nurse specialist is there to support them, as they prepare to go down another waterfall. If they are over 24 years of age and relapse, the nurse informs the young person of other nurses and services available to support them.

Ocean/Survivorship

Once they have completed their follow-up the young person flows out to **survivorship**, which is represented by the sea. They are encouraged to set sail and venture out into the seven seas and if there are any concerns in the future they are educated to seek their general practitioner's (GP's) input. Anxiety can resurface for young people when thinking about setting sail into an expansive ocean, as the fear of not having regular oncology/haematology reviews can be extremely daunting. However, young people are taught to check their chosen floatation device for the necessary safety equipment to withstand exposure to the natural elements, in other words young people are taught what signs and symptoms to watch for and where to access support. Young people are reminded that their oncology/haematology service and nurse are always there if they need assistance in the future.

It appears that Te Awa can assist young people, their whānau and friends to talk about any concerns or issues they have, and helps to recognise the various ways people cope with adversity. Utilisation of this tool can help them recognise and acknowledge the various ways they and others cope emotionally and physically when encountering adversity, to also understand how to deal with the emotional reactions they may encounter while navigating a cancer journey. Young people learn how to process health information and advocate for themselves during the illness experience. Te Awa also teaches young people, their whānau and friends how to deal with loss of friendships, manage changes within social relationships and life management skills.

Appendix B Anecdotal Feedback

Feedback has been collated since Te Awa’s inception, with some having been presented at various conferences to highlight the benefits of utilising this metaphorical conversation with young people traversing a cancer journey.

Feedback received via email, text or conversations:

“Ellyn, Our waka is sailing on really rough water at the moment, and many of the fish are swimming out of range.... we are hoping for smoother sailing soon.”
Mother of 15 year old

A Mum said “I’ve been telling other Starship parents your river analogy and they had found it comforting... just thought you might like to know.”
Mum of 13 year old

“I used my river journey to explain to my Mum why we’ve had some of the reactions we’ve had from people we knew – and why they acted the way they did”
Anna* 23 yrs

“Where am I on my river journey now?”
Sarah* 25 yrs

“Helps things stick and you can visualise it – so it’s easier to remember”
Joe* 23 yrs

“I can’t wait to smell the salt sea air!!!”
Tiria* 20 yrs

“I used to like waterfalls”
Sam* 24 yrs

Feedback received via a card:

‘Dear Ellyn,

Thank you so much for your support over the last eight months, it really means a lot to me. I’m so fortunate to have had you with me along this river journey. You’ve been one of the most helpful fish! For that I’m so grateful.

Much love,
Julie*’

Feedback received via a reflection written up in the CancerNet magazine:

Sweet Louise Support Coordinators attended the 10th National PONZ Conference (Psychoscial Oncology NZ) 18/19 November in Hamilton.

Mid Central SSC Geraldine Carswell writes about her experiences there.

The Conference theme was 'shaking up Psychosocial Oncology practice, practicalities and possibilities' with an overall objective of promoting the development of a national framework for the provision of services that address the ethical and culturally appropriate issues and concerns of patients and their families during their experience of cancer care.

PONZ's mission is to be 'a national multi-disciplinary focus for the support, promotion and advancement of psychosocial oncological developments amongst the range of health professionals working within, or supporting, oncology and palliative care services in NZ.' PONZ is there to 'support professionals as they deliver integrated health care services adapted to the psychological, social, spiritual and physical needs of people with cancer and their family/whānau.'

Among the presenters this year was Ellyn Proffit (Clinical Nurse Specialist, Adolescent and Young Cancer Service, [redacted] DHB) and I was particularly impressed by her presentation entitled Te Awa – The River where she used the analogy of a flowing river to help young people and their families talk about different aspects of their cancer diagnosis. Ellyn writes, "These aspects can range from coping with the impact cancer has on relationships and friendships, treatment pathways, emotional and psychological coping along the cancer trajectory."

