Men, Prostate Cancer and Complementary and Alternative Medicine: A Narrative Inquiry.

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

Master of Science
in
Psychology

At Massey University, Albany, New Zealand

Karen Anne Tapper

2014

Abstract

Cancer is the most feared illness in Western societies. Yet remarkable medical advances are being made that extend life-spans the once would have been cut short by cancer. Prostate cancer is now a chronic disease in most cases. However in many cases medical treatment of a slowly progressing disease has left men with undesirable sequelae of treatment, such as impotence and urinary incontinence. Psychosocial research into prostate cancer has tended to concentrate on questions related to these side-effects of treatment. This research investigates a different aspect of prostate cancer; the use of complementary and alternative medicine (CAM) by men with prostate cancer. It is a qualitative narrative inquiry that investigates the stories of six men, all diagnosed with this condition and all using CAM, either in a complementary sense or as an alternative to biomedical treatment. They ranged in time since diagnosis from two months to 17 years. The narrative account is divided into three sections; the first explores causal narratives, the second explores narratives of diagnosis with prostate cancer, and the third section examines narratives of treatment, both CAM and biomedical. It contributes to the understanding of how men with prostate cancer negotiate the phases of their illness and actively integrate CAM and biomedical narratives, treatments and practices. The production of positions consistent with culturally dominant masculine values is shown to be a part of this negotiation. The finding of 'sensitising events' that predisposed men to using CAM is discussed. Men with prostate cancer negotiate complex dialectics between their quantity of life and their quality of life and between active agency in their own healing and being a patient. The clinical relationship with both physicians and CAM persons is very important in ensuring that men make treatment decisions with full information and support. Implications of the findings and future research possibilities are discussed.

Acknowledgements

I wish to thank first the men who participated in this research, for your generous sharing of your stories. Thank you for the gift of everything you shared. Your commitment to healing yourselves and helping others to do so is inspiring.

Thank you also, to the complementary and alternative healers who shared their insights around the subject with me and helped me find participants.

Thank you, Professor Kerry Chamberlain, for your wisdom, humour, encouragement and critical voice; for inspiring me to write more logically, think more critically, and trust my own voice in my writing.

Thank you from my heart to my family, for your support, love and patience. You have been a blessing.

Last of all, thank you to my Spiritual Master, Adi Da Samraj. Your radical teaching of true health and healing is truly the inspiration for this work.

Contents

Chapter One: Setting the Scene.

The genesis of this project

This research project began as an enquiry into complementary and alternative medicine (CAM) from a critical health psychology perspective. That was the first part of the research topic that I made a commitment to. My decision to do a research project in this area arose out of my personal interest in complementary medicine, having practiced therapeutic massage for many years. I also have a wide circle of friends and acquaintances who use and /or practice complementary medicine. An interest in the experiences of cancer patients led me to consider researching CAM in the context of its use in New Zealand by cancer patients.

Cancer research by site is the norm, so I needed to make a decision about which site I would be focusing on. Breast cancer and CAM has been relatively well-researched in many different research methodologies, including qualitative methodologies. I saw an opportunity to do something different. I decided to investigate a male-specific cancer and the most common male cancer site in this country is the prostate (Baade, Youlden, Cramb, Dunn, & Gardiner, 2013; Engel, 1977) Of course, I could have chosen a non-gender specific site, however I feel glad that I followed my first impulse to investigate a male-only cancer. This was a seemingly counter-intuitive choice, given that I am not a man and have never lost a close friend or relative to prostate cancer. Yet once the choice was made it seemed obvious, even inevitable (as our choices often do, possibly due to cognitive bias). The issues around both men's health and CAM are a rich and fascinating mix and ones that will continue to increase in prominence. Also, as the population ages, more men will be living longer with prostate cancer and it is hoped that in some way this research or other research in the subject area makes a difference to their experience.

The structure of this chapter

Prostate cancer may have been the last piece of the research topic to fall into place, but it is the real beating heart of the project. It is the place this chapter will start. Part One of the introduction will look at the prevalence of prostate cancer and why it is a health issue of major concern for New Zealand men in the 21st Century. From there, there will be a brief discussion of men's health and the gendering of health.

Then, because this is a 'double-barrelled' research topic, the introduction will move into the parallel topic, CAM. Part Two will examine CAM; what is 'complementary' and 'alternative' medicine, its growing use by cancer patients in Western countries and the differing epistemological commitments made by proponents of CAM and 'conventional' Western medicine.

Hopefully the reader can forgive the abrupt transition between prostate cancer in Part One and CAM in Part Two, as the two paths will reunite in Part Three. The use of CAM by prostate cancer sufferers will be the focus in this final section of Chapter One.

Part One: Prostate Cancer in Context

The men's cancer of affluence.

Prostate cancer is now the most common cancer site among New Zealand men with an age-standardised incidence of 111.6/100,000 in Australia/New Zealand combined. This is the highest incidence in the world, even outstripping the USA at 97.2/100,000 (Baade et al., 2013). The Ministry of Health reported that in 2012, there were 97.3/100,000 registered cases of prostate cancer in New Zealand (Ministry of Health, 2013). Since 1995, the rate of incidence in New Zealand has not risen, however it still is the second highest in the world, after Australia (Baade et al., 2013). Testing for prostate-specific antigen (PSA), which is a marker for both cancer and some benign prostatic conditions, may have contributed to a small blip in reported incidence in New Zealand and other developed countries, as more very small low-grade cancers were discovered. However, it is not likely that the high rates of reported prostate cancer in developed countries and the rising rates in developing countries are due to more PSA testing in those countries, as there was a 50-fold difference between the highest rates (USA) and the lowest rates (Bangladesh) *before* PSA testing was introduced (Baade, Youlden, & Krnjacki, 2009).

The epidemiology points to the Western lifestyle being the main factor in the high incidence in developed countries. Prostate cancer rates are rising all over the Asia-

Pacific region, but the fastest rises are in rapidly westernising countries, e.g. South Korea, which experienced a 13% rise *per annum* in the decade from 1999 to 2009 (Baade et al., 2013). Breast, colon and prostate cancer have all risen remarkably in Asian countries that have transitioned to a westernized diet, with a ten-year lag in mortality behind that transition. The transition to a diet high in energy, red meat and animal fats is proposed as an explanation for this rise in these three common cancers in these countries (Zhang, Dhakal, Zhao, & Li, 2012). A mass of evidence supports a diet high in fruits and non-starchy vegetables and low in animal fats, salt and alcohol, in addition to daily moderate to vigorous exercise and a healthy body composition to help prevent cancer (World Cancer Research Fund and American Institute for Cancer Research, 2007). Unfortunately, the public health battle to prevent cancers, including prostate cancer, is far from over. With six times more prostate cancer in developed countries than undeveloped ones, it is very much a disease of affluence.

The better news, if it can be called that in the face of such high incidence rates, is that cancer mortality rates have fallen in developed countries, including New Zealand. It is not known how much the advent of PSA testing has contributed to that fall, by allowing cancers to be diagnosed while still small and treatable. It is more likely that more advanced treatments are behind the decrease in mortality (Baade et al., 2013).

It is worth noting, even though it doesn't directly relate to my research, that there are real inequities in prostate cancer in New Zealand. A Maori man, once diagnosed with it, is 76% more likely to die than his similar age and stage matched Non-Maori counterpart. The Maori death rate from prostate cancer is proportionally 59% higher than the Maori death rate. The reasons for this are unclear, as with most cancer inequities in mortality between Maori and non-Maori. Higher rates of co-morbidities, later diagnosis when cancer is further advanced, and reduced access to quality health care may all play a part (Prostate Cancer Taskforce, 2012). There were no Maori participants in my research.

PSA testing and over-diagnosis leading to possible over-treatment.

There has been considerable debate about the science behind PSA testing and what place screening has in the lowering of mortality from prostate cancer (Baade et al., 2013). At the moment, there not enough clear long-term randomised trial research to be able to establish clear benefits of PSA testing in non-symptomatic men (Bangma, Roemeling, & Schröder, 2007). In New Zealand, a mass PSA screening program is not being carried out and is not being recommended. However, PSA testing accompanied by a digital rectal examination (DRE) is the best tool for diagnosing otherwise asymptomatic cancers. Men can ask for both if they have difficulty passing urine, and it is recommended that both are given unless the DRE is refused. It is recommended that the only time a PSA test will be used is when a man requests it because he is having difficulty passing urine or has close relatives with prostate cancer (Prostate Cancer Taskforce, 2012).

The other question is around the possibility of over-treatment arising from over-testing and over-diagnosis. Currently, the science is not advanced enough to predict which cancers are indolent and which will be aggressive (Bangma et al., 2013) so the standard treatments may be suggested to many men who may not have a life-threatening cancer. An 'indolent' cancer may never become symptomatic, let alone life-threatening. This is over-diagnosis, of a cancer which would never have been a problem. It also exposes the man to the risks of biopsy, which include pain, anxiety, haemorrhage, infection and occasional impotence (Oliffe, 2009). The risk of over-treating prostate cancer due to the ability of screening to detect non-clinically significant cancer is a real one. Given the possible effects on a man's quality of life from aggressive treatment, over-treatment for a cancer that doesn't require it and would never prove to be life-threatening or even symptomatic within a man's lifetime, is obviously to be avoided.

Active surveillance

Active surveillance is now recommended for men with low-risk cancers as a way of avoiding over-treatment. Treatment is still available if it is needed later in life if the cancer becomes more threatening. In New Zealand, men would be considered for active surveillance if their cancer grade is low, their PSA is 10 or less, and with a

Gleason score of 6 or less. PSA tests and a DRE every six months is considered optimal, although every three months may be advised for some men. Another biopsy within 12 months is also recommended, to check that cancer is not more aggressive than originally thought. (Prostate Cancer Taskforce, 2012). This is a very active area of medical research; a search in the Discover database for research around active surveillance turns up 293 reviews and 5 meta-analyses in the last five years. The most mature trial of active surveillance with strict selection criteria found that over 10 years the survival rate (specific to prostate cancer) was 97.2%. Only 30% of the patients had radical treatment after that time (Klotz et al., 2010).

Active surveillance is an area of relevance to this research. Men in an active surveillance programmes may be more likely to use and benefit from CAMs. Also, as treatments are able to control the disease better and bring about remission for many years, it is more often a chronic disease than a life-threatening one. Men may be inclined to use CAMs while they tolerate years of living with cancer. More will be said about this later, in the section on CAM use by prostate cancer sufferers.

Possible sequelae of radical treatment

As a participant said, the prostate is in a reasonably sensitive area of the male body. Currently orthodox treatments available in the New Zealand medical system comprise surgery, external beam radiation, chemotherapy and hormone therapy. Side-effects of surgery include damage to the nerves that govern the urinary sphincter and the erectile nerves. In one study, 42% of men were still suffering an occasional lack of urinary control at 24 months after surgery, and 7% had frequent leakage. This was age-related, with men over 75 suffering the highest levels of incontinence. 60% of the men could not have firm enough erections for intercourse 24 months after surgery, and 78% of the men over 60 were impotent 24 months later. Patients receiving radiation therapy didn't fare much better, with bladder and bowel irritation, and impotence of 40% to 50%, increasing over time after treatment (Bangma et al., 2007) Hormone therapy is being used more now to reduce the chances of cancer recurring after surgery. Reduced sexual desire and ability to have erections are often experienced by men on androgen-deprivation therapy. They also have an increased risk of weight gain, osteoporosis, cardiovascular disease, diabetes type II and obesity. Breast development (gynecomastia) and the loss of body hair, decreased muscle mass and genital shrinkage are also common side-effects of hormone therapy. This can cause men a lot of distress (Oliffe, 2009).

There is a large developing literature on men's health and prostate cancer has been studies as part of that. Prostate cancer is not necessarily a good 'fit' with much of the men's health literature. Men's health literature explored the (usually negative) effects of traditional ways of being a man on men's health. These include ignoring of symptoms of illness and being reluctant to see a doctor until symptoms cannot be ignored. In the case of prostate cancer, because it is often asymptomatic and benign swelling of the prostate is more likely to be the cause of urinary difficulties, pre-existing health behaviours such as drinking and smoking cannot be linked specifically to prostate cancer. So it is difficult to make a direct link from prostate cancer to masculine health behaviours (Oliffe, 2009).

The sequelae of conventional treatments and the ways that men resist or adapt to changing narratives of masculine embodiment (Kelly, 2009) and masculine sexual identities (Arrington, 2003, 2008; Oliffe, 2005) is where research attention has been reasonably full in the area of men's health and prostate cancer. In one of the few narrative studies of prostate cancer and men's experiences, Arrington explores the narratives of men in a support group who have had radical prostectomies and experienced considerable changes to their sexual lives. Their biggest problem was constructed as 'impotence.

The term 'impotence' illustrates (and contributes to) the conflation of the man with his penis, to his detriment within the constructions of hegemonic masculinity, if his penis does not 'perform' adequately (Potts, 2000). I have used the term 'impotence' in this research as the one alternative, 'erectile dysfunction', is too medicalised and carries just as much cultural baggage. However, I do so with a critical awareness of the implication; that a man is 'powerless' if he can't get hard. The subject is not central to my research but can't be excluded from it, because the narrative of a man's sexual 'performance' (as it is currently constructed in western society) is a constant background note to the decision-making process around CAMs and male-specific cancers. In the actual event of having surgery, however, the problem of urinary incontinence is just as big an issue for men, if not more so, especially for those who are young enough to still be working. The constant trips to the toilet are felt to be stigmatising by men (Grunfeld, Drudge-Coates, Rixon, Eaton, & Cooper, 2013).

Part Two: Complementary and Alternative Medicine.

Despite the ascendancy of Western medical science and practice all over the world in late modern societies, no one paradigm of medicine or concept of health and healthful life, has an absolute monopoly. Paradigms of sickness, healing, and what constitutes 'right' ways of producing and transmitting medical knowledge differ hugely from culture to culture and through history. A marginal position or practice can shift across the fluid boundaries of orthodoxy in any society within a few years, to become 'mainstream' where once it was considered ridiculous. A medicinal practice or material may be considered entirely 'legitimate' in one context, even supported by the state as a product that can be obtained on prescription, but may be considered dubious in similar countries e.g. in Germany an extract of Vitex agnus-castus (chaste berry) is prescribed for premenstrual syndrome. It is considered a CAM therapy in the English-speaking world and anti-depressant medications are favoured for PMS, itself a contested 'medical diagnosis' (Weisz & Knaapen, 2009).

Why does CAM matter now?

CAM matters now because the public are embracing non-orthodox medical beliefs and practices in greater numbers every year. A 2012 review and meta analysis that utilised data from 152 studies of CAM use by over 65,000 cancer patients from Australia, New Zealand, Canada, Europe and the USA found that the rate of CAM use has risen from 25% in the 970's, to 32% in the 1990's, and 49% after 2000 (Horneber et al., 2012). A big problem in the descriptive statistical research investigating CAM is that the definitions of CAM vary hugely between studies. So can the perceptions of what is 'alternative' and 'complementary' in different cultural settings and communities. However, an older review by Ernst and Cassileth (1998) shows similar prevalence rates to the rates reported by Horneber and colleagues at that time, with use of around 31% by cancer patients being reported in 2000, taken from 26 surveys from 13 countries. So all these descriptive statistics point to a growing use of CAM over the last decades, with over a third of cancer patients using some form of CAM.

In New Zealand descriptive statistics on CAM use by cancer patients are hard to find. One survey study done in a regional cancer treatment centre found that 49% of the patients who responded to a survey (n=200) used CAM. 41% had discussed it with their oncologist. Around a third were already using CAM before their diagnosis (Chrystal, Allan, Forgeson, & Isaacs, 2003). Otherwise research tended to be focused on small groups of specific users, such as early-stage breast cancer patients. There are no New Zealand statistics specifically on CAM use by prostate cancer sufferers and survivors.

'Complementary' and 'Alternative' to What?

Once my father and I were having a conversation about 'complementary' medicine, or 'alternative' medicine as it tended to be called at that time. He asked me "but what is it *alternative* to? He is a sceptic, a natural scientist with a firmly empiricist and post-positivistic view of most things, including medicine. He was pointing to the non-empirical nature of some forms of complementary medicine and the underlying worldview they are based on. However, it is a valid question and one that has relevance for this research. The paradox of defining a huge and disparate set of endeavours that aim to heal illness or support well-being by what they are *not* seems an odd way to proceed. If 'alternative' and 'complementary' medicine are 'other', what are they 'other' to and how are they other?

Definitions of CAM

Various definitions of CAM have been advanced with different emphases. The definition of the US National Centre for Complementary and Alternative Medicine Centre (NCCAM) is widely quoted: "CAM is a group of diverse medical and healthcare systems, practices, and products that are not presently considered to be part of conventional medicine" (US National Institutes of Health, 2014). There are a few different systems of classification of the various CAMs, including NCCAM's own, which has body-based therapies e.g. massage, energy-based therapies e.g. acupuncture, biologically-based therapies e.g. dietary supplements and mind-body based therapies e.g. art therapies. They also have a category for 'whole medicine systems' e.g. Ayurveda, homeopathy and Chinese Traditional Medicine (US National Institutes of Health, 2014). Their system is flexible enough to acknowledge that there is often overlap between categories and that many practices may fit into many or all of the categories.

Tataryn (2002) has a more sophisticated approach, although superficially it seems similar to NCCAM's. He goes a step further by analysing the underlying paradigms that are presumed to be active in each therapy or intervention. He divides the CAMs into those that have a body-based paradigm (where the physical structure assumes a pre-eminent role) a mind-based paradigm where mind and body are a unity, an energy-based paradigm based on the existence and action of a 'subtle anatomy' in or around the body, and a spirit-based paradigm, where the healing or beneficial influences transcend time and space. The 'subtle anatomy' may variously be described as *prana, chi,* the four humours, vital energy, subtle energy and many other names (Rosch, 2009). Some researchers into CAMs include spirituality as a form of medicine and some do not, but prayer and meditation have been practiced for millennia by and for the sick, with intentions of beneficence and healing. I find this to be a more useful way of conceiving of CAM practices and principles. It recognises that the 'whole medicine systems' are a composite of all these levels It allows for the fact that a CAM practitioner and indeed their clients/patients may utilise one, two, or all of these paradigms in their search for healing. For instance, in my therapeutic massage practice, I use mainly physical methods, obviously massage itself, also herbal steeped oils. However, when I harvest the herbs to steep in the oil, I pick them at the full moon when the life forces of the plant are at their most powerful and I focus my intention on the healing and wellbeing of those I will use the oils on. I sometimes spend some time doing energy healing where a client has an injury. Over time I have discovered that I can sometimes sense blocked energy with my hands and even feel its effects in my own body. I offer silent prayer for the client's wellbeing if I feel so moved. The quality of the therapeutic relationship is also very important in massage, even though most would consider it only a 'physical' therapy. Some clients want no more than a manipulation of their muscles and with them I don't experience a flow of energy. So even in my massage practice, which is part-time at most, I utilise therapeutic practices from all four paradigms: body-based (the massage with herbal oil), mind/body (focused intention), energy (reiki) and spiritual (prayer).

Epistemologies and CAM; What's the difference between CAM paradigms and biomedical paradigms?

The clash of paradigms can be broken down many ways. One of the key differences is that modern biomedicine is based on a nomothetic paradigm that relies on all cases of a particular disease being similar enough that they can be reduced to essential elements. Furthermore, those essential elements are physical and measurable. Body and mind are fundamentally different and physical phenomena are reducible to physical prior causes, separate from the cultural, social and psychological. Thus, it is a reductionist and materialist paradigm. It is based in a model of health which is focused on the disease, the physical aberration from the norm. Research tends to utilise hypothesis testing and be population based, with post-positivist epistemological assumptions. The randomised controlled trial (RTC) is the gold standard of biomedical research evidence, with its rigorous application of empiricism that has eclipsed other forms of empirical observation, such as clinical observation.

CAM is based in a holistic paradigm, which is ideographic and based on the individual in whose life illness is occurring. This is a paradigm where 'illness' may be conceived as affecting (and having causal roots in) not only the body, but the mind and the 'subtle anatomy', or the spiritual dimension. The outcomes are often assessed by subjective qualitative reports, which do not meet the standards of 'scientific' evidence. Case-based research and pragmatic trials of CAM treatments as they are applied in clinical practice, are regarded by many CAM proponents as the most compatible forms of research evidence with CAM paradigms. This is because they preserve the ideographic individualised nature of CAM treatments (Keshet, 2009). However, these forms of knowledge do not constitute 'evidence' either, as far as orthodox medicine in concerned.

CAM use is higher among women than men, and the greater number of practitioners are women (Keshet & Simchai, 2014). The gendering of CAM is discussed theoretically by Sointuu (2011). She suggests on the basis of her qualitative research that CAM is associated with nurturing, pampering, caring, communication and irrationality (or intuition). Lacking institutionalised legitimacy and political support, CAM is associated with home-based 'soft and 'natural' care, all qualities associated traditionally with femininities. Biomedicine is 'hard', legitimate, rational, institutionalised and the dominant partner in the binary, all qualities associated with traditional (hegemonic) masculinity.

Gray (1998) examines both positions within the binary (biomedical and 'alternative') and introduces one that he terms 'progressive' which is the application of the biomedical paradigm to CAM substances. He comments that the 'progressive' approach is by no means value-free, and some CAM authors and researchers mistrust it for that reason; they believe biomedical values will always have the upper hand. The debates in the critical CAM literature about appropriate research methodologies tend to bear that out, to some extent. He terms the pluralistic final perspective (which he advocates to some extent) 'post-modern', This post-modern perspective is a social constructionist approach to medicine, where no one paradigm owns the exclusive truth. Treatment efficacy, as estimated by science and represented by means and standard deviations, will be but one of the criteria that patients and healers would use in the social construction of healing. Grey admits that from the perspective of a cancer patient, the certainties of biomedicine may be more attractive when newly diagnosed, but as the limits of biomedical certainty become apparent, the post-modern perspective may become a necessity as much as a choice.

The last perspective, the post-modern, is the fundamental perspective of this research, with its qualitative narrative methodology and its underlying social constructionist epistemology. In the context of prostate cancer, where there are still many uncertainties about the best evidence-based treatment decisions, this perspective may be all the more attractive to men, healers and researchers. Which brings this chapter, as promised, back to prostate cancer and CAM and where they overlap, in the lives of men.

Prostate cancer and CAM: Descriptive statistics.

