

**Interpersonal factors impacting the
decision to (continue to) use
Complementary and Alternative
Medicine (CAM)
in men with cancer –
a mixed-methods study**

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OVERVIEW OF CHAPTERS

Chapter One:

Reviews the literature on CAM in cancer care, gender differences in CAM uptake, and the influence of cancer patients' social network.

Chapter Two:

Provides the rationale for the mixed-methods methodology of the research.

Chapter Three:

Presents a published integrative review of the literature on family involvement in cancer patients' decision-making about CAM. **(Paper one)**

Chapter Four:

Reports about the prevalence and predictors of CAM use in Australian male cancer patients, and describes which CAMs have been discussed within the cancer patients' social network. **(Paper two)**

Chapter Five:

Demonstrates an analytical model of male cancer patients' reasons/motivations for CAM use, that can be divided into individual and social/interpersonal reasons. **(Paper three)**

Chapter Six:

Explores how, when, and why family members are involved in male cancer patients' uptake and maintenance of CAM, highlighting that CAM is practised as a shared and/or private activity. **(Paper four)**

Chapter Seven:

Illustrates how satisfied male CAM users practise and integrate CAM routines and CAM rituals in their everyday life, and use CAM with or without their family members over time. **(Paper five)**

Chapter Eight:

Summarizes the findings and implications of the current research.

SUMMARY

There has been an increase in the use of Complementary and Alternative Medicine (CAM) in cancer populations, with reported higher prevalence rates in women than in men. Men with a variety of cancers have been understudied in CAM research, as well as the contribution and involvement of their significant others, like close family members or/and close friends. The aim of this thesis was to investigate the use of CAM in men after a diagnosis of cancer. Specifically, the research aimed to explore how significant others impact on men's decisions to (continue to) use CAM, how they negotiate, talk, and practice CAM in everyday life, and how this affects their interpersonal relationship. A mixed methodological approach with two independent but related studies addressed the research aims: one quantitative study (survey) and one qualitative study (semi-structured interviews). The results are presented in *two published and three submitted papers* that contribute to our understanding of CAM use in men affected with cancer and how their CAM uptake is shaped by their social networks.

Paper one reports the results of an integrative review of the literature, and indicates that significant others of patients with cancer often act as information seekers, advocates, and/or role models in patients' decision-making about CAM. Despite the limited number of reviewed studies about familial involvement available, the results suggest that there may be important interpersonal consequences following patients' decision to use or not use CAM, that need to be further explored.

Paper two reports the results from the Study 1 survey involving 403 Australian men affected with cancer, a convenience sample of consecutive patients visiting two public and two private outpatient cancer clinics in Metropolitan Adelaide. The results indicate that the majority of male cancer patients (61.5%) have experience with CAM at some point during their cancer treatment, while more than half of the study sample (52.9%) were currently using CAM whilst receiving conventional medical treatment. It was also shown that family were the most frequent providers of information about CAM, and were significantly more often involved in patients' discussions about CAM use than medical professionals.

Papers three, four, and five report the results of Study 2, involving qualitative analysis of 43 semi-structured interviews with 26 men and 24 significant others, thereby exploring in-depth participants' perceptions and experiences of CAM. Paper three indicates that men with cancer use CAM for individual and social/interpersonal reasons, a unique category augmenting those previously discussed in the literature. Discourse analysis highlighted how the interpersonal dimension impact on men's

decisions to uptake CAM, and how the use of CAM functions to connect the male cancer patient with his social network. Paper four reports on the variations of significant others' involvement in men's CAM uptake and maintenance, and indicates that CAM is sometimes practised as a shared and/or private activity in everyday life. The shared practice of CAM was associated with interpersonal benefits, working to strengthen the bond between men and their significant others, but there were instances when men expressed a need to practice CAM as a private activity. It was found that CAM benefited both men and their significant others to reduce uncertainty and to regain control. Paper five reports on how regular and habitual male CAM users integrate CAM routines and CAM rituals in their everyday life. The discursive analysis illustrates how CAM routines provide male cancer patients with certainty and control. By contrast, CAM rituals function for cancer patients and their significant others as a means to create and maintain meaning, thereby working to counter fear and uncertainty consequent upon a diagnosis of cancer.

In summary, the results of these studies have shown that the majority of men with a variety of cancers use CAM in addition to conventional cancer care. Family members and/or close friends are a significant source of influence in men's CAM uptake and maintenance. The interactions about CAM between men and their significant others functioned to help them to connect with each other or strengthen their social bond, and constitute a beneficial effect of CAM use. In addition, it was found that regular CAM use helped men and their significant others to regain control and to reduce uncertainty. These findings may help healthcare professionals to better understand how interpersonal processes impact on men's CAM decisions. The results might also be translated into clinical practice, for example, in designing supportive cancer care programmes tailored specifically to men affected with cancer, with or without involvement of their significant others.

DECLARATION

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree. I give consent to this copy of my thesis when deposited in the University Library, being made available for loan and photocopying, subject to the provisions of the Copyright Act 1968. I acknowledge that copyright of published works contained within this thesis (as listed below) resides with the copyright holder(s) of those works.

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DEDICATIONS

TO MICHAEL, THE LOVE OF MY LIFE

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KEY TO ABBREVIATIONS

ABS	Australian Bureau of Statistics
ACC	Adelaide Cancer Centre
ACS	American Cancer Society
ARC	Adelaide Radiotherapy Centre
AIHW	The Australian Institute for Health and Welfare
CAM	Complementary and Alternative Medicine
CCA	Cancer Council Australia
CI	Confidence Interval
CINV	Chemotherapy-induced nausea and vomiting
CUP	Cancer of Unknown Primary
DP	Discursive Psychology
HREC	Human Research Ethics Committee
MBM	Mind-body medicine
NAFKAM	National Research Center in Complementary and Alternative Medicine
NCCAM	National Center for Complementary and Alternative Medicine
NCI	National Cancer Institute
NICM	National Institute of Complementary Medicine
RAH	Royal Adelaide Hospital
RCT	Randomised Controlled Trial
RRMA	Rural, Remote, and Metropolitan Area
SEIFA	Socio-economic Index of relative socio-economic advantage and disadvantage
SES	Socio-economic Status
SO	Significant Other
TNM	Tumour Node Metastasis Classification of Malignant Tumours
VCCC	Victorian Comprehensive Cancer Centre
WHO	World Health Organization

CHAPTER ONE: BACKGROUND AND RATIONALE FOR THE RESEARCH

Olver (2012a) emphasized the significance of the controversial debate about Complementary and Alternative Medicine (CAM) use in cancer patients and labelled the exploration of this complex topic, quoting Frost (1916), as “the road less travelled” (p. 1). Prior and subsequent research has contributed to understanding of the world-wide phenomenon of CAM consumption, highlighting benefits as well as dangers for cancer patients and their families. Anthropological research and case studies about individuals’ cultural healing systems and practices have been conducted since the 1970s (Janzen, 1978; Kleinman, 1980; Leslie, 1976), while psychological studies investigating individuals’ belief systems about using CAMs within industrialized societies have been conducted since the late 1980s (Eisenberg et al., 1998; Furnham & Forey, 1994; Furnham & Smith, 1988; P. Yates et al., 1993). There is a diverse body of recent research that has begun to identify reasons and explanations for the popularity and attractiveness of CAM in men with cancer.

This chapter will provide an introduction to the area of CAM use in men with cancer, discuss key concepts related to understanding CAM consumption, and review relevant studies focussing on cancer patients and their family members. The chapter will finish with a summary of the gaps in the literature, then outline the research aims and questions of the current research.

1.1 Cancer and psycho-oncology

Generally, cell division functions in a patterned way, but sometimes this automatic process is disturbed and loss of the orderly pattern of cell division may lead to abnormal growth. These tumours are benign if they remain self-contained, and are referred to as malignant or cancerous if they can spread to other body parts. Through invading the lymph and blood secondary growth can develop which is called a metastasis.

Cancer is a serious disease and a notable burden throughout the world (World Health Organization, 2011) and particularly Australia has the highest rate of cancer incidence globally (AIHW, 2012b). In 2012, The Australian Institute for Health and Welfare (AIHW) (2012b) stated that:

Cancer is a major cause of illness in Australia and has a significant impact on individuals, families and the health-care system ... 1 in 2 Australians will develop cancer and 1 in 5 will die from it before the age of 85 (p. 1).

Although survival rates for many common cancers have increased, cancer is still a major cause of morbidity and mortality. Cancer incidence is increasing and the most common cancers in Australia (excluding non-melanoma skin cancer) are prostate, colorectal (bowel), breast, melanoma, and lung cancer (AIHW, 2012b). Men have a slightly higher risk for a cancer diagnosis than women; 1 in 3 men and 1 in 4 women will be diagnosed with cancer by the age of 75 (AIHW, 2012b). The risk of a cancer diagnosis is expected to increase with age: 1 in 8 men will be diagnosed with prostate cancer before the age of 75 years, and 1 in 6 before the age of 85 (AIHW, 2012b). Prostate cancer is expected to have the second-highest cancer-related disease burden for Australian men, after lung cancer (AIHW, 2012b).