I understood how Ellyn's analogy of the cancer patient journey as a flowing river could help identify feelings and emotions. She related how a river can be fast and furious with many rocks, rapids, whirlpools and waterfalls to navigate (times of treatment, illness or results) or calm and gently flowing (times of wellness). Fish (people) swim along, some may do a U-turn upstream never to return or perhaps will meet you later downstream while others swim along with you unfailingly. At times the river may have very steep sides with nowhere to go except 'with the flow' or perhaps it feeds out to an estuary and out to sea (signifying death). She views the whole process as cyclic and a great way for young people to be able to express where and how they are feeling, e.g. "hit rapids at last Dr consult."

I am very grateful to have been able to attend this conference and found it very valuable and beneficial. The sessions have helped improve my understanding of the many aspects of the cancer journey and the experiences individuals go through and has reiterated that health professionals must never assume they know what patients want or need. It also heightened my awareness of 'language' and how important this is – for example, not everyone may wish to seen as a 'survivor' and it is heartening to know that research and development is ongoing.

Appendix C DHB Approval letter

[redacted] DHB Approval of Research

RD015066	Does the metaphorical conversation Te Awa assist young people to traverse their cancer journey

Project Personnel

Principal Investigator:	
Waikato DHB investigators:	Ellyn Proffit 021 233 6145 Ellyn.proffit@waikatodhb.health.nz
[redacted] **contact name and details:**	Ellyn Proffit [redacted]

Date Submitted:	09/07/2015
Type of Project:	Observational: qualitative/epidemiological
Multisite?	Not a multi-centre project.
Department:	Oncology
Service:	Oncology

Project Description:

Start: 9 July 2015
End:
Sample Size: 5-6

The proposed study will work alongside AYA's (adolescents and young adults) by using a narrative methodology to critique the metaphorical communication tool that young people diagnosed with a cancer in the Midland region are introduced to by the Clinical Nurse Specialist of the Adolescent and Young Adult Cancer Service.

Clinical Nurse Specialist will work with CanTeen Waikato to access participants. CanTeen Waikato have consented to this and also being able to use facilities to interview AYA.

Since the inception of this tool, the Clinical Nurse Specialist has received anecdotal evidence from AYA, their partners, families and health professionals of the experienced and perceived benefits 'Te Awa' can pro[redacted]nd the various aspects of the cancer journey. An aim of this research is to gain formal feedback to show if this is still the current experience of AYA.

[redacted] [redacted]

Waikato DHB research approval form V3 January 2013

Management and Resource Sign-offs

This study does not require HDEC review. (University Ethics).

Locality Review – *the undersigned agree to the following statements:*

- The study protocol and methodology are ethical and scientifically sound.
- This researcher has identified that this study does not require Health & Disability Ethics Committee (HDEC) review.
- The local lead investigator is suitably qualified, experienced, registered and indemnified.
- Resources, facilities and staff are available to conduct this study, including access to interpreters if requested.
- Cultural consultations have occurred or will be undertaken as appropriate
- Appropriate confidentiality provisions have been planned for.
- Appropriate arrangements are in place to notify other relevant local health or social care staff about the study, and for making available any extra support that might be required by participants, where relevant.
- Conducting this research will have no adverse effect on the provision of publicly funded healthcare.
- There is a stated intent that the results of the study will be disseminated and where practical and appropriate the findings of the study will be translated into evidence based care.

Queries about this research must be made to the Primary Contact person listed.

Dept/Service/ Org	**Role**	**Name (print clearly)**	**Signature**	**Date signed**
Oncology	Director	Amanda Wright	Gabby Reynolds (Discussed c̄ Amanda)	23/10/15
			Nurse Manager Oncology.	
Te Puna Oranga	Service Development Manager	Millie Berryman	MBerryman	21-10-2015

Clinical Support Services Sign-offs

CROSS OUT/ADD SIGN-OFFS APPLICABLE TO THIS PROJECT

SIGNATORIES DECLARATION: We agree that appropriate resources are available in our service to support this project

Clinical Support Service	Name (print clearly)	Signature	Date signed
~~DHB Pharmacy~~	~~Rajan Ragupathy~~		
~~Laboratory~~	~~Kay Stockman~~		
~~Radiology~~	~~Dr Muthu~~		
~~Medical Records~~	~~Marilyn Hunt~~		

Please return to the Research Office (via Sarah Brodnax, Menzies L9) along with required documents as identified in the checklist for final approval.

