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**Complementary and alternative
medicines for cancer treatment – a
patient perspective**

A thesis presented in partial fulfilment of the
requirements for the degree of

Masters of Science

in

Health Psychology with endorsement
at Massey University, Palmerston North,

New Zealand.

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2017

Abstract

Current research shows people diagnosed with cancer have a strong interest for complementary alternative medicine (CAM) to be an option for either sole treatment or used alongside conventional methods. This qualitative study aimed to investigate the attitudes of a sample of cancer patients to establish why they use CAM and explore their beliefs on the benefits (if any) they have from receiving this treatment. It is hoped that the current study will add to the limited CAM literature from Aotearoa.

The findings presented in this study arise from the thematic analysis of semi-structured interviews with five participants. They included adults diagnosed with any type of cancer who were currently undergoing, or had undergone either CAM treatment or a combination of CAM and mainstream treatment. The interviewees openly discussed their cancer journey and from these deliberations the five main themes found were: decision; empowerment; holistic; wellbeing; and social harm. While there were similarities found with other studies regarding why patients chose CAM, the thesis also discovered the participants were now wanting to share their information and experience with others considering CAM for cancer treatment, but did not know how.

Acknowledgements

I would like to thank my supervisor Dr Natasha Tassell-Matamua for her guidance, advice and support throughout this process, especially pushing me through the disrupted period of finding participants. Your professionalism and dedication during this project was remarkable. Particularly while on leave from work and still remaining committed to ensure the completion of my research. You are amazing! Your knowledge and expertise was gratefully appreciated and made the writing of this thesis less arduous. I would also like to thank Professor Kerry Chamberlain for your recommendations. The assistance you provided through the initial stages of the project was valuable and very helpful.

Thank you to the people who volunteered to be part of this research. Your willingness to come forward and share the difficulties you have, and are experiencing was extremely humbling and very sobering. The courage you all demonstrate with not only fighting the disease, but the battles you have faced along the way are truly inspiring.

My very appreciative thanks to my children, Caitlin, Georgia and Mathew who have picked up the slack around the home while their mother has been preoccupied. To my incredible husband, Ewen who has been my rock during this whole journey. Without you, I would never have been able to achieve to this academic level. Thank you for believing in me, your amazing patience and being 'Mr Mum'.

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CHAPTER ONE: OVERVIEW OF COMPLEMENTARY ALTERNATIVE MEDICINE

Complementary alternative medicine (CAM) has received increasing attention over the past several decades, from both a research perspective, and also as a form of treatment for a diverse range of medical conditions. But what exactly is CAM? The purpose of this chapter is to provide an overview of CAM. This will be done by firstly providing a definition of what CAM is and how the term will be used throughout this thesis, as well as a differentiation of CAM from what is commonly considered to be ‘conventional’ medicine. Because of the diversity of approaches that fall under the umbrella of CAM, a delineation of the five major CAM treatment modalities will be provided. To conclude, a summary of the chapter will be given.

1.1 Defining CAM

*The tawny colored, and the pale, the variegated and the red,
the dusky tinted, and the black – all Plants we summon hitherward.
I speak to Healing Herbs spreading, and bushy, to creepers, and to those whose
sheath is single,
I call for thee the fibrous, and the reed like, and branching plants, dear to Vishwa
Devas, powerful, giving life to men.
The conquering strength, the power and might, which ye, victorious plants possess,
Therewith deliver this man here from this consumption, O ye Plants: so I prepare the
remedy. (Griffith, 1895, p. 408)*

Defining CAM is not straightforward. There has been extensive discussion over the years considering what constitutes CAM and establishing a universal meaning and operational definition (Brundin-Mather, 2007). Earlier definitions focused on the

‘unconventional’ nature of CAM, suggesting it could be differentiated from more ‘conventional’ modalities of medicine. For example, Gevit (1988) suggested CAM as “unconventional therapy [that] refers to medical practices that are not in conformity with the standards of the medical community” (cited in Eisenberg et al. 1993, p. 246). Eskinazi (1998) further proposed CAM as “a broad set of health care practices (i.e., already available to the public) that are not readily integrated into the dominant health care model, because they pose challenges to diverse societal beliefs and practices (cultural, economic, scientific, medical, and educational)” (p. 1622). Today, the most cited definition of CAM originates from the National Center for Complementary and Integrative Health (NCCIH; 2012), which states CAM as: “a group of diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine” (p. 1).

Although widely accepted, the definition still explicitly states CAM as being differentiated from ‘conventional’ medicine. To gain a greater appreciation of this differentiation, it is important to define ‘conventional’ medicine, which might be described as: “Any health issue treated with medications or by doctors, nurses or other healthcare specialists” (National Cancer Institute, n.d.). Medications are usually those systematically manufactured through adherence to an endorsed scientific process (Lax, 2002), and can also include medical treatments such as surgery (Long, Xing, Morgan, & Brettle, 2011), and chemotherapy and radiation (Huang, Jain, El-Sayed, & El-Sayed, 2006). Before patients can receive such medications, they [the medications] must pass through a strict review process (US Food & Drug Administration, 2015).

1.2 Classification of CAM Practices

Although defined as “a group of diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine” (NCCIH, 2012, p. 1), the wide variety of modalities available and the varying belief systems within each (Barcan, 2011), make it difficult to delineate exactly what constitutes this diverse group of CAM systems, practices, and products. However, some authors have categorised the CAM treatments into five specific groups (Barnett, Shale, Elkins, & Fisher, 2014; Carroll, 2007; Strozier, 2008), which are listed in Table 1. A discussion of each major category and examples of particular treatment modalities that fall within each is provided below.

Table 1

The Five Major CAM Categories with Examples of Specific Treatments Associated with Each Category Available in Aotearoa New Zealand

MAJOR CAM GROUP	EXAMPLE TREATMENTS
Alternative medical systems	Traditional Chinese medicine; homeopathy; Ayurveda; naturopathy
Mind-body interventions	Meditation; prayer; interactive drawing therapy; dance therapy; hypnotherapy; yoga; acupuncture; tai chi; Pilates; Alexander technique
Biologically Based therapies	Dietary supplements; rongoā Maori; herbal products; aromatherapy; nutritional therapy
Manipulative and body-based methods	Massage therapy; chiropractic, osteopathy; reflexology; Bowen technique; breathwork; shiatsu; acupressure
Energy therapies	Reiki; therapeutic touch; biofeedback; qi gong; kinesiology; emotional freedom technique; colour therapy

1.2.1 *Alternative medical systems*

Alternative medical systems, which are based on a holistic healing philosophy, were utilised as a treatment modality prior to the extensive utilisation of conventional medicine (Berk, 2006). The holistic philosophy behind these approaches suggests a person becomes unwell when their body is unbalanced and blockages restrict the natural flow of energy (Grover & Vats, 2001). Alternative medical systems typically propose that humans have an inherent energy system that permeates the body, although this energy system is not observable (Mamtani & Cimino, 2002). An example of an energy system is evident in the Chinese notion of *chi*. According to Huff, McClanahan and Omar (2006) *chi* is “the natural energy of the universe” and “permeates all things, including the human body” (p. 2191). Similarly, an energy force is also evident in Māori notions of *mauri*, which is believed to be a sustaining life force inherent to all living beings (Best, 1954). To keep a healthy equilibrium and maintain one’s life sustaining energy force, good habits, such as exercising and eating a balanced diet, must be performed continuously (Cassileth & Deng, 2004).

1.2.2 *Mind-body interventions*

Mind-body interventions focus on the bidirectional communication between mind and body, and how psychological factors influence health and disease (Wahbeh, Elsas, & Oken, 2008). A similar analogy is evident in the discipline of psychology through the notion of psychosomatic influences, such as the correlation found between stress and inflammation (Littrell, 2015). The techniques used in mind-body interventions consider the mind is powerful enough to repair and keep the body well (Rice, 2001). For example, Carmody and Baer (2008) demonstrated the more time a

person spent meditating, the greater the reduction in stress and improvement in wellbeing. Likewise, Majumdar, Thompson, Ahmad, Gordon and Addison (2013) found prayer was common and had the greatest effect of reducing pain among sickle cell anaemia patients. These studies suggest an interaction between the mind and body, even if there currently is limited understanding regarding the nature of this interaction.

1.2.3 Biologically-based therapies

Biologically-based therapies are products found in nature, such as food, herbs and vitamin tablets, and are one of the most popular CAM remedies (Koithan, 2009). In many countries, they typically have less stringent regulations in terms of manufacturing and selling than conventional pharmaceutical medicines, have limited or no scientific evidence of efficacy, and can be bought ‘over the counter’ (Carroll, 2007). The philosophy underlying biologically-based therapies is that poor health results from the body being deficient in vitamins and minerals, and it is through increased supplementation that wellbeing can be optimised and maintained (National Center for Complementary and Alternative Medicine - NCCAM, 2004).

1.2.4 Manipulative and body-based methods

Through direct manipulation or movement of the body parts, manipulative and body-based practices address problems associated with bones and joints, muscles and ligaments, and circulation (Carroll, 2007). The procedures are designed to help strengthen and enhance the circulatory and immune systems by releasing endorphins and regulating metabolism (Kramlich, 2014). An example of this treatment modality is reflexology, which involves stimulating points on the hands and feet (Kunz & Kunz,

1993). The underlying philosophy of reflexology is that parts of the body can be restored back to health, by placing pressure on certain areas of the hands or feet that correspond to a specific part of the body (Pitman & MacKenzie, 2002). Another more common example of these types of methods are chiropractic approaches, which manually adjust the spine and joints (Meeker & Haldeman, 2002). By manipulating the spine, the chiropractor believes the nervous system can be restored to health (Mootz & Phillips, 1997).

1.2.5 Energy therapies

Energy therapies are based on the theory that everyone has an energy field surrounding the body that can be worked on for health benefits (Benor, 2002). A group of hands-on techniques or veritable equipment are used to work with the body's energy to guide and enhance balance within the field (Wieland, Manheimer, & Berman, 2011). For example, Whelan and Wishnia (2003) state "reiki therapy is a natural healing through laying on of hands that purports to transfer universal energy through the practitioners to the receivers of the therapy" (p. 209). Reiki was found by Esmonde and Long (2008) to relieve pain and relax a sample of individuals with multiple sclerosis. Another example of energy therapies is biofeedback. Biofeedback is the process of using electrical instruments to pinpoint areas of the body that need healing and then sending this feedback to the person (Ankerberg & Weldon, 2011). This method works for ailments such as migraines and constipation, by training people to become consciously aware of their bodily signals to aid their healing (Arena & Devineni, 2004).

1.3 Summary

This chapter has defined both conventional medicine and CAM. A discussion of the five major categories that CAM has been distinguished into has been given, as well as examples provided of specific modalities that fall within each of these categories. Given the increasing attention given to CAM in recent decades, the following chapter will discuss CAM usage, and some of the reasons why people choose to utilise CAM, either in association with or as an alternative to conventional medicine.

CHAPTER TWO: REASONS WHY PEOPLE USE CAM

Exactly who utilises CAM, and the reasons for such utilisation are multi-faceted. This chapter will provide an overview of who uses CAM. A review of literature will then explore what factors motivate CAM usage among people. The evidence behind why people shift from conventional treatments have been categorised into ‘push factors’, while those factors that attract people to CAM – ‘pull factors’ will be described. The chapter will conclude with a summary.

2.1 An overview of CAM usage

Although various CAM modalities date back thousands of years, documented trends in usage can be traced to nearly 100 years ago. Patient surveys undertaken by doctors in the 1920’s revealed between 34% to 87 % of clients were using or had tried what was considered cult medicine (Kaptchuk & Eisenberg, 2001). Since this time, literature claims the proportion of people using CAM has increased substantially in many places around the globe, with specific population demographics, and according to specific medical conditions.

2.1.1 CAM usage according to country

With regard to certain country populations, literature indicates CAM usage has remained quite stable over the past two decades in some countries. For example, 15 CAM practices identified by a small population sample of US citizens were evaluated during 1997 and again in 2002 to determine which procedures were increasing in recognition. Results revealed similar CAM use among people (36.5% in 1997 and

35% in 2002), however individually herbal medicine use increased 6.5% during that time (Tindle, Davis, Phillips, & Eisenberg, 2005). Recently, Clarke, Black, Stussman, Barnes and Nahin, (2015) gathered data from nearly 90,000 Americans and compared their CAM usage in 2002, 2007 and 2012. Their findings again showed no substantial growth in CAM usage, with the proportion of people indicating they used CAM still around 30%.

CAM usage has been documented as a 'growth industry' in many European countries (Richardson, Sanders, Palmer, Greisinger, & Singletary, 2000). Fox, Coughlan, Butler and Kelleher (2010) observed an increase from 20% (1998) to 27% (2002) of people seeking CAM practitioners in Ireland. An estimated 25% of the population resident in the United Kingdom, and at least half (50%) of the resident German and French populations, are believed to utilise CAM (Richardson et al., 2000), although a more recent study indicated the usage rate in Germany may be as high as 62% (Hartel & Volger, 2004). CAM usage among the general population in Denmark is estimated at 21% (Hanssen, Grimsgaard, Launso, Fonnebo, Falkenberg, & Rasmussen, 2005), while in Italy an estimated 15.6% of the population may use CAM (Menniti-Ippolito, Gargiulo, Bologna, Forcella, & Raschetti, 2002).

Countries located in the South Pacific region have also witnessed a sizeable proportion of people opting for CAM treatments. Harris, Cooper, Relton and Thomas (2012) reviewed three Australian surveys conducted in 1993, 2000 and 2004 and note CAM usage averaged 50%. Likewise, in Aotearoa, the Ministry of Health – (MOH,

2008) found from a survey of nearly 12,500 New Zealand adults, one in five had visited a CAM practitioner in the past year.

2.1.2 CAM usage according to demographics

An accumulation of literature over the past two decades suggests certain demographics are associated with CAM usage, including gender, age, education level and type, and household income.

In their systematic review of literature published between 1996 and 2005 on CAM use, Frass and colleagues (2012) found the majority of studies revealed women were more likely than men to report using CAM. Xu and Borders (2003) state women in general tend to visit health practitioners more than men, while Bishop, Yardley and Lewith (2008) suggest females are more likely to use CAM because it makes them feel good, whereas men view CAM from a practical sense, weighing up the benefits verses costs of treatment. Saher and Lindeman (2005) learnt women have different thinking styles to men and intuitively believe CAM would help their healing process, while males are more objective and logical in their thinking when deciding if CAM is appropriate for their needs.

Additionally, age of women appears to be related to CAM usage. In the same review, Frass et al. (2012) found the majority of studies reported CAM use to be most prevalent in women aged 35 years and above, which supports earlier findings (Richardson et al., 2000), suggesting younger participants (those aged 55 years or below) are twice as likely to use CAM than older participants (those over 55 years).

Education level and type, as well as household income, also appear to be predictive of CAM use. However, while there is literature suggesting those with higher levels of education (university) and higher incomes are more likely to report utilisation of CAM, irrespective of country of residence (Eisenberg et al., 1993; Koczwara & Beatty, 2011; MacLennan, Myers, & Taylor, 2006), Astin (1998) found income was not a predictive factor for CAM usage. Despite these findings, those with medical training are less likely to utilise CAM in comparison to those with other types of professional training (such as nursing or pharmacy) (Bishop & Lewith, 2010; Frass et al., 2012).