If cancer is detected early, conventional medical treatment is often successful in treating the cancer. The aim is to destroy the cancer cells and stop them from returning. This can be done by surgery to remove the growth, or by other cancer-destroying methods such as chemotherapy or radiotherapy. The growth of some cancers can also be controlled through hormonal therapy (particularly in prostate or breast cancer, the two most common cancers in males and females, respectively). Conventional cancer treatment, also commonly referred to as biomedical treatment, conventional medicine, mainstream medicine, orthodox medicine, or standard medical treatment, can be curative or palliative, and often carries side-effects, adding to the burden of the cancer diagnosis in cancer patients.

1.1.1 Adverse effects of a cancer diagnosis and treatment.

1.1.1.1 Physical.

There are a number of side-effects associated with conventional cancer treatment that are a burden to cancer patients. Research indicates that individuals undergoing standard medical treatment suffer a range of physical symptoms due to both treatment and progression of the disease (Olver, 2011).

Serious and frequent symptoms of surgery, chemotherapy, radiotherapy, and hormonal therapy include pain, fatigue, lack of energy, and breathing problems (Ashbury, Findlay, Reynolds, & McKerracher, 1998; Molassiotis, Zheng, Denton-Cardew, Swindell, & Brunton, 2010). In addition, the impact of chemotherapy and radiotherapy can be considerable, contributing to a distressing cancer experience (Burton & Watson, 1998). Acute and delayed chemotherapy-induced nausea and vomiting (CINV) is experienced by 39% and 68% of cancer patients, respectively (Hilarius et al., 2012), and is additionally associated with neuropathy (Ocean & Vahdat, 2004; Quasthoff & Hartung, 2002), chemotherapy-related cognitive impairment (chemobrain) (Hodgson, Hutchinson, Wilson, & Nettelbeck, 2012; Silberfarb, 1983), and hair loss that is a particular burden for younger female cancer patients (Trueb, 2010). Radiotherapy side-effects vary depending on dose extent and what tissues are in the radiotherapy field; and it has been reported that more than 80% of patients undergoing radiotherapy treatment experience skin irritation and discomfort (Barkham, 1993). There are also gender-related side-effects: radiotherapy to the ovaries will cause menopause in women, and men with urogenital cancer undergoing radiotherapy may have loss of libido (Burton & Watson, 1998).

1.1.1.2 Psychological.

The cancer diagnosis and treatment also convey a psychological burden for individuals with cancer, as well as their Significant Others (SOs), such as family members and/or close friends. A meta-analytical review about 58 studies from 1980 to 1994 has drawn attention to the fact that cancer patients are more depressed than the general population (van't Spijker, Trijsburg, & Duivenvoorden, 1997). As the prevalence of depression, however, varies due to the use of different concepts and measurements, Massie (2004) has suggested that up to 38% of cancer patients suffer major depression, while up to 58% suffer depression spectrum syndromes. Psychological problems remain a significant problem for both females and males affected with cancer, and need to be considered in clinical consultations. Distress, like anxiety, anger, guilt, and depression is experienced in up to 46% of breast cancer patients (Lampic, Thurfjell, Bergh, & Sjöden, 2001; Montgomery & McCrone, 2010), and up to 63.1% of women with a history of depression experience high levels of psychological distress following the diagnosis of breast cancer (Maunsell, Brisson, & Deschênes, 1992). It has been reported

that between 11% and 38% of men with prostate cancer suffer distress (Balderson & Towell, 2003; Cliff & MacDonagh, 2000), and that men with prostate cancer have a four times higher risk of suicide than men of the same age from the general population (Llorente et al., 2005). In addition, depression in patients with prostate cancer may be linked with higher uptake of healthcare services, thereby adding to the financial burden of prostate cancer in patients as well as the public health sector (Jayadevappa, Malkowicz, Chhatre, Johnson, & Gallo, 2012).

1.1.1.3 Psycho-social.

There is a growing body of research highlighting that cancer seriously affects family members of cancer patients (Baider, Cooper, & Kaplan De-Nour, 2000; Burton & Watson, 1998; Holland et al., 2010), and indicating that they need to be included in consultations and supportive treatments as well. A review article has suggested that between 20% and 30% of cancer patients' SOs become highly distressed or clinically depressed, and that this rate is even higher, namely between 30% and 50%, in SOs of patients who are on a palliative treatment plan, implying that a cure is not possible and death may be approached soon (Pitceathly & Maguire, 2003). A meta-analysis involving 21 samples of cancer patients and their carers reported about a significant positive correlation between the psychological distress of the cancer patient and the carer (Hodges, Humphris, & Macfarlane, 2005), indicating that an early intervention could help reduce distress in the dyad. Subsequent research has suggested that psycho-social interventions either tailored to both the patient and his caregiver, or the caregiver alone, should be included in standardized guidelines. Based on a review of five meta-analyses assessing psycho-social interventions on patient and caregiver outcomes, Northouse et al. (2012) have emphasized that the physical and psychological benefits of these interventions should become more accepted and implemented in clinical practice.

Over the last 30 years, the discipline of psycho-oncology established that cancer can be considered a "family disease," as this diagnosis affects the whole family of individuals suffering cancer (Baider, et al., 2000; Burton & Watson, 1998; Holland, et al., 2010). Generally, psycho-oncology services consist of counselling, cognitive behaviour therapy, and meditation for relaxation and/or stress reduction (Burton & Watson, 1998; Carlson & Garland, 2005; Carlson, Ursuliak, Goodey, Angen, & Speca, 2001; Holland, et al., 2010), and are increasingly implemented in

cancer care. Psycho-oncology services can be part of “supportive cancer care,” or “complementary cancer treatments,” implying that also other treatments than conventional cancer treatment can be offered to cancer patients. This will be discussed in the next section.

1.2 CAM

Interestingly, the reported increase of cancer incidence in Western industrialized societies (World Health Organization, 2011) matches an increase in the consumption of Complementary and Alternative Medicine (CAM) (ABS, 2008). This is despite the advances of specialised and highly technological medical treatment, that has led to an improvement in survival rates, but not to a cure for all variations of cancer types and stages.

1.2.1 Defining CAM – measuring CAM.

According to the National Center for Complementary and Alternative Medicine (NCCAM) (2013), a US research agency conducting evidence-based studies since 1998, “Complementary and Alternative Medicine (CAM) is a group of diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine.” The NCCAM classifies CAM into the categories:

- a) Natural products (e.g., herbs and botanicals, special diet)
- b) Mind-body medicine (e.g., meditation, relaxation)
- c) Manipulative and body-based practices (e.g., massage, chiropractic)
- d) Other CAM practices (e.g., acupuncture, naturopathy, Reiki)

This definition and classification system are the most widely used in research about CAM, even though others have been proposed by the American Cancer Society (ACS) or the World Health Organization (WHO).

A systematic review involving 26 surveys, conducted between 1977 to 1998, from 13 countries suggests that the prevalence of CAM use ranges between 7% to 64%, with an average prevalence of 31.4% (Ernst & Cassileth, 1998). The wide variability of CAM prevalence can be explained by the use of different definitions and different measurements. Thus, these study results highlight that it is crucially important to follow an established definition and classification of CAM, so that cross-cultural comparisons and analysis of CAM use over time can be accurately measured. Kristoffersen et al. (2008) suggested a novel approach,

measuring CAM on six levels ranging from “CAM 1: Seen a CAM practitioner at least 4 times” to level 6 “CAM 6: All CAM use including prayer,” so that the commitment of CAM users towards a specific CAM category/therapy can be better understood. These ideas have been implemented in the development of an international questionnaire to measure CAM, termed the I-CAM-Q, initiated by the National Research Center in Complementary and Alternative Medicine (NAFKAM) of the University of Tromsø, Norway (Quandt et al., 2009). In 2012, this questionnaire has been translated into German and deemed as being comparable with the English version measuring CAM use in a standardized way (Re, Schmidt, & Guthlin, 2012). Future research about CAM use involving individuals, with different physical and psychological conditions, from all parts of the world, will determine if the I-CAM-Q is effective for globally assessing CAM.

1.2.2 Increase of CAM use in cancer populations.

CAM is frequently and increasingly used in the general population, and particularly, in cancer populations. In the USA, CAM use has increased in the general population from 33.8% to 42.1% over the years 1990 to 1997 (Eisenberg, et al., 1998). In Australia, CAM use has risen from 48.5% (MacLennan, Wilson, & Taylor, 1996) to 52.1% (MacLennan, Wilson, & Taylor, 2002), based on data from two South Australian surveys conducted in 1993 and 2000 in the general population. The authors conducted a further survey in 2004 confirming that South Australians continue to use CAM with a prevalence of 52.2% (MacLennan, Myers, & Taylor, 2006).

In Europe, CAM use has been reported to vary widely between 30% to 86% in the general population (Eardley et al., 2012; Fisher & Ward, 1994). Due to the number of independent countries included, and their different healthcare systems and public statistics, it is difficult to compare the use of CAM on the Western and Eastern European continent. A survey involving 956 cancer patients from a total of 14 European countries has suggested that the prevalence of CAM use is 35.9%, ranging between countries from 14.8% to 73.1% (Molassiotis et al., 2005). The standardised application of the same survey and definition has been an improvement for measuring and comparing CAM between some European countries. The recruitment procedure and the statistical analysis could, however, be further improved: the numbers of study participants recruited for each country are not representative of the European population. For example, 81 Greek cancer

patients participated compared with only 34 English cancer patients. Other highly populated and influential European countries (e.g., Germany and France) were not considered in this European survey. Future research could clarify the current prevalence of CAM use in cancer patients, and additionally how to best address patients' preferences in a standardized and cost-efficient approach benefiting all European countries.