Office use only:
Quality & Patient Safety, [redacted] DHB

Signature:

Date: 4/11/15

Name: Mo Neville

Position: Director Quality & Patient Safety

Appendix D DHB Research Review

Waikato District Health Board

[redacted] Consultation Research Review Committee
[redacted]

25 September 2015
Ellyn Proffit

Re: Māori Consultation for “RDO15066”

Tēnā Koe Ellyn,

Thank you for submitting the above research proposal to the [redacted] *DHB* [redacted] *Māori Health Research Committee for Māori consultation.*

The Committee has reviewed the research application form and acknowledges the effort you have taken to consult with and include Māori in this research to improve health outcomes for Māori and to reduce inequalities.

1. The Committee encourages the research team to collect ethnicity data as part of a demographic background of the participant. Ethnicity is an important determinant of health independent of age and socio –economic position.

2. It has been stated in the research application that there are no known inequalities in this area of research however not monitoring health care by ethnicity risks increasing inequalities.

3. The Committee encourages the research team to aim to actively recruit equal numbers of Māori and Non Māori participants in this research, which is more likely to contribute to the reduction of health inequalities for Māori. The Māori participants would require sufficient face to face time with the researchers for informed consent to participate in the research. Inclusion of the whānau of the Māori participant is also encouraged to enable fully informed consent.

4. If cultural issues arise for the Māori participant during this research, they will inform the research team during the study that cultural issues have arisen. Cultural issues may not be obvious to the participant or the researcher prior to starting the research.

5. The Committee encourages the research team to continue to consult with [redacted], Māori Health service, should they have any further queries.

M M Berryman

Millie Berryman
Pou Whakahaere
[redacted] Māori Health Service
[redacted]

Appendix E Institution ethics approval

Wintec
WAIKATO INSTITUTE OF TECHNOLOGY
Te Kuratini o Waikato

Date: 28th of September, 2015

Name: Ellyn Proffit

Dear Ellyn

HUMAN ETHICS RESEARCH APPLICATION
Title: How does the metaphorical conversation Te Awa assist young people to traverse their cancer journey

Thank you for you application which was considered at the Human Ethics in Research committee meeting held on the 17th of September 2015. It is with pleasure I advise ethics approval for your project is granted.

Ethical approval is granted until the 31st of March 2016 or until the project has been completed, whichever comes first.

Please note that should there be any changes to the approved research project then it will need to be referred back to the committee for further consideration.

The Human Ethics committee wishes you every success with this project.

Kind regards

Dave Snell
pp Dr Bryan Bang
Chairperson
Wintec Human Ethics in Research Committee

Cc Supervisor

Appendix F Approval from Canteen

From: [redacted]
Sent: Monday, 7 September 2015 10:26
To: Ellyn Proffit
Subject: Consultation for Masters

Dear Ellyn
Thank you so much for attending our [redacted] Branch committee meeting on July 5th 2015.

I am pleased to confirm our committee has offered you the use of our facilities including the office rooms and access to our membership for the purpose of your research along with their support in obtaining participants.
We understand that these participants will be secured through information fliers and/or workshop and CanTeen staff will make themselves available to assist your endeavours.

On behalf of our membership, I would like to take this opportunity to thank you for considering CanTeen in your research that will in turn benefit our AYA.

Best wishes
Charlene

Charlene Bowie
YW-MS

M [redacted]
DDI [redacted]
E charleneb@canteen.org.nz

[redacted]

T [redacted]

www.canteen.org.nz
www.facebook.com/CanTeenNZ
www.twitter.com/CanTeenNZ

Appendix G Invitation letter from Canteen

Dear Member of CanTeen NZ,

Please have a look at this great study that Ellyn is doing.

She would really appreciate your input into Te Awa - the river discussion.
Ellyn will be able to learn from the experiences you share, so she can support others on a cancer journey.