2.1.3 CAM usage according to medical conditions

CAM popularity has also been associated with chronic, terminal and degenerative conditions, such as HIV (Furler, Einarson, Walmsley, Millson, & Bendayan, 2003; McDonald & Slavin, 2010), arthritis (Quandt et al., 2005; Unsal & Gozum, 2010), and diabetes (Bell et al., 2006; Egede, Ye, Zheng, & Silverstein, 2002). The use of CAM modalities among patients with cancer has also gained momentum, with some estimates suggesting increases from 25% in the 1970s, to 32% in the 1990s, to 49% in the 2000s (Horneber et al., 2012). More recent estimates suggest as much as 67% of cancer survivors use CAM (Mao, Farrar, Xie, Bowman, & Armstrong, 2007; Mao, Palmer, Healy, Desai, & Amsterdam, 2011). It has been suggested that in using CAM modalities, cancer patients typically combine these with conventional medical interventions for cancer, which is known by the term ‘integrative oncology’ (Bauml et al., 2015; Richardson et al., 2000).

2.2 Push factors for CAM use

The reasons why people use CAM are multi-faceted. However, it has been suggested that CAM use can be the result of dissatisfaction with conventional treatments, for a variety of reasons. Known as ‘push factors’ because they refer to the reasons why people disregard conventional treatments, Table 2 summaries the five main types that have been identified as reasons for CAM utilisation.

Table 2

The Five Push Factors Associated with Why People Disregard Conventional Treatments

PUSH FACTORS	SUMMARY	LITERATURE
Medications are harmful	The belief prescription drugs can be dangerous and are overused	Bishop et al., (2006) Furnham (2007) Danell (2015) Langhorst et al. (2005) Alhaddad et al. (2014)
Dissatisfaction with mainstream medicine	The motivation to use CAM because conventional treatments have failed consumer expectations	Sirois & Purc-Stephenson (2008a) Bishop et al., (2004) Sharples, van Haselen, & Fisher (2003) Tan, Uzun, & Akcay (2004) McLaughlin, Lui, & Adams (2012)
Negative effects of drugs	Failure to comply with recommended medication dosages because of side effects	Gerasimidis, McGrogan, Hassan, & Edwards (2008) Brown et al. (2010) Kitney et al. (2009) Xue et al. (2005) Sharples et al. (2003) Filipkowski et al. (2010)
Desperation	Failure of medications and/or health system to meet patient needs	Scott, Verhoef, & Hilsden (2003) Sirois & Purc-Stephenson (2008b) Sibbritt, Adams, & Lui (2011) Luff & Thomas (2000)
High cost of healthcare	Inability to afford mainstream medicines	Kisangau, Lyaruu, Hosea, & Joseph (2007) LaFrance et al. (2000) Jha & Rathi (2008) El-Dahiyat & Kayyali (2013) Fokunang et al. (2011)

2.2.1 Medications are harmful

The belief prescription drugs are poison and overused was noted by Bishop et al (2006) as predictive factors for CAM use. Furnham (2007) also showed the concern of medications being harmful was linked to increased CAM usage. Bishop et al. (2006) revealed some participants regard doctors unnecessarily recommend too many medicines. Langhorst et al. (2005) study states 63.1% of people with inflammatory bowel disease choose CAM to terminate or avoid steroid medication. Alhaddad et al. (2014) found although many participants knew the medicines they were taking could cause harm, they continued to use them. Only 9.2% believed medications would not hurt them. Similarly, Danell (2015) describes participant concern of conventional treatment dependency for their condition and would prefer to take CAM remedies. Akinci, Zengin, Yildiz, Sener and Gunaydin (2011) mention while there are benefits of including CAM into health regimens, such as massage and exercise, the authors also suggest CAM could cause harm if used alongside some medicines. This view is supported by many authors (Ladenheim et al., 2008; Lunny & Fraser, 2010; Rousseaux & Schachler, 2003; Smith, Ernst, Ewings, Myers, & Smith, 2004) who warn of the potential danger of drugs either becoming more or less potent when combined with herbal medicines. Conversely, other researchers have shown CAM usage to have minimal impact on certain medications (Ryan, Pick, & Marceau, 2001; Sood et al., 2008).

2.2.2 Dissatisfaction with mainstream medicine

Lack of confidence with biomedical approaches due to past unsatisfactory or difficult experiences was discovered by Bishop et al., (2004) as motives for seeking

CAM. This finding was reiterated by Sharples et al. (2003) and Sirois and Purc-Stephenson (2008a) who state the inadequacy of conventional methods disappointed the needs and expectation of patients resulting in them pursuing CAM options. Sharples et al. (2003) also found some CAM remedies could either completely or partly replace medications, which further strengthened the desire for alternative remedies. McLaughlin et al. (2012) established frustration with orthodox medicines was particularly evident among long-term users who were still struggling to gain control over their condition. Poor doctor-patient relationships was also categorised under dissatisfaction with mainstream medicine for individuals (Sirois & Purc-Stephenson, 2008a; Tan et al., 2004). Patients expressed discontent with how badly they were treated by doctors. When comparing Aotearoa's health system with 10 other countries, the initial overall care patients receive is effective, however the sicker adults become, the more medical errors are reported (Davis, Stremikis, Squires, & Schoen, 2014).

2.2.3 Negative effects of drugs

Not wanting to experience adverse reactions from medications was perceived as an incentive for people to choose CAM treatments (Kitney et al. 2009; Sharples et al. 2003). Brown et al. (2010) observed people would only use medications to treat their illness if nothing else worked, as they did not want to suffer any possible side effects. Filipkowski et al. (2010) believes fear of reacting to medications is a reason why people avoid them. Similarly, Gerasimidis et al., (2008) found because of the ongoing negative effects of drugs, individuals either sought CAM or preferred to tolerate the disease rather than remain on medications. Although Xue et al. (2005)

note there is a general perception that CAM will produce less side effects than conventional methods, people still mainly choose mainstream options. In contrast, Serfontein (2004) established because of the long-term consequences some conventional treatments can cause individuals, CAM remedies can be viewed as a better option. Faasse, Grey, Horne and Petrie (2015) consider if people think they are going to react to medications or are told of possible side effects, then more adverse reactions are reported. Furthermore, the author's state assuming sensitivity to medications will stop people from taking them.

2.2.4 Desperation

Feelings of hopelessness and despair are also considered motivations for people to turn to CAM. Scott et al. (2003) describes the anguish felt by people when orthodox medicines were no longer helping and being told nothing more could be done. Rather than accepting this outcome, some individuals were prompted to find other treatments themselves. Likewise, Luff and Thomas (2000) found people sought CAM because they had nothing to lose and trying the remedies seemed like the only option left. The desperation of turning to CAM was also associated with chronic illness sufferers who were frustrated by unsuccessful treatments of mainstream methods (Sibbritt et al., 2011). Sirois and Purc-Stephenson (2008b) explain despondency with medical services was linked to CAM seeking behaviour. The authors note when physicians are scarce and people are forced to wait days for doctor's appointments, some will consider alternative options.

2.2.5 *High cost of healthcare*

Issues relating to unaffordability of conventional medications appear to prevail mainly in developing countries. Articles from Tanzania (Kisangau et al., 2007), America (LaFrance et al., 2000) and India (Jha & Rathi, 2008) all state the high cost of Western medicine pushes individuals to use alternative treatments. El-Dahiyat and Kayyali (2013) believe Jordanian medical doctors are ignorant to individuals not having enough money as they continue to prescribe patients expensive medications which they cannot afford to sustain. Fokunang et al. (2011) highlights costs also affect South African people living in rural areas needing to take time off work and travel several days to obtain medical attention. The loss of work means loss of wages. This can force people to risk buying cheaper medications from unknown sources or visit a traditional healer which appears to be the safer choice. In Western countries the opposite is found regarding treatment costs – mainstream medicines are largely less expensive than many CAM therapies. Gollschewski, Kitto, Anderson and Lyons-Wall (2008) point out how costly CAM remedies in Australia can inhibit individual rights of being able to decide what treatment a person wants to use for their body.

2.3 Pull factors for CAM use

Just as there are reasons that propel people away from conventional medicine, and ‘push’ them towards CAM use, there are also reasons why people choose CAM as a treatment option. Not associated with a dissatisfaction with conventional medicine, these ‘pull factors’ entice individuals to CAM. Table 3 itemises seven pull elements suggested by literature.

Table 3

The Seven Pull Factors Associated with What Attracts People to Use CAM

PULL FACTORS	SUMMARY	LITERATURE
Noticeable positive effects	CAM remedies helped with injury/condition	Esmonde & Long (2008) Cartwright & Torr (2005) Zeng, Zhou, Chen, Luo, & Haung (2014) Jaiswal et al. (2015) Ceylan et al. (2009) Ernst & White (2000)
Communication and relationship with therapist	More emotional understanding from CAM practitioner and time spent with patient	Cartwright & Torr (2005) Luff & Thomas (2000) Shinto et al. (2005) Bann, Sirois, & Walsh (2010) Barnett (2007)
Personal beliefs and values	CAM approaches are aligned with clients wellness principles of treating holistically	Testerman, Morton, Mason, & Ronan (2004) Siahpush (1999) McFadden, Hernandez, & Ito (2010) Barnett (2007) Sirois, Salamonsen, & Kristoffersen (2016) Chao, Wade, Kronenberg, Kalmuss, & Cushman (2006) Sirois & Purc-Stephenson (2008b) Astin (1998)
Involvement in treatment	Patients feeling included in treatment process and decision making	Olchowska-Kotala (2013) Barnett (2007) Barrett et al. (2003) Warren, Canaway, Unantenne, & Manderson (2012) Chang, Wallis, Tiralongo, & Wang (2012) Luff & Thomas (2000)
Health maintenance and illness prevention	Ideologies of using CAM to keep well	Awad & Al-Shaye (2014) Sirois (2014) MacLennan et al. (2006) Araz, Harlak, & Mese (2009) Robinson, Crane, Davidson, & Steiner (2002) Sirois & Gick (2002)
CAM perceptions and values	Believing CAM is safe because it is natural	Bahall & Edwards (2015) Mbada et al. (2015) Nguyen et al (2014) George, Ioannides-Demos, Santamaria, Kong, & Stewart (2004) Student & Yeboah (2015) Jaiswal et al. (2015) Siahpush (1999)
Affordability and accessibility	CAM is cheaper and easier to obtain than mainstream medicine	Jaiswal et al. (2015) Kretchy, Owusu-Daaku, & Danquah (2014) Kucukguclu et al. (2012) Haque, Louis, Phalkey, & Sauerborn (2014) Aniah (2014) Onifade, Ajeigbe, Omotosho, Rahamon, & Oladeinde (2013)

2.3.1 Noticeable positive effects

Feelings of being more relaxed and reduced pain, which aid better sleep and easier movement, is a commonly reported ‘pull’ factor for using CAM (Cartwright & Torr, 2005; Ernst & White, 2000; Esmonde & Long, 2008; Zeng et al., 2014). Participants also often speak of increased strength and energy (Ceylan et al., 2009). Cartwright and Torr (2005) found CAM remedies gave symptom relief to several individuals, which enabled them to reduce their pain medication. The authors also state some participants were pleasantly surprised by having secondary health problems improve. Because CAM helps reduce the ailments of some diseases, some people feel they can cope a lot better and their relationships with others improved.

Jaiswal et al. (2015) note a number of chronic condition patients who had been using conventional medicine tried CAM and either received immediate relief of minor complaints, such as constipation or were cured of their illness. Likewise, He, Veiersted, Hostmark and Medbo (2004), compared chronic neck and shoulder pain sufferers who received assumed pain point acupuncture with a control group receiving placebo point acupuncture. Their investigation showed after six months both groups had reduced pain and associated headaches, however after three years the control group was back to pre-treatment pain, unlike the test group which remained pain free. The authors suggest had the follow-up study not been done, the success of the acupuncture treatment may not have been acknowledged.

2.3.2 *Communication and relationship with therapist*

Shinto et al. (2005) compared patient relationships with CAM therapists and medical doctors and found clients were significantly more satisfied with CAM therapists. The reasons included considerably more time was spent with the CAM therapists, who demonstrated better listening skills and appeared to care and show more concern than the specialists. These views were also echoed by Cartwright and Torr (2005) who note clients regarded their relationship with the CAM practitioner as an equal, trusting partnership, and felt reassured by their ongoing support.

Having longer appointment times with the CAM therapist allowed patients to share more about their issues which strengthened the rapport, making them more relaxed as well as building confidence (Luff & Thomas, 2000). According to Bann et al. (2010) clients were considered unique and treatments were tailored to individual needs. This required the practitioner to examine patients in depth to ensure their particular health concerns were addressed. As Barnett (2007) points out, patients should be treated as people not collections of symptoms. This may be why Shinto et al. (2005) found although participants thought conventional methods were better, they still visited a CAM therapist.

Health professionals recognise how they manage their schedules with patients is completely different from alternative practitioners – from appointment times, how they diagnose and treat as well as their accountability to medical boards (Berger, Braehler, & Ernst, 2012).

2.3.3 *Personal beliefs and values*

CAM principles for obtaining and maintaining optimum wellness centre on treating the whole person (Braun & Cohen, 2010). This means spiritual, physical, psychological and environmental factors of an individual's life all need to be considered and ensured they are in harmony for best possible health. Barnett (2007) notes CAM practitioners uphold these principles by designing treatment programmes which encompass the whole person. However, Baer (2015) disputes this, stating the societal aspects affecting a person's life are often not addressed.

Regardless of how much CAM deals with environmental factors, the holism approach of treating illness fits better than biomedical views when considering WHO (1948) definition of health, which declares "health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity." Many studies show positive correlations between CAM use and people who believe in a holistic approach to wellbeing (Chao et al., 2006; McFadden et al., 2010; Sirois et al., 2016; Testerman et al., 2004). Sirois and Purc-Stephenson (2008b) further suggested open and agreeable personality types were also factors influencing people's views of health being holistic. Astin (1998) found people with greater spiritual links were more inclined to address illnesses holistically. Likewise, Siahpush (1999) established several CAM users regarded health as balancing the body, mind and spirit.

2.3.4 *Involvement in treatment*

By allowing people to be involved in their treatment process, some investigations reveal disease management adherence is better (Barrett et al., 2003; Chang et al. 2012; Olchowska-Kotala, 2013; Warren et al., 2012). Luff and Thomas

(2000) discovered when CAM therapists provided individuals with the tools they needed to change their bad habits, they learnt how their illness was affecting their health and were empowered to make the necessary lifestyle adjustments. In contrast, Warren et al. (2012) describes the powerlessness some patients feel when doctors tell them what to do after being diagnosed. These participants believe CAM therapists gave them more opportunities to make decisions. This sentiment is shared by Barnett (2007) who stipulates CAM practitioners challenge people with the areas in their life that only they can alter. Barrett et al. (2003) states active participation gives the responsibility back to patients which provides strength, determination and the willingness to change. Some conventional doctors argue patients should not be included in their treatment plan as they are too emotionally involved to make rational decisions (Meredith, 1993). Differences between what each domain regards is best for the client is evident, however which method a patient will select appears to be an individual choice.