Cancer patients have been identified as higher consumers of CAM than the general population (Mao, Farrar, Xie, Bowman, & Armstrong, 2007). A 2012 meta-analysis has suggested an increase of CAM use from 25% to 49% during the years 1970 to post 2000 (Horneber et al., 2012). The remarkable increase of CAM use over time is also reflected in a comparative survey data study involving breast cancer patients, highlighting that the prevalence of CAM has increased from 67% to 82% during the years 1998 to 2005 (Boon, Olatunde, & Zick, 2007). With regard to prostate cancer patients, it has been suggested that the median prevalence rate of CAM is 30%, ranging from 8% to 50%, based on a review of 10 studies on CAM use specifically for cancer care published between 1999 to 2009 (Bishop et al., 2011).

The popularity and attractiveness of CAM in the general population as well as in cancer patients can be no longer ignored, as it is part of many peoples' everyday life. Cassileth (1989) was one of the first to consider the socio-cultural context of the popularity and attractiveness of CAM. She suggested that therapies outside the conventional medical system reflect the social trends and values of our time: the patients' rights movements, the change from passive to active patient roles, the holistic movement, self-responsibility and emphasis on physical fitness, as well as dissatisfaction with conventional medicine. The desire for a holistic and natural life-style becomes particularly interesting when studying individuals living in industrialized societies emphasizing consumerism and competition based on individual and rational choices. Before reporting about the users and consumers of CAM, the benefits of specific CAMs will be discussed, to demonstrate the efficacy of CAM beyond the placebo effect, another reason attesting to the significance of this modern topic.

1.2.3 Benefits of CAM as a complement to conventional cancer treatment.

The benefits of CAM use in cancer patients can be dramatic. In response to the growing interest and consumption of CAM in individuals living in the Western industrialized world, research about the efficacy and effectiveness of CAM has been promoted and supported by Western governments (Baer, 2009b). Despite the difficulties of measuring CAM in a randomized clinical trial (RCT)¹, considered the gold standard of research design in conventional medicine (Goldstein, 2003), there has been an increase in studies attesting that many CAMs are effective and safe (Ernst, Pittler, Wider, & Boddy, 2006; Zollman, Vickers, & Richardson, 2008). There is also emerging evidence that CAM therapies are cost-effective, as demonstrated in a 2012 systematic review evaluating CAM from an economic perspective (Herman, Poindexter, Witt, & Eisenberg, 2012). Reliable, current, and comprehensible information about CAM become especially important when consulting cancer patients about the possible use of CAM.

Some individuals with chronic diseases like AIDS, arthritis and rheumatism, asthma, back problems, pain, skin problems, and psychological problems like anxiety, obesity, depression use CAM *instead of* conventional medical treatment, particularly when medical treatment has failed to provide a curable or acceptable solution to the health problem (Astin, 1998; Caspi, Koithan, & Criddle, 2004; Eisenberg et al., 1993). This is not recommended for cancer patients. Current medical guidelines propose that cancer patients should use CAM only *in addition*, as a *complement to* conventional cancer treatment (Deng et al., 2009). Thus, CAM should only be used *in conjunction* with conventional medical treatment, and should be promoted as *adjuncts to* mainstream treatment.

There is high-level evidence that CAM help to reduce physical disease and treatment symptoms, and improve well-being and quality of life in cancer patients (Cassileth & Deng, 2004; Ernst, 2010). It has been highlighted above (see 1.1.1) that cancer patients often suffer side-effects from conventional cancer treatment, which can, however, be ameliorated by some CAM. For example, chemotherapy-induced nausea and vomiting (CINV) can be ameliorated by acupressure and acupuncture (Ezzo et al., 2006; Klein & Griffiths, 2004). Neuropathy can be relieved by Vitamin E (Argyriou et al., 2006; Argyriou & Kalofonos, 2011), pain can

¹ Such scientific studies should be double-blind, placebo-controlled, and randomized.

be reduced by acupuncture (H. Lee, Schmidt, & Ernst, 2005; Pan, Morrison, Ness, Fugh-Berman, & Leipzig, 2000), hypnosis (Bardia, Barton, Prokop, Bauer, & Moynihan, 2006), massage (Pan, et al., 2000) and therapeutic touch (Jain & Mills, 2010). Fatigue can be treated with exercise (Cramp & Daniel, 2008), and Yoga (Boehm, Ostermann, Milazzo, & Bussing, 2012). Hot flushes can be helped by acupuncture in men with prostate cancer (M. S. Lee, Kim, Shin, Choi, & Ernst, 2009) and in women with breast cancer (Hervik & Mjaland, 2009). It has also been reported that exercise (Conn, Hafdahl, Porock, McDaniel, & Nielsen, 2006), massage (Ernst, 2009), music therapy (Bradt, Dileo, Grocke, & Magill, 2011), and Qigong (Oh, Butow, Mullan, Clarke, et al., 2010) improve quality of life and well-being in patients with cancer, especially important for patients receiving palliative care. Psychological and emotional well-being, in reducing symptoms like stress, anxiety, depression, can be improved by aromatherapy and massage (Fellowes, Barnes, & Wilkinson, 2004), meditation/relaxation (Birnie, Garland, & Carlson, 2010; Smith, Richardson, Hoffman, & Pilkington, 2005), Yoga (Galantino et al., 2012; Moadel et al., 2007; Ross Zahavich, Robinson, Paskevich, & Culos-Reed, 2012), and exercise (Conn, et al., 2006).

In a 2012 systematic review of effective and safe CAMs for cancer patients, Pirri (2012) summarized the evidence of meta-analytic and systematic reviews, or when this was not available included a single RCT. He concluded that there is evidence for the efficacy of many CAMs, ranging from homeopathy to microwave therapy, but that there is also evidence for potential harm.

1.2.4 Dangers and harms of CAM.

While an increasing number of evidence-based studies contribute to the encouragement of CAM use, there is also evidence that some CAM, particularly natural medication and herbs and botanicals, can be a danger to human health, and the simultaneous use of multiple herbal medicines and conventional medicines can be dangerous and harmful. Examples include: Echinacea, garlic, Ginseng, ginger, Ginkgo biloba, green tea, Saw palmetto, St John's wort (Clarke & McLachlan, 2011; Carlo Pirri, 2011; C. Pirri, 2012). Obviously, any adverse interaction between oncology-related drugs and natural products involving herbs or dietary supplements can be unfavourable for cancer patients. It has been reported, however, that some of these CAM natural products are associated with favourable interactions (Block, 2012). For example, fish oil increases the

effectiveness of chemotherapy (Murphy et al., 2011), ginger helps to reduce CINV (Ryan et al., 2012), and probiotics ameliorate diarrhoea after chemotherapy treatment (Osterlund et al., 2007).

1.2.5 Integrative cancer care.

Integrative cancer clinics/centres (also labelled as comprehensive cancer clinics/centres) offer conventional cancer treatment and evidence-based CAMs to cancer patients. They may address cancer patients' physical and psychological needs and provide information and guidance for them and their family members. Olver (2012b) suggested that integrative cancer clinics may function as a bridge between CAM and conventional cancer treatment, so that potential and interested CAM consumers, can be consulted, guided, and treated with CAM in addition to their conventional cancer treatment.

The Memorial Sloan-Kettering Cancer Center, New York, the world's oldest and largest private cancer centre (Memorial Sloan-Kettering Cancer Center, 2013b), was founded in 1884 and in 1999, under the direction of Barrie Cassileth, established an Integrative Medicine Service (Memorial Sloan-Kettering Cancer Center, 2013a). This well-known Integrative Medicine Service offers information and evidence-based CAM treatments for cancer patients and their family members, and is leading the way in CAM research and translation into clinical practice. At the time of writing (February 2013), the "Memorial Sloan-Kettering Cancer Center is one of only 41 institutions in the United States that have been designated Comprehensive Cancer Centers by the National Cancer Institute" (Memorial Sloan-Kettering Cancer Center, 2013b).

Within Australia, at the time of writing, the Peter MacCallum Cancer Centre in Melbourne, Victoria, represents the largest Comprehensive Cancer Centre in Australia (Peter MacCallum Cancer Centre, 2013b). It was opened as a public hospital in 1950 and is dedicated to treating the cancer patient and the family with conventional treatment, that can be complemented with a range of CAMs, offered within the cancer services Allied Health, Psycho-Oncology, and the Familial Cancer Centre (Peter MacCallum Cancer Centre, 2013a). A new building is expected to be finished in 2015, for The Victorian Comprehensive Cancer Centre (VCCC), involving the Peter MacCallum Cancer Centre and other cancer research and clinical services, to further promote world-class research and treatment in comprehensive cancer care (Victorian Comprehensive Cancer Care Project,

2013). The SolarisCare Centre in Perth, Western Australia, is another institution combining cancer care and CAM in Australia (SolarisCare Centre, 2013). David Joske, Head of Haematology at the Sir Charles Gairdner Hospital, opened the SolarisCare Centre in 2011 to improve the cancer experience for cancer patients and their family members. The centre offers CAM, ranging from meditation, Reiki to hypnotherapy, free of charge to interested cancer patients. Based on the success of this novel integrative oncology centre in reducing symptom distress and improving quality of life in cancer patients (Joske, 2012), and providing a community for cancer patients with no family support, two more centres now operate in Western Australia, indicating that SolarisCare is an effective and sustainable model for future comprehensive cancer care.