Check out the information page attached, her contact details are there.
Please get in touch with her within the next week.

I really hope you take this opportunity to help other people like yourself!

All the best,
Char

[redacted]

Appendix H Participant information sheet

Wintec
WAIKATO INSTITUTE OF TECHNOLOGY
Te Kuratini o Waikato `

Wintec Research Office

Information Sheet (for participants)

The project:

How does the metaphorical conversation Te Awa assist young people to traverse their cancer journey.

Who is working on the research project?

Ellyn Proffit – Clinical Nurse Specialist: Adolescent & Young Adult Cancer Service.

The purpose of the research project:

The proposed study will work alongside AYA's (adolescents and young adults) by using a narrative methodology to critique the metaphorical communication tool that young people diagnosed with a cancer in the [redacted] region are introduced to by the Clinical Nurse Specialist of the Adolescent and Young Adult Cancer Service.

The Clinical Nurse Specialist will work with CanTeen [redacted] to access participants. CanTeen [redacted] have consented to this and also consented for the CNS to use their facilities to interview AYA.

Since the inception of this tool, the Clinical Nurse Specialist has received anecdotal evidence from AYA, their partners, families and health professionals of the experienced and perceived benefits 'Te Awa' can provide to understand the various aspects of the cancer journey. An aim of this research is to gain formal feedback to show if this is still the current experience of AYA.

What is expected of participants?

To share your thoughts and stories of the conversation tool: Te Awa – The River via an informal interview process.

How long it will take?

45 – 60 mins

Where will the data be collected?

The data will be collected at the CanTeen – [redacted] Branch Office

What will happen to the information provided?

The stories will be collected and analysed for various themes and threads that come from the interviews – and then collated and reported.

Is it compulsory to participate?

No, you can choose to take part in this research.

Can participants withdraw and how?

At any time you can withdraw without having to give a reason, either by informing the researcher, or the CanTeen Youth Worker via text, phone call or in person.

How is participants' privacy protected?

Your name will be removed from all the information that you provide during the research. The information you give will be kept strictly private and confidential.

Will participation be acknowledged and how?

Acknowledgement to participants will be made in the acknowledgement section of the research dissertation.

The results of this research may also be presented to other health professionals working with AYA's with Cancer both within New Zealand and internationally, and acknowledgement will be made here also.

Where can research results be found?

A copy of the research dissertation will be held at the [redacted] DHB Library, the Wintec Library and at the CanTeen – [redacted] Branch office.

The results of this research may be presented to other health professionals working with AYA's with Cancer both within New Zealand and Internationally.

If you have further enquiries please contact the researcher on:

Name of Researcher: Ellyn Proffit

Contact Details: 021 223 6145 ellyn.proffit@waikatodhb.health.nz

Date: 05/09/15

Appendix I Consent form

Wintec
WAIKATO INSTITUTE OF TECHNOLOGY
Te Kuratini o Waikato

How does the metaphorical conversation Te Awa assist young people to traverse their cancer journey?

Participant Consent Form
(one copy to be retained by the Research Participant and one copy to be retained by Researcher)

I………………………….. (Participant's name) consent to being a participant in the above named research project, and I attest to the following:

1. I have been fully informed of the purpose and aims of this project
2. I understand the nature of my participation
3. I understand the benefits that may be derived from this project.
4. I understand that I may review my contributions at any time without penalty.
5. I understand that I will be treated respectfully, fairly and honestly by the researcher/s, and I agree to treat the other participants in the same way.
6. I understand that I will be offered the opportunity to debrief during, or at the conclusion of this project.
7. I have been informed of any potential harmful consequences to me by taking part in this project.
8. I understand that I may withdraw from the project at any time (without any penalties)
9. I understand that my anonymity and privacy are guaranteed, except where I consent to waive them.
10. I understand that information gathered from me will be treated with confidentiality, except where I consent to waive that confidentiality.
11. I agree to maintain the anonymity and privacy of other participants, and the confidentiality of the information they contribute.
12. I have had sufficient time to discuss my participation with family/whānau or a friend. I understand that I can have a support person with me during the interview if I would like to.