2.3.5 Health maintenance and illness prevention

Regular consumers of CAM products are linked to those who are more aware of wanting good health to prevent illness (Araz et al. 2009; MacLennan et al., 2006; Sirois, 2014). Sirois and Gick (2002) add health conscious people who visit CAM therapists are educated more about disease preventative measures and had greater attentiveness to stress reduction, healthy eating and sleeping better than people who chose orthodox medicines. Biologically based therapies were the most popular CAM choice for desiring optimal wellbeing (MacLennan et al., 2006; Robinson et al., 2002), with several individuals taking these products to boost their immune system (Awad &

Al-Shaye, 2004; MacLennan et al., 2006). According to MacLennan et al. (2006) the consumption of CAM is greatly influenced by the media. Buying trends either go up or down depending on whether reports on CAM products are good or bad. While some CAM users believe multivitamins are essential for good health, there are others who consider taking these products as unnecessary. Sax (2015) states there is evidence when people are nutritionally deficient supplementation is beneficial.

2.3.6 CAM perceptions and values

The idea CAM is safer than drugs because they are derived from plants was a prevalent finding among study participants (Bahall & Edwards, 2015; Mbada et al., 2015; Student & Yeboah, 2015). Because of the underlying traditional principles alternative practices uphold, it is not surprising Nguyen et al. (2014) found CAM practitioners also believed their products were more natural than medical doctors. There was a certainty amid some people who thought the non-toxic values that CAM portrays meant the products were not dangerous (Bahall & Edwards, 2015; George et al., 2004). Jaiswal et al. (2015) established some CAM users did not experience side effects which Siahpush (1999) note gave people positive attitudes towards the remedies.

2.3.7 Affordability and accessibility

Comparable to the push factor of conventional medicine being too expensive for some people, the affordability and accessibility can draw individuals to CAM remedies. This reasoning was made obvious in Kretchy et al. (2014) research with almost four times as many participants using CAM because of being less expensive

than medications. Interestingly, Kucukguclu et al. (2012) showed how cost of CAM rather than wanting more natural approaches was the main appeal. Acupuncture and homeopathy practices were sourced less than other CAM methods and the authors thought this may have been because they were higher in price when compared with other CAM options. Similarly, Jaiswal et al., (2015) notes the readily available CAM approaches were used more by individuals than the CAM practices which were harder to access. For people who have difficulty paying for and obtaining conventional treatments, alternative clinics often provide the only obtainable service for people to manage their disease (Aniah, 2014; Haque et al., 2014).

2.4 Summary

The literature on CAM usage is by no means definitive or fixed. There is continuing discoveries being made within both areas of medicine, improving treatments and technology, extending life and reducing adverse side effects (Heuckmann & Thomas, 2015; Wong, Che, & Leung, 2015). Environmental dynamics have also changed over the years, such as soil depletion affecting food nutrition (Oliver & Gregory, 2015), increased stress (Seaward, 2016) and health information being more accessible (Moreland, French, & Cumming, 2015). The reasons specified assist with why people choose CAM for general health or non-life threatening purposes, however are those reasons the same when people are faced with death? It is important to compare the above literature with research on why individuals with cancer choose CAM treatments to establish if people have the same reasons for wanting CAM when they are in a crisis situation. Before contrasting the literature, the context of cancer will be discussed in the next chapter.

CHAPTER THREE

CANCER

This chapter begins with an overview of cancer, providing statistics and possible side effects after treatment. A literature review follows establishing the reasons why people with cancer choose CAM and includes motives of noticeable positive effects; communication and relationship with therapist; personal beliefs and values; involvement in treatment; integrative treatment; CAM perceptions and values; and affordability.

3.1 What is cancer?

“Cancer is a journey, but you walk the road alone. There are many places to stop along the way and get nourishment – you just have to be willing to take it.”

- *Emily Hollenberg, cancer survivor*

Hippocrates (400BC) termed cancer as *karkinos*, Greek for crab because of the crab-like appearance of tumours having a prominent centre with veins spreading out like the crustaceans legs (Reuben, 2005). The word ‘crab’ was later translated by the Romans into Latin - meaning cancer (Haddow, 1936). Most people know cancer signifies disease, however understanding what the disease is, is less familiar.

“Cancer is not one disease, but a collection of related diseases that can occur almost anywhere in the body. At its most basic, cancer is a disease of the genes in the cells of our body. Genes control the way our cells work. But, changes to these genes can cause cells to malfunction, causing them to grow and divide

when they should not—or preventing them from dying when they should. These abnormal cells can become cancer” (NIC, n.d.).

According to Micozzi (2007a), abnormal cells can destroy or invade healthy tissue by either spreading rapidly through the blood or growing into tumours. Tumours can be benign or malignant. Benign tumours are not cancerous, they do not multiply, so are not considered fatal (Sudhakar, 2009). On the other hand, malignant tumours turn carcinogenic and can disperse throughout the body creating secondary masses called ‘metastases’ (Gabriel, 2008). There are over 100 types of cancer which can affect any part of the body, the five most common being lung, liver, stomach, colorectal and breast (WHO, 2014). Nowadays, most people will experience cancer at some point in their lives, either through someone they know or developing the disease themselves.

Most people, until they are affected by cancer never consider the lifestyle they live could increase their chances of developing the disease. There is enough evidence now to link cancer with people who continually eat food high in sugar, fat and salt (Weisburger, 2000), drink alcohol (Chen, Rosner, Hankinson, Colditz, & Willett, 2011) and smoke cigarettes daily (Botteri et al., 2008), but still individuals never think cancer will affect them. Added to this, chronic stress and/or a sedentary life can lead to changes in the body’s immune system (Segerstrom & Miller, 2004). It is thought prolonged exposure to carcinogens, poor diets and environmental factors can cause human cells to mutate (WHO, 2005), making people vulnerable to disease (Reiche, Nunes, & Morimoto, 2004).

3.2 Statistics

Cancer survival rates not only depend on the type of cancer, where the cancer is located in the body and how soon the disease is diagnosed, but also the cancer survivor's age and their environmental factors, such as demographic location and support networks (WHO, 2014). In 2012, 8.2 million people died of cancer and 32.5 million people currently live with cancer worldwide (WHO, 2014). In 2009, nearly 30% of deaths in Aotearoa were attributed to cancer (MOH, 2012). This figure equates to about 8,500 deaths per year (MOH, 2015). The cost to this country for treating cancer using conventional medicine is over \$800 million per year (Blakely et al., 2015) and there is still no guarantee the treatment will cure the disease. Even though this huge amount of money has been dedicated to cancer treatment, the percentage of people surviving after five years has not greatly improved (MOH, 2015). Additionally, although the statistics may show an increase in survival rates for all cancers (Soeberg et al., 2012), what this data fails to illustrate is undergoing radioactive therapy increases the risk of patients dying from pneumonia (Daly et al., 2006) and heart attacks (Dieckmann et al., 2010), thus shifting the death from cancer to other fatalities. Surviving cancer is not just about existing - how treatments affect a person's life should also be considered.

3.3 Side effects of conventional cancer treatment

The most common and accepted conventional treatment options for cancer include chemotherapy, radiation and surgery (MOH, 2003), with each method presenting possible side effects for cancer patients. Table 4 provides a range of

potential acute (short-term) and chronic (long-term) effects from using chemotherapy, radiation and surgery for treating cancer.

Table 4

Possible Acute and Chronic Effects of Conventional Cancer Treatment

TREATMENT	ACUTE EFFECTS	CHRONIC EFFECTS
Chemotherapy	Fatigue Nausea and vomiting Menopausal symptoms Loss of hair and appetite Sexual dysfunction Neuropathy Chemobrain Heart failure Kidney failure Infertility Liver problems	Cataracts Early menopause Heart problems Increased risk of other cancers Infertility Liver problems Lung disease Nerve damage Osteoporosis Reduced lung capacity
Radiation therapy	Skin irritation Damage at regions exposed (salivary glands or hair loss if head or neck treated) Urinary problems (lower abdomen treated) Fatigue Nausea with or without vomiting Most disappear after treatment ends (some may be permanent)	Cataracts Cavities and tooth decay Heart and vascular problems Hypothyroidism Increased risk of other cancers Infertility Intestinal problems Lung disease Lymphedema Memory problems Osteoporosis Skin changes
Surgery	Scars Pain	Lymphedema

Individuals diagnosed with cancer are aware of these side effects before treatment begins, leaving many with real concerns and fear (Frenkel, Sierpina, & Sapire, 2015). This could be a reason why people are opting to look at alternatives and a review of literature follows investigating those motives.

3.4 Why people with cancer choose CAM

Corresponding with the push and pull factors stated in the previous chapter describing why people use CAM for a broad range of reasons, the following review of literature examines whether any of those aspects are comparable motives for cancer patients. While the wording for the reasons is essentially the same as the above mentioned pull factors, the significance of those reasons for cancer survivors differ. A summary is outlined in Table 5.

3.4.1 Noticeable positive effects

CAM therapies are popular among cancer patients who seek treatments to reduce the often debilitating effects of chemotherapy and/or radiation. For example, Carlson and Garland (2005) studied 63 patients with various types of cancer who frequently experienced disturbed sleep. Patients who used mind-body techniques obtained significantly better quality sleep, and less stress and enhanced mood also resulted from more efficient sleep. While Danhauer et al. (2009) found yoga made no immediate difference to breast cancer patient's wellbeing, over time individual energy increased and mental health improved compared to patients who did not partake in yoga. Nystrom et al. (2008) showed acupuncture and vitamin B6 injections had the greatest effect of minimising chemotherapy induced vomiting for ovarian, chest, lung and prostate cancer patients. Bates and Wilkinson (2009) revealed the belief of one participant who considered their increased energy levels and minimal blistering from radiation therapy was from homeopathic medicine. CAM treatments have established they can enrich cancer survivor's quality of life (Du, 2012; Ganz et al., 2002). When patients are given hope they may live the focus becomes about enjoying life.

Table 5

Seven Reasons Why Cancer Patients use CAM

REASONS	SUMMARY	LITERATURE
Noticeable positive effects	CAM was used to counteract side effects of conventional treatments	Bates & Wilkinson (2009) Ganz et al. (2002) Carlson & Garland (2005) Danhauer et al. (2009) Nystrom, Ridderstrom, & Leffler (2008) Du (2012)
Communication and relationship with therapist	CAM therapist spent more time with client Reluctance to disclose CAM usage to physician	Amichai, Grossman, & Richard (2012) Salamonsen, Kruse, & Eriksen (2012) Verhoef, Mulkins, & Boon (2005) Sirois (2008) Arthur et al. (2012) Tautz, Momm, Hasenburg, & Guethlin (2012) Tasaki, Maskarinec, Shumay, Tatsumura, & Kakai (2002)
Personal beliefs and values	Spirituality gave patients strength and hope to fight the cancer	Thomson, Jones, Browne, & Leslie (2014) Wanchai, Armer, & Stewart (2010) Arthur et al. (2012) Sirisupluxana, Sripichyaka, Wonghongkul, Sethabouppha, & Pierce (2009) Shorofi & Arbon (2010) Ustundag & Zencirci (2015)
Involvement in treatment	Treatment plans were patient-centred	Sirisupluxana et al. (2009) Tautz et al. (2012) Verhoef, et al. (2005) Salamonsen et al. (2012) Chartterjee et al. (2005) Watt et al. (2012) Thomson et al. (2014) White, Verhoef, Davison, Gunn, & Cooke (2008) Corner et al. (2009) Amichai et al. (2012)
Integrative care	Patients decided they wanted the best possible treatment available	Saibul, Shariff, Rahmat, Sulaiman, & Yaw (2012) Ustundag & Zencirci (2015) Chrystal, Allan, Forgeson, & Isaacs (2003) Trevena and Reeder (2005)
CAM perceptions and values	The belief that CAM was natural	Corner et al. (2009) Arthur et al. (2012) Wilkinson & Stevens (2014) Shorofi & Arbon (2010) Wilkinson & Jelinek (2009) Hok, Falenberg, & Tishelman (2011) Sirisupluxana et al. (2009) Amichai et al. (2012) Thomson et al. (2014) Watt et al. (2012) Bishop et al. (2008)
Affordability	Patient spending on CAM varied and also influence decisions to use CAM	Wanchai et al. (2016) Wilkinson & Stevens (2014) Saibul et al. (2012) Chartterjee et al. (2005) Wanchai et al. (2010) Chrystal et al. (2003) Patterson et al. (2002)

3.4.2 *Communication and relationship with therapist*

Patient-doctor interactions are another reason for some patients choosing CAM. Verhoef et al. (2005) found the benefit of therapists being respectful to client needs is the development of an open and trusting relationship. Sirois's (2008) research that included 185 people with any type of cancer, revealed over 40% of patients said poor doctor-patient relationships was a motivating factor to seek alternative therapies. Amichai et al. (2012) note participants voiced appreciation for being able to share their experiences freely and felt listened to which can be therapeutic. This sentiment was echoed by Chartterjee et al. (2005) who state patients report CAM therapists spent more time listening to their problems.

However, Snyder (2007) argues the reason why medical practitioners seem aloof with their clients is because they are the ones telling them they are dying. Quite often busy medical clinics do not have extra time to spend answering client questions, which can create the impression the doctor does not care (Hack, Degner, & Parker, 2005). Patients can also be either willing or reluctant to disclose their existing CAM usage or discuss the possibility of incorporating CAM into their treatment regimen with medical doctors (Tasaki et al., 2002; Tautz et al., 2012), which can create difficulties within the doctor-patient relationship. Arthur et al. (2012) note patients can view oncologists as experts only in conventional medicine, therefore believing it is pointless for them to share their CAM usage. Chrystal et al. (2003) ascertained older patients were more likely to not disclose CAM usage, and suggested this may be due to traditional views of perceiving the specialist as knowing what is best and not wanting to upset them. Literature also suggests levels of willingness to discuss CAM

with patients varies. Tautz et al. (2012) state of 63 breast cancer patients not using CAM, 13% were advised by physicians not to. Tasaki et al. (2002) found doctors reactions to patients suggesting CAM ranged from lacking interest to outward opposition.

3.4.3 Patient beliefs and values

Another common theme determined from previous research is the influence spirituality has in patient's lives. While Thomson et al. (2014) found religion was not a governing factor for people choosing CAM over conventional methods, Wanchai et al.'s (2010) study with nine breast cancer patients found their beliefs of God strengthened their confidence that CAM would help them. Other research acknowledges a person's faith is an essential part of the holistic healing that CAM offers (Arthur et al. 2012; Shorofi & Arbon, 2010; Sirisupluxana et al., 2009; Ustundag & Zencirci, 2015; Wanchai et al., 2016). Mind-body interventions, such as meditation and prayer, enabled the cancer to be blanked out for a time, which some patients believed facilitated their bodies to release chemicals to help fight the disease (Sirisupluxana et al., 2009; Wanchai et al., 2016). Spiritual resilience allowed the burden of cancer to be taken away from the individual, which gave a sense of peace and hope during treatment and recovery.