The prevalence of men using CAM while living with prostate cancer is not clear in the literature, for one main reason: definitions and measures of what constitutes CAM are wide and variable. Some studies include prayer as a complementary (or alternative) healing practice, some do not. This makes a considerable difference to the outcome where prevalenc is concerned. Likewise, some studies include taking vitamin supplements as a CAM intervention, but as vitamin supplements are commonly taken by the population at large, it is debatable as to whether they really are alternative or complementary treatments for cancer specifically. Bishop and her colleagues conducted a review of some 42 studies that had some prevalence findings relating to men with prostate cancer and CAM use, however only 17 of them focused exclusively on that cancer site. Remarkably, only 9 of the original 42 studies investigated men's reasons for using CAM. They found a prevalence range across studies of 8% to 50% (Bishop et al., 2011). They found some evidence for better-educated men and men with higher grades of cancer being more likely to use CAMs.

The largest study included in their review was by Chan and colleagues (2005), who surveyed a huge registry of prostate cancer patients who were 2-3 years post-diagnosis in the US and found that 33% reported using CAM and 26% ingested CAM substances, such as vitamins, herbs and antioxidants. Saw palmetto, selenium, Vitamin E and lycopene (the red antioxidant pigment in tomatoes) were the most common substances used specifically for prostate cancer. Boon and her colleagues (2003) found a similar prevalence in Ontario, Canada, of 29.8%. They found that attending a support group was correlated with a higher likelihood of CAM use and that less than 10% of the men had gone to a CAM practitioner. This was something the big American study by Chan and colleagues had not asked about, and Bishop and colleagues did not mention either. The last quantitative research into prevalence that seems worth mentioning is a survey study by Eng and colleagues (2003) that found that out of around 460 Canadian men, 39% used CAM. Once again, Saw Palmetto, Vitamin E and selenium were the most commonly ingested substances. If all these studies are taken into consideration, a prevalence of around 30% to 40% seems reasonable in these other English-speaking countries, and may also be the case in New Zealand. The only study that canvasses CAM use by cancer patients in New Zealand , by Crystal and colleagues (2003) included 18 men with prostate cancer at a provincial cancer treatment centre, but the authors did not break down the statistics relative to CAM use into different cancer sites.

There is certainly a gap in the quantitative literature around prostate cancer and CAM use in New Zealand. However, unless CAM is clearly defined, such descriptive statistics will be of limited value. What they do serve to illustrate is that in English-speaking countries there are a lot of men with prostate cancer using some forms of medicines/healing practices that are not orthodox biomedicine. They also point to the possible nature of the group; better educated and with a higher grade of illness, although I would question that last statistic as men may be using CAM at different stages of illness for different reasons and there may be a group of men with advanced illness that use CAM intensively, as biomedicine has no more hope to offer them. This last group may be skewing the statistics relative to disease stage.

Prostate cancer and CAM in qualitative research

Moving on to the qualitative literature, to say that there is a gap in the literature is an understatement. A small group of authors has provided all the qualitative literature on prostate cancer and complementary medicine in social science. Boon, Brown, Gavin and Westlake (2003) used focus groups to provide data for a thematic analysis that identified push and pull factors around CAM use for the men who participated. They claimed that the men in their study were mainly pushed to CAMs by dissatisfaction with biomedical options and treatments, or negative experiences with practitioners. Evans and colleagues did interesting work around men with cancer, not specifically prostate cancer, and CAM use. However, the standout research in the area (from my perspective) is by White and Verhoef (White & Verhoef, 2006). They take a more positive tack by assuming that men choose CAM for reasons that are meaningful to them and meaningful in the context of CAM itself, not just a reaction to orthodox medicine. Spirituality emerged as an important aspect of the decision by some men to decline conventional treatment in favour of CAMs. I found this research quite moving and surprising, as some of the men express gratitude for the cancer and the lessons it has brought them. Also, some display an extraordinary willingness to introspect, and to express their understanding of the process they are in. More information on the stage of cancer would have been useful, however. The meaning of CAM use for a man with advanced cancer will be entirely different from that of one with a small localised cancer, or someone newly diagnosed. Their study needed this 'stage of illness' context for me to understand more about the meanings expressed in the narratives.

This research; what questions and why?

This research investigates the narratives of men with prostate cancer to explore the following questions: What can those narratives tell us about the meanings that prostate cancer sufferers and survivors attach to CAM use. How do they construct their use of CAM? What positions do they take up within their cancer or CAM related talk? What part do CAM narratives play in their causal narratives around the genesis of cancer? What contradictory cultural narratives are men negotiating in their CAM-related and cancer-related talk? How do they achieve these negotiations? What are the changes and narrative reconstructions that take place in their narratives over time, as living with cancer progresses?

The intention of asking these questions is to give this group a 'voice' in the discussion of CAM and cancer, that tends to be constructed from a biomedical perspective, that is to say, somewhat negatively. Even the work by White and Verhoef (2006) cited in the section above, which is quite sympathetic to CAM goals of holistic healing and spiritual growth, is titled "Cancer as part of the journey: The role of spirituality in the decision to decline conventional prostate cancer treatment and to use complementary and alternative medicine". The emphasis in their title was on the declining of conventional cancer treatment (although that was not the tenor of the article, so an eye on publication may have influenced their titling). This negative construction of CAM tends to be common, especially around cancer because of its potentially life-threatening nature. It obscures the narratives of the people who actually *use* CAM. It also does not produce a fruitful relationship between CAM proponents and the biomedical world, obviously enough. It precludes an open discussion of both the risks and the possible benefits of CAM use and integration to patients/clients (see Wardle & Adams, 2012 for a balanced discussion of CAM risks by researchers from both sides of the 'paradigm gap'). So this research is a qualitative journey that attempts to unpack what CAM means to the people concerned, in the context of prostate cancer. The intention is to thereby gain insight into the social contexts and personal narratives of this group, beyond a bias either way, to CAM or biomedicine.

To be more specific and state rather prescriptive research questions; what would persuade a man to put his trust in alternative medicine when scientific evidence may be lacking, it is costly and to some extent socially marginalised? That is one research question many have asked (see Arthur et al., 2012; Boon, Brown, et al., 2003; Singh, Maskarinec, & Shumay, 2006). The other, which is far more suppressed and only occurred to me after some months of immersion in this research, is- what would persuade a man to submit to surgery, radiation treatment or hormone treatment that might leave him impotent or incontinent, and still might not give him more years of life, or a better quality of life in the years he has left? Why would he trust such a radical invasion of his physical boundaries, when alternatives might be available that could delay it or render it unnecessary? This is just as valid a question, one that many CAM healers may have asked themselves or their clients. It is a question that may not have been answered quite as clearly as I might have liked, since it was one that came out of the data as much as generated data. That is part of the iterative nature of qualitative research (Riessman, 2008). It part of the value of this kind of research that it generates questions just as much as answers, as suppressed or marginalised points-of-view are given room too.

Chapter Two: Methodology and Methods.

Methodology

This research is a qualitative work that uses a narrative methodology. Following from a social constructivist epistemology, I was looking for a way to research the social meanings of complementary and alternative medicine in the lives of men with prostate cancer. I was grateful to be led to the work of Catherine Kohler Riessman early in the process of starting research, to help clarify some of the complexities of narrative approaches to data collection, transcription, and analysis (Riessman, 1993, 2008). This social constructionist epistemology is fundamental to the research, despite my frequent citing of other post-positivist research. Descriptive statistics have been used to contextualise this project. Where possible I have looked for good quality qualitative research to cite, to support my points or develop an argument further. However, most research in the medical field seems to share post-positivist realist assumptions so that is what is often cited.

What is narrative analysis?

This is a somewhat contested question. Riessman points out that the various strands of narrative analysis are a family, and like other families, they have their points of difference and dissension, despite a lot of commonalities. A little confusing for the beginner! So I can only present my understanding of the field and what I have attempted to do in my research process. Narrative analysis is a way of investigating that most common, 'everyday' way of organising talk into a meaningful structure, the story. It can also be a way of investigating the bigger 'stories' that shape lives, the cultural narratives that transcend the personal even as they interact with it..From narratives, inferences can be made relative to the ways people create meaning in the social world. Subject positions that entail negotiating complex and contradictory moral and cultural influences are very suitable for narrative analysis e.g. the uninvited narratives that adolescent single mothers provided into how they came to be pregnant, were analysed as resistance to dominant cultural narratives and stereotypes, as part of a bigger project on teenage mothers in Britain (Alldred, 2010).

Narratives are first and foremost, social acts. As such they of interest to a wide range of disciplines and narrative methodology is being used throughout the social sciences in an inter-disciplinary and trans-disciplinary fashion (Stephens & Breheny, 2012). Narratives can be textual, visual and cinematic and combinations of all of these forms (Riessman, 2008). I chose this methodology for this project because I was interested in how the contested narratives of biomedicine and CAM were negotiated in practice by those affected by them; people with an illness that is regarded by most of society as serious.

Based on this approach, I have collected six personal narratives as data, to be used in case-based inquiry into the meaning of complementary medicine in the narratives of man with prostate cancer. By analysing them as narratives, not breaking them up into thematic units, I have attempted to preserve the wholeness and logic of the accounts. At times I have strayed into thematic analysis without noticing it (until my supervisor pointed it out!). I have also analysed 'small stories' as mini-narratives, to unpick how men with cancer negotiate shifts in their identities and masculinities, through identity positions taken within the interviews.

One of the consequences of a social constructionist epistemology, and one that both Riessman (1993, 2008) and Atkinson (2009) argue forcefully for, is that narratives are not 'transparent windows' into personal experience. They are a *text*, first and foremost. They are created by social actors in contexts, for certain listeners, to achieve certain ends. They often make commentaries on moral positions. In doing narrative analysis, one is constantly working to keep the awareness in mind that accounts are constructed, not views into events as they 'really happened'. At the interview stage, it is easy to ignore the situated and contextual nature of the narrative in the process of empathising with the participant. Or conversely, it is possible find oneself critical of the participant's account, as not being an accurate representation of the 'truth'. I fell into both traps at times and it is inevitable to some extent.

In short, narratives are a way that people garner agreement to certain versions of situated events. As a social actor, the researcher's own intentions, experiences, interests, cultural and gendered understandings are implicated. For example, when participants talked to me how they experienced the trans-rectal ultrasound biopsy

(TRUSbx) as an invasive procedure, I could empathise with them as (like many women) I have experienced invasive 'internal' medical procedures. I found myself wincing and feeling very sympathetically vulnerable as they spoke, or as I read the transcripts. A man (who had not experienced similar medical procedures) may have had a different response, maybe just as empathetic but without the bodily visceral dimension. Researchers' own cultural narratives will be involved in the construction of the text, and an analysis that acknowledges this and accounts for it to some degree is needed to represent the constructed nature of the text.

Riessman, from her interests in cultural forms narratives may take, argues that a narrative may not necessarily have a temporal structure that Western narrators or listeners would recognise as one. Other cultural forms of narrative may not appear as such in Western listeners' hearing, in that they may not have a recognisable beginning, middle or end. In Western cultural contexts, a narrative is "talk organised around consequential events. A teller in a conversation takes a listener into a past time or world and recapitulates what happened then to make a point, often a moral one" (Riessman, 1993, p. 3) As a beginning narrative researcher, I went looking for conventional narratives that had that 'consequential' structure of recounting a time-based sequence of events with an internal logic and causality. My participants were all well-versed in the cultural art of producing that kind of narrative, although some were more productive of them than others.

Another strand in narrative analysis is represented more in the first part of my analysis, the section on causal narratives, or genesis narratives (to be more true to the point of the analysis). Causal ideas are not straight-forward in narratives, as people do not follow the logic of positivist science in their causal attributions. They create meaning from a whole host of different elements, by imposing a plot on the chaos of lived past experience (Williams, 1984). It is an approach to narrative analysis that is a highly interpretive view of the 'big picture' of a life-story or an illness narrative, but one still based in the data of the text. This approach was appropriate to this section of the research as this was most obviously narrative reconstruction and interpretation of an event; being diagnosed with cancer. This is an event in the personal narrative that represents a significant 'autobiographical disruption', one that requires interpretation and the granting of meaning, so that a coherent identity can be maintained (Williams, 1984).

The analysis moves back and forward between the 'big story' level of analysis and the 'small stories' that participants tell to make moral points and assume subject positions. In this way, it is a bricolage in itself, of different strands in narrative research. It was by working this way that I endeavoured to analyse the bigger narrative of illness at the same time as taking pieces of text that were 'small stories' in themselves (and often had other actors in them) for a closer textual analysis.

Methods

Participants and recruitment.

The participants were six men, all of whom had been diagnosed with prostate cancer, who also use complementary and/or alternative medicine (CAM). The time since they had been diagnosed with prostate cancer ranged from 2 months to 17 years. They were all Pakeha New Zealanders and all aged over 60, and none self-identified as gay. They all spoke fluent English and lived within the greater Auckland area. I specified these last two criteria partly in order to make the process of interviewing participants more workable for myself with my limited student resources and to obviate the need for a translator. Also, I felt that immigrant (hence non-English speaking) groups may have patterns of use of their traditional medical systems which I do not have any cultural background in and would be hesitant to classify as 'complementary and alternative' (since they may be more prevalent in their country or community of origin than Western biomedicine).

They all had had at least one appointment with a practitioner of complementary and/or alternative medicine (CAM). I specified this as a criterion in order to distinguish between the common use of vitamins and other over-the-counter preparations that are part of the 'complementary' medicine picture, and the greater commitment required to go to a professional for a consultation. It was also because of my initial approach to recruitment that I specified this criterion. I initially believed that I would find all the participants through CAM professionals contacting their patients and sending them information about my research project. In the event, I only found some of them of that way. But it was a good basic criterion and one I would use again in a similar research project. I made no attempt to limit participation by age, stage of cancer, or types of CAM used. No Maori men came forward though the contact channels I used, but if they had I would have consulted with the kaumatua of the Massey School of Psychology around cultural issues, especially those pertaining to Maori traditional medicine if that was being used.

After obtaining ethical approval from the Massey University Humans Ethics Committee at Albany, I began the process of finding participants. I phoned approximately 25 CAM professionals, mostly in West Auckland or the North Shore and asked them if they could send out my material to their eligible clients. Some of them had no clients with prostate cancer, which was not unexpected by me, as considerably more women than men use CAM for cancer care (Fouladbakhsh & Stommel, 2010). Some did not want to be involved, or their clients did not respond, or they were not eligible because of a different cancer site. However, I did get some responses. I also spoke in person with the director of a large natural health clinic on the North Shore and a naturopath who works in the same clinic, both personal contacts of mine. I put my material in their clinic waiting room. I also put a letter on the notice board of a large health retreat centre on the North Shore. In all, two participants came through their CAM practitioners. One came from the letter on the board of the retreat centre. I also contacted the Prostate Cancer Society of New Zealand and talked to the co-ordinator and sent my material on to her by email. She sent my material on to a member of a support group who was eligible to participate. By snowball sampling, another two participants came from that contact. By starting with the CAM practitioners I probably delayed finding some participants, as it proved to not be a particularly efficient way of contacting the men I wanted to talk to. However, it did have the advantage that I was not just inviting men who were already in support groups to participate. Some of the participants had had no contact whatsoever with the Prostate Cancer Society or the Cancer Society New Zealand (CSNZ). In fact, only one participant had extensive support group connections. One of my participants commented that he was not involved in a support group because he had not had surgery or radiotherapy and did not think he would have the same concerns as men who had. Two others stated that they didn't join groups. Support group-based research has been a big source of insights into men with prostate cancer, especially in the work of Michael Arrington (2003, 2005). While I find his research very valuable, being able to reach men who weren't involved in a support group probably added to the diversity of my group in terms of disease stage, use of CAM and attitudes to biomedical treatment.

Data collection

I conducted two in-depth interviews with each participant, at their homes. I requested that the interviews take place in participants' homes because they would be more comfortable there and not required to travel. I asked that there be a private space for meeting, without partners or children present. They were all able to provide this. The interviews were around an hour in length each time, although some were shorter. None were shorter than 45 minutes, however. The interviews were unstructured as I did not know in advance what each participant would want to talk about. I also asked a range of different questions designed to elicit material related to my research interests. I responded to participants' interests and treated the interviews as a shared mutual process of social construction of the data we were generating. The questions I asked were usually open-ended and designed to elicit narratives, when they were not statements or questions responding to something the participant had said. Most of the participants responded quite well to being able to set the agenda in the talk. I did a lot of work to draw some participants into telling me the story of their specific journeys with prostate cancer, rather than talking about more general (non-narrative) ideas around health or other subjects, although a lot of that talk was interesting too. I knew, though, that if I was going to do a narrative analysis, I needed narrative talk to analyse. So the order of events was important and I had to sometimes ask participants to clarify the order of events. Sometimes they would correct me if I had got it wrong.. Some of my questions that I asked in one form or another include: "What happened when you first realised you were unwell?" How did you realise you were unwell?" "Why did you first go to the CAM practitioner?" This last question was usually not necessary, as they would tell me unprompted and often explained what the person had done or what they had said. Other questions were around the reaction of other people to their CAM use i.e. family members or their orthodox medical staff. I asked all of them why they thought they had developed prostate cancer. I also asked them questions designed to elicit responses that addressed the perceived effects of their CAM use all levels of the being; body, mind, emotions or relationships, and spirit. Sometimes that was a strategy I used intentionally, referring it my own mind to Mason Durie's (1994) simple image of a four-walled house, Te Whare Tapa Wha. The four walls of the house represent the biopsychosocial nature of persons and communities, with the addition of spirituality as the fourth dimension. This was not an image I was using in its Maori context, but a useful model of holism in health that helped me remember to 'touch all the bases'. I wanted to encourage participants to talk about the holistic nature of the effects of CAM in their lives. This was not especially productive of narrative material and I did not do it with all of them in an explicit way. Sometimes the 'walls' of the 'whare' still got discussed, but not because I actively asked about them, but more because they were of interest both to myself and the participant. Spirituality was the dimension that was the least discussed (except by one participant) and that surprised me to some degree. There were also some interviews where the narratives were less holistic in their focus, possibly because those participants were very much in the midst of a challenging crises, either around a new diagnosis or a setback in their progress.

The interviews were recorded, downloaded and transcribed. This generated 225 pages of transcript, at the same spacing as this text. Transcribing the data was painstaking, as I chose to leave in all the hesitancies and broken sentences (although I didn't mark the pauses as such). By doing that I was able to preserve the lived quality of the talk and also preserve a sense of when men were most hesitant or stumbling, something I would have forgotten as the interview time grew more distant. The temptation to 'clean up' the transcripts was nearly irresistible with some of the interviews, but I resisted it as long as the talk was still understandable to some degree. I did eliminate my back-channel communications such as "mmmm", "yeah, yeah" and so on from the analysis (although not from the original transcripts) unless they added to the meaning of the narrative.

Analysis.

I gave each of the transcripts pseudonyms and began to analyse them. The first level of analysis I used was to read the transcripts several times to get a sense of the whole narrative contained therein. I did this several times. At this stage I was reading to get a sense of the overarching ideas, the main ideas that the interviews and all the contextual information I had noted about the data. I tried to get the big picture of what the men were telling me about their lives, what the key events were and what the temporal relationships were. Also, I read for the key relationships and what roles they had in the narratives. I asked myself what sort of story I was reading. Was it one where the protagonist overcomes great odds; a romance? Or was it a story of the protagonist being overwhelmed by events beyond his means of coping; a tragedy? This is one approach to narrative analysis which is more literary in its approach and can allow one to find a way in to a narrative (Wertz et al., 2011).

I puzzled over how I was going to make sense of six stories that all had different time-frames (from 2 months since diagnosis, to 17 years) that also spanned different cancer stages (from spreading at the time of diagnosis, to indolent and non-threatening at the time of diagnosis). What is more, the narratives involved a huge diversity of complementary and alternative medicines, with each participant using multiple kinds over time. The narratives also covered all the fundamental biomedical treatment options available for non-metastatic prostate cancer in New Zealand. I had asked every participant one question designed to elicit a narrative of the genesis of their cancer (and that was new to prostate cancer research, as far as I know). I reasoned that every narrative had three things in common; a genesis narrative, a diagnosis section and a treatment section, since I knew that all those aspects had been addressed by every participant. So I decided to set up a three-part way to account for those elements.

The second level of analysis was to identify narratives within the text and analyse them. These were the stories, the sections of the text where there were clear accounts of events that had clear sequential relationships to each other, or to the events of the wider narrative. I analysed these 'small stories' for what subject positions were granted to the characters in them, including the protagonist. I also examined them for what gendered positions were maintained or affirmed within the story, and what moral positions were maintained or affirmed. I looked for what each narrative was achieving. What point was it making? If, as Riessman points out, narratives often have moral implications, what were they? What did the narratives say about CAM and biomedicine and the ways the constructed 'boundary', a cultural narrative, interacts with the personal narratives in this research?

As I worked through the analysis, I was writing about three stages; genesis, diagnosis, and treatment. At a certain point I realised I was losing the sense of working with whole narratives so I printed off the chapter and cut it up and re-pieced it according to which narrative I was discussing, with my discussions included. This was a way of physically enacting the process. I colour-coded the sections on the long taped-up sheets and stuck them on the window. This helped me to evaluate where I was placing my emphasis, privileging certain aspects of the whole while neglecting others, and where more attention was called for. It helped me make connections between the 'small stories' and the whole story, in the case of each narrative. If I was to do more narrative research then I would do this sooner, maybe right from the raw transcript stage.

The process of analysis was an iterative process, with stories being included and deleted, and directions being pursued and abandoned as the analysis developed. I asked, what was the main 'action' in each narrative? How was CAM being used and when in the cancer process? This produced a analysis that was detailed and complex and required a lot of inductive thinking to pull together into a mini-conclusion at the end of each section. Given the different stages of cancer and CAM use, this was inevitable.

Chapter Three: Analysis and Findings

The narratives of negotiating the interlocking, yet demarcated worlds of CAM and biomedicine that the participants shared in this research reveal a rich 'brew' of strategies and cultural narratives. These men actively negotiate and construct their sickening, treatment and healing in prostate cancer utilising both CAM and conventional medicine. They do this despite the disjunction between the different worldviews that they encounter. It is negotiated by them as creative agents, producing unique meanings and narratives through acts of cultural bricolage. All the men in this study have resisted, affirmed and reproduced, or adapted both CAM and biomedical narratives of sickening and healing/remission into their process of living with prostate cancer. They have put their bodies and lives in the hands of doctors, surgeons and healers. Some of them have taken on a very active role in their own healing and prevention of cancer recurrence, some a more passive role.