1.2.6 Medical pluralism.

Comprehensive cancer care might reflect evidence-based medical pluralism, indicating that biomedicine can co-exist with other therapies, that are popular and in vogue. Medical pluralism acknowledges that a range of other unconventional treatments have long been used by individuals before the advent of biomedicine, and is still prevalent in Western countries (Baer, 1995, 2009; Broom & Tovey, 2008b; Sharma, 2003). Individuals have always used different therapies for different needs. For example, Scott (1974) has identified that the multi-ethnic population in Miami, Florida, used the health system differently, making use of orthodox medicine as well as of specific health practices, therapies, and belief systems varying upon the ethnic tradition. Likewise, Janzen (1978) found that the BaKongo of Lower Zaire in Africa utilize both orthodox treatment as well as traditional healing practices, depicting this process as *therapy management* consisting of talks and thoughts about diagnosing the illness, selecting therapies, and evaluating different treatments. Confirming this concept, Nichter (1989) identified that patients in South India have clear expectations about treating different illnesses with different healing practices. His subsequent research focused on the *social relations of therapy management*, indicating that individuals' healthcare decisions are often shaped within their households and also by the socio-political environment (Nichter, 2002).

Medical pluralism has been the norm in countries all over the world (Baer, 1995; Baer, 2009a; Cant & Sharma, 1999; Sharma, 2003), but biomedicine has achieved dominance over unorthodox medical treatments, particularly in Western

industrialized countries (Baer, 1995; Baer, 2009a; Elliott, 2012). Biomedicine has certainly contributed to increases in the life expectancy and quality of life in many individuals, but despite these modern advances, many people turn to CAM products and providers, often associated with high costs and efforts (MacLennan, et al., 2006). It seems that the availability and use of a range of different therapies still constitutes a necessary norm in industrialized societies. Today, individuals use a range of therapies simultaneously or in a complementary way (Eisenberg, et al., 1998; Xue, Zhang, Lin, Da Costa, & Story, 2007). Sharma (2003) has suggested, however, that today's medical pluralism is not the same as the medical pluralism that existed before biomedical hegemony: some CAMs have been integrated into the conventional healthcare system supported by the government, while some CAMs will remain marginalized and available on the private market. Integrating CAM into conventional cancer care will remain challenging. The evidence-base for many CAMs, as well as patients' and their family members' demands and preferences, however, indicate some need to treat cancer patients holistically in professionalized Comprehensive Cancer Centres, ensuring safety, efficacy, and effectiveness of CAMs in combination with conventional cancer care.

1.3 Gender differences

CAM services in comprehensive cancer care need to be tailored to the various physical, psychological, and social factors impacting on the individuals' cancer experience. Only when the patients' and their family perceptions, opinions, and cancer experiences are fully understood, can this knowledge be best translated into integrative cancer care involving both conventional cancer treatment and CAM.

1.3.1 The typical CAM consumer.

Users of CAM are a heterogeneous group, and differ on socio-demographic and medical characteristics, motivations for use, and the socio-cultural context. Research consistently reveals that the profile of CAM users is female, young, highly educated, and with high levels of income; this pattern has been identified in the general (MacLennan, et al., 2006; Xue, et al., 2007) and in cancer populations (Fouladbakhsh, Stommel, Given, & Given, 2005; Hann et al., 2005; Hedderson et al., 2004; Kristoffersen & Norheim, 2012; Molassiotis, et al., 2005; Verhoef, Balneaves, Boon, & Vroegindewey, 2005).

There are many factors which may contribute to the observed gender difference in CAM uptake. Compared to men, women are socialised to perceive their body as vulnerable, ill, and weak, requiring constant medical surveillance (Illich, 1976; Riessman, 1983; Zola, 1972). This process begins early during childhood, puberty, and adolescence (Arms, 1975; Gabe & Calnan, 1989). As pregnancy and childbirth have become increasingly medicalised, the utilization of medical healthcare services increases even more in women in the reproductive age (ABS, 2009; Galdas, Cheater, & Marshall, 2005). It has been suggested that women care more and know more about human bodies, and are more aware of and interested in health-related issues, possibly because of their ability to give birth to new life (Nichter & Nichter, 1996). It is socially accepted, and also expected, that women are emotionally expressive, ask for and receive help and support, and in return use this knowledge and experience to inform and care for the health of their families (Annandale & Hunt, 1990; Moynihan, 1998; Sherwin, 1998). Females traditionally act as the caregiver and the family health expert; they provide more support to their families than they receive, and it appears that they are often involved in men's healthcare decisions (Carlson, Ottenbreit, St. Pierre, & Bultz, 2001; Norcross, Ramirez, & Palinkas, 1996). An interview study by Seymour-Smith et al. (2002) discursively analysed how clinical staff talked about male patients' healthcare behaviour within a general practice. The authors found that women often impact on men's decisions to consult a general practitioner, best illustrated in the title phrase "My wife ordered me to come." Men were commonly depicted as childlike by general practitioners and nursing staff, indicating that the influence of women is socially accepted and necessary. There has been, however, little exploration of the important interpersonal interaction between men affected with cancer and their close family members or friends, with regard to CAM treatment decision-making.

In contrast to women, men are socialised to communicate masculine traits like stoicism, inexpressiveness, independence, and to concentrate on somatic and physical facts rather than emotions (Moynihan, 1998). Thus, it is argued, as men want to be perceived and respected as masculine individuals, they perform risky and health-damaging behaviours (Courtenay, 2000; Mahalik, Burns, & Syzdek, 2007), resulting in higher rates of injuries, suicides, homicides, heart disease and cancer (AIHW, 2010b, 2012a), and lower rates of utilization of preventive treatments (R. Evans, Brotherstone, Miles, & Wardle, 2005). The stereotypical

picture of the tough, strong, controlling and protective male is deemed to reflect *hegemonic masculinity* (Connell, 1995), a term that was introduced into discussions of masculinity to deal with relational issues (Connell, 1995, 2000; Kimmel, Hearn, & Connell, 2005). It has been suggested that in most social settings, there is a narrow range of dominant ways to express oneself as a man, thereby indicating the difficulties faced by the majority of men. As the pattern of masculinity is not globally equal, Connell (2000) suggested that we need to speak of *masculinities*, rather than of *masculinity*, to take account of the fact that different cultures and different periods of history construct gender differently. This construct also highlights that masculinities, as well as femininities, are socially constructed and maintained in social interactions. It also implies the possibility for change and creation, as it is in social interactions where concepts can be contested, negotiated, and reshaped, resulting in a growth of diversity. The *men's health movement* (P. Baker, 2001) as well as the *sociology of masculinities* and *men's studies* (Connell & Messerschmidt, 2005; Doyal, 2000) have raised awareness of the need to consider such cultural constructs and to develop alternative men's health initiatives.

1.3.2 Reasons and motivations for CAM uptake.

Gender differences have also been reported in motivations/reasons for cancer patients' CAM uptake, but further exploration is warranted. A 2005 systematic review (Verhoef, et al., 2005) of 52 quantitative studies, including predominantly breast and prostate cancer patients, suggested that men and women use CAM because of similar expectations, namely, for therapeutic benefit, need for control, belief in the holistic paradigm, to try everything possible to increase survival, and to maintain hope. There is, however, other evidence that men may have different needs compared to women, and may use CAM for different reasons. For example, Hedderson et al. (2004) surveyed 178 male and 178 female cancer patients and reported that the male and female study participants differed significantly on their use of CAM. This gender difference may reflect a different psychological coping style with regard to the cancer diagnosis and cancer treatment. While distress increased the dietary supplement intake in men, it decreased the consumption of dietary supplements in women. The gender difference in reasons for CAM uptake has also been reported by Hann et al. (2005). Their survey involving 126 breast and 82 prostate cancer patients showed

that female and male CAM users differed on reasons and belief systems for their CAM use. For example, men reported significantly more often than women that they used CAM to regain control. In contrast, women said considerably more often than men that they used CAM as a stress relief, or as part of a holistic treatment for cancer. Most studies investigating CAM use in cancer patients have focused on females, particularly those with breast cancer. When men have been included they were mainly diagnosed with prostate cancer. Other cancer types like haematological malignancies, colorectal, or lung cancer, have been largely ignored.