3.4.4 Involvement in treatment

An entitlement to manage one's own body is another motive for CAM usage (Amichai et al., 2012; Chartterjee et al., 2005; Corner et al., 2009; Salamonsen et al.,

2012; Sirisupluxana et al., 2009; Tautz et al., 2012; Thomson et al., 2014; Verhoef et al., 2005; Watt et al., 2012). White et al. (2008) note many men with prostate cancer wanting an active role in their care were looking for physicians who would support them. Amichai et al. (2012) found relationships between the client and CAM provider were patient-centred, with the treatment plan individually tailored to the person's needs.

This finding is expected considering Micozzi (2007b) states each naturopathic consultation generally takes one hour. Salamonsen et al. (2012) discuss how breast cancer patients are encouraged to be aware of bodily signals and to share these sensations with CAM therapists, as this is how treatment plans are designed and adapted. The authors found patients felt strongly about their basic human rights, stating when a person is well these claims are not challenged, but once they become sick the medical profession strips them of these entitlements. Giving individuals the opportunity to be involved in their healing process provides patients a feeling of control (Verhoef et al., 2005; White et al., 2008). This helps to lessen the negative feelings that can be associated with cancer by distracting individuals from the distress and worry. CAM permits the patient to contribute and gives them the flexibility to choose which therapists and practices best suit their needs (Sirisupluxana et al., 2009; Tautz et al., 2012). As White et al. (2008) points out, researching CAM options helped patients feel empowered. It is natural for humans to want to be involved when something is amiss, especially if the issue concerns them.

3.4.5 Integrative care

Integrating conventional treatment with CAM is a popular option with many cancer patients (Chrystal et al., 2003; Saibul et al., 2012; Ustundag & Zencirci, 2015). Decisions to incorporate CAM with conventional medicine range from patients wanting to try and counteract radiation/chemotherapy side effects, such as pain and tiredness, to helping cope with the stress of cancer. Others believe CAM could enhance conventional treatment, thus increasing the chances of curing cancer. While breast cancer survivors in Saibul et al.'s (2012) study did not report any negative effects from taking CAM, Ustundag and Zencirci (2015) found of the 134 cancer survivors, 5.2% had adverse reactions to CAM when used in conjunction with chemotherapy, such as stomach aches and palpitations. This concern was shared by Chrystal et al. (2003) and Trevena and Reeder (2005) who state using CAM while undergoing conventional treatment can be dangerous. Smith, Clavarino, Long and Steadman (2014) reveal using CAM may interfere with chemotherapy by either making the treatment more toxic or non-effective. However, Chan, Lin, Shih, Ching and Chiang (2012) observed no toxic effects among CAM users who were experiencing chemotherapy induced complications. This study also found participants had less infections and were less reliant on antibiotics.

3.4.6 CAM perceptions and values

A patient's preference for natural remedies has been cited as one of the main reasons for maintaining CAM usage (Amichai et al., 2012; Arthur et al., 2012; Corner et al., 2009; Hok et al., 2011; Shorofi & Arbon, 2010; Sirisupluxana et al., 2009; Thomson et al., 2014; Watt et al., 2012; Wilkinson & Jelinek, 2009; Wilkinson &

Stevens, 2014). Many studies describe patient beliefs of CAM assisting their body's immune system to fight the disease without adding further toxins. Although, Thomson et al. (2014) conducted structured interviews which meant participant responses were standardised to gather statistical data on CAM usage. Using CAM as an alternative treatment assists in dealing with the underlying cause rather than just ministering to symptom relief (Bishop et al., 2008). How CAM products are marketed often includes language such as 'natural' and 'safe' (Wulffson, 2015) and according to Boon, Kachan and Boecker (2013), is a strong deciding factor for people choosing them instead of conventional methods.

3.4.7 Affordability

How much patients spend on CAM and how this influences decisions to pursue this form of treatment varies. Wanchai et al. (2016) disclose participants acknowledge the preference for CAM impacts them financially with some having to stop taking the products because they are too expensive while others chose a cheaper option. Maintaining CAM usage by opting for lower priced alternatives may also compromise the quality and effectiveness of the treatment. This may be why Wilkinson and Stevens (2014) note patient expectations of CAM were down slightly at the end of their treatment, as average spending was only \$41 per month. Saibul et al. (2012) found high prices could deter individuals from trying CAM, however, this study used structured interviews which meant the participants answers were not explained further. In developing countries Chartterjee et al. (2005) found the opposite – conventional methods were dearer. Although some patients recognised the cost of CAM was an issue, they believed spending their money to try and improve their health was more

important (Patterson et al., 2002; Wanchai et al., 2016; Wanchai et al., 2010). In Aotearoa, Chrystal et al. (2003) established patients spending on CAM varies from nothing (changing eating habits) to \$660 per month.

3.5 Summary

At first glance the comparison between cancer patient's attraction to CAM and others looks the same. However, when examining the underlying meanings of those reasons, cancer patients appeared stronger with their views and more determined with their decision to use CAM. The pull towards CAM for cancer patients almost seems a desperate attempt for survival. Noticeable benefits, whether physical or emotional were essential and CAM was often valued for increasing general wellbeing as well as decreasing side effects of conventional treatment. Feeling respected and supported with their chosen choice of treatment was a priority to cancer patients. Cancer patients all have different circumstances, from type of cancer and severity to varying financial and living situations. Minimal studies are found in Aotearoa of CAM usage and benefits. Therefore, this proposed research will update and add to the sparse body of CAM evidence found here. The following chapter will present a rationale for the study and provide the aims and questions for the research.

CHAPTER FOUR: STUDY RATIONALE

There is no doubt the growth in interest and usage of CAM throughout the world, not only for general health or minor illnesses, but also for potentially life threatening diseases, such as cancer has been phenomenal. Previous studies suggest the decision for people diagnosed with cancer to use CAM instead of, or in combination with conventional methods is multifactorial. However, whether cancer survivors in Aotearoa hold similar views to those suggested in previous research is largely under investigated. This chapter will provide justification for undertaking this research project and finish by specifying the associated aims.

4.1 CAM usage for cancer treatment in Aotearoa

In Aotearoa, most studies on CAM have focused on terminology used (Leibrich, Hickling, & Pitt, 1987), services available (Duke, 2005), users (Pledger, Cumming, & Burnette, 2010), regulations (Ministerial Advisory Committee on Complementary and Alternative Health - MACCAH, 2004) and cost (MACCAH, 2001). There has been little research on CAM as a treatment for cancer and why these remedies appeal to cancer patients in Aotearoa. Undertaking cancer research specifically designed for Aotearoa people is important because of how cancer impacts each person differently and the unique diversification countries provide. Cancer is the leading cause of death in Aotearoa (MOH, 2016), and gaining insight into why individuals choose to fight the disease with alternative methods may offer clarification and reassurance to cancer patients contemplating other options.

Some studies found in Aotearoa of cancer related CAM usage have attempted to meet this gap in research (Bennett, Cameron, Whitehead, & Porter, 2009; Chrystal et al., 2003; Trevena & Reeder, 2005), however these findings still show areas where more evidence is necessary to provide deeper awareness of why cancer survivors dismiss mainstream treatments. Bennett et al.'s (2009) investigation compared older and younger cancer survivor's information seeking behaviour on CAM remedies and how much this material influenced CAM usage. Participants were given a list of CAM treatments to indicate what they were using, however no detailed report of how CAM helped or not helped them followed. Chrystal et al.'s (2003) research enlisted cancer patients from an oncology clinic to examine their CAM usage. This meant it was not possible to examine the reasons why individuals refused conventional methods. While this analysis asked for reasons why CAM was used, no explanation for those reasons, such as how CAM relieved symptoms was provided. Trevena and Reeder's (2005) study recruited adults who did not have cancer and asked about their knowledge of CAM therapies and their views on these remedies for cancer treatment. As with any crisis, what a person says they will do could be completely different when personally faced with making that decision. The proposed thesis is designed to gather subjective experiences of adults who have survived cancer using CAM remedies as an active treatment in their healing journey.

4.2 Need for qualitative research

All three studies above were conducted using questionnaires. While these methods are cost effective and efficient for reaching large populations quickly, there are limitations. For example, participants were unable to explain their reasons for

using CAM or whether they experienced any value from the remedies. Consequently, questionnaires cannot provide in depth responses of how participants interpret what is being asked, so understanding the process of how and why patients arrived at these conclusions is not possible. Questionnaires also cannot disclose how truthful a person's response is or any other relevant information the participants might want to share, but were unable to because the questionnaire did not allow (Marshall, 2005).

In contrast, interviews can offer opportunities for participants to expand on their experiences as the interviewer is able to prompt for further information. Having face-to-face conversations allow more in-depth discussions to take place (Britten, 1995). Conducting the questioning in a comfortable meeting environment enables participants to relax, helping with uninterrupted reflective thoughts (Elwood & Martin, 2000). When the concern is for human health the issue becomes more sensitive and complex and reinforces the need for continued objective and subjective research. To obtain a true account of how cancer survivors perceive CAM as a possible treatment, semi-structured interviews were performed.

4.3 Research aims

There is considerable literature stating CAM should not be advised to cancer patients because of the lack of scientific evidence proving it is valuable and effective (Hassed, 2011; Koczwara & Beatty, 2011; Maha & Shaw, 2007; Olver, 2011). One purpose of this research project is to supplement the existing data available on CAM treatments for cancer. This information may also help policy makers and funding agencies' decision-making on whether CAM is a viable option for cancer treatment.

The main aim is to investigate the attitudes of a sample of cancer patients to establish why they use CAM treatment. Therefore, this research used semi-structured interviews to gain the perspective of a sample of cancer survivors in Aotearoa and add to the sparse body of CAM evidence found here. Although not an original aim of the study, through the course of the interviews participants often spoke of the benefits of CAM usage as well as some of the few perceived detriments, so these have been incorporated into the findings and discussion.

CHAPTER FIVE: METHODOLOGY

This chapter provides a systematic analysis of the design strategy used to direct the research. The main aim of this research was to investigate the attitudes of a sample of cancer survivors to establish why they use CAM treatments. Semi-structured interviews were conducted over a four week period. In total five interviews were performed. The rationale for using thematic analysis as the research approach will be discussed. The method will be described as well as how data was collected and analysed. Ethical considerations are also addressed. To begin with, a description of the more general qualitative standpoint will be examined.

5.1 Qualitative research

According to Green and Thorogood (2014) qualitative data offers the opportunity for unwell individuals to provide rich detail of their experiences. The subjective personalised discussion encourages participants to share in depth and often sensitive information, through the sharing of their story in a dyadic relationship (Finlay, 2015). This increases the likelihood each account will be explained from start to finish, especially if the interview environment is relaxed. In contrast, quantitative study designs focus on establishing causal links between observable phenomena (Barnham, 2015). Research conclusions are quantified using statistical data with as little human interference as possible. This suggests if these studies are undertaken in stringent conditions to eliminate possible variables they may be replicated, thus results can be regarded as being based on scientific evidence. The battle among researchers over the best approach regarding finding the truth is ongoing, but how is truth defined?

One could argue a person's knowledge through lived events is fact; evidence of what their experiential truth is, without the need for objective quantification.

Because the main aim of this research is to understand cancer patient beliefs regarding CAM treatment, or their truth through their lived experience of cancer, the most appropriate approach for this study is qualitative. Understanding how cancer treatment affects the individual personally is just as important as knowing how effective the remedies are. Each cancer experience has unique aspects because of the holistic nature that CAM treatment offers, incorporating factors such as spirituality, genetics and family influences (Verhoef, 2007). However, there can also be similarities regarding patient attitudes towards CAM as identified in the literature review. In this study, parallels were discovered comparable with previous studies, as well as distinctive themes. These themes were 'extracted' through conducting a thematic analysis.

5.2 Thematic analysis

Thematic analysis (TA) is often considered a means of unravelling particular representations within other epistemological assumptions, such as phenomenology and grounded theory (Guest, MacQueen, & Namey, 2012). However, TA has also been recognised as a stand-alone qualitative method used to ascertain and investigate emergent meanings within textual data (Clarke & Braun, 2013). The approach achieves this by categorising the main points from the descriptive accounts shared by people through an interview process (Vaismoradi, Turunen, & Bondas, 2013).

Questions are formulated to search for collective experiences and are presented as precisely as possible (Joffe, 2012). TA can focus on word content (semantic) and Vaismoradi, Jones, Turunen and Snelgrove (2016) believe any hidden associations (latent meanings) may be overlooked. This research centred on the semantic approach, to ensure the analysis was an exact record of what participants said during the interview, rather than the researcher making assumptions about what the participants may be implying. However, probing questions were asked to establish more reflective answers.

TA can also be adapted into different theories, such as conducting the realist standpoint (recording what reality is for people from the data), to constructionism which examines why the same experience can be shared by individuals, but have different meanings (Clarke & Braun, 2006). However, the researcher needs to avoid mixing theoretical assumptions by ensuring the questions are relevant to the aim of the study and study participants. A realist approach was the best option for this research, as the objective was to establish themes from the patient's perspective. Willig (2013) describes themes as being repetitive ideas highlighting meaningful information across the data set. Through this process, ideally new knowledge will be discovered. By applying this principle, an inductive "bottom up" approach is used, whereby themes are strongly associated within the research rather than developed from a specific theory (Clarke & Braun, 2006). In this study, an inductive approach allowed the participants to voice their experiences of cancer, why they opted for CAM and how these alternative treatments have affected them. How themes were defined is outlined below in section 5.7 of this chapter. The specific themes emerging from the data included:

1. decision;
2. empowerment;
3. holistic;
4. wellbeing;
5. social harm.

5.3 Participant recruitment

Ethical approval was sought and obtained from the Massey University Human Ethics Committee – MUHEC (SOA 16/17). Because of the sensitivity around cancer, the ethical issues involved in this research were addressed in detail as part of the documentation requirements of MUHEC. This study intended to target a sample of Aotearoa cancer patients receiving CAM treatments. Clinics specialising in treating cancer patients were approached and asked if they would be happy about the possibility of their clients partaking in the research. Upon agreement, an information sheet (see Appendix A) outlining the research project and participant requirements, as well as an advertisement (see Appendix B) giving a brief description of the research, participant eligibility and the researchers contact details was given directly to local clinics. Clinics within the Taranaki region were targeted, as these were closest to where the researcher resides, so were considered more convenient in terms of the researcher being able to meet face-face with interviewees. However, due to an initial low participant response rate, clinics outside of the Taranaki region were subsequently contacted. For clinics outside the Taranaki area (Whangarei and Tauranga), the information sheet and advertisement were emailed. From the recruitment strategy, six interested volunteers contacted the researcher. Potential participants who replied to

the advertisement were given the information sheet either by email or hand delivered. These respondents then contacted the researcher again within a couple of days wanting to participate in the research. Those who had received the information sheet from the clinics, contacted the researcher to ask questions and volunteer for the study. The interview time and setting was also scheduled at this point. All participants requested the interviews be conducted within their homes. This was not only the most convenient place for them, but the environment was quiet and somewhere they felt safe and relaxed. One interested person was deemed unsuitable for the study. This was because they had only recently been diagnosed with cancer and had not undergone any treatment at the time of responding to the advertisement.