This analysis demonstrates and explores the ways that the participants negotiated the challenge of continuing to align with masculine ideals. Most of them do this while suffering threats to their masculine functioning and identities through side-effects of treatment. Every participant made unique and idiosyncratic use of CAM and negotiated the relationships with CAM providers and biomedical providers in ways that produced a sense of agency and avoided assuming an often disempowering 'patient' role.

The narratives themselves are a level of interpretation of the transcripts and the transcripts are an interpretation of the talk (Riessman, 2008). Therefore I have chosen to put them in the analysis section, as a way of introducing the cases, instead of in the methods section as many do. The narratives are arranged in a dimensional manner, based on the degree of trust they display in biomedicine, from the most trusting to the least trusting. I could have done this in regard to CAM. However, CAM is a very broad term that covers so many different treatments and paradigms. A CAM treatment may be based in a materialist paradigm e.g. vitamin mega-dose therapy. It can be based in a mind/body paradigm e.g. visualisation, or an energy-based paradigm e.g. homeopathy. It may be based in a spiritual paradigm e.g. intercessory prayer (Tataryn, 2002). With such heterogeneity, trust is a more complex matter in CAM. A person may trust one paradigm, or one treatment within a paradigm, and not others. So I have used trust in the biomedical paradigm as a starting place for this dimensional arrangement.

What makes such a categorisation doubly difficult is that all these men are at different stages with their treatments and their healing processes. One has been very recently diagnosed and had surgery between our two interviews. Another has been 17 years since diagnosis. As one would expect, there has been a developmental process. Their trust in their physicians, the health system, and biomedical narratives has changed over time, and so has their relationships with the CAM sources and healers they have chosen.

The first, most bio-medically trusting narrative is that of 'Peter', a 60-year old professional man, self-employed and married for the last 17 years. His wife runs a natural therapies retreat on their property, in an area of great natural beauty on the outskirts of Auckland. At the time of our first interview, it had been eight weeks since his diagnosis with prostate cancer. He had a prostectomy around a month later, before our second interview. He was one of only two participants that discussed their Gleason score, which was 8, and the urologist who diagnosed him recommended surgery as soon as possible, to prevent the cancer from spreading. His willingness to delay surgery and his interest in CAM stemmed largely from his wife's influence.

> Peter; "Currently I'm booked into have it out at the end of this month. Ah, because according to him (the urologist), my own doctor and nearly everyone else I talked to, for my fitness, age in life and the level of cancer and that it may not have spread, and everything including the MRI suggests it hasn't, um, removing the prostate is about the best thing to do. 'Cause him, my urologist and my doctor, both said they feel if I do that I'll die of something else. I won't die of prostate cancer. 'Cause I said, well what if I do nothing? And they said, well, you know, you'll bumble on for a while and eventually, in about four or five years or something it'll start to get bad and then it'll all go down-hill. So, um, so you know, I wanted to go in the next day and have it done. Now, [my wife] practices, all sorts, she

> practices in alternative therapy and she runs a retreat centre here and has all sorts of people come and do therapy stuff here and she wanted me to think a little harder and try a few things first, um, before racing in."

Second on the continuum is the story of 'Frank'. He is 66 years old, single, and self-employed with some property renovation, although he does not work full-time. His is a difficult case to categorise as being more trusting in bio-medicine than the two that follow, as his narrative has developed over 17 years since his first diagnosis at the age of 48. The original carcinoma was small and his PSA was low (he did not quantify it in our interviews). He self-selected 'active surveillance' and had regular PSA counts at intervals of 18 months to two-yearly intervals. This is an approach where treatment is deferred until later, with regular monitoring (Bill-Axelson et al., 2011). But after 17 years he is undergoing treatment from biomedical sources, with a transurethral resection ('re-boring' is his terminology) followed by beam radiation therapy. He also seems a little jaded around the CAM treatments and products he has been researching and receiving for years. However, it should be noted, he has avoided biomedical treatment for 17 years, which may not provide firm evidence for the efficacy of his CAM approach, but it certainly points to his commitment to it over the 'long haul' of living with a slow-growing prostate cancer.

The third in this continuum is 'Roger', a 68 year old man, single, self-employed and working 20 to 30 hours a week outdoors. He was diagnosed 12 years ago with cancer that had spread beyond his prostate, and the urologist told him that he had a 'significant cancer' He had a radical prostectomy, followed by radiation therapy and hormonal therapy. He periodically has a course of hormone treatment when his PSA starts to rise. He lives in a quiet bush-filled outer suburb of Auckland. He only became actively involved in CAM after his diagnosis, although he was first exposed to it through his ex-wife. He heard about various CAM treatments through the media and reading popular CAM literature around prostate cancer.

> "Roger; "Well actually, when I was diagnosed it was about the same time as Leighton Smith the Newstalk ZB announcer was diagnosed and he mentioned this book here, ahh, by Ron Glilately, the Australian, who is a

> homeopath-naturopath and he virtually cured himself, because it had already spread to his bones."

He showed me a well-read copy of 'How to Fight Prostate Cancer' (Gellatley, 2000). This book tells the compelling narrative of Ron Gellatley's diagnosis with prostate cancer and his treatment of it with CAM methods and substances, including diet, supplements, meditation and positive thinking, after discontinuing the hormone treatment he was using. He claims to have cured his prostate cancer through these CAM means. Roger had misunderstood Gellatley's account, because the prostate cancer had not in fact metastasised to his bones. A dark mass in an x-ray turned out to be arthritis (Gellatley, 2000). None-the-less the book argues for the possibility of a 'natural' cure for prostate cancer. He also read 'You Can Conquer Cancer' by Ian Gawler, founder of the Gawler Foundation in Australia (Gawler, 2013)

Currently he sees a local physician who has an integrated approach, using CAM approaches and research as much, if not more, than biomedical treatments.

> KT: "This approach which you've taken, you said to me that you looked first of all at your diet and that was pretty much from this, was it? (By 'this' I mean Gawler's book)
>
> Roger: Partly from there, but also from other books I've read as well. About cancer in general, really. The Gawler Centre book, basically, I read it. Funnily enough, my ex-wife had been diagnosed with breast cancer, umm, almost ten years before I was diagnosed with the prostate cancer. So she went through all that sort of stuff as well, you know? And, so, I picked up from some of the stuff that she found out about it, y'know?....I went to see this guy here. This is the doctor in [Roger's local area]. (he shows me a pamphlet)
>
> KT; Oh yes.
>
> Roger; You know about him? Of course, he does alternative treatments and things.
>
> KT; Yes, I do. He does, sort of, integrated [medicine]

> Roger: In fact, he tends to go down the alternative line, regardless of what you turn up with, before he goes down the conventional line, actually. And, um, so I see him on a regular basis now."

'Tom' is fourth in this dimensional list. Tom has a considered approach to medical science, viewing it as appropriate for emergency treatment but not so useful for chronic illness (like cancer). He is very committed to CAM paradigms. At the time of interviews, Tom was 75. He is semi-employed on a contract basis by health companies to develop and market products. He was diagnosed 13 years ago (around 2000) with prostate cancer. The cancer was described as 'aggressive' by medical staff, according to Tom. His PSA was around 15.7 before the radiotherapy and hormone therapy, which is considered fairly high by prostate specialists. Surgery was not considered an option. He felt he 'owed it' to friends and family to have conventional treatment so he had radiotherapy and a course of hormone therapy. However, his reluctance around the treatment comes through in his talk right from the beginning of his narrative.

> " KT:...And so, then they offered you radiotherapy and hormone therapy, and you were fairly reluctant around that.
>
> Tom: Yeah. And the reluctance was really based on a fear of long-term effects of impotence and, ah, incontinence and the other sort of things that occur. And although at the time, I think, Auckland hospital had beam radiation which was fairly targeted, they were still having a lot of problems."

Tom suffered unpleasant short-term side-effects of the radiation therapy itself, especially bad diarrhoea. He rather stoically evaluates the treatment as moderately effective, while acknowledging the limitations of such treatment.

> Tom: "... after the radiation and a course of the hormone ablation prior [to] and also somewhat after it, it came down to about 0.4. So it was less than 1.00. So that was kind of [pleasing]. But of course there was scarring and burning and all that sort of thing, and ah, parts of the body burned. So it wasn't a comfortable experience, umm, but it certainly

> deals with about 70% of the cancer. It doesn't deal with it a 100%. So there's still a likelihood that it will come back."

Tom's use of CAM as a source of treatment specifically for prostate cancer began at this time, as he had acupuncture during the radiation therapy. He also began to research CAM options for treating his cancer, based on a life-long interest in complementary approaches to healing.

> "Tom: So, I felt it was very important to manage my lifestyle and diet, and so I started to explore, umm, with some knowledge of drugless healing. I did a diploma in drugless healing in 1962. And in those days it was, the training and the teachings were not that different from now. But now there's been a lot of research. So the efficacy of what people do now, there's more knowledge, there's more foundational evidence based, ah, on supplements and food choices.
>
> KT; And so that diploma in drugless healing that you did in 1962, was that something, did you ever work in that field?
>
> Tom; Over the years, umm, I have engaged in different kinds of things, I formulated products, health products. I've got a library of something like 2000 books....Mainly they reflect my interests in nutrition and natural healing and so on."

Much of Tom's education in the CAM field has been self-taught from his library although he also has formal training in various fields such such as hypnotherapy and nutrition. He has also been initiated into the Zhog Chen school of esoteric Tibetan Buddhism. His approach to CAM modalities ranges across body-based therapies (herbs and supplements), mind-based therapies (hypnotherapy and meditation) and energy-based therapies (acupuncture.) A spirit-based near-death experience of choosing to return to life in the midst of a near-fatal bout of meningitis removed his fear of death, which up to that point had been very strong. As a reflexive researcher I have to admit to feeling the greatest rapport and meeting of minds with this participant and that he most nearly conformed to my ideal image of a CAM-using cancer survivor (an ideal I was unaware I held before I interviewed him!). I admired the depth of his knowledge, his commitment to CAM and his spiritual path, and his helping of other men with prostate cancer through a hypnotherapy practice and mentoring. However, I was aware that this would possibly predispose me to privileging his narrative (which would not serve the research process) and to the best of my ability I have avoided this.

'Stewart' comes fifth in this dimensional arrangement because of his ambivalent relationship with physicians, which predates his diagnosis with cancer by many years. He is "almost" (his word) semi-retired, managing property rentals, doing some carpentry, and renting out part of his large house to several tenants. He was diagnosed at 63 with a still-localised carcinoma and had a prostectomy. He was offered radiation therapy but has so far declined it. Now aged 67, he attributes becoming ill with prostate cancer to mercury toxicity from old amalgam dental fillings. He describes himself as having an unusual sensitivity to mercury, similar to an allergy. His response to his presumed toxicity has included the removal and replacement of all his amalgam fillings. He also had an extensive course of chelation therapy (the removal of heavy metals from the blood with a chemical agent). This is not a CAM therapy in itself, as this treatment is used for heavy metal poisoning in biomedicine. However, his belief that he has an unusual sensitivity to mercury and that it has been at the root of fatigue and 'flatness' all his life, as well as being the cause of his cancer, is a construction that would certainly gain more credence in CAM circles than with biomedical practitioners.

In his narrative of mercury-related health concerns over his life-time, ill-health began in his teens, well before he had cancer diagnosed at the age of 63.

> Stewart; "I knew there was something wrong in my teenage days. I had a fine tremor, and I used to get rashes and that sort of thing. There was something, and oh, there's quite a few other things. You know, I knew there was something wrong. And when I eventually had my fillings out, there was quite a bit of relief in certain areas. It was quite noticeable"

When he talks of experiencing symptoms they are not neatly demarcated into physical and psychological, but encompass both and also are deeply entwined with his life story. I asked Stewart if he had married or had children, and after answering in the negative, he attributed his single status to symptoms of toxicity.

> Stewart; "I put a lot of that down to mercury. I felt so, never felt good at all, you know? Umm, didn't feel (pause). I've always felt very flat. I've likened myself to a flat battery. Like a torch, a flat torch, you know? Some days I'm right, some days I've just felt terrible, just wanted to stay home, and that sort of thing, you know".

The narrative that reflected the least trust in the medical system in New Zealand was that of 'Geoff'. He is seventy years old and works full-time as a painter and lives in a 'middle income' part of Auckland, not in a wealthy part. He is married and has adult children. He was diagnosed in February 2010. He had a PSA of 21, which is relatively high, at the time of diagnosis. He was referred to North Shore Hospital, where he had a biopsy. This was a highly unpleasant experience for him, which undermined his trust in the health care system.

Geoff was receiving hormone treatment to shrink the tumour after his diagnosis, to prepare for conventional radiation therapy, when he decided to have transurethral hyperthermia therapy in Germany instead. This therapy is currently only available in Germany, at least in the form Geoff received it (as a stand-alone treatment). It is offered in other countries as an adjunct to radiotherapy, although its efficacy is debated and currently the standard of evidence supporting its use as an adjunct is not of the highest level (Baronzio, Gramaglia, & Fiorentini, 2009). It could be debated as to whether this therapy is actually a CAM therapy, as it sits right on the borderline, as a somewhat experimental practice with a basically materialist theory of sickening and treatment, that may in the future receive more research attention and move into the fold of accepted biomedical treatments. However, for now it fits the definition of CAM as a therapy that sits outside of current allopathic treatments for cancer, especially as it is accompanied with an intensive supplement regime and mistletoe extract (Wieland, Manheimer, & Berman, 2011).

Analysis

Structuring the accounts in this analysis: Causation, diagnosis, treatment.

The men in this research have what is essentially a chronic illness, as prostate cancer is usually slow growing. Survival past five years is now expected in nearly 100% of cases and survival past ten years (in all stages of the disease) of 93% has been achieved (Doyle-Lindrud, 2007). So the experience of living with prostate cancer may be one that encompasses decades of a man's life. Active surveillance has now become the recommended medical strategy for low risk prostate cancers in New Zealand (Prostate Cancer Taskforce, 2012). This is an approach to managing prostate cancer with regular biopsies and testing for prostate-specific antigen (PSA). So more men will be living with the disease rather than having it treated with surgery and/or radiation therapy, as active surveillance is increasingly offered to New Zealand men.

The participants in this research ranged in the time since diagnosis from two months to 17 years. They also had a range of disease at different stages and seriousness when they were diagnosed. Their use of CAM and other treatments differed. So I had to find a way to connect the common points of their narratives, in order to be able to analyse them. The three-fold structure of the analysis is based on the three distinguishable phases that most cancer narratives will share; before diagnosis, diagnosis itself, and treatment. These three phases might be a recurring cycle, in a narrative where the cancer metastasizes. Obviously, in the best circumstances it would not be and lasting remission/healing would be achieved.

The first section, *Causation*, is situated before the diagnosis in a chronology of an illness, since logically it can't be diagnosed until it has been 'caused' to happen. The reconstruction of it (as the account) takes place after the diagnosis. It is a reconstruction after the fact. As such, it is a meeting place of cultural and personal narratives around the causes of illness. Causation narratives represent the attempt to not only explain but to interpret illness, in ways that generate a consistent narrative of a meaningful life. This narrative reconstruction allows the person experiencing illness to reconcile their new identity with the social and cultural narratives available to them. Williams (1984) uses the term 'Genesis' which is a larger understanding of causal narrative than the scientific narrative of causation, one that includes the contextual factors and larger social narratives that may be moral, political or gendered.

Diagnosis, the second section, represents the moment when medical science gathers the collection of odd symptoms and worries a man may have had, and its own biomarkers and diagnostical criteria, and gives them a name. Or as is commonly the case with prostate cancer, the doctor's concerns with diligence result in a PSA reading, since prostate cancer often has ambiguous symptoms or no symptoms. Diagnosis is a process as well as a designation (Jutel, 2011), and the men constructed narratives of both the process and reception of the designation.

The third section, on treatment, is the place where complementary and alternative medicines come into their own. The men shared a wide diversity of stories around their use of CAMs and their submission to biomedical treatment. It is in treatment that the differences in paradigms really start to bite.

'Why did I get prostate cancer? Genesis narratives.

There is epidemiological evidence that only 9% of men have an inheritable form of prostate cancer (Prostate Cancer Taskforce, 2012). Genetics is commonly invoked as a cause of cancer, but such a 'thin' narrative is unsatisfying to the human impulse to knit together a narrative that accounts for biographical disruption and allows for a healing of the sense of self that has been challenged by illness. When I asked him why he thought he had got cancer, Peter talked about a very difficult period earlier in his life that he attributes to having a role in the genesis of his cancer.

> "KT; ... so [to] what do you attribute your having developed prostate cancer?
>
> Peter: ....For me, why did I get it? (he pauses, breathes in two small tense gasps) Some of it could be that I allowed a terrible amount of stress into my life after [my step-daughter's] accident, that was a terrible few years and I feel that stress has a significant impact on cancer and the body's ability to deal with it. I think that's got something to do with it.

He elaborates further on the change he has experienced in his identity, in having gone from being a fit and very active 60 year old man with no known health issues to one facing surgery for prostate cancer in a month. He describes in some detail a moment of feeling quite satisfied with his life and physical health, even to the point of a "touch of arrogance". He denies that he considers this sense of satisfaction part of the genesis of his cancer. In the usually understood sense of causation it couldn't be, unless some sort of moral retribution principle is invoked by Peter (and it is not, at least not overtly). Yet he offered this reflection on his previous self in response to my question around the reasons why he got cancer.

> Um, in a way I don't know that it, no I don't think it's a cause but it's interesting that it was only a few months ago that I was sorta sitting back and thinking, Jeez, it's all just happening, y'know, everything's good, the house is good, life's good, the health is good, you know, and when you get a little, and I suspect there's a touch of arrogance in that, and there wasn't meant to be, but I know so many people who are getting older and getting unwell and unfit and putting on weight and I've been like this for 30 years (pats slim body). And I get on my bike and I ride and I do stuff and I work around here and people say gee, you look young, you never get any older. And I think there was a, as I say I don't think that was a cause, but there was certainly there was a touch of arrogance in the system about , hey you know, you lot are getting older and falling apart, not here.

Peter has made a life-long study of both Eastern and Western philosophy and here he seems to be reflecting on his 'touch of arrogance' as a kind of hubris, a moral failing. A slim, fit and relatively young man could certainly be expected to ask 'why me' in response to developing cancer. He had earlier told me that every person in the previous generation of his family on both sides had died of cancer; some early and some later on. His brother had also died from bowel cancer, so a genetic explanation would be an understandable, and some would say, a sufficient causal narrative. But fundamentally it is the period of extreme stress where he and his wife were the main support for his step-daughter after an accident that he attributes as the cause of his cancer. He does not make it clear whether he means emotional demand or financial demand (on himself), but the attribution is clear.

Tom resisted a genetic causal explanation, while in the same breath acknowledging that his father had died from prostate cancer.

> Tom; "I think genetics can be an influence, but genetics can also be influenced. I mean, we know that now, we don't have to be subject to them. 'Cause my father died of prostate cancer doesn't mean to say I have to. In fact it's quite likely I'll die from other causes.

'We don't have to be subject to them' is talk that strongly asserts his personal agency. This talk accomplishes both an alliance with biomedicine and resists biomedical discourse at the same time, which was common in the CAM-oriented talk in this research. The personal agency that Tom asserts in this way in is in strong contrast to the way he discusses having radiation treatment because he felt he owed it to others. He says he now regrets having it, but whether that is because he believes now that he did not need it, or because it contributed to the impotence he now lives with, he did not make clear.

Frank also resists the explanatory power of genetics and asserts the power of environmental influences, especially diet. He was quite critical of those who he considered ate poorly. By diminishing (unspecified) others in this way, he elevates his own choice to engage in CAM and his own moral positioning.

> Frank; A lot of people think it's just down to bad luck. "I've got cancer 'cause it's bad luck", or something. Or "It runs in the family". I don't even subscribe to that "Oh, it runs in the family". "Oh, my sister's got breast cancer, so I might get it" I'm probably sounding a little bit flippant there, but you know? Ahh, it probably runs in the family because the family all eat the same sort of food, that's the reason it runs in the family.
>
> KT; So you see it as environmental rather than genetic?
>
> Frank; Yep. That's why it runs in the family, because we've always had roast beef and three veg, and y'know, lots of gravy, and all this sort of stuff.

He also told a detailed narrative about life on the oil-rigs where the choices of healthy food were few and the temptations were many. He confronted the staff of the catering firm about the options available and positions himself as having tried to change the catering policy, against the odds. By doing this, once again he strengthens his position as a morally responsible citizen who is aware of health as a social good, unlike the catering staff on the rig.

> Frank: In fact I did mention it to the catering crew that, y'know, that their menu was a little, umm, unhealthy, loaded with saturated fat and salts and sugars, and they sort of took it all on board, sort of, but some of them took it a little bit personally, and I quite cynically remarked to one of the cooks, who didn't like it very much, that all he really was, was a petrol pump attendant in serving out food and he didn't really... (laughs, KT also laughs). He was just, y'know, following instructions, he had a menu, and this is it, y'know, and I said it wasn't personal, I'm not attacking you personally, but that's where you are in the food chain (laughs). He suggested I might have been a bit of a food Nazi, actually.

Frank's narrative describes an arc of 17 years of active surveillance accompanied by CAM treatment, in which diet played a major role. He monitors his diet carefully. In his talk, he tends to discuss general principles rather than his own story, but he did talk about his mother's illness with a benign tumour and his belief that her diet caused to it. This is part of the 'genesis' narrative of his prostate cancer as it talks about key relationship and a key event and what it means to him in the context of his living with cancer for many years. It also demonstrates his interest in having some medical evidence to support his CAM choices, (evidence the dairy industry would prefer not to have aired, no doubt).

> Frank:I have become quite aware diet-wise, and so my diet precludes any dairy products, I don't have any dairy products, and I think there's quite a lot of evidence to suggest that dairy products aren't that wonderfully good for you, certainly not consumed in huge quantities. My mother had a parietal lobe brain tumour at the age of, well, she had it before that, but it took a tragic toll on her at the age of 61. They had to operate and she did

> survive it, but they removed a huge benign tumour, y'know, in the order of 200 plus grams, y'know? That is big. At the age of 61. She did recover from that. She's still alive, but got dementia. But, ummm, she had a diet that was hugely.... she consumed huge amounts of cheese, macaroni cheese was a very favourite sort of dish that would be produced, probably maybe up to three times a *week*, you know? And so I believe that was sort of a contributing factor to it. You know? Of course I don't consume any cheese or any dairy actually.