There is conflicting evidence regarding whether men with cancer use CAM because they are *pushed* or *pulled* towards CAM. The push and pull model was devised by Furnham and Smith (1988), and suggests that individuals use CAM because they are either *pushed* towards CAM because of dissatisfaction with conventional medical treatment, or *pulled* towards CAM because their philosophical beliefs and values are congruent with the holistic paradigm underlying many CAM treatments. A qualitative focus group study including 29 prostate cancer patients, reported that men used CAM because of the push factor, that is, because of discontentment or disappointment with conventional medicine (Boon, Brown, Gavin, & Westlake, 2003). In contrast, a recent quantitative survey study with 225 prostate cancer patients predicted CAM use by the pull factor, or by positive representations of CAM (M. C. Porter & Diefenbach, 2009). Further research is needed to clarify if CAM use in men with cancer is merely the result of dissatisfaction with conventional cancer care. It may, however, be too simplistic to explain male cancer patients' CAM use by the dichotomous model push/pull, as patients may use different CAMs for different reasons, including their socio-cultural environment. A qualitative study (M. Evans et al., 2007a), examining the attitudes towards CAM use mostly in men with colorectal and prostate cancer, provides evidence for this claim. The authors reported that men with cancer used CAM because of dissatisfaction with conventional cancer care, but noted that this was, however, only related to the psycho-social care rather than the conventional cancer treatment itself. In addition, the authors (2007a) reported that it was often the family who influenced the male cancer patient to try using CAM as the phrase "My wife found the cancer centre and she DRAGGED me along ..." (p. 522) illustrates.

To further clarify men's specific needs, perceptions, and belief systems, more research is needed, including men with a variety of cancer types, and additionally their SOs, like family members and/or close friends who often play a major role in men's healthcare decisions. Qualitative methods are particularly useful to explore men's special needs, expectations, and experiences of CAM for cancer care. As there is evidence that female SOs play a significant role in men's healthcare decisions (Seymour-Smith & Wetherell, 2006; Seymour-Smith, et al., 2002), it is valuable to include them in research designs as well.

The different needs and characteristics of female and male cancer patients is also acknowledged in psycho-oncology, where men are perceived as problem-focused copers, coping with *masculine traits* (inexpressiveness, stoicism), while women are depicted as emotion-focused copers and coping with *feminine traits* (expressiveness, optimism) (Moorey & Greer, 1989; Moynihan, 2002). There is, however, a need to further explore the utility of this framework on decisions and practices surrounding CAM use by men and women with cancer, so that integrative CAM services can address, communicate, and provide coping tools and strategies to men in an appropriate way.

All these concepts may in part explain why men are under-utilising CAM. There is, however, insufficient research explaining this phenomenon in-depth and thus the questions still remain: What is the prevalence of CAM use in Australian men with a variety of cancers? What are men's perceptions and experiences of CAM use? How do SOs contribute to men's decisions to use CAM? What are the interpersonal implications of CAM use in men and their SOs?

1.3.3 Social influence – involvement of family members and friends.

Family members and friends often influence individuals' healthcare decisions (e.g., Hirai et al., 2008; Tautz, Momm, Hasenburg, & Guethlin, 2012), marking choices in healthcare as a dynamic and social process. Kleinman (1980) defined three different sectors of healthcare to understand health-related behaviour in individuals living in medical pluralistic societies: the *popular sector* reflects lay and non-professional treatments, as well as advice given by family members and/or friends; the *folk sector* includes herbal and/or spiritual treatment administered by sacred and secular folk healers, and the *professional sector* comprises Western biomedicine which is well organized and legitimate in industrialized societies. It is important to acknowledge that 70% to 90% of illness

treatments occur in the popular sector, and that ailments are first treated and consulted about in the family (Kleinman, 1980; Nichter, 2002). Nichter's (2002) findings about the *social relations of therapy management* implies that healthcare choices and therapy management are influenced and negotiated in households and larger networks, which may again be influenced by the broader social and political context.

As it has been discussed above, and will be further reviewed in Chapter Three (paper one (published) – Literature Review about Family and Complementary and Alternative Medicine) (Elliott & Klafke, 2011), females are likely to impact on men's healthcare decisions, as they perform the caregiver and health expert role. Ultimately, it may be inferred that men's CAM healthcare choices are often shaped and formed in patients' homes, with processes, steps, and implications not yet fully understood.

1.4 The current research

1.4.1 Gaps in the literature.

The review of the literature on CAM use in men with cancer has shown that there has been an increase in CAM consumption, particularly in Western industrialized societies. This trend is important because there is also increasing evidence that some CAM help to reduce physical disease and symptoms, and contribute to emotional well-being and quality of life in cancer patients, and may also add benefits to the relationships in cancer patients and their SOs. The published literature on CAM consumption in individuals affected with cancer suggests that females are more likely to consume CAM, and that CAM use constitutes part of a current social trend, promoting active participation and independence, as well as growing awareness and interest in health, fitness, and beauty, and finally, a "search for more" treatment entailing holistic care and spiritual guidance.

There are, however, significant gaps in the literature that this research aims to fill:

- 1) The paucity of studies involving men with a variety of cancer types, and their SOs;
- 2) The scarcity of mixed-methods investigations, providing a comprehensive data base;

- 3) The absence of investigation of the interpersonal dimension/socio-cultural aspects in the context of men's uptake and maintenance of CAM use.

It is essential to investigate the social context impacting on men's CAM decisions, because in order to recommend and provide CAM treatments in integrative cancer services, we need to know patients' and their family members' perceptions and experiences of such treatments. Qualitative research provides an opportunity to directly gain personalised information about benefits and difficulties about CAM consumption. Further, mixed-methods research provides an in-depth opportunity to explain the meanings behind statistical results from quantitative research, and to uncover social processes that are salient in both methodological approaches (Clark & Creswell, 2008). There is also a lack of studies that have used the coping model defined by Lazarus and Folkman (1984; 1999) as a framework for analysing data involving the male patient and his SOs, in research using both qualitative and quantitative methods. This research aims to explore the usefulness of this well-established model in accounting for the increase of CAM consumption. In addition, the current research aims to clarify if and why coping with the cancer diagnosis "together" by using CAM may be beneficial for patients and their family members. Further, there is a lack of studies using discourse analysis (Potter & Wetherell, 1987) for the systematic, accurate, and detailed in-depth analysis of interview data. In this thesis, patients' and their family members' talk is analysed according to discursive analytical principles, to outline the functions and consequences of CAM use in cancer patients and their social networks.

1.4.2 Aim and research questions.

The aim of this thesis was to investigate the use of CAM in men after a diagnosis of cancer. Specifically, the research aimed to explore how SOs impact on men's decisions to (continue to) use CAM, how men and their SOs negotiate, talk, and practice CAM in everyday life, and how this affects their interpersonal relationship. To achieve these aims, this thesis specifically drew upon the theories of Lazarus and Folkman (1999; 1984) and principles of discourse analysis (Potter & Wetherell, 1987).

The specific research questions of the thesis are:

1. What is the prevalence of CAM use in Australian men visiting outpatient cancer services?
2. What are the socio-demographic, personal, and clinical characteristics of CAM users and CAM non-users?
3. Which CAMs have been discussed within the cancer patient's social network?

4. How do SOs impact on men's decision to use CAM during cancer treatment? How do men and their SOs talk about and negotiate about CAM?
5. How do significant others contribute to uptake and maintenance of specific CAMs? How and when do men practice CAM as a shared or individual activity?
6. How do men with cancer integrate CAM in their everyday life, and use it over time? How do SOs benefit from long-term use of CAM?

Research questions 1-3 were addressed by using survey data gained from 403 Australian men affected with cancer undergoing conventional cancer treatment. Research questions 4-6 were addressed by using 43 semi-structured interviews to understand in-depth men's perceptions, expectations, and experiences about CAM use, and further to explore how their SOs contribute to their CAM uptake and maintenance. The following chapter will provide the rationale for the methodology and an outline of the thesis format.

CHAPTER TWO: METHODOLOGICAL RATIONALE AND EXEGESIS

The literature review in Chapter One outlined the need for further research about men's CAM healthcare decisions, particularly arguing the importance of including Significant Others (SOs) in research designs and interventions. SOs seem to contribute and impact on CAM healthcare decisions in men with cancer, but there remains a lack of understanding of how men are influenced to use and maintain Complementary and Alternative Medicine (CAM). In this Chapter, the methodological approach, applied to provide a comprehensive analysis of men's and their SOs' CAM use over time, will be introduced and clarified.

2.1 Mixed-methods research design

The methodology applied for this research was a mixed-methods approach, employing quantitative and qualitative methods. More precisely, this research applied a quantitative survey (Study 1), and semi-structured interviews (Study 2), as represented in Figure 1. Paper two (Chapter Four) and paper three (Chapter Five) have been published/submitted and report about the quantitative and qualitative methods, respectively.