5.4 Method

Semi-structured interviews were conducted to provide a verbal interaction between the researcher and participants. The same questions were administered to the cancer participants allowing the researcher to compare across interviews. Using probes, such as “can you tell me more about that?” also helped each interviewee explore their experience deeper. By letting the interviewee expand on their thoughts, an in-depth discovery of their feelings regarding being burdened with cancer occurred. The use of open-ended questions permits these responses, which cannot be gained through forced choice questions (Longhurst, 2009), thus enabling participants to be free in their thinking. According to Wilkinson, Joffe and Yardley (2004) people do not always think in a consistent and stable manner, particularly on sensitive issues, yet some researchers have a tendency to make it appear to be so in order to be persuasive. Because cancer is a highly emotional topic, the researcher was careful not to impose

their perspective on the participants. By not interrupting with suggestive ideas, Rossetto (2014) describes an atmosphere is created where respondents can relax and expose unconscious, emotive associations.

5.5 Participant characteristics

A total of five participants were recruited for this study. As indicated above in section 5.3, participant numbers were limited for this study because of difficulties encountered with the recruitment process. Initially, the research was focused on the cancer patients of a specific CAM therapist, however two months into the enrolling stage, the therapist stated her patients were too sick to be interviewed. Other CAM clinics treating cancer patients then needed to be found as well as approval of the changes from MUHEC, which shortened the time to find suitable participants. All respondents considered for the research were English speaking male or female adults aged between 18-74 years. The participants could be receiving conventional and/or CAM treatments, however there were no criteria for the type of cancer, how long patients had been treated, whether they still had cancer or are considered terminal. Current job status and position, ethnicity or socio-economic level did not influence recruitment. People excluded from the research were children, and participants who are not fluent English speakers. This was because the researcher can only speak and understand English. Table 6 provides details of the cancer participants. Pseudonyms are given to maintain confidentiality.

Table 6

Cancer participant details

NAME	AGE	TYPE OF CANCER	CLINIC	TREATMENT
Rachel	25-34	Bowel	Taranaki Base Hospital; Northland Environmental Health Clinic; own knowledge	Surgery, oral chemotherapy drugs, supplements, nutrition, reiki, yoga, tai chi, meditation
Margaret	65-74	Breast	No clinic - friends and own knowledge	Mastectomy, tamoxifen, homeopathy, energy healing, yoga, tai chi, supplements, nutrition, meditation
Jessica	45-54	Breast	Natura Medica Limited, New Plymouth; FEM Limited, New Plymouth; own knowledge	Lumpectomy, homeopathy, paleo diet, supplements, meditation, intravenous vitamin C, saunas, tai chi, nutrition, yoga, acupuncture
Cheryl	55-64	Breast	No clinic – friends and own knowledge	Mastectomy, nutrition, supplements, kinesiology, exercise
Amanda	45-54	Breast	No clinic – friends and own knowledge	Mastectomy, nutrition, supplements, yoga, meditation, emotional freedom technique

5.6 Data collection

The data collection process occurred over a four week period with each participant having one interview. A \$20 petrol voucher was provided to the participants as compensation for their time and/or travel costs. The interviews were approximately one hour and conducted at a date and time mutually convenient to the researcher and participants. Written informed consent (see Appendix C) from the participants was sought prior to the interview commencing, and an explanation of confidentiality was also given at this time. A simple questionnaire (see Appendix D) was completed at the beginning to gather contextual information. The interviews were

audio recorded using an interview schedule (see Appendix E) and transcribed verbatim.

5.7 Data analysis

Analysis for this research followed Braun and Clarke (2006) six phases for TA, which are outlined in detail below.

5.7.1 Phase 1: Familiarising yourself with your data

After each interview, information that could not be captured from the recording was noted, such as participant body language and the impressions the researcher had about the interview. Every interview was listened to first and notes were taken. Transcribing involved listening to the data twice more to ensure the information was written down accurately and a true description was given.

5.7.2 Phase 2: Generating initial codes

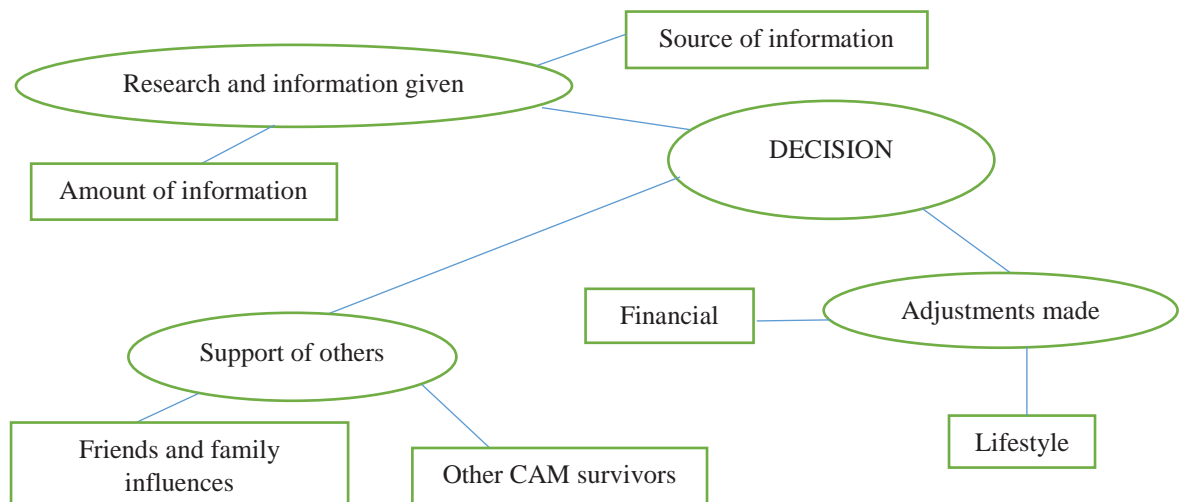
Codes were manually produced by working through each text and highlighting significant passages, which were then labelled with a code that captured the meaning of the segment. The codes were inductive to portray the participants' experiences and opinions. The formulation of the codes was also examined by the author's supervisor who checked the transcripts for validity. Twenty two codes were generated from the initial coding stage.

5.7.3 Phase 3: Searching for themes

The list of codes identified were then categorised and grouped into overarching themes and sub-themes. Figure 1 shows how the codes were combined to form the various themes.

Figure 1

Example of Mind Map of Initial Themes for Decision



5.7.4 Phase 4: Reviewing themes

Phase 4 involved reassessing the themes, to ensure they suitably corresponded with the codes and transcribed data set. Because the themes are only a few words it was important to reflect on these statements to ensure they summarise the interviews in a credible and captivating way. Each theme became distinctive during this stage, as similar ideas were merged or themes were dissected further, or discovered to be irrelevant so required the data to be revised. This process was again checked by the author's supervisor.

5.7.5 Phase 5: Defining and naming themes

This step entailed exploring the themes and developing stories, to ensure they matched the overall research questions. Sub-themes were also refined during this process and the ‘essence’ of each theme was captured with a short, sharp, explanatory title.

5.7.6 Phase 6: Producing the report

The concluding stage of writing the report involved integrating the investigative description with interview quotations to add emphasis and fact, which coincide with the objectives of the research.

5.8 Researcher position

I have always had a personal desire to maintain good health and was a client in the past of a CAM therapist for general preventative healthcare. While being under this therapist’s care, I learned she also treated people with cancer. Understanding why people would choose these treatments and whether they were working for them became an interest for me. Unfortunately, the original objective to investigate this particular CAM therapist and her unique treatment regimens did not eventuate, however exploring other cancer survivor’s journeys has also been thought-provoking and inspiring. Although I have a particular interest in CAM, the results of this study did not deliberately favour these treatments. When participants realised I valued alternative treatments, their opinions about CAM seemed more passionate. This provided valuable insight in the greater care of cancer individuals who choose CAM

remedies and a greater understanding of cancer from a patient's perspective for health practitioners, researchers and the general public of Aotearoa. I am also a mother and believe this has enhanced my empathy, patience and understanding towards others. I have been a volunteer for Victim Support and worked for Pathways New Zealand. Both these experiences enabled me to develop better listening skills, support people often in despairing moments and help them gain strength and take control of their lives again. I have also worked for the New Zealand Heart Foundation. This role permitted me to provide education to school children about making healthy food choices as well as supporting adult stroke and heart disease survivors to encourage lifestyle changes to lessen the chances of secondary illnesses. Undertaking these duties reinforced my passion of wanting to make a difference in the lives of people with health issues.

CHAPTER SIX: FINDINGS

This chapter presents the results from the interview data. Table 7 presents five main themes and the additional sub-themes that emerged from conducting a thematic analysis, and through adhering to the research questions during the interviews with five participants. The themes are divided into three sections with their accompanying sub-themes, linking them to the aim of the thesis and are discussed citing literature as appropriate. Participant interviews are also contrasted.

Table 7

The Three Main Discussion Categories and Five Themes with their Accompanying Sub-Themes Produced from the Thematic Analysis

DISCUSSION CATEGORIES	THEME	SUB-THEMES
Why is CAM used?	Decision	Research and information given Support of others Adjustments made
Benefits from using CAM	Empowerment	Taking responsibility for own health Searching experience
	Holistic	Psychological changes Balancing life
	Wellbeing	Reduced side effects Looking and feeling healthier
Disadvantages from using CAM	Social harm	Selective support Abandonment

6.1 Why is CAM used?

The aim of this thesis was to investigate participant attitudes to establish why they use CAM. While there is considerable international literature on this subject, as explored in previous chapters, there is limited research found here in Aotearoa. The theme that emerged from the interviews regarding this question was based on *decision* and is discussed further below:

6.1.1 Decision

The decision to use CAM as treatment of cancer was not always a simple or easy choice for the participants, with deciding influences based on *research and information given; support of others; and adjustments made.*

6.1.1.1 Research and information given

The information on mainstream treatments for cancer given by medical professionals as well as the participants own research on CAM and conventional methods, impacted their decision to use CAM. Their confidence in CAM is demonstrated in their comments below:

... I think it was I read, and I have read and read and read and in the end it was pretty well obvious at my age ... (Margaret)

... once I got my diagnosis I looked into PubMed and ya know, the little bit of information and did, ya know there's, there is a great wealth of stuff out there ... I consider myself reasonably intelligent, intelligent enough to figure out what's good for my own health and wellbeing ... (Jessica)

... it's a personal thing, but as long as you've got information and good information of both alternatives, then you can make an informed decision, but if you haven't got information of an alternative, then you don't think you've got one, I guess. (Amanda)

... I had time to decide about that [chemotherapy] um, but I guess, and I was given information, so [interviewer: about chemo?] about, I was given a report so I could look at the statistics of the benefits [interviewer: ok] and have time to weigh that up ... I questioned the doctors about everything, I wrote questions down, I asked the surgeons, I wanted to know ... (Rachel)

Jessica and Rachel also reveal they have spent time researching conventional treatments for cancer and how their findings have made them query the methods, and ultimately led them to use CAM:

...just the fact, ya know, where it [chemotherapy] came from, the history of it, ya know, I know where Bayer, ya know, the German company, the Americans getting those scientists from, ya know, after World War II and then, ya know, forming those early pharmaceutical companies and chemotherapy coming

from mustard gas originally and ya know, so the history of it didn't make sense
... **(Jessica)**

... I had been aware of various um, aspects of questioning mainstream treatment and I have seen um, interesting documentaries, such as Cancer the Forbidden Cure ... **(Rachel)**

Jessica shared how important it was for her to remain in control of deciding what she regarded as the best way to treat the cancer:

... I'm open to all information, but not um, giving my own authority away ...

Similarly, Rachel's rationale for investigating and using CAM was:

I want to look back and have done everything I can.

6.1.1.2 Support of others

Significant others can and often are involved in decisions regarding health and wellbeing. How much significant others impacted the participants decision to use CAM is evident in the participant's discussions:

... everyone just accepted what I have done and have been quite encouraging
... my parents, close relatives, friends. Some friends were sort of like, ooh we've seen this stuff and chemo isn't necessarily that good, but I think it's a case of, when you're in your own shoes and going through it, you can't, and

I've had friends say that to me, ya know, you've got to make the decision for yourself, so, but they could see I was doing everything ... (Rachel)

... so there was a point of talking to my husband, but he was very supportive and he was probably more alternative than me in many ways ... (Margaret)

... everybody else was [supportive], and my Mum, she supports me in whatever I want to do ... I've got a friend who's right into that to [nutrition], [interviewer: ok], that's, ya know helped me research that and she'd come up with different things that I could look at ... (Amanda)

Non-significant others can also play a role in decisions regarding health and wellbeing, typically through the anecdotal accounts they provide of their own experience. Jessica talked about people she knows and had met at the hospital who were receiving intravenous vitamin C at the same time as her. Their stories reassured her about the decision not to undergo conventional treatments:

... there are people up there with secondary cancers that wish they had never got chemo and done, yeah, and there are people up there that have done other things and have been told they, they have six months to live and there's a guy up there, is alive two years later ... so it was interesting to sit there and have these discussions with these people ...

...I know two women who have had mastectomies and that's it, not had anything else and very, very um, firm ... absolutely would not had gone chemotherapy ... (Jessica)

Rachel also discussed her knowledge of people surviving cancer using alternative treatments, which helped her decision to try CAM:

... people have survived by being treated, say with the Gerson diet, or um, through various other uses of medicinal herbs and um, things such as mistletoe ... (Rachel)

6.1.1.3 Adjustments made

The participants desire to use CAM required making adjustments to their lives. These discussions were mainly around how they manage their CAM costs and whether or not they found them to be a burden:

... the CAM stuff is all purely me, and I think that was one of the big things also about coming down [to live with parents], was so I pay a little bit of board to my parents and I buy my own food and that meant I could concentrate on putting all my finances into good food, so I try to go organic and I try to get better quality stuff. Doesn't always happen, it's, it's a balance, but um, I feel like I am doing what I can and it feels a lot better, also being able to grow food in the garden ... (Rachel)

... they're all cheap. I haven't gone down the way of a lot of supplements, which I know, I buy um, again [name] helps really well, she tells me what's alternative and what would be a cheaper way of doing it, or this one's really good, you need this one ... I don't believe in taking a supplement forever ... so no the cost isn't there in supplements, which I think a lot of people get hooked into ... (Margaret)

... I was getting vitamin C therapy, which I did take immediately ... [interviewer: is that intravenous vitamin C?], yeah, yeah. I didn't do it for long, it's hugely expensive so [interviewer: ok] um, I ended up having to weigh up, ya know whether I wanted to tap into my mortgage and go whole into that and watch my mortgage expand and then ya know, I'd have to take on the stress of that ... I just had this set amount I allowed myself without even considering anything, without letting it be an issue and then when it, when it did start coming into my mind that it was an expense, ya know I just dropped it ... now it's not too much of an effort, ya know it's um, it's what I see as insurance ... (Jessica)

... I added it [expenses] up the other day and I was horrified, I thought that's why I work [laughs] work so I can live ... on bad weeks I probably spend nearly \$20 a week, I mean a day ... which is horrifying, so I cut the vitamin tablet in half now and give half to my husband and give myself half [laughs] and that's why I still go along to the kinesiologist, just to make sure that I'm not overdoing things ... my daughter [owns health shop] gives me discount, she's

very good, we eat lots of rotten fruit and veges [laughs], which is fine cause it's still organic ... (Cheryl)

... that essaic, my friend bought it for me ... that was expensive ... she even bought me my blender, cause I didn't have a blender to do smoothies um, I ended up buying a cheap juicer, but ya know that kinda stuff is simple stuff um, that you need if you wanna do it that way, all natural. It's not cheap ... (Amanda)

It is evident from the above statements, why the participant's use CAM and the way they made decisions to feel assured of their choice was not a simple procedure. The participants did not rush the process, taking into account all the information they received from specialists as well as material they had researched themselves. The viewpoints of other people the participants associated with also played a role in their conviction towards CAM. Knowing those closest to them supported their decision and hearing stories of regret from individuals having used conventional methods, strengthened certainty in CAM usage. The willingness to modify habits and residing location indicates the seriousness and commitment the participants have to use CAM.