In his narrative, this was the *only* personal relationship he alluded to. His mother's illness (and possibly the ensuing dementia) seem to be a clear 'warning', a sensitising event that has anchored Frank's commitment to a wellbeing-enhancing diet and a program of herbal medicines and supplements. Some of the other men also had similar sensitising events', notably relatives dying of cancer. This event was key for Frank, as demonstrated by his general reluctance to speak personally being set aside to tell this touching personal narrative.

Roger situates the genesis of his cancer in his over-work while farming. He also touches upon his marriage breaking down, which he describes as an unsupportive relationship. In his narrative, it is the combination of the two that gives him prostate cancer.

> KT; "So what do you attribute your becoming unwell with cancer?
>
> Roger; Stress, probably.
>
> KT; Yeah? Tell me a bit more about that. Because stress can mean a huge number of different things.
>
> Roger: Well, ... I was running a farm on my own, up until the late 80's, and that can be a very stressful business at certain times of the year, especially at the calving time, and when you're virtually working 15 hours a day, virtually every day, seven days a week. And, umm, there were also problems... in my marriage, that perhaps I didn't feel I was getting the support I deserved in some way. And I think a combination of that went on for quite a while."

Roger also talked about the role that farm chemicals might have played in the genesis of his cancer. He was somewhat equivocal about the role agrichemicals might have played, relying quite heavily on biomedical understandings of risk and giving a counter-example.

> Roger: I mean you can never say exactly what it was, I mean there's, there's certainly chemicals, there's certain chemicals that are not good for you either, environmental sort of stuff that's going on which is, umm, not good for you, and they'll never, they might have theories on what causes various diseases, but they'll never know for sure. 'Cause I mean, unless you subject someone to permanent chemical toxicity, you know, how can you know whether it's going to affect them or not? Some people may survive it and some won't. It depends again on your make-up, and probably other things that are going on in your life as well.
>
> KT; ...And so were you working with agricultural chemicals?
>
> Roger: Yes, I was, yeah, yeah. Umm, one which has now been banned, umm, 245T, which we used to spray blackberries and ragwort, things which were common sorts of farm weeds at the time. In the summer time I'd be out there with my tractor and spraying things with no shirt and just shorts and boots on, you know? Nobody told us it was killing, killing you, probably, you know, this toxic thing that was going on. It had the dioxin in it. And they banned it eventually (KT quietly breathes 'yeah, yeah'). But, again, there was a guy I met, he was a contractor of some sort and he used to spray willows with the same stuff, with a back-pack. And the thing used to slop out the top and run down his back, you know? Well, he was 88 when I met him, so (laughs). You know? It's not going to kill you right away, but it might [cause problems in the long term]. But even if it does, if you do get things wrong with you, you can't sort of say was that the cause of it or not. It may be or it may not be, you can never say."

If his talk is examined in terms of what Roger achieves with this equivocation and counter-example, he can be seen to side-step the issue of a possible *moral* responsibility for exposing himself to potentially cancer-causing sprays. Yes, he used sprays, sprays which are implicated as carcinogenic, including the notorious 245T with its dioxin contamination. But it is impossible to make a direct causal link from the exposure to his cancer, so he cannot be held responsible. By being fairly non-committal about the possible role of agrichemical toxicity in his cancer genesis Roger can simultaneously affirm his masculine adherence to the values of hard physical work and farming of the land and avoid blame for the exposure to possible carcinogens. To claim that agrichemicals may have led to one developing cancer is a socially marginal position to take, possibly because of the huge economic investment and value of agrichemicals to the New Zealand economy. According to Canadian research, a significant correlation exists between the use of herbicides (as the number of acres sprayed) and prostate cancer in farm workers (Morrison et al., 1993), and a meta-analysis of studies from Europe and North America found that exposure to pesticides is positively linked to prostate cancer (Van Maele-Fabry & Willems, 2003). Even so, for a New Zealand male to claim to have been poisoned by the very chemicals that made his farm profitable may require some negotiation to protect his valued identity as a 'good kiwi bloke'. There is a tension between his trust at the time in the agrichemical companies' narratives around the sprays (that they were non-toxic) and his subsequent realisation that some of the sprays were highly toxic.

Stewart constructed a causal narrative where mercury toxicity (and super-sensitivity to mercury) was the main genesis of his cancer. He also discusses overwork at times as well, as a possible reason for the prostate cancer becoming symptomatic when it did, some ten years after all his mercury amalgam fillings were replaced. He has received a lot of support from CAM healers for his assessment of himself as suffering from mercury toxicity, which he first self-diagnosed from a book he found in the local library. He cited this finding this book several times as a turning point in his understanding of his health issues from childhood on. As far as Stewart is concerned, mercury toxicity is his fundamental health issue, and the primary reason he developed cancer.

Initially he told me his cancer was caused by stress. I asked him what he meant.

> KT: Want to tell me a bit about ... the stresses?

> Stewart: Yeah, well, a lot of it was medical. Mercury fillings. I sort of put a lot of my ill-health down to stress and problems [with mercury]. I put a lot of it down to that. You know, from a young age. And I did see a guy, what's his name [names a CAM practitioner] who tested me a few, ooh a few, years ago. Now, he said I was very very sensitive to mercury. You know, he said, oh you're much more sensitive than most people. And, when he was testing, as you might know, what they do?

He elaborates;

> Stewart: ... They have little containers that you held ... they connect you with them, anyway, and then he got your reaction. He checked your, that's right, muscle test, just the old basic muscle test. And there was this one in the circle, that the whole body just slumped, you know? And that was the mercury one.... There's very little prostate cancer through my family on both sides. So I put that down to, basically, the mercury.

Stewart finds the mercury explanation very convincing, when a CAM healer constructs a plausible narrative of super-sensitivity with a muscle-testing diagnostic procedure. He is aware that physicians would *not* find this explanation very plausible and says, rather humorously "But if I'd gone to a doctor, they couldn't, you know, you'd tell them all this stuff , affected by mercury and they'd ring up the people and have you taken away. Committed." His narrative was a fascinating example of a contested diagnosis (Jutel, 2011), but as much of his medical/CAM-related narrative had little to do with prostate cancer it could not be included in this research

None of the participants told narratives of genesis that relied on explicit social, cultural or gendered positioning of themselves as cancer sufferers. The gendering of social responses to cancer were mentioned by participants in the context of funding for cancer support groups and health promotion campaigns, in the sense that breast cancer was perceived as being better supported by society than prostate cancer by some of the participants. The greater publicity, research funding and fund-raising around breast cancer particularly rankled with Roger. However, no participant explicitly linked social contexts to their own sickening. However, the men placed their sickening narrative in the context of the masculine imperative to be strong in the workplace or the economic sphere. Frank's narrative of struggling with the caterers on the oil rigs and Roger's narrative of his agricultural sprays occur in the context of working life. They position themselves as morally health-aware citizens who preserve their agency, despite eating foods or using sprays that may have contributed to their cancer.

Sered and Agigian (2008) suggest that a holistic model of healing also necessitates a holistic model of sickening, in their research into the practices and beliefs of CAM healers. I expected to find these holistic ideas of causation to some extent in my data. However, my participants privileged fundamentally biomedical (or at least materialist) genesis narratives around their cancer. The narrative resources the men drew on to explain their cancers were also standard ones for their culture, that of Pakeha (New Zealanders of European origin). None of them discussed electro-magnetic radiation (such as microwaves) or significant emotional trauma. This last explanation was common one in Sered and Agigian's (2008) research, but the men in this study did not talk about emotional trauma or grief as causing their cancer. This is quite consistent with hegemonic masculine imperatives to remain strong. Notably, only one of my participants (Tom) invoked any theories of causation that involved energy (such as prana or chi) or a spiritual dimension. He mentioned an energy blockage as having a role in the genesis of his cancer. None of the others mentioned energy blockages, chakras or anything metaphysical. These are not cultural resources that Pakeha men of 60 and over would be expected to use, and my findings do not challenge that assumption. Yet it can be seen that the way that the men told their own stories freely combines Western biomedical cultural resources and others which are marginalised within conventional medical practice, such as toxicity or poor diet.

Toxicity is narrative which finds a place in both biomedical causal narratives and CAM. However, in CAM it assumes a far greater importance as an etiological explanation and quite elaborate narratives of causation are constructed around environmental toxicity, situating the genesis of cancer sometimes in childhood exposure to toxins, or exposure many years before. I found I had a lot of sympathy with the narrative of toxicity leading to cancer as I interviewed, transcribed and analysed the material. 'Stress' as a narrative resources is common to both CAM and conventional medicine. This suggests, that as Ana Ning (Ning, 2013) points out, the presumed dichotomy and opposition between CAM and biomedicine may be more fluid than most commentators presume.

The narrative of genesis that a person has around their illness is part of the way they construct their illness and their relationship to it. It may be the influence that prompts them to seek CAM treatments, or it may be confirmed and strengthened by CAM narratives. It is certainly the area where CAM practitioners often excel in clinical practice over the biomedical mainstream, as they pay detailed attention to the genesis of an illness and listen closely to what their clients tell them They also have many well-developed narratives around causation that a client can build into their own personal illness narrative, where biomedicine has quite thin ones. 'Genetics' is a thin resource, that did not suffice even for Peter, despite his losing so many relatives to cancer.

Diagnosis in narratives of prostate cancer: The turning point

Diagnosis is a key moment in the narrative of illness. Prostate cancer is paradoxical, in that it is often diagnosed as a disease before the man in question suffers any illness. Illness has been defined as a "disvalued state of being" that is presumed to have a biological cause (Jutel, 2011, p. 64). This definition is implicitly biomedical and culturally determined. A different cultural understanding of illness might presume a spiritual malaise or energetic imbalance as a cause, or even have a different understanding of the physical body/mind connection. For instance, Amazonian plant-medicine shamanic healers ('vegetalistas') diagnose illnesses that Western medicine would consider psychological, such as sexual abuse trauma, as a build up of phlegm in various parts of the body. The phlegm is then purged with the aid of powerful 'plant spirits' and 'dieting' with various plant medicines (Espinoza, 2014). This and many other examples point to the socially constructed and determined nature of diagnoses.

Due to its often asymptomatic nature in the early stages, a man may not be aware of the disease until medical investigation of his biochemistry (PSA) and cytology (the biopsy) make a diagnosis certain. Three of my participants report feeling vague 'flu symptoms, asthmatic symptoms or a hacking cough, which took them to the doctor, but it seems likely that the doctors did not link those complaints to the men's prostates and were rather carrying out routine PSA tests because of their patients' ages. So the prostate cancer diagnosis came 'out of the blue' for most of the participants. The shift to having a serious illness came suddenly for them.

The impact was tangible in the narratives, even that of Frank, 17 years later.

> Frank: Well, ahm, as I heard a little while ago on the radio in an interview,...to quote, was it Samuel Johnson, "nothing focuses the mind like the Hangman's noose."
>
> KT: Right. ...So that's what you feel, since you had your [diagnosis]?
>
> Frank: Well, pretty much, y'know, all of a sudden, hey, y'know. And one of the specialists that I sorta saw, actually it was the first one I saw, he wheeled me in, cause his colleague was in the next room and he said, listen, you know, you need to take this serious you know. In a few years you could be dead, y'know? So I was, that was like a real wake-up call then. When he sorta said that. And umm, I guess, whenever anybody hears the word 'cancer' they also think similarly, I guess. Time to think about a few things.

Frank initially had a small cancer and a relatively low PSA so it is difficult to know on the basis of this mini-narrative alone why the doctor felt he needed to emphasis the life-threatening nature of the condition. However, Frank himself cites the focusing effect of the 'hangman's noose' as the spur to changing his life-style extensively. He opted for active surveillance, with the possibility of biomedical treatment later if he should ever need it. He attributes his awareness that active surveillance might be an option for him to the words of a nurse from the Cancer Society who he met with around the time of his original diagnosis.

> KT; ... You said that the nurse from the cancer society was really helpful, that she said something to you which you found quite valuable, which was not to rush into surgery and invasive treatments.
>
> Frank; Probably the most valuable statement she made was, you know, prostate cancer is very very slow growing, y'know? It's not gonna take you out quickly, unless of course you've got advanced stages, but in the early stages, y'know? Which is pretty much reinforced by what [Frank's CAM

> practitioner] has written there in that newsletter. There's no mad rush to go out and get some treatment.

So while Frank was shocked and distressed by his diagnosis, he was empowered by the nurse's comment enough to consider active surveillance when it was not standard treatment in 1996. His own research uncovered CAM materials and practitioners, which reinforced his commitment to active surveillance. At one point in our interviews he brought up the story of the highly decorated American military commander, General Norman Schwarzkopf, who had a prostatectomy despite having a low-grade small lesion. He offered this story as an example of the kind of attitude that he believes was prevalent at the time: "rip it out". He goes on to say "I will say that in the ensuing 15 or so years, everybody has backed off this ripping-it-out business, this slash-and-burn business has been, yeah. They've backed off from that now, they've sort of said, 'Oh yeah, we understand we over-reacted'" So he acknowledges that biomedical treatments have developed and attitudes have changed, since he was diagnosed with prostate cancer.

If Frank's narrative of diagnosis represents the retrospective view of someone who has lived with cancer for 17 years, Peter's narrative is the raw reaction of someone who is in the thick of responding to a new diagnosis. The shock is palpable in his account. He had been diagnosed just eight weeks before our first interview.

> Peter: So then [the urologist] said we'll have a MRI and so we had an MRI, but he said to me at the time, with a PSA of 2.1, I'm pretty confident it hasn't spread out of the prostate, so, let's whip it out. Oh, that's a good idea, let's have it out (adopts an ironic sing-song voice). And um, do you want me to talk about what I felt? (I indicate that whatever he wants to talk about is fine) Of course, the immediate reaction is holy shit, I got cancer (Peter's voice drops almost to a whisper). I lost a brother to cancer, da da da, it was, y'know, it was a difficult week or two.

The understatement in the last sentence is a very good illustration of the way the men tended to downplay their emotional vulnerabilities, consistent with the on-going need to produce masculinities that accord with an ideal of self-reliance, strength and rationality (Courtenay, 2000; Wenger, 2013). His use of 'we' is an odd merger of identity with the urologist, who certainly did not have a biopsy along with Peter! Given that Peter has a high degree of alignment with the urologist, this ironic sing-song voice signals his acute discomfort and shock at the prospect of having his prostate "whipped out'. Peter generally speaks of all the physicians who treat him with high regard and aligns with them, unlike Geoff in the narrative of diagnosis that follows.

Geoff's narrative of the time around his diagnosis has implications for everything that follows in his account. His distressing experience during a biopsy was the beginning of a distrustful relationship with many of the professionals he encountered in the New Zealand healthcare system. In his accounts of the interactions he had around his biopsy, he feels betrayed by the specialist staff not adequately warning him about the possible pain. He also suspects the biopsy of *causing* his subsequent urinary problems. It was Geoff's wife that provided the impetus for him to attend a doctor, as is typically the case when men 'do health'.

> Geoff: [My wife] happened to have a blood test, so I thought, oh, I suppose I'll, I've never been to the doctor hardly ever, I suppose you're getting on and I should go and have a blood test really. Expecting it'd be [all ok], 'cause I was feeling quite ok. I didn't believe it, when the doctors said it's possible you might have prostate cancer. I said, no I haven't got prostate cancer, I said, oh no I doubt it because I've got no problem going to the toilet, never got up at night, anything like that. I tell you what, after the biopsy I used to get up at night. And I still do. I was getting up two or three times a night. Before the biopsy I didn't have to get up. You know, what have they done to me?

The 'they' he refers to here make a fuller appearance when he recounts a story about the biopsy experience itself.

> KT; " Ok, so you were telling me that you went for a biopsy at the hospital, and it was really really uncomfortable."
>
> Geoff; Yeah, well they told me that I might find it uncomfortable but that it's usually not a problem. But oh, man, they started at it and it was terrible. Absolutely terrible. I did get into such a state that they decided to

> abandon it half way through. And they packed up their gear and left the room and left me with the male nurse there, who was sort of assisting him at the time. And I said to the male nurse, I said to him, they told me that it might be a bit uncomfortable. I said to him, would you call that uncomfortable? He said, no, he said that was a harrowing experience for you, wasn't it? He said, the trouble with you was, was your haemorrhoids, that's where your pain was coming from. So *he* knew why there was pain. I can't understand why they kept on, causing me so much pain for such a, you'd have thought they could see I was in quite a bit of pain and sort of stopped it straight away. But the pain went on for too long as far as I was concerned.
>
> KT; Why do you think that they allowed that pain to go on for so long?
>
> Geoff; I don't know. I've got no idea. The head lady urologist came back a bit later and she said well it's obviously a problem for you so we'll let that settle down for six months and we'll have another go. I said you won't see me back here again! (Laughs). And she said but we need to know what's going on in your prostate. And I said the only way I'll come back and have another go with that, is that you'll have to put me to sleep. She said, if you're feel you need anaesthetic we can arrange that. But they never offered it, you know? I'm sure they were just going to try the same thing again in six months time. Without anaesthetic. No way I would have had that on. I just thought, from that day on, I'm going to try to find some alternative, if it's the last thing I do. Because, what other nasty surprises have they got there for you? Down the track, you know.
>
> KT; That must have been quite a blow to your trust.
>
> Geoff; You just don't trust them, do you?"

There are interesting power positions at play in this narrative, short as it is. The nurse gets presented as a sympathetic character, one who empathises with Geoff and does not minimise his distress. He is not apparently one of 'them'. However, the nurse is also presented as implicitly powerless in the drama to act on his knowledge that Geoff is in pain. He is limited to empathising after the fact. The power rests with 'them' and *they* decide to abandon the procedure half way through, not Geoff. He does not ask them to stop, despite the pain. It is hard to imagine a more vulnerable position to be in, literally and figuratively, than that of a patient during a prostate biopsy. Geoff's account reflects the lack of agency he felt during the procedure, the anger at being mislead, and his determination to 'find some alternative, if it's the last thing I do'.

Geoff is quite challenging of the urologist's power, in his slightly humorous declaration "You won't see me back here again!" Her response "but we need to know what's going on with your prostate" is not an empathetic one, but a depersonalising one. It echoes one of the main criticisms that CAM proponents and others make of biomedicine; that it treats the disease not the person (Broom & Tovey, 2007; Engel, 1977). Broom and Tovey (2007) discuss how biomedical language is depersonalising i.e. the 'patient' is treated not the individual. Biomedical imagery (e.g. MRI scans) and quoting of statistical probabilities of survival are experienced as depersonalising by cancer sufferers. The unit of treatment is at the cellular or biochemical level, not even the whole physical body. Tellingly, Geoff never remembers the urologist's name when she crops up again in his story and her impersonality is reflected in his account (although to be fair to the urologist, Geoff's PSA of 21 was high and a sense of urgency would be understandable). But in terms of the subsequent development of Geoff's illness narrative, that experience of betrayal and un-empathetic treatment was a turning point. Geoff went on in the course of our two interviews to recount another two episodes where he was unhappy with what he viewed as dismissive treatment by a cancer specialist, and several others where he considered other men have had negative outcomes from conventional treatment for prostate cancer. The one that makes a critical difference to his story is meeting a man who had an unhappy story of side-effects from radiation treatment, which I will discuss in the next section on treatment.

Tom's story of diagnosis is one where the shock and surprise of his receiving a cancer diagnosis is voiced by his employer, rather than himself. Yet it is quite clear that he remembers it vividly.

> Tom: It was just a routine annual check. And it showed that the PSA was a bit elevated and then the physical check showed there was some lumpiness

> on the prostate. So then of course I was recommended to see an oncologist, which I did. That was the beginning of it. When I was diagnosed I went into work and I told my employer. Sat down in front of him and said, guess what? I've got prostate cancer. I'm kind of, a bit of a health nut, always have been, been fussy, don't drink alcohol, don't smoke, umm, live a clean life I suppose. Diet's always been pretty fussy, for me. So my employer, he just about fell off his seat. Within half an hour he had gone off to see his doctor and he was also diagnosed with prostate cancer. So he started his journey. Um, and then another friend of mine, ... he died recently, actually, but he was diagnosed as well. He was a pharmacist, a clean liver, and started a health supplement enterprise that was bought out recently by [a large pharmaceutical company], just before he died. So, um, so this is a serious problem for a lot of men.

The shock of a 'clean liver' being diagnosed with cancer could be said to be 'projected' in this story on to his employer, in the psychodynamic sense of an uncomfortable emotion being situated in the 'other'(Garland, 2001). He had also lost his own father to metastatic prostate cancer just three months prior to his own diagnosis. Yet he does not reflect on his own emotions at the diagnosis. The story communicates that his employer was surprised enough to get a test immediately, so it lends a lot of credence to the claim he makes to being a 'health nut'. It also produces the masculine appearance of a pragmatic and unemotional response to what one can only imagine would have been devastating news.

However, he is 12 years down the track by the time of our interviews and the initial shock has been modified by many narrative reconstructions and his Buddhist faith and philosophical acceptance of sickness and death The focus on helping other men with prostate cancer that he has developed professionally and personally since his diagnosis over the 13 years since then is underlined by his assessment of the problem this disease represents for a 'lot of men'. This desire to help other men with cancer is a way that many men cope with the distress of a cancer diagnosis (Heron-Speirs, 2013). For him, losing his father and his friend to the same disease that he has just had diagnosed, is a catalysing force in his story, one that propels him into exploring options for helping others alongside his own search for healing. Because he was already committed to

CAM philosophically, that is the direction of his efforts to help other men. He practiced hypnotherapy with cancer patients for around two years and also made himself available to men with prostate cancer as a mentor, mainly by phone. He also formulated products specifically for prostate cancer. With his father's death occurring so soon before his own diagnosis, Tom was sensitised to mortality and distressed by the way his father had died 'in agony', castrated and irradiated. With his CAM leanings and knowledge already in place, the logic of his narrative is undeniable.

Tom was the most forthcoming of all the participants about the existential crises and very real confrontation with mortality that he went through around the time of his diagnosis with cancer. He moves in this excerpt from a specific narrative (of his father's death) to a more abstract consideration, which was not uncommon when confronting issues came up in the talk (for all the men, not just Tom).

> Tom: I mean, my father contracted it in about, um, he died aged 82. And he died in the same year I was [diagnosed]. I nursed him through his dying stage. ... And it was a very good experience for both of us, but he had never considered the issue of dying. Death was something that happened to everybody, but it wasn't something that he'd come to terms with. Something that, really, this is going to occur. You'd have to let go some time. So, it was a big deal for him, in that sense. (pauses, almost changes subject and then goes back to it)
>
> And death is a big deal. (quite loudly and abruptly). I mean, being diagnosed with cancer is facing one's mortality. Any kind of cancer. I mean, it's an issue. And the ego pops up, all the conditioned mind and says, hey, you know, this is not good. So probably if we're talking about conditioned consciousness, it's underpinned by fear. And the greatest fear of loss is actually death.