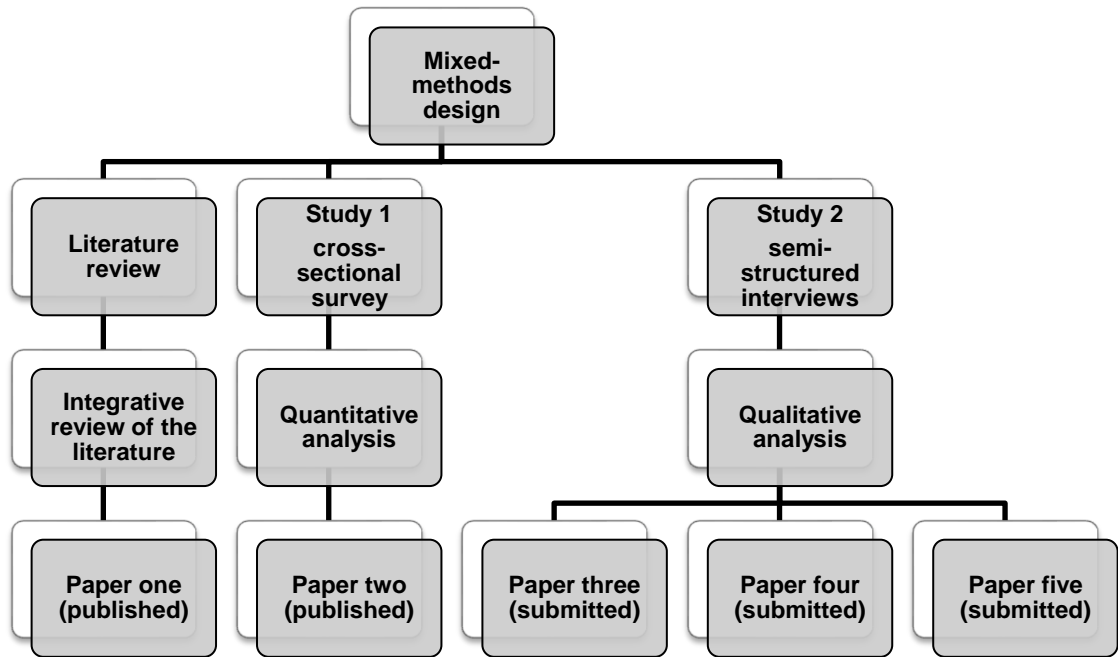


Figure 1. Schematic of the mixed-methods research design used in this thesis

Study 1 featured a patient survey to determine the prevalence of CAM use in men affected with cancer at one time point. Data from the cross-sectional survey were also used to assess independent predictors of CAM uptake and to identify appropriate candidates for inclusion in Study 2, an interview study which aimed to gain an in-depth understanding about men's use of CAM during cancer treatment. The following information from the Study 1 survey was used to select men with cancer, and their SO, ensuring diversity for the Study 2 interviews: type of cancer, cancer prognosis (curable or non-curable), level of CAM use (high or low), and perceived levels of intrapersonal and interpersonal conflict regarding CAM use (high or low). The data from the semi-structured interviews were analysed according to discursive analytical principles (Potter & Wetherell, 1987).

There are multiple benefits of applying both quantitative and qualitative methodology in health research (Adamson, 2005; Lingard, Albert, & Levinson, 2008). First, the overall research question "How do SOs impact on men's decision to (continue to) use CAM after a diagnosis of cancer" could be best investigated by gaining multiple insights into this under-researched topic. The quantitative survey in Study 1 provided an overview about the prevalence of CAM use in an Australian male cancer population, and specified socio-demographic, medical, and personal characteristics of the study sample, as well as described the involvement of cancer patients' social network with regard to CAM uptake. The subsequent qualitative investigation in Study 2, enabled men with cancer and their SOs to express their perceptions, experiences, and opinions about using, continue to using, or not using CAM. This in-depth exploration of the interpersonal dimension impacting on patients' healthcare decisions further explained the results of the survey, particularly by analysing why a high number of male cancer patients are experienced with CAM, why they use specific CAMs, and how they use CAM over time, with or without the contribution of their SOs. By triangulating the data results from the survey and the interviews, a greater insight and understanding about men's use of CAM was gained, than by using a single method only. Methodological triangulation is widely used to enhance the "quality in qualitative research" (Mays & Pope, 2000, p. 50), and refers to the concept of combining and checking different data sources and results, so that the validity of both methods will be enhanced.

Second, mixed-methods research designs are increasingly used in health research, as they enable the researcher to account for the complexities in health

care, marked by dynamic and interdisciplinary processes (Pope & Mays, 2006). There is a substantial body of research reporting the application of mixed-methods, and the advantages of a comprehensive data analysis including numbers and meanings, as well as the translation into clinical practice or implications for future research (Clark & Creswell, 2008; Johnson & Onwuegbuzie, 2004; Tashakkori & Teddlie, 2008). Quantitative research can either precede or follow qualitative research (Pope & Mays, 2006). The research questions determine if participants' perceptions and belief systems, gained by qualitative data analysis, need first to be explored and then incorporated into the quantitative study design, or the other way round. In the current research, the quantitative study preceded the qualitative study, as the prevalence and predictors of CAM use in men with a variety of cancer types has neither been reported in the academic literature before, nor investigated in an Australian context. Thus, it was deemed essential, with Study 1, to first provide an overview about male cancer patients' CAM consumption, and then, with Study 2, to zoom in to more comprehensively explore men's reasons for using and maintaining CAM use in addition to conventional cancer treatment.

Third, a mixed-methods design allows the possibility of investigating a health phenomenon holistically, thereby looking at the bigger picture without neglecting or getting lost in too many details. Quantitative research generates "hard, generalizable" data (Sieber, 1973, p. 1335), while qualitative research produces "deep, detailed" data (Sieber, 1973, p. 1335), and both are essential for understanding the consumers of health care. Statistical measures may explain and predict how one health care consumer relates to the general population, but statistical tests cannot calculate human behaviour in multifaceted dimensions, or evaluate how individuals create and produce meaning in their everyday social life. Conversely, while qualitative data gained from interviews, focus groups, or participant observation produce a detailed understanding of why, how, and when an individual may act in this specific way at this specific time point, these results cannot be generalised to the wider population. Due to the limited generalizability, predictions of human behaviour or thought patterns may not be possible, but the reporting about specific cases may contribute to the evidence for a varied and ever changing social world. By combining both quantitative and qualitative approaches, in a complementing and non-competing way (Brewer & Hunter, 1989), social

processes and phenomena particularly related to health care research may be better understood.

2.1.1 Participants.

In total 403 men and 24 SOs were involved in the two studies. The recruitment procedure is outlined in Figure 2.

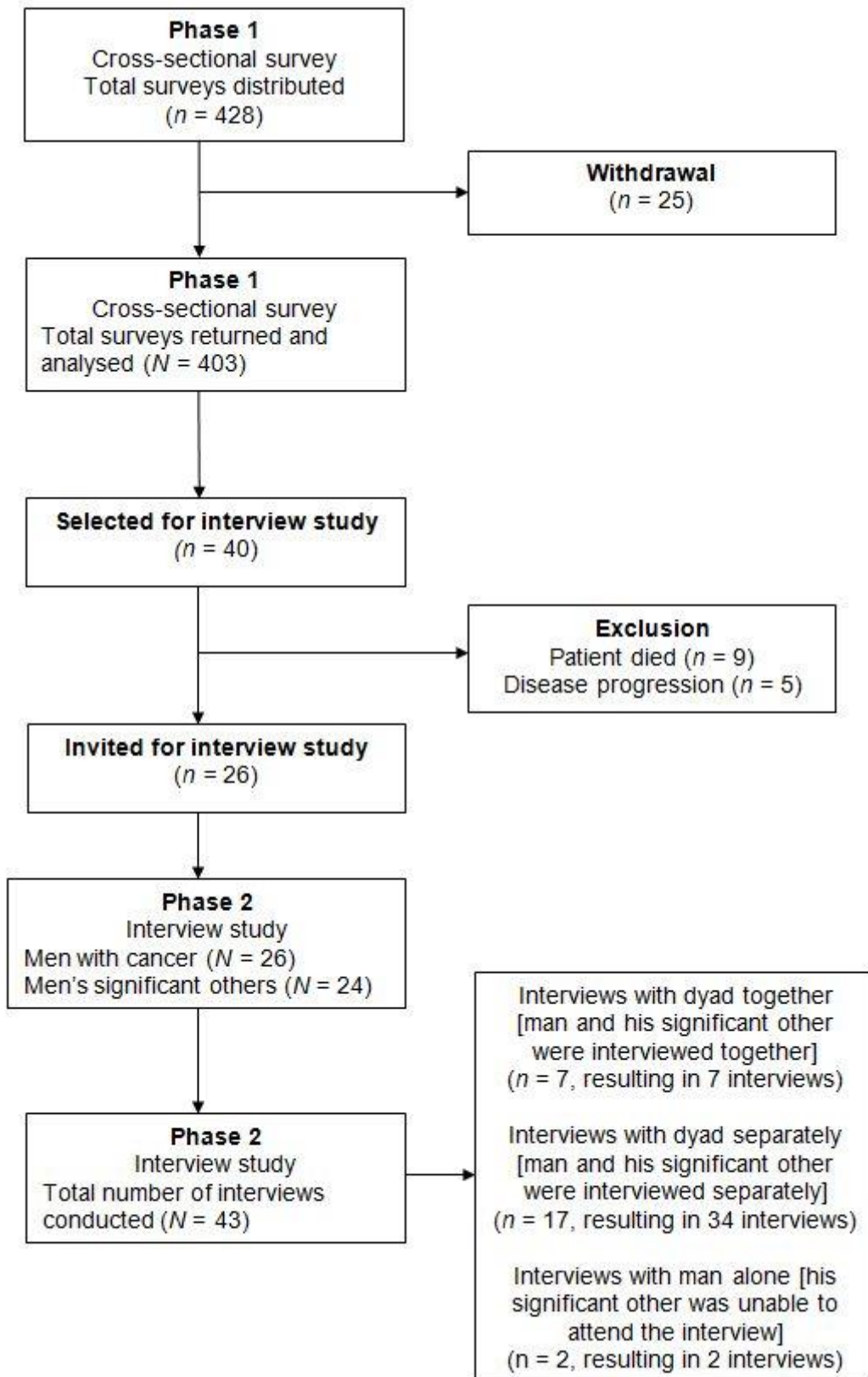


Figure 2. The recruitment process

2.1.1.1 Study 1 – 403 male cancer patients.

During November 2010 and February 2011, 428 surveys were distributed by the PhD researcher NK to a consecutive sample of men with cancer attending four cancer outpatient services in Metropolitan Adelaide. Of the 428 surveys, 403 were completed and returned (94% response rate). The final sample represented a variety of cancer types, and had a median age of 66 years.