6.2 Benefits from using CAM

Although not an original aim of the thesis, throughout the course of the interviews participants spoke of their beliefs about the benefits from receiving CAM treatment. Again, overseas research is increasing around this area, however no studies

relate to cancer survivors in Aotearoa. The findings regarding any benefits relate to the themes of *empowerment; holistic* and *wellbeing*.

6.2.1 *Empowerment*

The feeling of empowerment was expressed by participants and the sub-themes of *taking responsibility for own health* and *searching experience* were strongly emphasised.

6.2.1.1 *Taking responsibility for own health*

The view of individual responsibility for health was echoed by Rachel who points out, exploring the use of CAM to beat the cancer can take the focus from dwelling on the negative aspects of the disease:

The benefit for me of being able to research and look up stuff and gather information and decide what I could do for myself is hugely positive, absolutely.

Rachel and Jessica also discuss how having a plan is an important part of the recovery process:

... and that's something I do have, is um, self, self-will, determination, yeah so personally I've had to follow this diet, yeah, but I feel much better for it ...

(Rachel)

Initially with the homeopath ah, I enjoyed, it was good going to him because, um, you know it was a sort of a strengthening thing for me to have, to see him and to have his plan, his protocols, you know in place ... so it was good to have that protocol to follow and having seen people online that have um, survived cancers, ya know, ah they have followed a protocol, so there seems to be something in following a plan ... (Jessica)

Cheryl spoke of her love of reading and researching natural options for health and how this inspired her to be in charge of her healing:

... so I kinda knew that I needed to take responsibility for my own health ... to be responsible for myself and just try to stay on track ...

6.2.1.2 Searching experience

Because of the internet, accessing information today is easier. However, having the freedom to search for answers can be helpful, misleading and/or overwhelming all at the same time. All the participants shared how being able to explore CAM psychologically benefitted them:

... I learnt a lot and did my own research ... (Amanda)

... I did a lot of reading. I got help from [name] cause she could get me a lot more magazines and we'd always have this little swap of what book are you reading? What, ya know, what, what's new and so my job was really to, I suppose was to research as much as I could ... (Margaret)

... you can help yourself, yeah. I'm not going to sit back and just have them [doctors] tell me this is the only way and this is all that will work and if it doesn't, sorry ... (Rachel)

... I love to be able to research more and just like, read all the latest things ... (Cheryl)

6.2.2 Holistic

Having a holistic approach to treating cancer was expressed by the participants in this study also reiterated these points with sub-themes *psychological changes* and *balancing life* developing from the interviews.

6.2.2.1 Psychological changes

Part of the benefit from using CAM is the emphasis placed on mental healing as essential for overall wellbeing. The participants talk about the mind working either positively or negatively with the body, with some participant's sharing the techniques they used to help improve their mood:

... I was doing that ah, what's it called, EFT I think it is, the tapping ... it's kinda like bringing up the emotional issues that you have with it ... I don't let a lot of emotions out and let people see that side ... it felt really good afterwards though. (Amanda)

... I've been doing a lot of visualisation, relaxation and breathing techniques and just general healthy exercise ... I used my visualisation and put myself in a good space and put the good energy through me and sent down the river all the issues of life [laughs] and did all the things that I've learnt, it's been great and stuff that I would never have taken the time to do before ... (Rachel)

Rachel and Amanda also discuss how they think the psychological aspect is an important component to their healing:

... I feel like it's all good, it really does, mind and body, it's really, it's just restorative stuff ... (Rachel)

... just my mind set as well I reckon, that had a lot to do with it ... (Amanda)

... I have always been a meditator, for years and years and years of sort of varying degrees and success [laughs] ... you can run meridians mentally and it's very powerful thing, you actually find where you've got a problem that your meridian will block on your meditation, so I'd always run meridians ... (Margaret)

... mental clarity is and um, stability and emotional wellbeing are important ... (Jessica)

6.2.2.2 *Balancing life*

The participants realisation there were areas in their lives that needed changing were also noted, and how utilising CAM has benefitted them by helping bring those matters to their attention:

... meditation, simple things like um, ya know diaphragmatic breathing and eating ya know, how you eat and chewing your food and mindfulness and ya know, so these things I knew of, but maybe I didn't apply them so well ...

(Jessica)

... because a lot of it is to um, ya know obviously it's the physical, the mental, the emotional, the spiritual and you can't have one without the other ... as you get older you realise you've got to have this ... **(Cheryl)**

... you've got to look at your exercise, you've got to look at your nutrition, you've got to look at your mental state, you've got to look at your relationships, you've got to look at your attitude, and if you get those in a balance, you'll be happy ... **(Margaret)**

6.2.3 *Wellbeing*

For the participants, observations of improvements in wellbeing using CAM centred on *reduced side effects and looking and feeling healthier*.

6.2.3.1 Reduced side effects

All participants received surgery for their cancer, however Rachel was the only person who opted for further allopathic treatment (oral chemotherapy) after the operation. How CAM has assisted their recovery is shared below:

... I must say I've had minimal impact, negatively side effect wise, maybe that's because I've been doing other things, yeah. I certainly noticed it one day, the bottoms of my feet were very sore. I had a reiki session and the next day they felt much better ... the side effects you can get with this chemotherapy is diarrhoea, nausea, neither of which I've really had [interviewer: ok] tenderness of the feet, ah and or the hands, um ulcers in the mouth, ah general fatigue. General tiredness is the one thing I feel, I, I have to watch that, but I go to a yoga session and, or I go to tai chi and I feel great when I come out of it. So just that low key, non-stress exercise is really beneficial, even a gentle walk is really beneficial ... (Rachel)

... I did wake up at certain times after my diagnosis and ya know, obviously my adrenals were getting a work out um, but then I can apply ya know, minerals that help that ... that diet I went on, I was energised ... (Jessica)

... I couldn't move my arm for ages ... still actually numb in a lot of places around the neck, cut heaps of nerves, but I did have to do a lot of exercises ... I get the achiness in my arm and my shoulder sometimes um, depends what I'm doing ... I do stretches and do, I don't do yoga every day like I use to, but I do some yoga stretches ... (Amanda)

6.2.3.2 Looking and feeling healthier

How CAM has improved cancer patients physical appearance and feelings of health were also discussed:

... as far as the diet goes, I drink the juice and feel quite energised ... I also noticed in photos that my skin looked yellowy and quite gaunt and I did get comments of how much better I looked, shortly after I'd arrived [in Taranaki] once I'd started really concentrating on everything, um [interviewer: is that from ...] friends and Mum's friends [interviewer: ok], yeah [interviewer: so they'd noticed], yeah, yeah, they'd thought I was just putting on weight cause I looked fuller in the face ... (Rachel)

... everyone noticed that I recovered very fast, but I do feel that one, arnica afterwards was absolutely brilliant. I just think my meditation and visualisation of actually telling everything to grow again. I, I see, I took milk thistle, St Mary's thistle to clear the liver, cause I have a real thing about general anaesthetics and ya know, I've had a few, because I think that can last ... I took that and I got over really fast ... so yes, people said, whoa you've recovered well, wow ... (Margaret)

... I'm stress free more, when I come up against situations I can deal with them better, ya know, yeah better responses to, to potentially stressful situations ... people have said I'm looking good ... (Jessica)

... sometimes people come in the shop and say, ya know like, oh you look good
... (Cheryl)

... I healed really well, cause I did detox and I did change my whole lifestyle, pretty much for my recovery, cause I don't like the pills they were giving me either, cause I was just in la la land, so I was detoxing and trying to get off that, painkillers and sleeping pills I was on, pretty strong ones to ... once I'd healed and that and got off those drugs they'd given me for the recovery, um yeah, I carried on with the lifestyle and I, I healed really well and they were really impressed on how um, how fast I'd recovered and healed ... I got a lot of ah, compliments, I guess on how I handled it ... (Amanda)

The participants described a number of benefits from using CAM, relating to physical and mental aspects, together with decreasing the consequences of cancer. Because of the freedom and flexibility of being able to investigate CAM the participants were encouraged which helped them feel in control of their recovery and any possible future setbacks. Taking time to experience some CAM practices was regarded as rewarding and enabled unhealthy areas of the participant's lives to be emphasised and addressed. The CAM techniques also relieved the side effects of conventional cancer treatment. This was not only noticed by the participants, but observed by other people as well.

6.3 Disadvantages from using CAM

Although also not an original aim of the thesis, participants also spoke of some of the drawbacks from using CAM. Given no studies draw attention to the personal after-effects of cancer survivors in Aotearoa who choose CAM, including this information in the findings was deemed important. The findings regarding the disadvantages of using CAM relate to the theme *social harm* and is considered as follows:

6.3.1 *Social harm*

As a result of using CAM, the participants were sometimes confronted with disapproval from significant individuals, which affected them socially. This is expanded in sub-theme *selective support*. The downside to choosing CAM over conventional treatments was also apparent in sub-theme *abandonment*.

6.3.1.1 *Selective support*

Jessica talks of how careful she was with who she told about her cancer diagnosis:

... with that initial diagnosis I was also ya know, didn't sort of go out and pronounce what I was doing to everyone [interviewer: ok] because I wanted to um, just be focused and not have that conflict ...

Amanda recalls how one friend was supportive until she realised she was not going to use conventional treatments:

... my friend [name] she'd been through it herself a few years earlier and had the same as me, a mastectomy of one breast, um she ah, she had done the radiation and the chemo and she, I remember her texting me after the operation and saying oh, how you going, when do you start your, ya know your chemo, blah blah blah, and I said, oh I'm, I've decided not to do it and she was like, why not, ya know, she was, because she'd been through it and done it, and she was all good, she was healthy as far as I knew, ya know you wouldn't even know, to look at her that she'd been through it ... she was the only one that didn't support me, in my mind, um in my decision not to do anything, she thought I should.

Margaret spoke very candidly about how she protected herself from the people who did not support her decision to continue with conventional treatments:

... my husband was totally supportive and all my friends were too, and I didn't have anything to do with the ones who weren't ...

Rachel's situation was slightly different. Her partner thought she should not incorporate chemotherapy in her treatment regimen. She decided to move away to ensure she was in an environment which gave her the best chance of recovery:

... everyone has just accepted what I've done and been quite encouraging. I think the person who was the least happy I went in chemo was my partner ...

while my partner really wants to support me, he's not that good at it and um, so that was sort of like my ultimate, well I'll come down and let Mum and Dad pamper me ...

6.3.1.2 Abandonment

Abandonment was primarily evident when participants spoke of feeling like they had been deserted by their oncologist. Margaret and Cheryl describe how they were dismissed by the specialist when they declined the drugs:

... so that's when he said, right well we don't need to see you anymore and I remember saying to him, he said, come back if you need it, I said what, what should I come back for? He said, well you know, if, if things go really wrong. That was it. That's the end of your care, if you don't take any of their drugs, that's the end, that's it, which, and I think that is the worst of all, that's when women need, you see you're off the records, you're not even part of their research anymore [interviewer: mmm] you're not even part of where you got to after five years ... (Margaret)

... I think I only, they checked me once after that just to say, well no, ya know go away we don't want to see you again ... (Cheryl)

Amanda's recollection of feeling disregarded was related to the dismissive responses she received from the oncologist when she asked about possible CAM remedies:

... so I just thought, ok I'm getting no support here in anything other than chemo, radiation and whatever that pill was ...

Likewise, Jessica mentions her enquiry to the oncologist asking his advice about ways to improve her health and how his recommendation seemed flippant:

... I did say to him, what about diet, are there any suggestions you could give me as to what, and he said, oh just stay away from saturated fats ...

These comments point out how not everyone the participants discussed CAM with shared their optimism for the remedies. This caused them to distance themselves from those people and become discerning of who they did associate with. The lack of support and disregard from medical specialists once the participants decided not to pursue conventional treatments was also clearly voiced.

6.4 Summary

This chapter explored the viewpoints of five women who either had recently been diagnosed with cancer or had survived cancer for at least five years. The major themes paralleled the findings of some other studies regarding why cancer patients chose CAM treatments, such as the amount and type of information gathered or wanting to personally take control of health care. The support received also impacted cancer survivors attitudes towards CAM. The benefits of pursuing CAM showed the participants making positive mental and physical changes, as well as having side effects reduced and other people noticing their improved wellbeing through using

CAM remedies. The opposite to the benefits of deciding to use CAM, however meant the participants felt abandoned and needed to be careful about who they shared their experiences of using CAM with. The findings are discussed in more detail in the following chapter.

CHAPTER SEVEN: DISCUSSION

This chapter examines the findings of the current research, which investigated the attitudes of a sample of cancer patients, to establish why they use CAM, and explored their beliefs regarding the benefits and/or disadvantages of receiving this treatment. Thematic analysis was used to explore their stories and experiences. The major themes of the research are discussed in this section, specifically in relation to previous findings relating to CAM usage in general. Study limitations are highlighted, as well as suggestions for future research.

7.1 Major findings

The major findings of the study suggest that many of the reasons for CAM use among this sample align with the ‘push’ and ‘pull’ factors that have been identified in previous literature. As previously mentioned, participants also spoke of the benefits and disadvantages of using CAM, which also had some resonance with some of the ‘push’ and ‘pull’ factors that have been previously discussed as reasons for CAM usage. These are discussed in more detail below.

7.1.1 Why was CAM used as treatment?

Recognising some of the motives that sway individuals to feel secure in their decision to use CAM is essential for understanding the dynamics behind why people choose alternative treatments for illnesses such as cancer. The main findings of why the participants used CAM for their cancer treatment solidified from the research and information they obtained, how much support they received from others and whether the adjustments they needed to make to their lifestyle was achievable. The participants

spoke of the desire to pursue alternative treatment options as a personal choice and felt very sure of their viewpoints. Previous research suggests there can be a number of reasons for people using CAM, including their reservations about medications and their experiences with doctors (Bishop et al., 2004; Bishop et al., 2006; Furnham, 2007). The participants spoke of their misgivings towards conventional treatments for cancer and these moralities have been linked to the 'push factors' associated with why people disregard these methods. A large part of why the participants pursued CAM was based on the research and information they were given as well as sourcing themselves. To lessen the uncertainty of knowing whether a decision is the right one, it is common for individuals to gather as much background information as possible to help verify their choice (Rimal & Turner, 2015). However, when a person is diagnosed with cancer they are generally given information on orthodox treatments only (Schofield, Diggins, Charleson, Marigliani, & Jefford, 2010), meaning information on other treatment options must be sourced by themselves.