Tom's Buddhist philosophy and practice have helped him come to terms with mortality to the extent that has. He and Frank were the only participants that explicitly acknowledged that a cancer diagnosis carries a lot of fear, that is to a large extent existential fear of death itself. Tom's talk about death displays a reflexive awareness and a present-time existential grappling with the fear of death. Tom's account of the time around his diagnosis is of course a reconstruction, 12 years down the track from the initial sudden shock. He is now actively inquiring into 'conditioned consciousness' and its fear of loss.

To summarise, diagnosis of prostate cancer for these men was a tremendous shock. Those of us, like myself, who have not received a diagnosis of a life-threatening or life-changing illness, may struggle to comprehend the fear and grief that accompanies such news. Men downplay their shock and anxiety at receiving a diagnosis of prostate cancer. Diagnosis is a time when men may not even acknowledge to themselves how shocked they are. Sensitive awareness from healers and physicians is very important at this time. Support groups have a big role to play in assisting newly-diagnosed men, by supplying information which will be actively sought. Emotional support may be only reluctantly received, depending on whether it allows the enactment of masculinities that emphasise stoicism and self-reliance or not. (Wenger, 2013) .

Another area where men and the medical system itself tend to enact traditional masculinities is around the biopsy process. In Australia and New Zealand, there has been a reluctance to offer men anaesthesia for the transurethral biopsy, which is only now beginning to change as patient's perspectives are being researched. Men tend to be stoic about enduring the pain and specialists have often failed to realise the pain that some patients were feeling (Chapple, Ziebland, Brewster, & McPherson, 2007; Oliffe, 2009). Geoff was not the only participant in this research to voice surprise and dismay about the pain of biopsy, although it did not play a pivotal role in any of their stories as it did in his.

For men that are already inclined to CAM because of their values or prior learning, a diagnosis of cancer can be the spur to an extensive exploration of CAM practices and healing methods. The process of investigating and using CAM often begins at diagnosis or assumes much greater importance to the man as he faces the biographical disruption of cancer. Men may already have CAM-related concepts of why they have cancer, and if they are listened to with respect, will be more likely to discuss them.

Treatment for prostate cancer, both CAM and biomedical.

What do the stories of men with prostate cancer say about the way they construct their treatment decisions and include CAM principles, narratives and practices? These are the questions this section of the analysis will be looking at. These men were concerned by the side-effects of medical treatment before having it and they were coping with changes in their embodiment after treatment. (Kelly, 2009). The tension between the desire for the individualised and holistic treatment offered by CAM and the greater certainty promised by the scientism and better resourcing of biomedical treatments had to be negotiated (Broom & Tovey, 2007). They had to weigh the possible sequelae of biomedical treatment with the long-term risk of metastasis, a fraught matter in prostate cancer. They used CAM to ameliorate side-effects of biomedical treatment and also for its own beneficial effects. Information on CAM came from books, trusted others and the internet. Relationships with both biomedical physicians and CAM healers were key to how the men constructed their experiences. Relationships and practices within both camps had mixed results in the men's narratives.

Tom went on to explore CAM therapies and in the process, received diagnoses from CAM healers that addressed his health in a holistic way, as the background to his cancer and his healing.

> Tom: ... I started a serious sort of look at different options for natural therapy.... I spoke to a lady in Orewa who does homeopathic diagnosis and healing, and she has a method using a computer, of determining the immune system function levels, how it's functioning. So I went to her and she was showing that my immune system was down quite a bit.

Tom then went to a practitioner of BodyTalk therapy. In BodyTalk, a practitioner receives feedback by testing muscles for strength or weakness when the client/patient is exposed to various substances or makes certain statements, the stimuli varying from client to client. In this excerpt he discusses BodyTalk and how the healing he received by using it was confirmed again by the homeopath's measure of what he calls his immune function. It is another example of the use of biomedical terminology ('immune system') in a way that many doctors would have difficulty accepting, yet one that is empowering for the cancer sufferer and allows him hope and a sense of agency.

> Tom: It's a very intuitive approach. So she'll actually talk to the body, and I think, [obtain] a kinaesthetic response. And so she went through the whole process of BodyTalk and ah, healing on my body over the period of a couple of hours. And then I went back to the first lady, the homeopathic lady, to determine my levels of immune function. And my immune function had gone right up, it had improved like, it was better than normal. After that healing, that session.

The website of the Body Talk Association makes these claims:

> "The BodyTalk System gives the practitioner protocols to be able to assess all the systems of the body for dysfunction. The practitioner can consult your 'innate intelligence' via neurological bio-feedback (muscle testing) to discover where these dysfunctions lie. As every individual is so unique only their innate intelligence knows what is to be balanced and in what order, therefore using The BodyTalk System, we ask each individual body what needs balancing, so you get the treatment you need rather than the treatment the practitioner thinks you need."(New Zealand Body Talk Association, 2007)

The narrative that Body Talk offers, of being able to communicate *directly* with the body of the client/patient without their cognitive involvement is an attractive one, one that has a likeness in the biomedical world of imaging using MRI or other forms of medical imaging. One difference is that an MRI scanner 'sees' into the physical body and creates an image that can only be interpreted by experts. The intelligence and agency resides in the experts, the body of the cancer patient is itself only 'dumb' matter. Body Talk offers a narrative of communicating directly with the 'innate intelligence' of the client's body to diagnose the holistic 'imbalance' and no interpretation is required. The 're-balancing' treatment is carried out at the same time as the diagnostic muscle-testing. The unique nature of the client and their bodily intelligence is emphasised and this is possibly a big part of the appeal of systems like BodyTalk, as well as their non-invasive nature.

Tom adopted practices from a number of different sources, including a 35 minute daily session of stretching and energy work. He also practices a Buddhist standing meditation.

> Tom: ...the way that I prefer to meditate is really standing meditation, now. And um, I think the body energies, all the energies, flow much more freely in a standing meditation. And I think, living in the West we don't have the advantage of a flexible Eastern kind of body without a lot of, for most of us, a lot of yogic work to gain that flexibility. And diet and so on. But the standing meditation is challenging in a different way and I have found that by focusing on a distant tree or whatever, so the eyes are open, one can slip into a very clear state quite easily. And there's also one theory, that if you do it for a few hundred hours over time, that healing will occur for most disease states because you're in total alignment and the energies are flowing so freely.

Tom's interest in energy healing is consistent with his attribution of energy imbalances as a cause of his cancer. He is quite clear on the effects of his diet on his wellbeing, including but not limited to his PSA measure. He produces a strong position of agency in his talk of managing his health in this way. He cites the effect that diet has on his PSA as proof that his approach works and positions himself as an expert in his own health.

> Tom; Once or twice my PSA has started to go up, and the doctor's said to me, we need to get you to go and see the oncologist. And I said, no, give me a month, I'll see what I can do. During one of those periods I went on a strictly vegan diet and um, the PSA came down and it normalised again. So that showed me clearly how diet can affect this condition.

He took the same natural self-administered therapy route when doctor wanted him to go on blood pressure medication. He recorded his own blood pressure two or three times a day and showed it to the doctor. He says the doctor 'sort of pushed it aside, he sort of went 'oh yeah' and pushed it aside. Next please'. Tom affirms his own agency and the power of CAM self-treatment through these stories, which diminish the power of the biomedical narrative and provide powerful support for his position as a CAM expert.

Tom demonstrates a very integrated approach to managing his health in practice, which includes elements of both biomedical 'watchful waiting' and a strong multi-armed CAM approach on all the levels of body, mind, energy and spirit. In this way, he is able to utilise both the greater certainty of biomedical diagnosis and the holistic individualised healing offered by CAM. Previous research around CAM as a path to wellbeing has usually focused on women (Sointu, 2006). This current research demonstrates that men can be similarly intent on achieving wellbeing. Tom is now prioritising his holistic well-being and sees the PSA measure as only one dimension of that.

Roger initially used complementary medicine to treat the side-effects of radiation therapy. His narrative of seeing a homeopath during radiation therapy demonstrates that a treatment with no strong bio-medical evidence base can be highly valued by the recipient.

> Roger: ... I went to see a homeopath. A Dutch lady, who is a classical homeopath. So, umm, classical homeopaths, I don't know whether you know much about them, they tend to treat the whole body, so that the whole body heals itself, rather than specifically targeting any one disease or ailment.... I told her what I was doing and she said "I can give you something that might help that". She didn't say what it was, she often didn't tell me what they were, you know. Ahhh, I went through the rest of the radiation treatment and I didn't have any side-effects at all.... The nurses, every time I went for a treatment, the nurses would say, how things are going, you got any problems, I said no. They sort of did a bit of a double-take, sometimes, and think "Oh well, you should've had [side-effects] by now, but you're not, so that's good"

While doing this research, every time homeopathy was mentioned, I found I was quite sceptical about this form of treatment and I was surprised how many of my participants had used it and claimed to have positive results (or mixed positive and negative results, in one case). However, one of the strengths of a narrative approach is that it allows detailed analysis of participants' stories without assigning a truth value to the material they are providing (Atkinson, 2009; Riessman, 1990), so I set aside my own views of homeopathy. I realised my own beliefs around CAM might seem contradictory or just plain wrong to some within bio-medical circles *and* to some in CAM camps. My participants displayed the same freedom to be contradictory and inconsistent. Research into the basis of decisions to use CAM (and which kinds of CAM to) use has found that men with cancer value scientific evidence as a guide to decision-making, but they value personally meaningful and trusted sources far more. That includes personal stories of cure or help, a long history of use e.g. acupuncture, a plausible mechanism of effect and trust in a particular provider or therapy (Evans et al., 2007). Homeopathy, for Roger, has enough of those elements present to recommend its use.

Roger explained that the homeopath did a detailed first analysis of his entire life, which lasted over an hour.

> Roger:... as I say, I had the homeopath-type thing and we used to go down fairly philosophical lines when I was talking to her about things. You spend, sort of, an hour for the first visit, and she goes over your whole lifestyle, what you think, what you like, what you don't like, all that sort of thing. Do you have chocolate, do you like salt, what you eat, and that sort of thing, and that's part of their diagnosis and what they want to give you, to get your body to heal itself."

This kind of consultation, where the focus is on the patient as the causal agent in the healing process rather than the intervention, is typical in a CAM setting and has many benefits, as Norwegian research bears out. The patient/client has more control of the agenda, can discuss their theories of cancer genesis more readily, and feel more cared for and listened to by CAM practitioners. They come away feeling more empowered by the CAM practitioner and retain more hope (Steinsbekk & Launso, 2005). The participants in this research were mainly women. However, men may have a different, more functional approach to the time such a holistic consultation process requires. Roger humorously grumbled about the time his integrated doctor takes to do a consultation.

> Roger: It can be rather annoying going to see [the integrated medical practitioner] at times because he's so bloody behind time. I could sit there for three quarters of an hour past my appointment time before he actually comes and sees me, you know. 'Cause you know, he does go into all the details with whoever he's seeing. Why he keeps to a timetable or tries to keep to a timetable, I'm buggered if I know, quite frankly.

The integrated doctor was the first person Roger would go to for information about new research into CAM treatments. He says he has read about recent research into Vitamin D as an effective anti-cancer agent and he will ask his integrated physician about it.

> Roger: I think next time I see [the integrated medical practitioner] I might go for a blood test, I might get my Vitamin D levels taken. 'Cause he's getting a lot of this stuff from the States, a website in the states. A herbal place. He gets his vitamin D from there, apparently it's just something you put under your tongue.

He clearly has a high degree of trust in this physician/healer, who has conventional medical training as well as extensive studies in alternative medicine, from an Anthroposophical perspective.

Geoff says he decided early on to 'find an alternative' after his biopsy experience. Unusually among the participants, he did not find his way to CAM use through the agency of a woman friend or partner, but through his own research process.

> Geoff: So when I went back and seen the head urologist, forget her name now, it was a lady. She said the best thing is, we need get your prostate out as quickly as we can. But I'd actually been surfing the internet every available moment I got, and I actually got on to a book on the internet called Don't Touch My Prostate and there was some interesting things in that. One of the interesting things in it was a blood test there that that they said you can get. 'Cause they said if, ah, you've been told that you've got prostate cancer, you know, what do you do? They said the first thing you should do is take this blood test, it's actually a diabetes-type blood test. It's

> something to do with protein floating in your blood. Some people have it loosely in their blood and some people have it tight in their blood. If you tested that your protein is tight in your blood, the chances of your cancer spreading is pretty minimal.

The authors of the e-book were basing their claims on research from Harvard Medical School that found a strong predictive link between certain insulin growth factors and advanced-stage prostate cancer developing, in their study of 530 case-controlled prostate cancer cases (Chan et al., 2002). Geoff got the test done by a doctor and interpreted the results as showing he was in the 'safe zone' and should delay surgery. He also sought second opinions from a well-known surgeon and an oncologist, both of whom advised him to have radiation therapy. He decided to go ahead with it, on the strength of an MRI scan that showed a large tumour pressing on his bladder. But he also continued his internet-based explorations, with mixed results.

> Geoff; ... In the meantime, I also found on the net a company called Nutrition 2000 and I actually tried their products. It was actually a trans-dermal cream which you rubbed on twice a day. And that actually brought my PSA down to 4 within about three months. But it actually wrecked my liver. So that's something you gotta be careful of if you try these alternative treatments, you should be having liver tests quite regularly. And I actually developed really bad hepatitis. And it took me nearly a year to get over it. And they reckon it was probably through that trans-dermal cream. I took that product in to the specialist, the liver specialist, and she said there's nothing written on the product that would actually harm your liver, but there must be something in there that's not written on the product.

Geoff also says "To be fair, it did say, they did tell you not to take any alcohol, which I was taking. I didn't think I was taking much, a small bottle of beer a night, maybe a glass of wine, but they did say no alcohol". He seemed fairly uncritical of the product and the company that sold him it, and that may be because he did not follow their recommendation. He was sick for a year with hepatitis, and in the meantime his PSA went up to 47, alarmingly high. He started hormone treatment in preparation for radiotherapy as soon as he was able. But a key chance meeting was to change his thinking about radiation therapy.

> Geoff; So I was into the second month [of the hormone therapy] and I had a month to go before I was starting to do the radiation and, ah, I met a guy who'd had radiation two years previously and it was an absolute horror story. *Absolute* horror story....He said you don't see the same person twice, you know, they're giving you the treatment, so sometimes you get an experienced one, some of them are maybe not that experienced. He developed, he developed an ulcer in the prostate and he said you've got no idea of the pain. He was on morphine for over a year. He showed me, he still had morphine tablets there. He said the pain was unbearable. And he made enquiries why you would get an ulcer on your prostate and he said he was told it was probably because the radiation was left in the one place for too long. So I thought, that could happen to me too. It may not, I mean (doesn't complete the sentence). So I cancelled the radiation.

Given that Geoff had already had one experience of painful treatment and insensitive handling of his distress, it seems he was primed to pay close attention to the 'horror story' his acquaintance shared. He cancelled the radiation treatment. He did further internet research and located a German clinic where he received a course of transurethral hyperthermia.

> Geoff: Well, there's actually a prostate site on the net called Ben Ong prostate information, he's got all sorts of prostate information. So I actually wrote to him asking him what he advised me. 'Cause they've been doing this heat treatment for 25 years....It's only done in Germany. They put a tube in your urethra and they put a heat treatment and heat it (the prostate) up to 48 degrees for two hours. And that kills the cancer. And you go back a couple of days later and he repeats the dose.... then they give you all sorts of other therapies to stimulate your immune system, so it slows down the cancer. The cancer will come back again. But it should last eight years, they said."

> The other therapies included intravenous doses of Vitamin B12, Vitamin C and selenium, and extra oxygenation of the blood. Mistletoe extracts were also used intravenously. This aspect of the treatment is definitely 'alternative'.

When I interviewed Geoff the second time, he had received bad news the previous month, as his PSA had shot up from 2.5 to 42 in six weeks. However, a course of tablets prescribed by the German doctor had brought it down again in two weeks to 18, with no side-effects. Geoff is planning to go back for another round of treatment in Germany, one that will be more intensive and hotter. If that doesn't succeed, there is another CAM therapy he will try, one that costs $150 a week from a clinic in Auckland. He says he knows a man who eliminated his prostate cancer in a year using it alone. He recounted yet another story of what he considered to be off-hand and disrespectful treatment by an oncologist.

In all, Geoff tells a narrative of disappointment with the New Zealand conventional cancer-treatment system, and doing a lot of concentrated research on-line to find alternatives. His attempts to discuss his research and experiences often met with a response that he found quite unsatisfactory, which made him ever more determined to follow his alternative directions and seek CAM cures for his cancer. Geoff's story demonstrates the complexities of the factors that promote CAM use and the decision-making processes involved. If he had been able to discuss his CAM use with an empathetic and informed physician or healer, possibly his hepatitis could have been picked up earlier, or avoided altogether, with implications for the course of his cancer. This is an important implication of this narrative, as Geoff was not the only participant to use CAM products and practices without the knowledge of his physician. His reliance on a trusted personal contact for information is fairly typical of men with cancer who use CAM.

This story also demonstrates how internet research can represent a double-edged sword by making CAM information available only a click away. Because CAM is not resourced by the state in New Zealand and quality CAM practitioners charge similar rates to other professionals, lower-income users (like Geoff) may be inclined to use the internet exclusively as their source of information. They then lack the guidance of experienced and credentialed CAM practitioners. Commonly, physicians do not ask about CAM use and many patients do not tell them (Shelley, Sussman, Williams, Segal, & Crabtree, 2009). This raises the risk that unintended drug interactions and side-effects may occur. If cancer sufferers do not trust their physicians to adopt a non-judgemental attitude to their CAM use, they will not disclose it (Evans et al., 2007). Men, especially, are unlikely to risk the compromise to their status, given that they are very concerned with protection of their masculine identities. The medical professions tend to discuss the risk of covert CAM use guided by internet sources (or popular CAM authors) as being very problematic, which indeed it can be (Ernst & Schmidt, 2002). Geoff has used the internet to access information on the treatment of his choice, a less invasive approach than those offered to him by the medical system in New Zealand. It remains to be seen whether it is the sole treatment he will use to control his cancer.

Peter was the most recently diagnosed of all the men, and our first interview took place a month before his surgery. At the time I spoke with him, he was taking supplements and delaying surgery (which being well-off and able to afford private treatment, he could have had immediately after diagnosis as the urologist had advised). He wanted to see if the CAM methods would lower his PSA significantly. He was seeing an energy healer at his wife's request. His narrative reveals some of the complexities of the decision-making process around CAM and bio-medical treatment. The medical advice he received was quite straight-forward; to have surgery sooner rather than later. However Peter delayed it in order to give his CAM treatment the best possible chance to work.

> Peter:'... [The surgeon] said you don't have to panic, it's not that sort of cancer, it doesn't race away. So I said, what if we left it until after Christmas? He said, I think that's a bit long, I'd feel really bad if it's spread outside in that period. So, he said, get it done before Christmas, I'd be comfortable.

The focus of Peter's talk here is on the surgeon's comfort, not his own, which illustrates the power of the biomedical narrative to garner alignment and Peter's willingness to align with it. Yet Peter is also strongly aligned with his wife, to the point where his own scientific convictions have wavered.

> So we put the operation off until the end of November. And [my wife] then had me taking, I'm taking some raspberry powder that has shown some benefit for prostate cancer sufferers. I'm taking some lypospheric Vitamin C and every other potion in creation, but that's ok, all good stuff (Peter doesn't sound especially convinced of the efficacy of the 'potions'). Also, she asked me to go and see the guy over at [a large retreat centre]. And that's [healer's name], whose an energy healer. He's some sort of energy healer. So, umm, I went to see him and it was fascinating. 'Cause I'm an engineer, a scientist-type person, for me, mostly this stuff I've gone, not sure. But I've, since I've really known [my wife], I've learned to suspend my disbelief 'cause I've actually seen some things which have made me go, well, there might be something here. And that was the key, cause I think that if I hadn't known [my wife] I would have said get me in [to surgery] the next day, I don't want to know about any of this other stuff.

The role of significant others of cancer patients in making decisions about CAM was explored in Canadian research, that identified four distinct styles of involvement, each one involving more input from the partners. They noted that the participants in their research who had prostate cancer perceived their partners' offers of help and research and the decisions they took as a result, as basically collaborative (Ȍhlen, Balneaves, Bottorff, & Brazier, 2006). Possibly this reflects the gendered role that women play as the guardians and 'doers' of health.

I n any case, Peter trusted his wife's recommendation to see the energy healer, who is also a herbalist.

> So I went to see [the energy healer] and ah, he laid me on a couch, on a thing there, and looked at me and he said, oh yeah, I can see this and that. He just sort of stood there and shook his hands slightly and gave me a couple of drops of some sort of homeopathic remedy, and ah said yes, there's definitely cancer there and then he proceeded to tell me, it's trying to spread into your lungs. Thank you, I feel good about that (Peter is being

> ironic to indicate his dismay). But he can fix that. That was the second-worst day after going to see the [urologist] because in the medical profession nobody told me that there might be anything else, ok? He said, look, I pick these things up ten years before the doctors will see them. And he said, I can fix it....So he told me to stop drinking coffee and stop drinking alcohol, give my liver a rest, he said there's some problem in your liver, he said there's some sort of virus and it's never really gone away, I'll get rid of it now. And he gives me this stuff and after about ten minutes he said, I can see it's starting to work now... And that's all he's done. I felt, and there's no basis for this, but I just felt that he, that there was something going on there, I have no idea what he was doing, I did not feel that he was, that he was conning me. It may be nothing's going on, but he was, I think he believes he's doing what he's doing. So, that's ok (Peter has a way of indicating his mixed feelings and reserved judgement with his voice tone that is not conveyed by the text alone. His approach seems to be one of 'wait and see if it works')

The healer has diagnosed and treated Peter in this one session. Peter says he was "willing to suspend his disbelief", despite his distress at being told the cancer is 'trying' to spread to his lungs (an interesting personification). However, he is hardly embracing the non-physical energy and spiritual paradigms that the healer is working within. It is clear that for Peter the biomedical paradigm is pre-eminent and he is willing to 'suspend disbelief' around CAM treatments that his wife has more faith in then he has. He went on to have surgery and was pleased with the outcome, although he also stated that urinary incontinence was a problem for him in his work situation. Fortunately, it was temporary. He also has difficulty achieving an erection but claims that it is not a problem for himself and his wife.