2.1.1.2 Study 2 – 26 male cancer patients and 24 significant others.

Of the 403 potential participants who answered the questionnaire in Study 1, 349 participants agreed to be contacted for an interview in Study 2 (86% consent rate), conducted between July 2011 and January 2012. Interested study participants were selected according to the matrix illustrated in Table 1 on page 31, and then the man and his nominated SO were invited to take part in the interview study. Of the 40 men who were invited for Study 2, nine patients died before the interview, and five declined participation due to disease progression. The final sample consisted of 26 male cancer patients, and 24 close family members/friends. Female partners/spouses were mainly chosen as the patient's SO.

2.1.2 Measures.

2.1.2.1 Study 1 – questionnaire.

The self-administered questionnaire used in Study 1 (see Appendix A) was divided into the following four sections:

1. Socio-demographic, personal, and clinical characteristics of CAM users/non-users

Socio-demographic information obtained from survey questions 1 to 8 (see Appendix 1), was used to create the following variables:

- age groups (18-40, 40-60, 60-80, 80+),
- relationship status (living with spouse/partner = married/de facto relationship, not living with spouse/partner = never married, divorced/separated, widowed),
- religion (Christian, other = Jewish, Moslem, Hindu, Buddhist, none, other),

- actively practising religion (yes, no),
- education (Primary, Secondary = year 10, year 12, Tertiary = tertiary non-University, tertiary University, post-grad),
- private health insurance (yes, no), socioeconomic status (based on post-code: low, moderate, high),
- geographical area (Rural, Remote, Metropolitan).

Socio-economic status (SES) was ascertained from the Australian Bureau of Statistics (ABS) (2006) Socio-economic Index of relative socio-economic advantage and disadvantage (SEIFA). The postcode of patients' residence was used to allocate a SEIFA score ranging from 1 to 10, with a lower score indicating more social and economic disadvantage. SEIFA scores 1-3, 4-7, and 8-10 were classified as low, moderate, and high SES, respectively. Patients' postcodes were also used to allocate Rural, Remote, and Metropolitan scores developed by the Australian Government Department for Health and Ageing (AIHW, 2004).

In addition, medical information was extracted (with patient consent) from the patients' medical records within the clinics' databases. After collecting the relevant information from various hospitals' databases the following variables were created:

- stage of cancer (non-metastatic = stage I, II, III, metastatic = stage IV) (National Cancer Institute, 2011),
- type of cancer (prostate, haematological malignancies, colorectal, lung, other²),
- chemotherapy (yes, no),
- radiotherapy (yes, no),
- surgery (yes, no)
- hormonal therapy (yes, no).

The variable CAM use was created according to the answers given to question 9 (see Appendix A), where patients found a list of CAM therapies, based on the widely established taxonomy of the National Center for Complementary and

² The cancer types bladder, brain, breast, CUP (cancer of unknown primary), head and neck, mesothelioma, melanoma, neuroendocrine, ophthalmic, renal, sarcoma, (non-melanoma) skin, testicular, and upper GI were combined into the "other" category to be able to represent the five most common cancer categories in men, as well as to compare these groups for statistical differences.

Alternative Medicine (2013), and were asked to answer the following question for each:

- Have you used it? (yes, no)
- Are you still using it? (yes, no)

Based on responses, patients were grouped into the categories CAM user, CAM ex-user, or CAM non-user as follows:

- CAM users were classified as those patients who indicated still using at least 5 CAMs. (This means that they ticked at least 5 boxes to the questions “Have you used it?” and the associated question “Are you still using it?”)
- CAM ex-users were classified as those patients who indicated having used at least 5 CAMs, but do not use them anymore. (This means that they ticked 5 boxes to the question “Have you used it?” and no boxes to the associated question “Are you still using it?”)
- CAM non-users were classified as those patients who indicated having used no CAMs. (This means that they ticked none of the boxes to the question “Have you used it?”)

The categories “CAM user” and “CAM ex-user” were used as an equivalent for the category “high CAM use” (see matrix under 2.1.2.2). Likewise, the category “CAM non-user” was used to reflect the category “low CAM use.”

2. Awareness, prevalence, referral rate of CAM

To determine the awareness and prevalence of CAM, and the CAM referral rate, patients’ answers to question 9, the list of CAM therapies, based on the widely established taxonomy of the National Center for Complementary and Alternative Medicine (2013), were used for assessment:

Awareness of CAM

- Have you heard about using this during cancer treatment? (yes, no)

Prevalence of CAM

- Have you used it? (yes, no)

Current use of CAM (whilst receiving conventional medical treatment)

- Are you still using it? (yes, no)

CAM referral rate

- Did your cancer specialist refer you to use it? (yes, no)

3. Information, discussion, intrapersonal and interpersonal conflicts about CAM used by the patient

Those patients who registered as having ever used any CAM (i.e., CAM user, CAM ex-user) were specifically asked which CAM therapies (to a maximum of three) they used have evoked the strongest reaction in other people; where they did get information about this CAM; and, how much money they spent for it. Survey questions 10 to 36 (see Appendix A) included Likert scales ranging from 1-10 to assess:

- how difficult it was for the patients to continue using CAM,
- who was involved in any discussions about its use,
- how enthusiastic they perceive (significant) others were towards it,
- how enthusiastic they were themselves towards CAM,
- if they would recommend CAM to other patients.

4. Information, discussion, intrapersonal and interpersonal conflicts about CAM not used by the patient

All patients were asked which CAM therapy anyone suggested they use, but they did not use (survey questions 37-44, see Appendix A). Patients were asked the same questions listed in the above section 3 (with the exception that patients were not asked how difficult it was to continue using this CAM).

2.1.2.2 Study 2 – purposeful sampling, interviews.

For a better understanding of male cancer patients' CAM use, semi-structured interviews were conducted with selected survey participants and their SOs. Therefore, survey participants were sampled purposively (Patton, 2002), using a maximum variation technique (Troost, 1986) to select for variety in stage and type of cancer, high and low CAM use, and perceived levels of intrapersonal and interpersonal levels of conflict regarding CAM use. An illustration of the matrix

used for sampling is outlined in Table 1 below, supported by a detailed justification of the selection criteria.

Table 1

Matrix for determining sample of Study 2

(Information collected in Study 1)

Stage of cancer	Stage I-III								Stage IV							
Type of cancer	Prostate				Other				Prostate				Other			
CAM use*	High		Low		High		Low		High		Low		High		Low	
Conflict**	High	Low	High	Low	High	Low	High	Low	High	Low	High	Low	High	Low	High	Low
Numbers (N=48)	4	2	4	2	4	2	4	2	4	2	4	2	4	2	4	2

Note. * "High" means "high use of CAM", "Low" means "low or no use of CAM." See below for further explanation.

** "High" means "high conflict," "Low" means "low conflict." See below for further explanation.

The following criteria are central for this selection process, as they reflect those factors that previous research have found to be associated with patients' use of CAM. Variation in patients' use of CAM have been associated with difference in stage of cancer (Boon et al., 2003; Kristoffersen, Fonnebo, & Norheim, 2009; Miller et al., 1998), type of cancer (Hann, et al., 2005; Hedderson, et al., 2004; Patterson et al., 2002), and extent of CAM use (Balneaves, Bottorff, Hislop, & Herbert, 2006; Kristoffersen, et al., 2008; Richardson, Sanders, Palmer, Greisinger, & Singletary, 2000), implying that CAM users often combine multiple CAMs and involve members of their social network compared to CAM non-users (who never tried any CAMs.)

A) Stage of cancer (stage I-III, stage IV)

B) Type of cancer (prostate, other)

C) CAM use (high, low)

The category "high CAM use" combined CAM users and CAM ex-users as defined above in section 2.1.2.1 as both groups have experience with CAM in contrast to CAM non-users who have never used any CAM. Hence:

- "High CAM use" = CAM user, CAM ex-user
- "Low CAM use" = CAM non-user

D) Conflict (high, low)

To enable examination of the issues of social influence/impact, social interaction/conflict, and disagreement/discordance in the interview sessions, participants were identified as "high CAM use/high conflict," "high CAM use/low conflict," "low CAM use/high conflict," and "low CAM use/low conflict." These categories were determined from participants' responses to 5 questions from the survey (see Appendix A) used in Study 1:

- Question 9 categorized participants into CAM user ("high CAM use"), CAM ex-user ("high CAM use"), and CAM non-user ("low CAM use").
 - Questions 15/24/33 A-C assessed perceived levels of conflict for those patients having ever used any CAM, i.e., CAM users and CAM ex-users.
 - Question 41 A-C assessed perceived levels of conflict for all patients including CAM non-users.