Making health decisions often involves emotion and adding time pressures can also affect this process (Fagerlin et al., 2006). Notably, all the participants in the present study accepted the material and advice they received from the oncologists, signifying they were willing to hear and consider conventional options. However, they were also proactive in researching alternative treatment options such as CAM, which often involved much time and effort pursuing activities such as searching the internet or reading books. Having the responsibility to research the CAM treatments themselves did not appear to bother the participants, rather the task was seen as something which just needed to be done.

Participants also spoke about conversing with others and discovering some of the negative side effects of conventional cancer treatments, which fed into their decisions to use CAM. Combined, both these self-seeking behaviours align with some findings from previous research. Specifically, a dissatisfaction with conventional medicine by patients and a dislike of the negative side effects of some medications have been outlined as ‘push’ factors leading to CAM use.

The ability to research CAM as an option may have made the participants feel as if they were more involved in their treatment process, which is similar to previous research that has expressed patient’s desires to be involved in decision making around their treatment as a ‘pull’ factor leading to CAM use. Each participant evaluated what the best regimen was for them, and in some cases opted to supplement their conventional medical treatment with CAM. Previous research suggests many cancer patients – as many as 68% - may choose integrative oncology as an option, whereby they use a combination of both conventional and alternative treatments (Bauml et al., 2015; Mao et al., 2007). The participants’ experiences outlined in this study are also suggestive of this.

Much of the research relating to cancer patients deciding which treatment they will use discusses how considering CAM delays patients from receiving conventional treatment and the consequences of this (Freckelton, 2012; Stub et al., 2016; Wardle & Adams, 2014). While White and Verhoef (2003) state there is a risk of disease progression if patients postpone orthodox methods for prostate cancer, Kato and Neale (2008) found contemplating CAM did not delay medical treatment for head and neck cancer patients. Therefore, type of cancer may play a role in the type of treatment

people choose, and the length of time they take to make a decision regarding that treatment. Although type of cancer was not explicitly discussed as a decisive factor for CAM use in the present study, it is possible this may have influenced CAM usage to some degree. Determining what type of treatment a cancer patient will choose is an individualised choice, one which should be made as quickly as possible. However, the patient must feel confident in their decision which requires information being readily available from both alternative and conventional professions.

The process of weighing up the most suitable choice has been ascertained by Balneaves, Weeks and Seely (2008) as a natural practice for cancer patients, with social factors often considered. Andersone and Gaile-Sarkane (2008) recognise the power that social influences can have on decision making. The authors believe when a person has continual association with certain groups, such as friends and family, the behaviour and judgements made within these alliances can sway choices. The negative opinions about chemotherapy made by the friends of one participant are an example of this. When cancer patients do not get advice from their medical professional about CAM, they may turn to people they trust for their opinion (Evans, Sharp, & Shaw, 2012). This was evidenced in the present study, with the participants expressing the importance of having loved ones alongside them through their cancer journey to strengthen them and give reassurance with the decisions they made concerning CAM. This finding also supports previous research. Hirai et al. (2008) found cancer patients were more likely to use CAM when their family approved, along with Molassiotis et al. (2006) who stated family often provide their loved ones with the CAM information. The support of those closest to individuals dealing with cancer

is important as the focus should be on managing or eliminating the disease, not on needing to continually explain their reasons for choosing CAM.

The other notable finding from discussions with the participants was their knowledge of other cancer patient's not receiving chemotherapy and surviving using CAM, which aided their decision to do the same. This parallels with previous studies showing how using CAM improves cancer survivor's quality of life (Du, 2012; Ganz et al., 2002). Being able to approach individuals surviving cancer without undergoing conventional treatments gives confidence to others contemplating what treatment they should have.

Interestingly, the discussions one participant had with individuals who regretted having chemotherapy aligns with the 'push' factor relating to the negative effect of drugs identified in previous research, which can serve as a motivator to use CAM. Studies show there are only a small number of people who regret having mainstream treatment for their cancer (Davison, So, & Goldenberg, 2007; Wilson et al., 2016), and yet previous studies indicate the adverse effects of mainstream treatment serve as one of the main 'pull factors' motivating CAM usage. This suggests there may be further research needed to better explicate the relationship between satisfaction with so-called conventional treatment for cancer and decisions to utilise CAM.

The *adjustments made* sub-theme related to the financial decisions the participants made regarding how they incorporated CAM into their budget. For some participants this meant weighing up the expense of CAM and the sacrifices needed,

while others found the cost manageable and happily altered their routines to accommodate CAM. The decision to seek out a CAM therapist was also influenced by how much the participants could afford. The inability to afford CAM was expressed by one participant and could only be achieved with the help of others. This finding aligns with previous research (Gollschewski et al., 2008), who states the high cost of CAM can affect an individual's rights of choosing which treatment they want to use. Previous research has indicated the level of income to be a predictive factor for CAM usage (Eisenberg et al., 1993; Koczwara & Beatty, 2011; MacLennan, Myers, & Tylor, 2006), however the findings of this study are consistent with Astin (1998) who found income not to be a determining factor for using CAM. These findings also align with previous research noting CAM type and frequency of usage can vary for people depending on price (Chrystal et al., 2003; Wanchai et al., 2016). The determination expressed by the participants to find ways to include CAM in their regimen is also comparable with previous studies showing individuals with a desire to use CAM see the treatments as necessary at whatever cost (Patterson et al., 2002; Wanchai et al., 2016; Wanchai et al., 2010). Deciding how much vitamin and mineral supplementation was included in the participants regimen varied, however the use of these biologically based therapies coincides with previous studies as the most popular CAM choice for people (Koithan, 2009; MacLennan et al., 2006; Robinson et al., 2002). This may be because these remedies are regarded as being more affordable (Chrystal et al., 2003).

Beatty, Koczwara, Knott and Wade (2012) discuss how the expense of these remedies can stop individuals from considering using them, although findings of other studies indicate the cost of conventional medicine can serve as a 'push factor'

motivating people towards CAM usage (LaFrance et al., 2000). While this research was not focused on why people do not use CAM, it is not known whether the costs of conventional treatment served as a motivating factor for CAM usage. No other known studies have been found demonstrating the changes cancer survivors make to incorporate CAM into their lives and any possible sacrifices made as a result of these adjustments. This illustrates the determination the participants have to find ways to include CAM and their confidence in these remedies. These results also suggest CAM treatments can suit all budgets. The key is for individuals to be open about making changes and adhering to those adaptations long-term, for the benefits to be noticed.

7.1.2 Benefits of using CAM

The key findings from the benefits the participants received from using CAM included the empowering feeling they developed from exploring alternative treatment options, the holistic way they were able to treat themselves and the noticeable improvement in their wellbeing. By taking responsibility for their own health the participants were able to concentrate on remaining positive, which stimulated a hopeful spirit. When someone is told they are ill, exploring options to restore health has been recognised as empowering for the individual (Evans et al., 2007). Hilsden and Verhoef (1999) state “patients may use complementary therapies to gain a greater sense of being in control of their disease, to play a greater role in its management ...” (p. 105). This statement is supported by this research, as participants both explicitly stated and implicitly implied that being in charge of their own treatment regimen through CAM usage allowed them to individualise their care to best suit their needs.

Participation can also be regarded as a way of coping for cancer survivors (Dunn et al., 2006). There is plenty of research available stipulating how some patients want to be active participants in their health care (Foote-Ardah, 2003; Thorne, Paterson, Russell, & Schultz, 2002; White, Verhoef, Davison, Gunn, & Cooke, 2008; Wong, Chan, Tay, Lee, & Back, 2010) and CAM provides this means. One participant discussed how the involvement of a CAM therapist giving her a plan to follow was strengthening and reassuring. Previous research suggests the communication and relationship CAM therapists offer is a definite ‘pull factor’ for individuals turning to CAM (Cartwright & Torr, 2005; Shinto et al., 2005). In fact, an earlier study suggests 40% of cancer patients seek alternative therapies because of inadequate doctor-patient relationships (Sirois, 2008). Furthermore, having a plan to follow specific to the clients’ needs is also noted in a previous study as an attraction to use CAM (Bann et al., 2010).

Taking responsibility for one’s future wellbeing demonstrated how having control over the decisions concerning their body generated a strong determination and created a purpose where the participants saw cancer as a challenge to overcome. This was reiterated in one participant’s comments of how they refused to just accept what the doctors recommended and hope that their treatments worked. This finding aligns with the ‘pull factor’ of how being involved in the treatment process attracts people to use CAM. Previous research shows the motivation and willpower that comes from allowing patients to have involvement in their healing process creates empowering feelings (Verhoef et al., 2005; White et al., 2008). The accounts of the participants correspond to these findings.

Another advantage voiced by the participants was how being in control of researching treatments meant there was less time to focus on the undesirable aspects of the disease, which in and of itself may have assisted in maintaining a sense of wellbeing. Investigating treatment options can also divert attention from the illness having control over the individual and give them some power and dignity back. Previous studies note the successful effects people have noticed from using CAM, such as pain reduction and relieving illness symptoms (Cartwright & Torr, 2005; Esmonde & Long, 2008). These benefits have also been specified as ‘pull factors’ enticing individuals to use CAM. The importance of having an optimistic attitude not only through the early stage of cancer, but staying as upbeat as possible thereafter is essential for increasing serenity and wellbeing. One unanticipated finding arose from the empowering benefit of researching and using CAM. Some of the participants were left with the desire to share their experiences and newly found knowledge with others who were dealing with cancer and wanted to know what they had done. Such a desire could have practical implications for cancer care, for example in the form of support groups being available to discuss treatment options with people recently diagnosed with cancer. Knowing whether there are support groups available for cancer patients using or wanting to use CAM could help these individuals with deciding which treatment option is best for them.

Part of the benefit from using CAM is the holistic way of healing these therapies emphasise. An individual who has a holistic approach to health incorporates physical, spiritual, emotional and mental aspects into their wellbeing (Payyappily, 2005). These characteristics are also strongly regarded by CAM users as requirements for being healthy and staying well. Previous research associates holism with CAM

usage (Chao et al., 2006; McFadden et al., 2010; Sirois et al., 2016; Testerman et al., 2004) and is regarded as an appealing ‘pull factor’ to use CAM. By having this view the participants were able to appreciate the complexity of cancer and the diverse areas they needed to address in their daily lives.

The participants considered the complete bodily inclusiveness that the CAM techniques offered helped them relieve the tension and worry that is associated with cancer. One participant also shared how the CAM treatments brought up their emotional issues that otherwise would not have happened. Being open to other forms of treatment can allow other areas in a person’s life to be addressed and begin to heal. This finding aligns with research that has also shown CAM is useful for alleviating psychological stress (Branstrom, Kvillemo, Brandberg, & Moskowitz, 2010; Kang & Oh, 2012; Speca, Carlson, Goodey, & Angen, 2000). By using meditative CAM methods, the participants were able to recognise the areas they believed were detrimental to their health. Likewise, previous studies describe how CAM users identify the mind as an essential component for overall health (Siahpush, 1999). These same views were shared by the participants of this research as they recognised the importance of mental clarity to restore and maintain good health.

Additionally, in order for the improvements to become habitual, the participants needed to make adjustments in their routine. For a number of people obtaining a balanced life can mean compromising some areas (Peronne, 2000). Cano (2011) suggests individuals need to be aware when their lives are not in balance and make changes before becoming overwhelmed, but acknowledges this is not always possible. The demands of life can sometimes make it difficult for someone to find

time to relax, which can lead to illness. Jeon et al. (2010) reveal when people are faced with a life threatening disease, they can be forced to make changes to their lifestyle, affecting areas such as finances, relationships and work. These ideals were also articulated by the participants who voiced the importance of now taking time for themselves and examining every aspect of their life. From using CAM, the areas of the participants' lives needing improvement for better health were accentuated and addressed, such as diet and exercise. When these things are in balance the participants believed life is less stressful. However, knowing whether it is cancer, CAM usage or a combination of both that enhances motivation to undertake these enriched behaviours needs further exploration.

Research demonstrates when individuals initiate changes that concern them, there is an increased chance those changes will remain long-term (Baban & Craciun, 2007). The aspiration to incorporate CAM more diligently into daily life was exhibited by the participants since their cancer diagnosis. Some of the participants have survived cancer for a long time and still use CAM, which is similar to previous research stating better adherence of managing illness occurs when the patient contributes (Barrett et al., 2003; Chang et al. 2012; Olchowska-Kotala, 2013; Warren et al., 2012). Because of the holistic understanding the participants held as a result of using CAM, they have become a lot more aware of their behaviour and are stricter at maintaining a healthy regimen to reduce the risk of the cancer returning. Comparing if there are differences in the upkeep of any new routines between CAM and conventional treatment cancer survivors, as well as knowing whether the practices improve longevity, may provide health professionals with suggestions they can share with other cancer patients and needs further investigation.

The benefits of using CAM for cancer patients also relates to their wellbeing. How the participants determined their wellbeing since surviving cancer is different from those never having the disease. While the participants try not to think about the cancer, they are inevitably reminded through the repercussions of their surgery and the constant battle with low energy which results from cancer. This finding affiliates with why people become dissatisfied with mainstream methods and is identified as a ‘push factor’ to individuals detracting from conventional treatments (McLaughlin et al., 2012). Conversely, the noticeable improvements the participants expressed of pain relief, increased energy and decreased side effects of conventional treatments from using CAM is consistent with other research outlined in previous chapters (e.g., Bates & Wilkinson, 2009; Nystrom et al., 2008), and is considered a ‘pull factor’ for patients using CAM. The negative side effects of conventional treatments expressed by one participant are also regarded as a ‘push factor’ for individuals. As previous studies have shown, while patients can be aware of the negative effects drugs may produce, they still take them, but attempt to offset the consequences by using CAM (Xue et al., 2005). This finding also aligns with previously mentioned studies (Bauml et al., 2015; Richardson et al., 2000), noting patients often integrate CAM with conventional treatments for cancer.

The comments from participants regarding other people also observing their recovery process highlights there are benefits from using CAM. While some studies have exposed situations where alternative treatments have failed to show any noticeable health improvements (Bloch & Hannestad, 2012; Hanna, Day, O'Neill, Patterson, & Lyons-Wall, 2005; Kilincaslan, Tutkunkardafi, & Mukaddes, 2011),

other research reveals the opposite (Cen, Loy, Sletten, & McLaine, 2003; Man, 2009; van den Biggelaar, Smolders, & Jansen, 2010). The findings of this study appear to support this latter research. The participants spoke of the observations sighted by others, such as weight gain, quick recovery and looking well. Receiving feedback from loved ones gave the participants confidence the CAM remedies were helping, which reinforced the decision they made to use these products as being the right one. This finding is similar to previous research (Cartwright & Torr, 2005), which found because of the relief CAM provided the users had become more tolerable and their relationships improved. However, this study did not obtain responses from the people who the participants associated with and no studies have been found specifically targeting the friends and family of cancer survivors using CAM treatments. Further exploration focusing on these individuals could provide more impartial remarks of whether or not they think these remedies are assisting their loved one.