These stories of treatment demonstrate that while many men with prostate cancer may be using both CAM and biomedicine, there can be huge differences in the meaning that an individual attaches to his CAM use. It may be his primary mode of managing his cancer, and part of a holistic commitment to his wellbeing that incorporates yet transcends biomedical 'watchful waiting' or 'active surveillance'. This approach treats conventional means as a fall-back position should CAM methods eventually not be enough. It presumes a certain level of income and education, as well as commitment, that may make it uncommon. The commitment to using CAM for cancer treatment may also be strengthened by a strong religious or philosophical commitment to holism that may pre-date diagnosis with cancer.

As the active monitoring of his PSA gives a man feedback, he can monitor the effectiveness of his approach and build trust in it. A man may be able to delay surgery and radiotherapy by many years by using effective CAM treatments. Which treatments are effective definitely needs more high-quality longitudinal research that is both methodologically sound and well-versed in the paradigms of CAM systems e.g. Traditional Chinese Medicine or homeopathy (Wardle & Seely, 2012).

In an ideal situation, a man would be in the care of an integrated physician, with both CAM and biomedical expertise. However, Bishop and Yardley (2004) advance the intriguing possibility that part of the attraction for some cancer patients in CAM may precisely be the 'alternative' construction of it. That 'alternative' construction may be attractive in that it provides the possibility of the construction of agency and expertise for the self that may be lacking in the biomedical 'patient' role. They do not elaborate on the idea or link it to their data. However, the narratives of Tom and Frank seem to support this idea. These two men both recounted detailed and vivid stories of challenging authorities and winning the point and asserting their own expertise. Perhaps there will always be an 'alternative' medicine for this reason.

CAM use may be part of a reaction to unsympathetic care and depersonalised treatment by health professionals, as in the narrative of Geoff. This kind of CAM use is probably not preceded by a strong commitment to holism, as it is reactive in character. Such a commitment might develop over time, or it may not. It is based more in a distrust of biomedical treatments and fear about the side-effects of treatment, than in a trust of CAM holism. Geoff was willing to use biomedical markers to evaluate the progress of his CAM treatments. However, such reactive CAM use may run the risk of leaving a man isolated and reliant on dubious sources of information, such as the internet.

If a man has an unusual narrative of cancer causation such as heavy metal toxicity or spiritual forces at work, then his treatment choices may reflect this (by 'unusual' I refer to narratives unusual in Western culture or current biomedical science). Because his CAM practitioners may be more open and less disputing of his views, he may be more inclined to trust them than his physicians, as with Stewart. This would possibly also be true of Maori or immigrant men, whose cultural understandings of causation and treatment may not accord with Western narratives.

CAM use may be engaged cautiously by some men, possibly at the suggestion of family members. It is quite likely that for these men, biomedical understandings remain firmly in place. It is likely that for these men, a materialist paradigm of treatment will be the best fit. They may be looking for a stronger evidence base before proceeding with a treatment. Evidence-based complementary treatments will appeal to these men and they would be a good fit with an integrated cancer service that works within this paradigm or healers that tend more toward evidence-based CAM cancer support.

Because prostate cancer is a chronic illness, a man may have time to experiment with a wide range of therapies and do ample research over the years of watchful waiting/active surveillance. Some of the men in this study who had invested considerable personal and financial resources into CAM therapies had done so for over a decade. CAM use can also change in its meaning and even importance to a man. More longitudinal qualitative and quantitative research is needed to identify which treatments would be most useful and *when* in the cancer trajectory. Possibly when active biomedical treatment ends, as with Peter, CAM use provides a way to remain active and committed to one's healing rather than passively waiting and watching one's PSA. The relationship with both physicians and CAM persons is very important in ensuring that men make treatment decisions with full information, to the limits of what it is possible to know or predict in advance.

Discussion

Broom and Tovey (2007) suggest that cancer patients who use CAMs manage a complex dialectic between what they term 'individuation' and 'depersonalisation'. By 'individuation' they refer to the personalized nature of CAM, where a subjective epistemology is supported over a positivist epistemology. Depersonalisation is implicit in an evidence-based biomedical approach and is always in its own dialectical tension with clinical practice. Clinical practice has an individual at its heart and an evidence base has statistics at its heart. Evidence-based medicine always has an element of depersonalisation, while CAM tries to deliver individualised care.

Broom and Tovey also argue that the stage of cancer and whether medical statistics are favourable or not has considerable influence on how that dialectical struggle is weighted. Because none of my participants were in advanced stages of disease, I can't comment on the latter finding. But this research does support, and I believe extend Broom and Tovey's findings on dialectical tensions in the use of CAM by cancer patients.

In my analysis, men with prostate cancer manage a complex dialectical relationship between the fear of death and the desire for life in all its richness and quality. They must live with this dialectic tension, sometimes for many years. Concepts of holism, vitalism and natural healing that promise greater *quality* of life, as well as the possibility of avoiding medical sequelae that compromise it, are balanced against the security of statistical evidence bases that imply that a certain treatment may provide the possibility of a longer *quantity* of life.

The goal (and implicit motivation) of biomedical treatment for cancer is remission. The goal (and implicit motivation) of CAM is less clear, but it can be described as well-being, balance and healing. These goals do not seem incompatible. The apparent incompatibilities between CAM and biomedicine spring from a fundamental difference in epistemology and the men had to negotiate that as best they could. They negotiate this with the diligent application of both critical appraisal and faith.

Critical appraisal and faith.

The six case narratives in this research displayed many different versions of critical appraisal, both of biomedical and CAM practices and narratives. The main criticisms men raised of CAM were doubts about effectiveness, the cost, and the difficulty of integrating CAM practices and principles into their lives. The main criticisms men had of biomedical practices were poor relationships with providers, and the undesirable sequelae of treatment. At the same time, some men had a high degree of faith in either CAM or biomedicine. CAM narratives of the genesis of cancer, and narratives of the healing of cancer in the context of body/mind/emotional/ energy/spirit as a holistic process, were very attractive to some of the men in this research. They considered that they had experienced benefits in quality of life (and possibly quantity) from CAM use. Other men had a high degree of faith in biomedical practices and providers and in the narrative of medical science as the way to extend their life-spans (although trust in the quality of life after treatment was more tentative).

This can be represented as a four-fold window, with CAM and biomedicine as two reasonably distinct domains, although the boundaries are far more permeable than commonly believed. The ontological and epistemological boundaries are heavily policed by biomedicine (Keshet, 2009) but can be observed to shift like river beds over time. The dimension of trust vs criticality is more obviously permeable and indistinct, more like a continuum. Both trust and criticality are constructed in each man's narrative, influenced by what I term 'sensitising events', philosophical leanings, relationships with others and both fears and hopes. The primary fear is the fear of death and the primary hope is the hope of healing. It might be expected that men with high faith in either CAM or biomedicine would have a high degree of criticality towards the other side of the binary, but the narrative analysis demonstrates that the situation is far more complex. For example, as in Peter's narrative, a man may have a strong affiliative desire to engage with CAM for the sake of others even if his ontological leaning is basically to biomedicine. Also, the dialectic develops in a time-bound process and can be expected to move over time, if the disease progresses, if wellbeing becomes more important once the initial shock and fear abate, or for a multitude of different reasons (as demonstrated in the analysis).

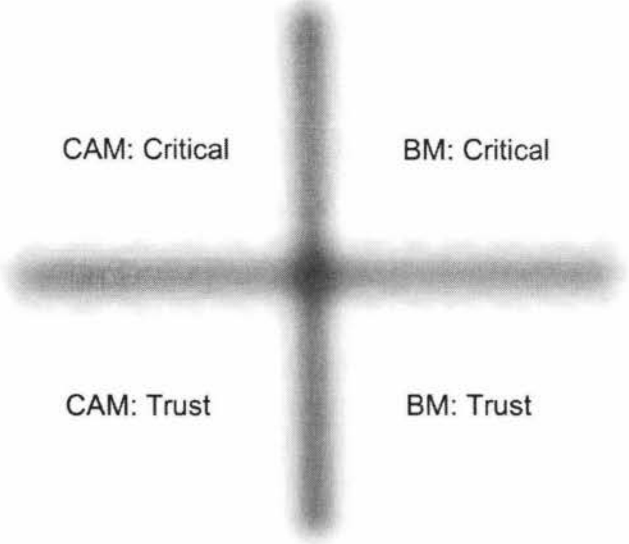

Fig. 1. Critical appraisal and faith

The men in this research were very active agents in the process of constructing their own unique pathways to remission/healing. In every case, the benefits and drawbacks of both approaches were discussed in a very considered way. The idea that CAM practitioners prey on vulnerable and uninformed people desperate for a cure for their cancer was not borne out by my research.

'Taking responsibility' vs 'Being a good patient'

Another dialectical tension that the narratives in this research draw out is the tension between two cultural narratives that cancer sufferers must carefully negotiate to maintain valued 'moral' positions. Cancer sufferers must be especially careful, because of the fear and anxiety that surrounds cancer, not just for the person themselves, but for the others in their lives. The first one is the 'patient' position that is culturally privileged within the biomedical context; one where the specialist is in effect the agent. The 'patient' relies on their expertise and trusts *them* to make decisions regarding care. The specialist then assumes responsibility for those decisions being correct. This is generally constructed as a morally 'good' position for a cancer patient to take. However, it directly contradicts the other morally privileged position in our individualistic culture; that of the self-responsible agent who makes their own decisions and is the 'captain of their own ship' (Bishop & Yardley, 2004). This is also a gendered position, as active agency is constructed as an intrinsic aspect of culturally privileged (therefore hegemonic) masculinity.

Bishop and Yardley use discourse analysis to demonstrate that 'complementary' medicine use offered some of their participants a way to 'have their cake and eat it too' (to use another narrative cultural resource). 'Having the cake' is deferring to medical expertise in the 'appropriate' that a cancer patient should, while 'eating it' is having the agency afforded by making one's own treatment decisions. My own research supports and extends their analysis. My participants, in their narratives, used vivid stories to justify their use of CAM e.g. Geoff with the story of his biopsy, with all its drama and reported speech that makes it extremely convincing. They also use narratives to justify their use of biomedicine; Tom makes it clear that he had radiation therapy for the sake of 'others', so avoiding total responsibility for submitting to a treatment that left him impotent. This is an alternative way, also, of reading the stories of the deaths or illnesses of those close to participants from cancer. They make a strong and emotional argument for the use of CAM, thereby justifying its use. I do not wish to imply anything Machiavellian in the participants' motives, as undoubtedly they have experienced real suffering and grief. I am simply pointing to the uses of narrative in justifying subject positions that are complex and morally ambiguous.

Alternative narratives

One finding in this research is that in most of the narratives there was a 'sensitising event', a critical event that predisposed a man to using CAM. For Frank, his mother's illness with a benign tumour stood out in his account, as did the advice of a Cancer Society nurse and reading key books. For Tom, his father's death from prostate cancer was a key event in his narrative. For Geoff, meeting the man who experienced huge pain after radiation therapy was a turning point, as was his own biopsy experience. Reading certain key books sensitised Roger to the CAM narrative of well-being and healing. Stewart likewise found a convincing explanation for his health dilemmas in a book on mercury toxicity, a causal explanation which later predisposed him to seeking CAM treatment for his prostate cancer.

This is quite a different view of decision-making than that proposed by some authors in the field. Some researchers who subscribe to the Health Beliefs Model of medical decision-making have adapted it to CAM decision-making (Caspi, Koithan, & Criddle, 2004). They ask whether there are 'alternative patients' rather than 'alternative medicine' and propose models for those 'alternative' patients' decision-making processes. This research instead proposes 'alternative narratives' for men with cancer. 'Alternative narratives' grow out of a developmental process of increasing knowledge, conviction and commitment. They a may hinge on events that occurred in time years, even decades, before the diagnosis with prostate cancer, or relationships that are also well-established for many years. Beliefs about health and CAM certainly may be part of the process, and the representations proposed by Caspi and colleagues (and other authors using similar social cognition health models) may have some useful aspects. However, they tend to suggest that decision-making around CAM is a mainly cognitive process and also that it is a static one that only happens once. I propose that often the sensitising events come before CAM even begins to be investigated, or they make CAM possibilities salient and a matter of urgency. Also, I propose that the meanings that cancer sufferers ascribe to key events in their narratives are more important to the choices they make around CAM use, than beliefs about CAM per se. The narratives demonstrate that the process of decision-making around CAM can take all kinds of forms as the holistic healing process goes on.

Chapter Four: A Story about a Search for Healing

The following narrative is a 'suggestive' wording of the way that the process might unfold for a man with prostate cancer, based on the data in this research (and influenced by the work of researchers cited elsewhere). The analysis were presented in sections, which imposed a sense of order on the narratives, but also 'chopped them up' in ways that do not represent the sometimes chaotic reality of living, especially around autobiographical interruptions like illness. I wanted to re-establish a narrative 'flow' that is truer to the life-world of men where the stages are not so neatly demarcated. Also, this approach provides a way make suggestions as to how the use of CAMs might unfold over time, at different stages of the illness and (hopefully) the healing process. Of course, not all men with prostate cancer, with or without the use of CAMs, will conform to this outline. The contexts in each and every life will be interpreted in a different narrative, which is uniquely situated in its telling and so will change over time and in different social contexts. This story is a broad suggestion only.

None of my participants were in an advanced or metastatic stage of the disease, or dying, so I have not written about those alternative pathways through prostate cancer.

A Search for Healing

You go in for a routine check, or because you feel a little unwell. You have a nagging cough perhaps, or a 'flu. You don't make a habit of going to doctors, they whip out the prescription pad a bit too fast, in your view. And you just don't have time to worry too much about your health. But this time, perhaps because your wife or sister pushes you into it, you go. So when your doctor suggests a routine test for some enzyme, you agree. Hearing that some PSA number is higher than it should be is the first cold inkling of something not quite right. A digital rectal examination confirms that there may be a problem. But these tests can be misleading, your doctor says, so you go to the biopsy worried but not frightened. The biopsy is embarrassing and uncomfortable, even painful, and you hope you never have to go through that again.

Diagnosis is a big surprise, a huge shock. You didn't know you had cancer, because you had no symptoms. Now you are 'sick', even though you feel the same as you did before. Was the 'flu or cough that took you to the doctor actually your immune system breaking down, not just a flu or cough? You review your life and you wonder why me, why now? Was it the stress of that business failing, that marriage that was unsupportive? Was it the diet you ate when you had no choice? Was it the toxic sprays you had to use, because your farm needed them or your job depended on it? Have you always suspected you had heavy metal poisoning? Or maybe it doesn't occur to you to wonder 'why me, why now? Maybe that comes later as you read and explore the stories you hear, the things that healers and other cancer sufferers/survivors have to say.

You may have had people close to you die of cancer. The grief of seeing how the conventional treatment added very little to their quality of life and gave them only a questionable increase in the quantity of life is still with you. Or you believe a person close to you got sick because they ate badly or had too much stress in their lives. You resolve not to do as they did, or let yourself be 'done to' as they were. You feel they were disempowered, maybe that they didn't have to sicken or die as they did.

You now have to make decisions based on what an specialist tells you and trust that person or those people implicitly with your life and potency, your very self -image as man. They may be very trusted by you or only trusted to a point. The way they treat you as a person, not a cancer, will have much bearing on this. Are they respectful? Do they listen to you? If not, you may lose trust in them to some degree. Biomedicine and its answers to cancer may seem less convincing to you. You may not trust the biomedical narrative so much anymore. So naturally you go looking for information, and gain a sense of agency and control by doing so.

You are afraid of death, for real. So you decide to 'fix the problem'. Or you may be more inclined to wait and watch and monitor your cancer, because it is small and your Gleason score is low. It is still a risk though, so you arm yourself with as much information as you can. You find the information you can trust, the convincing stories, the research that gives you hope, the internet sites that put you in touch with the world

of alternative treatments and give you concrete steps you can take to your own healing. You feel you are taking responsibility for your own health, where being a 'patient' leaves you disempowered.
You are afraid of the changes to your embodiment that may result from conventional treatment. Impotency, urinary incontinence. It all sounds like the exact opposite of the valued male body, 'silent' in its completeness. You are afraid of being 'less of a man'. You hear about stories that seem to hold out hope of a remission without surgery, radiotherapy or 'castration' through hormone treatment'. You meet people who have stories to tell you about their positive or negative experiences of biomedical treatment. You meet people who tell you about their experience of benefits from CAM. Maybe you join a support group, but probably not, because you don't want to lean on other men. You are trying to stay strong. You rely heavily on your partner, if you are lucky enough to be in a long-term relationship, for their unconditional love, help and support. You research treatments on the internet and you buy or borrow books that supply hope and information. These books sometimes rely on riveting and inspiring narratives of remission from cancer, even cancer deemed 'incurable'.

You may feel you owe it to the people around you to have some form of biomedical treatment, and you don't want to take the risk of the cancer progressing. So you decide you will give it a go. You might use homeopathy or acupuncture to help with the side-effects of treatment.

You decide to use a CAM modality, or maybe more than one. Maybe you already have a holistic philosophy of sickening and healing, which is about to be put to the test. Are you prepared for the financial cost of it? It won't come cheap. And the changes to your lifestyle may be considerable.
You choose a CAM therapy based on the recommendations of others and whether the therapy seems to be based on plausible principles. You may check what scientific evidence exists for that therapy, if you can find any. The scientific evidence base is not your main concern, but you take it into account. You go to a healer, a naturopath, or a doctor practising integrated medicine. He or she listens intently to your whole story, gives you all the time you need. He or she seems to want to treat you as an individual, with real attention to your whole life, not just the cancer. He or she has convincing

diagnostic techniques and tells you what you already suspected; that stress, bad diet, toxins and energy blockages have contributed to your illness with cancer. He or she has treatments for these problems that you find more or less convincing. He or she may prescribe supplements and treatments that you find more or less convincing. You may tell your oncologist or urologist about the CAM treatment, but if you suspect they will be biased and make you feel stupid you probably won't tell them. They probably won't ask you.

You continue to see the healer and take the supplements, either in hope of healing completely, to treat the unwelcome side-effects you are experiencing from conventional treatment, or to slow down the cancer. By slowing down the cancer, you hope to delay more treatment from the physicians, or even delay starting it in the first place. You reason that since advances in surgical techniques, radiotherapy and other methods are happening all the time, delaying treatment could be advantageous. You watch your PSA.

You notice how the changes to your diet and getting more exercise have all contributed to an increased sense of well-being. You may become more interested in meditation, or more committed to a meditation practice you already had. You experiment with dietary approaches such as eliminating wheat and sugar, or weekly fasting, and you watch you PSA carefully. You may notice that it varies with the dietary changes and other measures you take.

You may undertake travel to international clinics that offer programs that have reputations for bringing about cancer remission for some people. Once again, the scientific evidence base (or absence of it) is just one of the things you weigh when you make your decision. Convincing testimonials from people you know can be very influential. Having a trusting relationship with a physician you respect will help you when you make decisions (and having a close trusting relationship with a credentialed and clinically well-experienced CAM practitioner will also be beneficial). You may continue to have periodic hormone treatment to slow the disease, or you may be more intent on achieving holistic healing through CAM means. You may try do both. You find the combination of the modalities in an idiosyncratic way that reflects the stage of your disease, the relationships you have with the professionals and lay-people in your life and your underlying philosophy of health and sickness. Your financial means will have a bearing on your choices.

You may wish to help other men with prostate cancer, whether by participating in a support group, or practicing some form of CAM yourself, or participating in research. You may find that helping other men helps you regain your sense of wellbeing. You find your sense of self has changed. Your sense of embodiment has changed. Your relationship to your sexuality has changed. Your understanding of medicine has changed. You may become quite sceptical of the presumptions of biomedical science to have the sole claim to social support. There have been losses along the way and you have weathered them. Your partner (if you have one) has weathered the changes with you.

At some point you may consider yourself a 'cancer survivor.' You may invest yourself in healing practices that allow you emotional catharsis and relaxation, such as in-depth music appreciation, art or spiritual practice.

Chapter Five: Future Directions

Some of the limitations of this research.

One limitation of this research was the limited diversity of the participants. There were no gay/bisexual/transgender men and no Maori men. The man were all Pakeha, all urban dwellers within greater Auckland and all worked, either part-time or full-time. They were all over 60. The experiences/stories of younger working men with families were not discussed. This would be a group with distinct needs of their own.

There were also no men in palliative care, for whom biomedicine could offer no more hope of remission. Research into the use of CAM in the palliative care setting is reasonably well-represented, but not specifically around men with cancer or men with prostate cancer (this last may be because by the time a man is dying, the cancer has metastasized to other sites). In any case, it was not a part of this research, so a group of men with prostate cancer who use CAM was not represented. The needs and narratives of this group may be quite distinct from the ones I studied, or they may may have much in common.

Another limitation is that in focusing on men with prostate cancer, I excluded men with other forms of cancer. Wenger and Oliffe (2013), two of the most prolific authors in men's health, call for men's health research to move beyond prostate cancer. The majority of research in men's health has focused on men with this illness. This has been very valuable research but it does not address the needs, narratives and experiences of the 78% of men with cancer who do not have it in this site. Also, it tends to contract the focus of research on to sexuality and related areas, which runs the risk of reinforcing an essentialised notion of men's health. This can sometimes produce a version of men's health research which is only about biological sexual difference, rather than cultural and historical factors in gender construction. I have tried for the most part to avoid this, and my subject matter was happily not focused entirely on the biological aspects of prostate cancer. However, because so much previous research in the field does revolve around the psychosocial effects of impotence and the other sequelae of treatment, it was difficult at times to avoid letting this focus dominate. However, my participants did not emphasise it in their narratives and therefore it was only one thread to the overall narrative of this research work.

In retrospect, a section on survivorship would have been useful too, because four of the participants are 'survivors' of prostate cancer, it being over five years since their diagnoses. British thematic research found that people who had lived five years since the diagnosis of breast, colorectal and prostate cancers (that often have relatively good prognoses now) did not feel the use of the term 'survivor' suited their experience (Khan, Harrison, Rose, Ward, & Evans, 2012). A section on 'living for a long time past a diagnosis of prostate cancer' would have been a useful addition to the research, because it would be a way to draw out the experience of living for a *long* time with a 'silent' non-symptomatic cancer that is mainly monitored through PSA testing, as a discrete phase that is separate from active treatment. As it is, some of the narrative material addresses those issues anyway, but it is included in the treatment section. Since CAM treatments and practices are on-going in the lives of all the men no matter how long ago they were diagnosed, there is also some justification for keeping the section the way it is.

Future research possibilities.