Participant…………………………………………………………Date…………..

Principal Researcher…………………………………………………..Date…………….

Appendix J Interview schedule

Research INTERVIEW QUESTIONS – NARRATIVE RESEARCH:

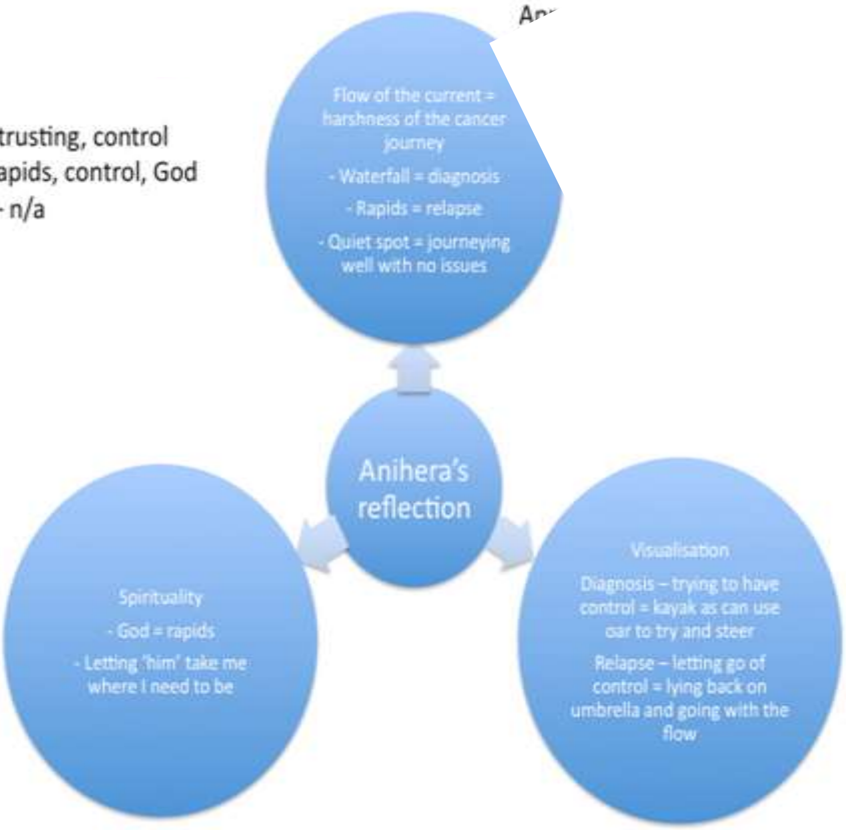
How does the metaphorical conversation Te Awa assist young people to traverse their cancer journey?

1. Tell me how you found using ‘Te Awa’ metaphor during your cancer journey.
2. How has using ‘Te Awa’ affected the way you relate to yourself, to others?
3. As you look back, what were the main things that stand out &/or come to mind when using ‘Te Awa’ metaphor?
4. Having experienced ‘Te Awa’ could you envision using this metaphor in other areas of your life?
5. Is there anything else you would like to add?

Appendix K   Example of Thematic Map

-Recurrence – trusting, control
-Repetition – rapids, control, God
-Forcefulness – n/a

Owen's 1984



Braun and Clarke's (2006)

Appendix L Participant Characteristics/Reflections

1st interview:

This young person was living independently away from home and undertaking tertiary studies when diagnosed. They had to return to living at home during treatment for support. They appeared to have good whānau support, with their parents accompanying them to treatment and clinic appointments. This AYA had to cease being involved with physical activities during treatment which limited their involvement in favored pastimes. The AYA lived relatively close to the Regional Cancer Service and had two types of treatment modalities for their cancer treatment.