7.1.3 Disadvantages from using CAM

The major findings from the disadvantages the participants obtained from using CAM related to the negative social aspects they encountered. The participants spoke of their feelings of abandonment and their careful approach regarding who they informed about using CAM. A lot of research around the disadvantages of using CAM tends to focus on the interference CAM possibly has with conventional cancer treatments (Gupta, Lis, Birdsall, & Grutsch, 2005; Hardy, 2008; McCune et al., 2004; Sparreboom, Cox, Acharya, & Figg, 2004). Ekwall, Ternestedt and Sorbe (2007) note how people can feel isolated when diagnosed with cancer. Because it is ultimately up to the individual to fight the disease, no one else can truly comprehend their situation (Wells & Kelly, 2008), unless they have been through a similar experience. Isolation

can mean being unable to partake in previous social activities (Tan, Tien Tau, & Lai Meng, 2015), undergoing treatment alone (Stephens, 2005), and family and friends distancing themselves or vice versa (Yildirim & Kocabiyik, 2010). However, for some cancer patients being alone is welcomed as they have freedom and privacy to make decisions without receiving advice from others (Benoot, Bilsen, Grypdonck, & Deschepper, 2014). These feelings were comparably expressed by the participants, with their cautionary approach of who they told about their refusal to have chemotherapy and/or radiation, instead opting to treat their cancer using CAM. They spoke of the surprised reactions received and how they distanced themselves from supportive people.

This validated how the choice to use CAM can be difficult and how resilient to social pressures an individual needs to be to not use mainstream methods. Being diagnosed with cancer did not always bring together the support networks the interviewees wanted. The off-handed behaviour shown by the participants appears to be an age-old response for individuals when their views are threatened (Sartain, North, Strange, & Chapman, 1958). The vulnerability felt by the participants instigated ways to protect themselves from people who did not agree with their decision to pursue CAM treatments, such as being careful about who they told and who they associated with.

Most of the research regarding patient support during cancer treatment relates to conventional treatment. Furthermore, studies pertaining to patients informing others about their decision to use CAM often apply to the physician. No studies were found demonstrating how much involvement loved ones have concerning cancer

survivors decision to use CAM instead of conventional methods and the outcomes of this. It was apparent from the moment of refusing conventional treatments how alone, confused and guarded the participants were for a time. Tovey and Broom (2007) discuss the noncommittal attitude of health professionals concerning cancer patient queries about CAM remedies. Leach (2006) suggests practitioners trained in orthodox procedures can lack knowledge concerning CAM as well as holding bias views. The fear of rejection from medical establishments can be a motivating factor for cancer patients to not inform physicians of their decision to refuse conventional treatments (Koczwara & Beatty, 2011). The abruptness shown by the specialist to end their care once they knew the participants were not going to use their treatments was a shock for the participants. This finding aligns with previous research (Sirois & Purc-Stephenson, 2008a; Tan et al., 2004; Tasaki et al., 2002), demonstrating unhelpful doctor-patient interactions are factors that can 'push' individuals away from using conventional treatments. It was discouraging to hear that the conduct demonstrated by the study participants' oncologists is similar to some overseas. Now that this behaviour has been highlighted, research needs to be undertaken in other regions to establish if these actions are occurring elsewhere in Aotearoa. While there remains resistance for individuals to use CAM for cancer treatment by others, the reassuring aspect cancer survivors may take from this finding is the previously mentioned benefits may help to offset any opposition.

7.2 Study limitations

The aim of the current study was to investigate the attitudes of a sample of cancer patients to establish why they use CAM treatment and explore their beliefs about the benefits (if any) they have from receiving CAM treatment. However, a

number of limitations were evident in this research and should be considered when interpreting the findings and their implications.

The number of participants for the study was low (n=5), which means the recommended number suggested by Guest et al. (2006) of 12 interviews required to reach saturation was not met. However, due to the time constraints for the research, extending the recruitment period was not possible. As mentioned previously in the methodology section, the original motivation for the study to investigate the cancer patients of a specific CAM therapist did not eventuate, which reduced the enrolling stage further. Although the advertising for participants was expanded to other clinics outside Taranaki, the final sample included only individuals from this area.

Because the enlistment procedure was self-selection, this also may be viewed as a potential limitation, as only individuals with strong opinions about CAM could have participated. The research results found all of the participants had optimistic standpoints and involvement with CAM. Indeed, previous research has indicated women of older age are more likely to be users of CAM, and more likely to have positive views of the treatment modalities (Frass et al., 2012). Given the entire sample were women with the majority aged 45 years and over, the overall optimistic perspectives of CAM found in the present study could be accounted for by this. Although generalisation is not a pertinent outcome of qualitative research, it is acknowledged that the experiences of Aotearoa cancer patients who are men of any age or women of younger age are not known, neither are the experiences of those who have used CAM without noticing any improvements. Additionally, some of the participant's cancer events occurred over five years ago, and their retrospective recall

of CAM usage may have been biased in the direction of positivity, given their survival from the disease over such a long period of time. Research suggests as many as 67% of cancer survivors utilise CAM (Mao et al., 2007); which again suggests somewhat of a 'survivor bias' may account for some of the findings.

Researcher bias is always possible with qualitative investigations (Chenail, 2011). The issue of the researcher influencing the data with their personal opinion during the interview process and/or the analysis stage poses a threat to study validity (Pannucci & Wilkins, 2010). Because the author has an interest in CAM as previously stated, there was the potential for this bias, however the researcher was careful not to impose their beliefs throughout the exploration. Having an awareness of these remedies was considered an advantage as the participants were more relaxed and open to sharing their experiences.

7.3 Future research

The findings of this research highlighted several points of interest that could be investigated further in the future. Firstly, the study enlisted people who have survived cancer longer than five years using CAM. However, it is acknowledged these individuals also received conventional medical treatment. Future exploration could focus on qualitatively investigating the experiences of cancer survivors who have chosen to use CAM only, and what benefits there are to taking this option. This will provide information about why CAM treatments are used exclusively for cancer, which in turn could provide useful information to individuals interested in pursuing these remedies in the absence of conventional therapies.

Because all participants in this study were female and mainly breast cancer survivors, future research could look at the experiences of both men and women with a range of other cancers, as it is possible the rationale and benefits of using CAM may differ according to gender and cancer type. Another possibility is a quantitative design using survey questionnaires with cancer survivors who have and have not used CAM. The questionnaires could compare the reasons for using or not using CAM, as well as looking at the benefits of both CAM and conventional treatments across groups. Undertaking a longitudinal study comparing cancer survivors who have used either conventional and/or alternative treatments for specific cancers, would be useful for providing information about how these methods impact people over time, particularly their quality of life and survival rates.

Another area drawn attention to from this investigation is the lack of Māori participation. Although a variety of reasons may have led to this, having Māori viewpoints on CAM treating cancer is very important because of the significant percentage of Māori dying from cancer in Aotearoa. Therefore, future studies may look more specifically to recruit cancer patients who identify as Māori, to explore their experiences of using CAM, and some of the reasons for that. It is possible traditional beliefs surrounding culturally-specific treatments that could be considered as CAM, such as rongoā Māori, may play a role in CAM usage for some Māori individuals.

7.4 Conclusion and Final Reflections

In summary, this research emphasised that while the type of cancer people get may be similar, how individuals react to treatment and recovery is very personal and individualised. CAM offers an empowering, holistic and informative way cancer

survivors can deal with their life threatening illness, giving them back some control, which cancer can take away. The interviews showed how including CAM allowed the participants to adopt positive attitudes and changes towards their cancer experience, with each one having a regimen that best suited their needs.

The disappointing aspect to this investigation was the defensive approach the participants felt they had to use when discussing their queries and usage of CAM not only with the specialists, but also family and friends. It is hoped that on-going qualitative research will further enhance the reasons why people choose CAM to treat cancer and the necessity for patients to continue to have this remedies available to them if they desire. My only concern regarding this much needed evidence is, after directly attempting to enrol CAM therapists and their clientele, there are reservations amongst these establishments about sharing their information.

My initial motivation for undertaking this research can be summed up by quotes from two of the participants:

... I'd been suspicious of chemo and hearing what it does, I mean it's certainly not a selective treatment, it doesn't target just that cancer, it targets you in general ... (Rachel)

...I think science has become a religion in some aspects, and in doing so it's closed itself off to what it truly is in essence. Science is about keeping an open

mind ... that's where you get the inspiration ... it has become that closed off, narrow field ... (Jessica)

I wanted to provide more testimonies of individuals using CAM to demonstrate these remedies can obtain positive results. Also from these discussions it was shown just how individualised people are with their opinions, emphasising what they desire for treatment to their bodies as unique and a personal choice. I believe individuals should be able to make the decision for themselves which treatment option they want by receiving in depth, honest facts and statistics from both CAM and mainstream doctors. Allow people the right to make the decision without being pressured or misled and give them the support regardless of whatever option they choose. I admire all individuals who have the courage to stand strong in what they believe. I hope this research highlights to organisations dealing with cancer patients in Aotearoa, the need to find better ways to fight cancer together, rather than wasting time on fighting each other.

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Appendix A



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TE KURA PŪKENGĀ TANGATA

Complementary and Alternative Medicines for cancer treatment

INFORMATION SHEET

Who is doing this research?

My name is Karen Darling and I am completing a Masters of Science at Massey University. I have previously been a patient of the CAM therapist, Dr Monica Maritz for general preventative healthcare, and have a general interest in CAM treatments and how they might benefit those who use them. My supervisors are Professor Kerry Chamberlain and Dr Natasha Tassell-Matamua, both researchers from the School of Psychology at Massey University.

What is this research about?

The project will investigate the attitudes of cancer patients to establish why they use CAM treatment; explore beliefs on the benefits (if any) of receiving CAM treatment; and evaluate the influence of CAM on cancer patients subjective wellbeing by conducting individual interviews.

Who can take part?

If you are a New Zealand citizen or resident, are over the age of 18 years, and have ever been diagnosed with cancer, AND are currently receiving CAM treatment for cancer, I would love to hear from you. Because English is my first language, you must also be confident in English, as I would like to interview you. I am looking for 12 people in total.

What do you have to do?

I am interested in interviewing you about your experiences with CAM. If you wish to participate, I will ask you to complete a simple questionnaire to gather contextual information; this should take about 15 minutes. If you live locally, I will invite you to a face-to-face audio recorded interview with me at the clinic or another suitable location of your

choice, at a date and time mutually convenient for us both. If you do not live locally, I will invite you to a Skype meeting, at a date and time mutually convenient for us both. Interviews should take about one hour to complete. During the interview, I will ask you questions about your cancer and the treatment process. In total, I would appreciate about 1 hour and 15 minutes of your time for this research.

What if you become distressed during the interview?

It is possible discussing cancer may raise emotional distress. Should you become distressed during the interview, the process will be stopped and you will be asked if you want to continue. At no point will you be forced to answer questions you are not comfortable with. If you become distressed after the interview then I will stay with you until you are calm. You will also be asked if you still want the information you have disclosed to be used. I will be able to direct you to counselling and other support services as appropriate (see attached).

What else do you need to know?

If you decide to participate, I will be very grateful. However, it is important you know that you have no obligation to take part in the research, and if you do, then you have the right to:

- decline to answer any particular question or talk about any particular issue in the interview;
- withdraw from the study at any time up to 31 October 2016;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used;
- be given a copy of the project findings when it is concluded.
- ask for the recording to stop at any time during the interview.

Will you be compensated for participating in the research?

A voucher (\$20) will be offered at the completion of the interview to contribute towards time and/or travel expenses.

Can you get a summary of the research findings?

Before the commencement of the interview, you will be given the option of whether you wish a summary of the findings to be sent to you. If you do, I will email you a summary of the findings at the completion of the research.



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Who can I contact?

If you would like to take part in this study, please contact me, Karen Darling, by phone or email. If you have any questions about this study and would like to know more about what is involved in any aspect, please contact myself or my supervisors and we will be happy to talk with you further.

Karen Darling 027 946 6455 succeedfromhome@xtra.co.nz

Dr Natasha Tassell-Matamua (06) 356 9099 ext. 85080 N.A.Tassell-Matamua@massey.ac.nz

Professor Kerry Chamberlain (09) 414 0800 ext. 43107 K.Chamberlain@massey.ac.nz

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 16/17. If you have any concerns about the conduct of this research, please contact Mr Jeremy Hubbard, Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63487, email humanethicsoutha@massey.ac.nz



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Support services

Cancer Society of New Zealand	0800 226 237
Prostate Cancer Foundation of New Zealand	0800 477 678
Breast Cancer Support	0800 273 222
Skylight	0800 299 100
TSB Cancer Support Centre	(06) 757 3006
Tui Ora	(06) 759 4064

Appendix B

PARTICIPANTS WANTED FOR STUDY ON CANCER TREATMENT



I am conducting a study to establish why patients choose complementary alternative medicine (CAM) for cancer treatment and are seeking people aged over 18 years to give about 1 hour of their time to be interviewed.

The aim is to investigate the attitudes and beliefs of a sample of cancer patients in Aotearoa

For more information, or if you are interested in taking part in the study, please contact

Karen Darling: 027 946 6455 or email: succeedfromhome@xtra.co.nz

Dr Natasha Tassell-Matamua: N.A.Tassell-Matamua@massey.ac.nz

Appendix C



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Contemporary and Alternative Medicines for cancer treatment – a patients perspective

PARTICIPANT CONSENT FORM - INDIVIDUAL

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interview being sound recorded.

I wish/do not wish to have my recordings returned to me.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature:

Date:

Full Name – printed.....

Appendix D

Questionnaire

Participant name: _____

Address: _____

Postal address (if different from above): _____

Email address: _____

Telephone No. _____ Cell ph. _____

Geographic location: rural town city

Gender: Male Female

Age range: 18-24 25-34 35-44 45-54 55-64
65-74 75-84 85+

Ethnicity: NZ European Maori Pacific Islander Asian
Other (please specify) _____

Marital status: Single, not married Married Living with partner
Separated Divorced Widowed Prefer not to answer

Education level: High school Certificate/diploma
Bachelor degree Postgraduate degree

Employment status: Employed full time Employed part time
Not employed, but looking for work
Not employed and not looking for work
Retired Student Homemaker
Other (please specify): _____

Household income: Under \$20,000 \$20,000-\$29,999
\$30,000-\$39,999 \$40,000-\$49,999
\$50,000-\$69,999 \$70,000-\$99,999
\$100,000-\$149,999 \$150,000+ Prefer not to answer

Appendix E

Interview schedule

1. What type of cancer is the CAM treatment for and when were you diagnosed?

2. Have you used conventional treatment or are you currently using conventional treatment? If still undergoing conventional treatment, does the oncologist know? If not, why?

3. Do you have any background knowledge/training of CAM? If so, what.

4. What are your reasons for undergoing this particular CAM treatment? How did you hear about this treatment? What made you decide to use CAM/conventional treatments? (feelings, ideas, experiences, other influences regarding the decision to use only CAM or a combination of both treatments)

5. How long have you been a client?

6. What treatment regimen are you undergoing?

7. How well do you understand your treatment?

8. Can you explain the treatment process to me?

9. How do you feel the CAM remedies are helping you?

Evidence?

10. Have other people noticed an improvement in your wellbeing? If yes, what?

Do you think this is due to alternative or conventional medicine?

11. How often do you visit the CAM therapist?

Is the travel a burden for you? If so, how?

12. How much does the treatment cost you every month?

Is this cost a burden for you? If so, how?

13. Do you have any concerns about receiving this CAM treatment?

If yes, what are they?