This project sits in an intersection of research interests: complementary and alternative medicine, 'integrated medicine', cancer, chronic illness, men's health, masculinities, to name but a few. Any one of these has room for more good qualitative research and descriptive statistics. I could also pick out fascinating issues specific to the narrative cases themselves. These could include the place of contested causal narratives and contested CAM-based diagnoses (such as 'mercury sensitivity') in cancer illness narratives. Another example is the place of music in the wellbeing of cancer survivors. The last topic was a huge part of one participant's narrative, but didn't make it into the final draft. This is a research project I personally would like to do because of my interest in the arts and their place in healing and wellbeing. An interpretive phenomenological analysis of cancer survivors' experiences of healing or wellbeing through music would be one possibility.

Other potential research directions are looking into the use of CAM in another population with a chronic illness e.g. people suffering from arthritis or autoimmune disorders. There is very little qualitative research in these fields. As far as cancer is concerned, there is a lot of room for more qualitative research into CAM use, by children with cancer and their families, for example, or people with non-gendered cancers. Breast cancer patients have contributed to by far the most research on CAM use, especially in thematic analysis. There could be value in critical qualitative approaches such as discourse analysis or narrative analysis with this community, in areas related to well-being and being a 'survivor' using CAM. So there is no lack of possibilities!

However, for the sake of simplicity and brevity I have limited the next section to a more in-depth discussion of future research possibilities that have to do with both prostate cancer and CAM, and address obvious gaps in the present research. They are: research into the experience of gay men, the partners of men with cancer, and Maori men with prostate cancer.

Gay men and prostate cancer and CAM

As mentioned in the limitations section, this project could have been enriched by the inclusion of participants that self-identified as gay, bisexual, transsexual or queer. These men were certainly not excluded, but none came forward to participate. This is an under-researched area in prostate cancer research. Ascencio, Blank, Descartes and Crawford (2009) point to the heteronormative assumptions that are made by researchers that men with prostate cancer will be in long-term, heterosexual, monogamous relationships, if they are sexually active. They touch on the intersection of prostate cancer with the masculinities of gay men of colour and older gay men. However, their research was not conducted with actual prostate cancer sufferers or their partners, and it did not look into the role that complementary and alternative medicine might play in the prostate cancer experience of gay/transsexual/bisexual men. I suggest that there is qualitative research waiting to be done around the experiences/narratives of gay/bisexual/transsexual men who use CAM and the experiences/narratives of their partners. One reason that CAM may be important to these men is that masculinities within the gay world may be as predicated (if not more predicated) on sexual potency as a means of enactment of those masculinities (Asencio et al., 2009). So gay men may have a strong motivation to choose conservative treatment; conservative treatment being one of the motivations in my research for

CAM use. Research that recognises that CAM use may have different meanings for gay men in the different phases of their illness will represent the complexities better and allow a nuanced understanding by both biomedical and CAM professionals. A larger project investigating the experiences/narratives of gay men with prostate cancer could include CAM use.

The partners of heterosexual men with prostate cancer, and CAM

The female partners of heterosexual men with prostate cancer are another under-researched group. Arrington (2005) notes in his narrative research into men attending prostate cancer support groups, that heterosexual men tend to perpetuate very gendered stereotypes of women as their selfless caregivers and supports. Wives are represented as having no needs of their own, sexually or otherwise. The men tended to represent their wives as coping 'wonderfully' and to take their wives' silence around their own needs as confirmation that they were quite content with the supportive role they played. The wives and partners were represented in the men's narratives as being their primary sources of emotional support and practical help and other family members generally had a much smaller role, as sources of information. The wives of the men in his study did a lot of health-related research, including research into diet and vitamins, although alternative and complementary medicine was not discussed as such.

I find it quite likely that often the women in heterosexual couples will be the first to investigate specific CAM treatments when their husbands are diagnosed with cancer. Then they will adapt their own diet to suit their husbands' new diet. They may also already be using and practicing CAM before their husbands are diagnosed. The diagnosis may be the life-event that prompts a man to investigate further into his wife's CAM interests (as in one narrative in my research).

There are several areas where more research is needed. The first is research into the way that CAM narratives support these gendered assumptions of the selfless role of female partners in relationships affected by prostate cancer. It could be part of a larger study into the social construction of feminine caring in marriages where one partner has prostate cancer.

Other research could investigate the place CAM may have in supporting women to cope with the demands of having a partner with prostate cancer. Female partners may use CAM for themselves to cope with the exhaustion that this caregiver role can entail, especially as they may have many other work and familial obligations. It may be that the narrative of traditional caring femininity is being challenged and modified by the 'wellbeing' narrative of CAM, which places the care of the self front and centre. Use of some CAM modalities may be allowing (possibly mainly middle-class) women to care for *themselves* in addition to caring for others (Sointu, 2011). This may be a part of the prostate cancer experience for female partners. It is quite possible that CAM may play a positive role in a marriage affected by cancer. It may also be something that that brings partners together, as they find or develop a shared way to seek well-being and healing and a sense of agency. Research into these possibilities that is sensitive to the shifting meanings of CAM use over the course of living with prostate cancer, for both men and women, will be a valuable addition to the literature. It would possibly have applications in counselling and support groups. I feel this would be also valuable in broadening the discussion of prostate cancer and relationships away from sexuality-related issues, while not excluding them.

Maori men and traditional, complementary and alternative medicine use in the context of prostate cancer.

Cancer statistics reveal an appallingly large gap in morbidity and mortality between Maori and non-Maori in Aotearoa New Zealand. Maori men are more likely to be diagnosed with prostate cancer at an advanced stage and therefore need more radical interventions. Remission will be harder to achieve for these men and they are more likely to die. A Maori man, once diagnosed, is 60% more likely to die than a non-Maori man with the same age and stage of cancer. The Maori death rate from prostate cancer is proportionally 59% higher than the Maori death rate (Prostate Cancer Taskforce, 2012). A large community screening of men with no prior cancer history revealed that Maori men, Pacific Island men, and European New Zealanders had very similar rates of elevated PSA, therefore a similar risk of developing the disease (Gray, Borman, Crampton, Weinstein, & Nacey, 2005). So a greater risk of getting cancer does not explain the disparities. Maori men are offered screening at less than half the rate that non-Maori men are offered it, and are a massive 354% more likely to be diagnosed late (Robson, Purdie, & Cormack, 2010). These serious inequities are a troubling context of research into prostate cancer and Maori men.

So what could research into complementary and alternative medicine add to the picture of Maori men's prostate health? The first thing that must be acknowledged is that traditional Maori medicine (rongoa Maori) is likely to be used by a considerable number of Maori men in a way that is either 'complementary' or 'alternative' to Western biomedicine. What proportion of Maori men use rongoa Maori is a subject needing more quantitative research.

Mark and Lyons (2010) discuss the holistic nature of traditional Maori medicine in their qualitative research. According to them, Maori healing is 'inevitably holistic'. They have developed a model, Te Whetu ('The Star') based on their research with Maori Spiritual healers, which represents five interconnected aspects that all influence and are influenced by each other. Body (tinana), mind (hinengaro), spirit (wiarua), geneology (whakapapa) and land (whenua) are the points of the star. The star is a unity. All these aspects may be involved in diagnosis and healing of an illness. Illness may well be conceived and sensed by a healer as a malaise with its genesis in previous generations of a Maori whanau. Equally it may have its genesis in wrong relationship to a piece of land. These causal narratives have nothing to do with Western conceptions of individuality and what is personal and what collective in those conceptions. They certainly have nothing to do with Western conceptions of separation between body and mind, or body and spirit. One of the healers quoted by them comments that the concept of a separate 'mind' is itself an imposition on Maori culture by colonialism, and she engages with the mind of a person seeking her help only as a bridge to Spiritual healing of the whole being (Mark & Lyons, 2010).

Even if some Non-Maori complementary healers seek to align with biomedical narratives and seek confirmation from nutritional science, biochemistry, psychoneuroimmunology and so on, such concerns are likely to be somewhat peripheral for most Maori healers. They are working within a holistic paradigm that is even more inclusive than that of most CAM healers. Biomedical paradigms are likely to be quite discrete from Maori paradigms. Narrative research would be a very appropriate methodology (as would interpretative phenomenology, such as Mark and Lyons have used) to research the stories of Maori men using traditional Maori medicine for prostate cancer, if it was conducted in a culturally appropriate and sensitive way. If this research could help scientists and clinicians understand the Maori world-view better, as men with cancer reveal it, then it could contribute to understanding the reasons for the inequities in Maori cancer statistics and, more importantly, changing them. If Maori men were able to access culturally appropriate integrated cancer care earlier, then survival rates might go up. More than that, the Crown has an obligation under the Treaty of Waitangi to provide such care. Research is needed, that may help Western biomedical staff and organisations better understand how they can provide appropriate services for Maori men. The marginalising of Maori traditional medicine, even subtly and covertly, will not contribute to equity. The usual objections that are aired to the use of CAM, such as interaction effects and the possibility of CAM use leading to late presentation, would be utterly inappropriate and damaging. I see the place of rongoa Maori in cancer care as an exciting area for Maori researchers to investigate in the future. Resourcing of such research should be a matter of priority, given the current inequities.

Implications of this research

Seeking information will be a key concern for men when they are diagnosed. Some of the key books that New Zealand men are quite likely to read for information are 'You Can Conquer Cancer, by Ian Gawler (2013) and 'How to Fight Prostate Cancer and Win' by Ron Gellatley (2000). Both these authors are Australian and have charismatic narratives of healing their own cancer and achieving well-being beyond their previous levels. Gawler in particular has been a prolific author. The Gawler Foundation, the organisation he founded, has many links on their website to research articles into the benefits of nutrition, supplements and meditation for treating health conditions, including cancer (The Gawler Foundation Inc, 2014). . If physicians are aware of the key internet sites that men may be going to for information, they will be able to discuss the information on them with men. The second author Gellatley has many flaws, from an academic perspective anyway, but he represents a role-model for men with prostate cancer. If physicians are aware of what complementary and alternative approaches these authors recommend, they will be better placed to discuss CAM with their patients. This understanding would be most useful if it included a working knowledge of the principles treatments are based on (in terms of body, mind, energy or spirit-based paradigms), what substances are used and what research support and controversies exist around specific treatments.

Diagnosis is a time when men may not even acknowledge to themselves how shocked they are. This is a time when sensitive care and psychosocial skills are very important. Some men may already have CAM-related concepts of why they have cancer that is at odds with accepted biomedical views of disease aetiology. If they feel that they will be 'committed' for having them (in the words of one participant), they are unlikely to share them.

Newly diagnosed men could possibly benefit from counselling to help them with making treatment decisions. Diagnosis is a time of great upheaval and fear. The threat of a shortened lifespan will probably outweigh the threat of reduced quality of life, at least in the short term. Men may feel impelled to 'fix up' the problem, rather than consider active surveillance, even if they are suitable for it from a clinical perspective. Counselling, MBSR, and designing a comprehensive program of dietary modification, exercise and supplementation, in consultation with a natural healing cancer support specialist may help men cope with the anxiety long enough to make a considered response to their cancer dilemma. If they are not suitable for active surveillance from a clinical perspective, then MBSR, counselling, and the other CAM lifestyle interventions will assist men in negotiating their dilemmas as they make treatment decisions. Given that men had 'stress' as a common explanation for developing prostate cancer, treatments aimed at 'stress reduction' should be well-received by them.

Research supports meditation as an effective tool for reducing the psychological challenges of cancer treatment and illness, such as fear, fatigue, depression and poor sleep (Ledesma & Kumano, 2009). The religious/spiritual dimension of cancer care is receiving more research attention (Aldwin, Park, Jeong, & Nath, 2014; Lepherd, 2014) and the links between meditation, mindfulness practice and increased well-being in cancer sufferers are becoming well-established (Matchim, Armer, & Stewart, 2011; Ott, Norris, & Bauer-Wu, 2006). Mindfulness-Based Stress Reduction (MBSR) is a structured group program with a strong research base behind it that prostate cancer sufferers may find psychologically and physiologically beneficial (Grossman, Niemann, Schmidt, & Walach, 2004). Their partners and wives are also likely to benefit from it. Referrals that include them it will maximise healing and wellbeing for both the man and his partner.

Longer consultations and more sensitive listening to men's concerns, fears and specific contexts will engender more trust in the medical profession. Survey-based descriptive research into New Zealand physicians attitudes to CAM revealed a low rate of knowledge of CAM, low estimates of the number of their patients using CAM by the physicians, and a low rate of asking patients about their CAM use (Bocock, Reeder, Perez, & Trevena, 2011). If physicians are to learn about their patients' use of CAM, they will need to educate themselves or have more CAM content in their training. Then when cancer sufferers are referred to them, they will have a working knowledge of what men may be looking into and be able to address concerns around interaction effects (theirs or the patients). Listening to men and what concerns they have around the psychosocial implications of treatment will also enable medical staff to make referrals to support groups, counselling or specialist psycho-oncology programmes in a timely manner.

Integration of CAM and orthodox medicine: the way forward.

An integrated model of care delivery where professionals offering these and other CAM services work alongside biomedical oncology staff is the holy grail of many CAM professionals, who see it as both possible and desirable for patient welfare (Hsiao et al., 2012). However, in practice there is usually little integration between the care offered by CAM professionals and biomedical staff and institutions. The only 'integration' in that case is initiated by the patients themselves, with potentially harmful or non-effective results, as well as possibly quite effective ones.

Integrated medicine is a new and developing area of medical research and practice, driven by many of the factors already discussed: wide-spread CAM use by patients (often without discussion with health care professionals) and increased demand by patients for a holistic psychosocial approach. My participants achieved their own forms of 'integration' by necessity. They lacked the benefit of a team of practitioners with a holistic understanding of their very individual bio-psycho-social-spiritual contexts.

I, for one, support such an integrated approach. A successful integrated approach would ideally involve co-ordinated treatment plans that involved both CAM and orthodox medical providers working as a team (Bell, Caspi, Schwartz, & et al., 2002).

A common barrier to integration is the perception (and reality) that CAM paradigms and practitioners are not treated as equals, but are subordinates in the delivery of care (Shuval & Mizrachi, 2004). This will not be resolved quickly, but there are ways forward. Boon and her colleagues (2004) have developed a continuum of seven different models of health care provision, that range from not integrated at all ('parallel') to fully integrated, based around integrated philosophy, structures, processes and outcomes. They comment that in an emergency situation e.g. an acute myocardial infarction, a patient will need rapid assessment and treatment and the non-integrated model will be most workable. However, for patients suffering from chronic illnesses the most integrated model would be appropriate. In this fullest vision of integration, CAM and orthodox medical professionals would work together across disciplines in a non-hierarchical way that would provide seamless holistic care. This vision of full integration is probably rarely, if ever, achieved in practice, because of the complexities of structure, the need for consensus, the complex and diverse outcomes, and the philosophical challenges to the biomedical paradigm (Boon et al., 2004). However, this is the vision of healthcare that I advocate for men with prostate cancer, based on my research. Men with a chronic, rather than acute (but nonetheless potentially life-threatening) illness will be best served in an integrated environment. This research demonstrates that men with prostate cancer take a very active role in creating their own treatments across the 'paradigm gap'. This suggests that in an integrated setting they would be active in defining their own desired outcomes and very motivated to achieve them.

The much-to-be desired integration between CAM and biomedicine is in its infancy in New Zealand and confined to a small number of conventionally-trained practitioners who have taken up the healing arts to varying degrees to augment the power of science. Given that reality, more education into CAM modalities for new doctors would be a beginning of the integration process. This salutogenic focus on the process of healing and the production of wellbeing, as well as the treatment and remission of disease, would enhance communication and understanding between CAM practitioners and biomedical practitioners. It would also promote better self-care for physicians themselves (Rakel, Guerrera, Bayles, Desai, & Ferrara, 2008). Both biomedical evidence-based research and qualitative research from health psychology, medical sociology and anthropology all have valuable insights to contribute and should be included in an integrative curriculum. The bigger question is; can CAM and biomedicine ever really integrate with the epistemological difference at their hearts? Or will CAM practices be integrated without the holistic and vitalistic worldview coming too?

Final Reflections

The process of doing this research has been a journey of discovery. It has deepened my own commitment to holistic healing of a biopsychosocial nature, in my own body, mind and society. It has introduced me to a growing literature around complementary and alternative medicine I never knew existed. Like most people perhaps, I knew something about some CAM therapies, but very little about the research literature which is rapidly expanding. I have gained an appreciation of the methodological and epistemological challenges in CAM-related research, both qualitative and quantitative. I have discovered that both the need and the opportunity for good qualitative research in the CAM area is huge.

The emerging possibility of an integrated healthcare was something I mentioned even in my ethics application. At that time I had only a vague idea that this project would contribute, at least in some small way, to that possibility becoming a little bit closer. However, this project has demonstrated to me that in practice, integration is already happening, at least at the level of the lives of some of those living with a potentially serious illness. This is a fertile and exciting area for further research.

I have also gained a lot of insight into the enormous amount of biomedical research effort currently going into prostate cancer; its clinical course, predicting that course, and of course, the treatment of it. If I could wish two things for the sake of men and their families, it would be that a similar amount of research effort was going into two other related areas; the prevention of prostate cancer (indeed all cancer) and research into the lifeworlds and narratives of those with cancer. Beyond research, the costs involved in delivering mainstream cancer care are enormous and will continue to rise, as will the suffering of those affected. If prevention of cancer (and other chronic illness) was as valued as its treatment, the health of our societies could be very different.

The vast biomedical resources that go into treating disease in the Western world may be one of the chief flowers of our civilisation, yet many are asking questions about the sustainability, as the population ages, of such a resource-heavy way of doing medicine. Is Western biomedicine an appropriate export to the developing world, where small-scale traditional medicine may in fact offer more contextually appropriate solutions to health dilemmas? (see Broom, Doron, & Tovey, 2012; Fan & Holliday, 2012). Is there a way of doing medicine that acknowledges other dimensions of the person than the merely physical? Has the biopsychosocial model proposed by Engel (1977) gained any traction in the intervening decades since he first proposed it? What are the places of complementary, alternative and traditional medicines in developing a truly 'whole' medicine for the future?

These questions are obviously way beyond the aims and capabilities of any research a Master's student can dream up for their year of being a novice social science researcher. But they are among the big questions that the critical health psychology and health sociology of the 21st century need to be engaged with.

The End

References

Aldwin, C. M., Park, C. L., Jeong, Y.-J., & Nath, R. (2014). Differing pathways between religiousness, spirituality, and health: A self-regulation perspective. *Psychology of Religion and Spirituality, 6*(1), 9-21.

Alldred, P. (2010). 'How come I fell pregnant?': Young mothers' narratives of conception. *International Journal of Adolescence and Youth, 16*(2), 139-156.

Arrington, M. (2003). "I don't want to be an artificial man": Narrative reconstruction of sexuality among prostate cancer survivors. *Sexuality and Culture, 7*(2), 30-58. doi: 10.1007/s12119-003-1011-9

Arrington, M. (2005). "She's right behind me all the way": an analysis of prostate cancer narratives and changes in family relationships. *Journal of Family Communication, 5*(2), 141-162.

Arrington, M. (2008). Prostate cancer and the social construction of masculine sexual identity. *International Journal of Men's Health, 7*(3), 299-306.

Arthur, K., Belliard, J., Hardin, S., Knecht, K., Chen, C.-S., & Montgomery, S. (2012). Practices, Attitudes, and Beliefs Associated With Complementary and Alternative Medicine (CAM) Use Among Cancer Patients. *Integrative cancer therapies, 11*(3), 232-242. doi: 10.1177/1534735411433832

Asencio, M., Blank, T., Descartes, L., & Crawford, A. (2009). The prospect of prostate cancer: A challenge for gay men's sexualities as they age. *Sexuality Research and Social Policy Journal of NSRC, 6*(4), 38-51. doi: 10.1525/srsp.2009.6.4.38

Atkinson, P. (2009). Illness narratives revisited: The failure of narrative reductionism. *Sociological Research Online, 14*(5), 16.

Baade, P., Youlden, D., Cramb, S., Dunn, J., & Gardiner, R. (2013). Epidemiology of prostate cancer in the Asia-Pacific region. *Prostate International, 1*(2), 47-58.

Baade, P., Youlden, D., & Krnjacki, L. (2009). International epidemiology of prostate cancer: Geographical distribution and secular trends. *Molecular Nutrition & Food Research, 53*(2), 171-184. doi: 10.1002/mnfr.200700511

Bangma, C., Bul, M., van der Kwast, T., Pickles, T., Korfage, I., Hoeks, C., . . . Schröder, F. (2013). Active surveillance for low-risk prostate cancer. *Critical Reviews in Oncology/Hematology, 85*(3), 295-302. doi: 10.1016/j.critrevonc.2012.07.005

Bangma, C., Roemeling, S., & Schröder, F. (2007). Overdiagnosis and overtreatment of early detected prostate cancer. *World Journal of Urology, 25*(1), 3-9. doi: 10.1007/s00345-007-0145-z

Baronzio, G., Gramaglia, A., & Fiorentini, G. (2009). Review. Current role and future perspectives of hyperthermia for prostate cancer treatment. *In Vivo (Athens, Greece), 23*(1), 143-146.

Bell, I. R., Caspi, O., Schwartz, G. R., & et al. (2002). Integrative medicine and systemic outcomes research: Issues in the emergence of a new model for primary health care. *Archives of Internal Medicine, 162*(2), 133-140. doi: 10.1001/archinte.162.2.133

Bill-Axelson, A., Holmberg, L., Ruutu, M., Garmo, H., Stark, J. R., Busch, C., . . . Johansson, J.-E. (2011). Radical prostatectomy versus watchful waiting in early prostate cancer. *The New England Journal Of Medicine, 364*(18), 1708-1717. doi: 10.1056/NEJMoa1011967

Bishop, F. L., Rea, A., Lewith, H., Chan, Y. K., Saville, J., Prescott, P., . . . Lewith, G. T. (2011). Complementary medicine use by men with prostate cancer: a systematic review of prevalence studies. *Prostate Cancer And Prostatic Diseases, 14*(1), 1-13. doi: 10.1038/pcan.2010.38

Bishop, F. L., & Yardley, L. (2004). Constructing agency in treatment decisions: negotiating responsibility in cancer. *Health, 8*(4), 465-482. doi: 10.1177/1363459304045699

Bocock, C., Reeder, A. I., Perez, D., & Trevena, J. (2011). Beliefs of New Zealand doctors about integrative medicine for cancer treatment. *Integrative cancer therapies, 10*(3), 280-288. doi: 10.1177/1534735411403476

Boon, H., Brown, J. B., Gavin, A., & Westlake, K. (2003). Men with prostate cancer: making decisions about complementary/alternative medicine. *Medical Decision Making, 23*(6), 471-479.