This was the first interview I conducted and was nervous that I was not confident with the narrative interviewing process. During the interview I also felt conscious that I was talking too much and this flustered me as I wanted the conversation to flow and not bias the participant in anyway. The interview was conducted at their home, seated around the kitchen table. I purposefully chose not to sit directly across from the participant as I didn't want to be too in their face. The environment was nice and quiet at the home, I wasn't sure if anyone else was home however I did wonder if they felt uncomfortable as they left the front door open. However it was a warm day and may have purposefully left the door open for fresh air.
We discussed the consent process and then gave them an overview of Te Awa rekindling memories of the tool as some time had passed since we had met and used it together. While there was a danger of biasing reflections by providing this overview, it seemed important as when participants visualize traversing their river once through the initial rapids usually pick something totally different to the kayak they were thrown out of, over the waterfall. However this participant continued to navigate the cancer waters on their kayak as voiced this was a reminder of the achievement they made.

2nd Interview:

This young person started their cancer journey a number of years ago, whilst working fulltime. They appeared to have good whānau support, with partner and parent accompanying them to treatment and clinic appointments. They lived relatively close to the Regional Cancer Service and initially had one type of modality of treatment for their cancer, then required another treatment modality after relapsing.

I chose to conduct the interview in my office however this turned out not to be ideal, as I was aware my colleague would finish her meeting within the hour and didn't want her returning and disrupting the interview. This participant interviewed well considering they are quiet and reserved in general and provided education on river systems, where they geographically start and flow to. It was really interesting to hear that they wanted to get away from their supports, as felt they were too close and couldn't wait for themselves and their partner to leave their home region. Was this because they served as a reminder of their cancer journey and the participant wanted to leave this behind? They voiced that they pushed a lot of people away during treatment, as not to worry people close to them and then went onto saying they allowed them back once their health and wellbeing returned. This participant managed to use their cancer journey positively to educate their friends of the signs and symptoms of cancer. A key aspect they reinforced to me was letting me know that they wanted to be a part of this research to give back in regards to the support they received during their treatment through cancer.

Interview 3:

This young person started their river journey years ago whilst in their last few years of secondary school. They appeared to have good whānau support; with parents taking turns to accompany to treatment and clinic appointments. They lived a fair distance from the Regional Cancer Service and had three types of treatment modalities for their cancer treatment, which required involvement with two tertiary hospitals.

I was looking forward to this interview as the AYA had seen me previously present Te Awa at an international conference and prior to attending the presentation they sent a text informing me how beneficial Te Awa had been for them during their journey, and that they were looking forward to hearing the talk.

This interview was conducted at their home; initially we set up in the kitchen but decided we should move before starting, as flat mates were due home soon. The interview was conducted in the lounge and I chose to sit on the ground, not directly facing the participant to gain a relaxed feel. During the interview the AYA shared a picture (should I add it?) of their river, they had drawn whilst admitted in hospital during the middle of the night. It reflected their experiences of navigating through rough waters and the rocks they had hit along their cancer journey. Seeing this young person's drawing really amazed me, as did hearing the thoughts of the participant of 'Reflection 2' as it was surprising to learn how this model 'Te Awa' can impact on people. I use Te Awa to talk and educate AYA about various elements in a cancer journey, not really realizing how powerful or how people can own it and take it on board to make sense of their cancer diagnosis. This was valuable input for the research, as I have learnt through the young people's experiences how Te Awa works through their eyes at a very hard time for them.

The AYA also voiced they felt this tool could be used across other services such as community health services and disciplines such as social work. They also voiced how Te Awa was a great tool

4th Interview:

This young person started their river journey in many years ago, whilst working and living independently on his or her own. They appeared to have good whānau support; with parents and sibling taking turns to accompany them to treatment and clinic appointments. At one stage in the AYAs cancer journey the family moved closer for support. The AYA lived relatively close to the Regional Cancer Service and had three types of treatment modalities throughout their cancer treatment, and traversed two waterfalls as relapsed and required further treatment.

I felt this was the perfect interview in regards to literature on narrative interviewing, as it went for the 'allocated' time of an hour. I also managed to conduct the interview appropriately, being quiet and letting the participant guide where the interview went. I thought I had a good room to conduct an interview, as it was in a quiet room in the hospital however this backfired as the phone in the room started ringing during the interview for a lengthy amount of time, however the AYA managed to not let it distract them. The participant gave really good constructive feedback about Te Awa and how beneficial they had found it. They also felt it could traverse cultures without issues and can be transferred to other subjects, as they found themselves using it with others to assist them with issues such as breakups and other people's cancer journeys.

For this AYA they emphasized wanting their supports in there, on the river with them along the way. Whilst another voiced they used Te Awa "selfishly" for themselves. This is important to the research as it demonstrates the flexibility of the tool and how socially and psychologically this tool can be adapted.

5th Interview:

This young person started their river journey a number of years ago whilst undertaking tertiary study. They appeared to have good whānau support with parents taking turns to accompany to treatment and clinic appointments. This AYA had to cease being involved with physical activities during treatment which limited their involvement in favoured pastimes. They lived relatively close to the Regional Cancer Service and had two types of treatment modalities for their cancer treatment.

This was my last interview which was conducted at the hospital in a meeting room. It was a good environment as no one else would need the room so we would not be interrupted. I chose not to sit directly across from the AYA as the table was narrow but long; I didn't want to be 'in AYA's face sitting opposite'. I was excited about this interview as the AYA had been eager from the start to take part. The AYA had conducted interviews as part of a previous training course, knew what the process was like and was happy to help someone else out. The AYA voiced a number of times that she/he could do the interview at the time chosen as they didn't have anything else on that afternoon. Despite their eagerness and willingness to take part this was the quickest interview and I felt like they were trying to gallop their way through it. At the end of the interview the AYA remembered they had something to say which I thought was going to be positive. However, they reiterated that they liked a consultant's metaphor more than the one used in Te Awa, and suggested to maybe work with what the AYA brings to the table. Initially I felt disappointed, as I had hoped there was going to be a great epiphany to end. Yet, on the other hand after some reflection I was excited by the disclosure as the AYA's comments reiterated or supported what international literature was saying, to be mindful and open to using the metaphor the person uses. This was a valuable addition to the research. The ability for the AYA to give me constructive feedback also showed how safe they felt to give me this information to enhance working with AYA going forward.

1st Reflection:

This young person was living independently away from home and undertaking tertiary studies when diagnosed. They had to return to living at home during treatment for support. They appeared to have good whānau support, with their parent accompanying them to treatment and clinic appointments. The AYA lived relatively close to the Regional Cancer Service and had to have two types of treatment.

This meeting I met them at their home and I talked to the AYA about creating a piece of reflective writing as opposed to an interview as I had a number of participants respond to my requests for participants. I was advised to limit the number of participants as there would be too much data to manage however, I wanted to acknowledge and respect each AYA's input as they had taken time out of their lives to take interest and make contact to be apart of this research. We discussed the consent process and then gave them an overview of Te Awa rekindling memories of the tool as some time had passed since we had used it together. While there was a danger of biasing reflections by providing this overview, it seemed important as participants talked about the side effect they experienced around their cancer journey. This information was also important, as I had never heard any other AYA talk about this effect that is written about in the international literature, relating to the side effects of treatment and referred to as 'chemo brain'.

2nd Reflection:

This young person started their river journey a number of years ago whilst in their last few years of secondary school. They appeared to have good whānau support; with parents taking turns to accompany to treatment and clinic appointments. They lived relatively close to the Regional Cancer Service and had two types of treatment modalities for their cancer treatment, and relapsed a year into their journey requiring further treatment.

This young person sadly passed away, ascending skywards from their river journey. One of their parents sought my consent to share their young person's Te Awa reflection at their funeral. I voiced this would be an honour; thinking it would be a couple of sentences however it turned out to be three paragraphs of reflection.

I was really overwhelmed and amazed to hear and learn how this young person took this 'tool' I shared with them at various times throughout their cancer treatment and discover how Te Awa had impacted their lives and thoughts, especially at such a crucial time as a relapse. To think this young person took time out to reflect and write a journal entry about their Te Awa; hit me how powerful this tool can be. Especially when I shared with my manager about this reflection and I was told how powerful this would have been to the AYAs parents to know that their young person was open to 'going with the flow' with whatever lay ahead of them.