Boon, H., Verhoef, M., O'Hara, D., & Findlay, B. (2004). From parallel practice to integrative health care: a conceptual framework. *BMC Health Services Research, 4*(1), 15.

Boon, H., Westlake, K., Stewart, M., Gray, R., Fleshner, N., Gavin, A., . . . Goel, V. (2003). Use of complementary/alternative medicine by men diagnosed with prostate cancer: prevalence and characteristics. *Urology, 62*(5), 849-853.

Broom, A., Doron, A., & Tovey, P. (2012). The inequalities of medical pluralism: Hierarchies of health, the politics of tradition and the economies of care in Indian oncology. In J. Adams, G. Andrews, J. Barnes, A. Broom & P. Magin (Eds.), *Traditonal, Complementary and Integrative Medicine*. Houndsmill, UK: Palgrave Macmillan.

Broom, A., & Tovey, P. (2007). The dialectical tension between individuation and depersonalization in cancer patients' mediation of complementary, alternative and biomedical cancer treatments. *Sociology, 41*(6), 1021-1039. doi: 10.1177/0038038507082313

Caspi, O., Koithan, M., & Criddle, M. W. (2004). Alternative medicine or "alternative" patients: A qualitative study of patient-oriented decision-making processes with respect to complementary and alternative medicine. *Medical Decision Making, 24*(1), 64-79. doi: 10.1177/0272989x03261567

Chan, J., Elkin, E., Silva, S., Broering, J., Latini, D., & Carroll, P. (2005). Total and specific complementary and alternative medicine use in a large cohort of men with prostate cancer. *Urology, 66*(6), 1223-1228. doi: http://dx.doi.org/10.1016/j.urology.2005.06.003

Chan, J., Stampfer, M., Ma, J., Gann, P., Gaziano, M., Pollak, M., & Giovannucci, E. (2002). Insulin-like growth factor-I (IGF-I) and IGF binding protein-3 as predictors of advanced-stage prostate cancer. *Journal of the National Cancer Institute, 94*(14), 1099-1106. doi: 10.1093/jnci/94.14.1099

Chapple, A. B., Ziebland, S., Brewster, S., & McPherson, A. (2007). Patients' perceptions of transrectal prostate biopsy: a qualitative study. *European Journal of Cancer Care, 16*(3), 215-221. doi: 10.1111/j.1365-2354.2006.00766.x

Chrystal, K., Allan, S. G., Forgeson, G., & Isaacs, R. (2003). The use of complementary/alternative medicine by cancer patients in a New Zealand regional cancer treatment centre. *New Zealand Medical Journal, 116*(1168).

Courtenay, W. H. (2000). Constructions of masculinity and their influence on men's well-being: a theory of gender and health. *Social Science & Medicine, 50*(10), 1385-1401. doi: http://dx.doi.org/10.1016/S0277-9536(99)00390-1

Doyle-Lindrud, S. (2007). Prostate cancer: A chronic illness. [Article]. *Clinical Journal of Oncology Nursing, 11*(6), 857-861. doi: 10.1188/07.cjon.857-861

Durie, M. (1994). *Whaiaora-Maori health development*. Auckland, NZ: Oxford University Press.

Eng, J., Ramsum, D., Verhoef, M., Guns, E., Davison, J., & Gallagher, R. (2003). A population-based survey of complementary and alternative medicine use in men recently diagnosed with prostate cancer. *Integrative cancer therapies, 2*(3), 212-216. doi: 10.1177/1534735403256207

Engel, G. (1977). The need for a new medical model: a challenge for biomedicine. *Science, 196*(4286), 129-136. doi: 10.1126/science.847460

Ernst, E., & Cassileth, B. (1998). The prevalence of complementary medicine in cancer: a systematic review. *Cancer, 83*, 777 - 782.

Ernst, E., & Schmidt, K. (2002). Alternative cancer cures via the internet? *Br J Cancer, 87*, 479 - 480.

Espinoza, Y. (2014). Sexual healing with Amazonian plant teachers: a heuristic inquiry of women's spiritual–erotic awakenings. *Sexual and Relationship Therapy, 29*(1), 109-120. doi: 10.1080/14681994.2013.861060

Evans, M., Shaw, A., Thompson, E., Falk, S., Turton, P., Thompson, T., & Sharp, D. (2007). Decisions to use complementary and alternative medicine (CAM) by male cancer patients: information-seeking roles and types of evidence used. *BMC Complementary and Alternative Medicine, 7*(1), 25.

Fan, R., & Holliday, I. (2012). Which medicine? Whose standard? Critical reflections on medical integration in China. In J. Adams, G. Andrews, J. Barnes, A. Broom & P. Magin (Eds.), *Traditional, Complementary and Integrative Medicine*. Houndsmill, UK: Palgrave Macmillan.

Fouladbakhsh, J., & Stommel, M. (2010). Gender, symptom experience, and use of complementary and alternative medicine practices among cancer survivors in the U.S. cancer population. *Oncology Nursing Forum, 37*(1), 7-15.

Garland, A. (2001). Reclaiming the rubbish: A study of projective mechanisms. [Article]. *Psychodynamic Counselling, 7*(2), 177-185. doi: 10.1080/13533330110040238

Gawler, I. (2013). *You can conquer cancer: A new way of living* (3rd revised edition ed.). Melbourne: Michelle Anderson Publishing.

Gellatley, R. (2000). *How to fight prostate cancer and win* (3rd ed.). Wetherill Park, N.S.W.: Cargel Press International.

Gray, M., Borman, B., Crampton, P., Weinstein, C., & Nacey, J. (2005). Elevated serum prostate-specific antigen levels and public health issues in three New zealnd ethnic groups: European, Maori and Pacific Islands men. *The New Zealand Medical Journal, 118*(1209), 1-15.

Grossman, P., Niemann, L., Schmidt, S., & Walach, H. (2004). Mindfulness-based stress reduction and health benefits: A meta-analysis. *Journal of Psychosomatic Research, 57*(1), 35-43. doi: http://dx.doi.org/10.1016/S0022-3999(03)00573-7

Grunfeld, E. A., Drudge-Coates, L., Rixon, L., Eaton, E., & Cooper, A. F. (2013). "The only way I know how to live is to work": A qualitative study of work following treatment for prostate cancer. *Health Psychology, 32*(1), 75-82. doi: 10.1037/a0030387

Heron-Speirs, H. A. (2013). *Understanding the cancer-related distress and coping of men from provincial New Zealand: 'Bullet-proof meets radical prostectomy'.* Doctor of Philosophy, Massey, Plamerston North.

Horneber, M., Bueschel, G., Dennert, G., Less, D., Ritter, E., & Zwahlen, M. (2012). How many cancer patients use complementary and alternative medicine: A systematic review and metaanalysis. *Integrative cancer therapies, 11*(3), 187-203. doi: 10.1177/1534735411423920

Hsiao, A.-F., Ryan, G., Hays, R., Coulter, I., Andersen, R., & Wenger, N. (2012). Variations in provider conceptions of integrative medicine. In J. Adams, G. Andrews, J. Barnes, A. Broom & P. Magin (Eds.), *Traditional, Complementary and Integrative Medicine; An International Reader*. Houndsmill: Palgrave Macmillan.

Jutel, A. G. (2011). *Putting a Name To It: Diagnosis in Contemporary Society*. Baltimore: The John Hopkins University Press.

Kelly, D. (2009). Changed men: The embodied impact of prostate cancer. *Qualitative Health Research, 19*(2), 151-163. doi: 10.1177/1049732308328067

Keshet, Y. (2009). The untenable boundaries of biomedical knowledge: epistemologies and rhetoric strategies in the debate over evaluating complementary and alternative medicine. *Health:, 13*(2), 131-155. doi: 10.1177/1363459308099681

Keshet, Y., & Simchai, D. (2014). The 'gender puzzle' of alternative medicine and holistic spirituality: A literature review. *Social Science & Medicine, 113*, 77-86. doi: 10.1016/j.socscimed.2014.05.001

Khan, N. F., Harrison, S., Rose, P. W., Ward, A., & Evans, J. (2012). Interpretation and acceptance of the term 'cancer survivor': a United Kingdom-based qualitative study. *European Journal of Cancer Care, 21*(2), 177-186. doi: 10.1111/j.1365-2354.2011.01277.x

Klotz, L., Zhang, L., Lam, A., Nam, R., Mamedov, A., & Loblaw, A. (2010). Clinical Results of Long-Term Follow-Up of a Large, Active Surveillance Cohort With Localized Prostate Cancer. *Journal of Clinical Oncology, 28*(1), 126-131. doi: 10.1200/jco.2009.24.2180

Ledesma, D., & Kumano, H. (2009). Mindfulness-based stress reduction and cancer: a meta-analysis. *Psycho-oncology, 18*(6), 571-579. doi: 10.1002/pon.1400

Lepherd, L. (2014). Spirituality in men with advanced prostate cancer: "It's a holistic thing . . . It's a package". *Journal of Holistic Nursing, 32*(2), 89.

Mark, G. T., & Lyons, A. C. (2010). Maori healers' views on wellbeing: the importance of mind, body, spirit, family and land. *Social Science & Medicine, 70*(11), 1756-1764. doi: 10.1016/j.socscimed.2010.02.001

Matchim, Y., Armer, J. M., & Stewart, B. R. (2011). Mindfulness-based stress reduction among breast cancer survivors: A literature review and discussion. *Oncology Nursing Forum, 38*(2), E61-71. doi: 10.1188/11.onf.e61-e71

Ministry of Health. (2013). Cancer: Selected Sites 2010, 2011, 2012. Retrieved 19/06/2014, 2014, from www.health.govt.nz/publications/cancer-selected-sites-2010-2011-2012

Morrison, H., Savitz, D., Semenciw, R., Hulka, B., Mao, Y., Morison, D., & Wigle, D. (1993). Farming and prostate cancer mortality. *American Journal Of Epidemiology, 137*(3), 270-280.

New Zealand Body Talk Association. (2007). Retrieved 12/07, 2014, from http://www.nzbodytalk.org.nz/bodytalk/index.html

Ning, A. (2013). How 'alternative' is CAM? Rethinking conventional dichotomies between biomedicine and complementary/alternative medicine. *Health, 17*(135), 135-158.

Őhlen, J., Balneaves, L., Bottorff, J., & Brazier, A. (2006). The influence of significant others in complementary and alternative medicine decisions by cancer patients. *Social Science & Medicine, 63*, 1625-1636.

Oliffe, J. (2005). Constructions of masculinity following prostatectomy-induced impotence. *Social Science & Medicine, 60*(10), 2249-2259. doi: http://dx.doi.org/10.1016/j.socscimed.2004.10.016

Oliffe, J. (2009). Positioning prostate cancer as the problematic third testicle. In A. Broom & P. Tovey (Eds.), *Men's Health: Body, Identity and Social Context*. Chichester, UK: John Wiley & Sons, Ltd.

Ott, M. J., Norris, R. L., & Bauer-Wu, S. M. (2006). Mindfulness meditation for oncology patients: A discussion and critical review. *Integrative Cancer Therapies, 5*(2), 98-108. doi: 10.1177/1534735406288083

Potts, A. (2000). "The Essence of the Hard On": Hegemonic Masculinity and the Cultural Construction of "Erectile Dysfunction". *Men and Masculinities, 3*(1), 85-103. doi: 10.1177/1097184x00003001004

Prostate Cancer Taskforce. (2012). *Diagnosis and management of prostate cancer in New Zealand men: Recommendations from the Prostate Cancer Taskforce*. Wellington. Retrieved from http://www.health.govt.nz/publication/diagnosis-and-management-prostate-cancer-new-zealand-men-recommendations-prostate-cancer-taskforce

Rakel, D. P., Guerrera, M. P., Bayles, B. P., Desai, G. J., & Ferrara, E. (2008). CAM education: promoting a salutogenic focus in health care. *Journal of Alternative & Complementary Medicine, 14*(1), 87-93. doi: 10.1089/acm.2007.0562

Riessman, C. K. (1990). Strategic uses of narrative in the presentation of self and illness: A research note. *Social Science & Medicine, 30*(11), 1195-1200. doi: http://dx.doi.org/10.1016/0277-9536(90)90259-U

Riessman, C. K. (1993). *Narrative Analysis*. Newbury Park: Sage Publications.

Riessman, C. K. (2008). *Narrative methods for the human sciences*. Los Angeles: Sage Publications.

Robson, B., Purdie, G., & Cormack, D. (2010). *Unequal Impact II: Maori and Non-Maori Cancer Statistics by Deprivation and Rurual-Urban Status*. Wellington: Ministry of Health.

Rosch, P. (2009). Bioelectromagnetic and subtle energy medicine. *Annals of the New York Academy of Sciences, 1172*(1), 297-311. doi: 10.1111/j.1749-6632.2009.04535.x

Sered, S., & Agigian, A. (2008). Holistic sickening: Breast cancer and the discursive worlds of complementary and alternative practitioners. *Sociology of Health & Illness, 30*(4), 616-631. doi: 10.1111/j.1467-9566.2007.01076.x

Shelley, B., Sussman, A., Williams, R., Segal, A., & Crabtree, B. (2009). 'They don't ask me so I don't tell them': Patient-clinician communication about traditional, complementary, and alternative medicine. *The Annals of Family Medicine, 7*(2), 139-147. doi: 10.1370/afm.947

Shuval, J., & Mizrachi, N. (2004). Changing Boundaries: Modes of coexistence of alternative and biomedicine. *Qualitative Health Research, 14*(5), 675-690. doi: 10.1177/1049732304263726

Singh, H., Maskarinec, G., & Shumay, D. (2006). Understanding the motivation for conventional and complementary/alternative medicine use among men with prostate cancer. *Integrative cancer therapies, 4*(2), 187 - 194.

Sointu, E. (2006). The search for wellbeing in alternative and complementary health practices. *Sociology of Health & Illness, 28*(3), 330-349. doi: 10.1111/j.1467-9566.2006.00495.x

Sointu, E. (2011). Detraditionalisation, gender and alternative and complementary medicines. *Sociology of Health & Illness, 33*(3), 356-371. doi: 10.1111/j.1467-9566.2010.01275.x

Steinsbekk, A., & Launso, L. (2005). Empowering the cancer patient or controlling the tumor? A qualitative study of how cancer patients experience consultations with complementary and alternative medicine practitioners and physicians, respectively. *Integrative Cancer Therapies, 4*(195), 195-200.

Stephens, C., & Breheny, M. (2012). Narrative analysis in psychological research: An integrated approach to interpreting stories. *Qualitative Research in Psychology, 10*(1), 14-27. doi: 10.1080/14780887.2011.586103

Tataryn, D. J. (2002). Paradigms of health and disease: a framework for classifying and understanding complementary and alternative medicine. *Journal of Alternative & Complementary Medicine, 8*(6), 877-892. doi: 10.1089/10755530260511874

The Gawler Foundation Inc. (2014). Research Links Page. Retrieved 06/07/2014, 2014, from gawler.org/research/

US National Institutes of Health. (2014). National Center for Complementary and Alternative Medicine website. Retrieved 17/06, 2014, from http://nccam.nih.gov/

Van Maele-Fabry, G., & Willems, J. L. (2003). Occupation related pesticide exposure and cancer of the prostate: a meta-analysis. *Occupational & Environmental Medicine, 60*(9), 634-642.

Wardle, J., & Adams, J. (2012). Indirect risks of complementary and alternative medicine. In J. Adams, G. Andrews, J. Barnes, A. Broom & P. Magin (Eds.), *Traditional, Complementary and Integrative Medicine: An International Reader*. Houndsmill, UK: Palgrave Macmillan.

Wardle, J., & Seely, D. (2012). The challenges of traditional, complementary and integrative medicine research: A practitioner perspective. In J. Adams, J. Barnes, A. Broom & P. Magin (Eds.), *Traditional, Complementary and Integrative Medicine: An International Reader*. Houndsmill UK: Palgrave Macmillan.

Weisz, G., & Knaapen, L. (2009). Diagnosing and treating premenstrual syndrome in five western nations. *Social Science & Medicine, 68*(8), 1498-1505. doi: 10.1016/j.socscimed.2009.01.036

Wenger, L. (2013). Moving through Illness with strong backs and soft fronts: A substantive theory of men's help-seeking during cancer. *Men and Masculinities, 16*(5), 517-539. doi: 10.1177/1097184x13501177

Wenger, L., & Oliffe, J. (2013). Moving beyond the prostate: Benefits in broadening the scope of research on men and cancer. *American Journal of Men's Health, 7*(2), 138-141. doi: 10.1177/1557988312463420

Wertz, F., Charmaz, K., McMullen, L., Josselson, R., Anderson, R., & McSpadden, E. (2011). *Five Ways of Doing Qualitative Analysis: Phenomenological Psychology, Grounded Theory, Discourse Analysis, Narrative Research, and Intuitive Inquiry*. New York, NY: Guilford Press.

White, M., & Verhoef, M. (2006). Cancer as part of the journey: The role of spirituality in the decision to decline conventional prostate cancer treatment and to use complementary and alternative medicine. *Integrative cancer therapies, 5*(2), 117-122.

Wieland, L. S., Manheimer, E., & Berman, B. M. (2011). Development and classification of an operational definition of complementary and alternative medicine for the Cochrane collaboration. *Alternative Therapies in Health & Medicine, 17*(2), 50-59.

Williams, G. (1984). The genesis of chronic illness: narrative re-construction. *Sociology of Health & Illness, 6*(2), 175.

World Cancer Research Fund and American Institute for Cancer Research. (2007). *Food, nutrition, physical activity and the prevention of cancer: a global perspective.* Washington DC: AICR.

Zhang, J., Dhakal, I. B., Zhao, Z., & Li, L. (2012). Trends in mortality from cancers of the breast, colon, prostate, esophagus, and stomach in East Asia: role of nutrition transition. *European Journal of Cancer Prevention, 21*(5), 480-489 410.1097/CEJ.1090b1013e328351c328732.

APPENDIX A: Long Information Sheet

Men, Cancer and Complementary Medicine

Information Sheet

Introduction

My name is Karen Tapper, and I am a Master's student in Health Psychology at Massey University. My supervisor is Professor Kerry Chamberlain. I am researching the stories of men with prostate cancer who receive treatment or help from complementary and alternative healers. I would like to invite you to participate in this study, if you have been diagnosed with prostate cancer. If you have had at least one appointment with a complementary or alternative practitioner and live in Auckland, I would like to invite you to participate in this study.

Who am I?

I am a mature-age student (late 40's) who lives in West Auckland with my husband and teenage daughter. I am not a cancer survivor or sufferer myself, but like everyone, I have friends and family affected by it. I have a background in the visual arts and my long-term goal is to work with cancer sufferers and others with arts-based therapies.

Why is this Research being done?

I am researching stories from men like yourself because they may help psychologists, doctors, complementary healers and others to better understand the meaning of complementary and alternative medicine use for men like you. There is more research into the use of complementary and alternative medicine (CAM) by women and men's health in general has been under-researched. This is also true of cancer research and men. I hope that this research may contribute to CAM practitioners and conventional medical systems working together better and being truly 'complementary'. I also would like to see that sufferers and survivors of prostate cancer benefit from this research.

What would participation in the study involve?

If you are willing to participate, then I will interview you twice for an hour or so each time, at a time convenient for you. The interviews will ideally take place in your home, but if this is not possible then another venue can be arranged. All material generated in the study will be kept securely and only accessed by myself or my supervisor. Names will not be linked to the data. Data will be disposed of after five years.

As a token of appreciation for your time, you will receive a $40 petrol voucher at the end of the second interview.

When the project is finished, you will be mailed a summary of the results. I may also publish the results as part of my thesis, and possibly the results could be included in scientific papers or presentations to conferences. You will not be identified by name or any personal details.

Your rights

You have no obligation to accept this invitation and if you do you have the right to

- withdraw from the study at any time. If you do choose to withdraw, I will remove your data from the study, unless two weeks have gone by since an interview. In that case, I would retain the data from that interview.
- decline to talk about any topic if you wish
- be confident that your name will not be used in regard to any information you provide
- ask for the recorder to be turned off at any time in the interview
- be sent a summary of the project findings when it is concluded.

Ethics Approval

This project has approval from the Massey University Human Ethics Committee: Northern. If you have any concerns about the conduct of this research, please contact Dr Ralph Bathurst, Chair, Massey University Human Ethics Committee: Northern, *telephone* 09 414 0800 x 43404, *email* humanethicsnorth@massey.ac.nz

Project Contacts

If you would like to participate, have any questions or would like further information please contact either myself or my supervisor.

Karen Tapper; 022 6918944, angelfish64@windowslive.com

Kerry Chamberlain ; K.Chamberlain@massey.ac.nz

Thank you for taking the time to consider participation in this study. Your generous gift of your time will be very much appreciated, should you decide to take further part.

Yours sincerely, Karen Tapper

APPENDIX B: Brief Information Sheet

Men, Cancer and Complementary Medicine

Hello, my name is Karen Tapper, and I am a Master's student at Massey University, in a health-related field of social science. My supervisor is Professor Kerry Chamberlain. I am researching the stories of men with prostate cancer who receive treatment or help from complementary and alternative healers. If you have been diagnosed with prostate cancer and have had at least one appointment with a complementary or alternative practitioner (and live in Auckland), I would like to invite you to participate in this study.

Who am I?

I am a mature-age student (late 40's) who lives in West Auckland with my husband and teenage daughter. I am not a cancer survivor or sufferer myself, but like everyone, I have friends and family affected by it. I have a background in the visual arts and my long-term goal is to work with cancer sufferers and others with arts-based therapies.

Why is this Research being done?

I am researching stories from men like yourself because they may help psychologists, doctors, complementary healers and others to better understand the meaning of complementary and alternative medicine use for men like you. There is more research into the use of complementary and alternative medicine (CAM) by women and men's health in general has been under-researched. This is also true of cancer research. I hope that this research may contribute to CAM practitioners and conventional medical systems working together better and being truly 'complementary'. I also would like to see that sufferers and survivors of prostate cancer benefit from this research.

If you are interested in finding out more about this project, or might consider participating, then please contact me on 022 6918944 or email me at angelfish64@windowslive.com

There are information packs at reception (also with my contact details). I look forward to hearing from you if participating in this research speaks to you.

APPENDIX C: Participant Consent Form

Men, Cancer and Complementary and Alternative Medicine

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 data placed in an official archive.

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

Signature: ______________________________ **Date:** ____________

Full Name - printed ______________________________