Responses on the Likert scales of questions 15/24/33 A-C (assessing the enthusiasm of people within the patient's social network towards the use of a specific CAM therapy), and question 41 A-C (assessing the enthusiasm of people within the patient's social network towards the non-use of a specific CAM therapy) were combined to produce the categories:

- Participants (CAM user and CAM ex-user) indicating conflict levels at 3 or less for questions 15/24/33 A-C were classified as “high levels of conflict,” and those indicating scores above 8 were classified as “low levels of conflict.”
- These conflict levels were reversed for question 41 A-C, where all participants (CAM user, CAM ex-user, CAM non-user) indicating conflict levels at 3 or less were classified as “low levels of conflict”, and those indicating scores above 8 were classified as “high levels of conflict.”

Since Study 2 focused on interpersonal implications resulting of men's CAM use, the decision was made to look in detail at the category “high conflict” in order to explore conflicts and disagreements. For recruitment, the number of participants indicating “high conflict” were twice those indicating “low conflict” (i.e., four and two participants, respectively). Thus, an example for “high CAM use/high conflict” was where the participant reported “high CAM use” and also indicated that his SO was not very enthusiastic about it (marked as 1-3 for questions 15/24/33 A-C).

The review of the literature indicated a lack of clarity regarding whether CAM use is associated with family conflicts or disagreements, or if it contributes to family functioning and cohesion. Hence, to take account of possible difficulties in recruiting enough (16) participants for the category “high CAM use/high conflict,” the sampling strategy included instances when the patient reported:

1. “High CAM use” and indicated in questions 13/22/31 (asking the participant how much money he spend for this specific CAM) that he pays/paid over \$100 per month for one CAM treatment.
2. “High CAM use,” and indicated that his SO was very enthusiastic (marked as 8-10 for question 41 A-C) that he should try a specific CAM therapy which he did not use.
3. “High CAM use” and disagreement between his enthusiasm/opinion and the enthusiasm/opinion of his SO.

The following schema was used for assessing this disagreement for questions 15/24/33 A-C (assessing the enthusiasm of people within the patient's social network towards the use of a specific CAM therapy) and the associated questions 16/25/34 (assessing the enthusiasm of the patient towards the use of a specific CAM therapy), as well as for question 41 A-C (assessing the enthusiasm of people within the patient's social network towards the non-use of a specific CAM therapy) and its associated question 42 (assessing the enthusiasm of the patient towards the non-use of a specific CAM therapy):

- Scores of 1–3 = not enthusiastic
- Scores of 4–7 = enthusiastic
- Scores of 8–10 = very enthusiastic

Accordingly, conflict was deemed more likely to occur if the SO is not enthusiastic while the patient is very enthusiastic, or vice versa.

An example for “high CAM use/low conflict” was if the participant reported “high CAM use” and indicated that his SO was very enthusiastic about his CAM use (marked as 8-10 on questions 15/24/33 A-C). This would mean that both the patient and his SO had the same opinion about the use of CAM, which is less likely to result in conflict. Similarly, the category of “low CAM use/high conflict” includes instances wherein the patient reported “low CAM use,” and indicated that his SO was very enthusiastic about the use of a specific CAM therapy (marked as 8-10 on question 41 A-C) which he did not use.

The sampling strategy took account of the possibility of not recruiting enough (16) participants within the category “low CAM use/high conflict.” Hence, participants were also selected if the patient reported “low CAM use” and disagreement between his enthusiasm/opinion and the enthusiasm/opinion of his SO. The following schema was used for assessing this disagreement for question 41 A-C and its associated question 42:

- Scores of 1–3 = not enthusiastic
- Scores of 4–7 = enthusiastic
- Scores of 8–10 = very enthusiastic

Accordingly, higher levels of conflict were deemed more likely to occur if the SO was very enthusiastic while the patient was not enthusiastic, or vice versa.

“Low CAM use/low conflict” included instances where the patient reported “low CAM use” and indicated that his SO was not very enthusiastic (marked as 1-3 on question 41 A-C) about the use of a specific CAM therapy which he did not use anyway. This would mean that both the patient and his SO had the same opinion about the non-use of CAM, which is less likely to result in conflict.

The interview schedules for the semi-structured interviews are attached in Appendices F and G, including the first and the final modified version, respectively. The questions of the interview began and remained open-ended, with the interviewees determining the general content and pace of the interview (Gillham, 2000; Grbich, 1999; Rice & Ezzy, 1999). In later interviews, questions arising from the analysis of previous transcripts were included. By this means, emerging categories and themes from earlier interviews were integrated, elucidated, contrasted, and validated, and contributed therefore to changes in the interview schedule.

The following topic areas were explored in the interviews with both men and their SOs:

- 1) Introduction
- 2) Opening development of the interview
- 3) Central Core of the interview
(Exploration of data from survey)
 - Information-seeking
 - Experience with CAM
 - Social influence/involvement
 - Conflict
 - Integration of CAM in everyday life
 - Increase or decrease of CAM consumption
 - Cancer experience
 - General beliefs about health and illness
- 4) Close

2.1.3 Procedure.

This was a multi-site study recruiting patients at two public and two private cancer outpatient services in Metropolitan Adelaide, namely at the:

- Medical Oncology Unit, Royal Adelaide Hospital (RAH) Cancer Centre
- Radiation Oncology, RAH Cancer Centre
- Adelaide Cancer Centre, Tennyson Centre
- Adelaide Radiotherapy Centre, Tennyson Centre

Both studies were approved by the relevant institutional Human Research Ethics Committees (HREC). More precisely, the ethics approval was gained by the HREC at the Royal Adelaide Hospital. This approval was been deemed acceptable by the HREC at the University of Adelaide. It was also accepted by the Adelaide Cancer Centre, and the Adelaide Radiotherapy Centre, who agreed to waive the ethical clearance from Bellberry Limited which is a HREC to service the private sector.

2.1.3.1 Study 1 – data collection at four cancer outpatient clinics.

Between November 2010 and February 2011, male cancer patients visiting one of the four outpatient cancer clinics were approached by the study investigator NK and asked to complete the questionnaire. Sometimes, nurses, administrative staff, or oncologists introduced the study to patients, who, if the patient agreed, were then approached by NK. Patients were given a questionnaire pack which included the information sheet and consent form (see Appendices B, C, D, and E) and the questionnaire (see Appendix A).

Completion of the questionnaire took 10 to 20 minutes dependent upon each patient's condition, and the number of questions relevant to them. Patients answered the questionnaire in the waiting room, chemotherapy chair, or took it home and returned it at their next clinic visit or via mail. Those who chose to complete during treatment were asked to return it with a signed consent form to NK, or in a box positioned at the reception desk of the relevant clinic; those who preferred to complete at home were asked to return it via a return prepaid envelope, or to bring it to the clinic for collection during their next appointment.

2.1.3.2 Study 2 – data collection in hospital, home, or University

settings.

Between May and July 2011, the questionnaires from Study 1 were classified according to the matrix in Table 1 (see p. 31), and potential participants were then contacted via telephone. Following a brief explanation of the study aims, the potential participant was asked if he would like to take part in an interview with a nominated SO. These SOs were recruited via a snowball technique, wherein the initial respondent (patient) was asked to pass on study details to his SOs who might be willing to participate. This technique is useful when respondents are known to each other, and might otherwise be difficult to access directly (Bernard, 1988).

Patients were asked for permission for the interviewer to refer to the questionnaire completed in Study 1 during the interview. Potential participants were informed that they could receive a copy of their questionnaire via mail to check the answers they provided. Those willing to participate in an interview with a SO were sent an invitation letter (see Appendices H and I) and three information sheets and consent forms (see Appendices J-Q) and stamped envelopes (e.g., where the potential SO lives elsewhere). Provision of the envelopes enabled the volunteering male cancer patient to forward the study details on to his SO who may be willing to participate. During the initial phone call, the potential participant was asked to work with his SO to determine a suitable time and preferred place for the interview, given the options regarding interview location (i.e., at the clinic, at their home, at The University of Adelaide).

Arrangements were made to call the potential male participant 10 to 14 days after the initial contact to schedule the interview at a time and place convenient to the participants. During this phone call, participants were also asked if they prefer to indicate answers given on the questionnaire which they do not want raised in a (joint) interview context. Consented participants were sent a stamped addressed (to NK) envelope together with a letter confirming the scheduled details about the interview time and place, and providing instructions of the interview location if needed.

Between July 2011 and January 2012, interviews lasting between 40 and 90 minutes, were conducted with selected survey participants and their SOs. On meeting at the interview location, the study investigator NK reiterated the content

of the Participant Information Sheet and Consent Form (specifically including the purposes of the study, assurances of confidentiality, and option of withdrawing from the study), and collected the signed Consent Forms from all participants before commencement of the interview.

This study seeks to understand how SOs are involved in male cancer CAM decisions. Hence, NK consulted with her supervisors whether interviewing SOs and patients together (dyads) or separately provided the most informative data. After interviewing and analysing data from 11 dyads (7 dyads were interviewed together and 4 dyads were interviewed separately), the research team identified separate interviews as preferable. The subsequent 13 dyads were interviewed separately; two patients attended the interview alone as their SOs were unable to attend. Figure 2 (see p. 25) illustrates the number of dyads and interviews.

Although previous research indicated that the opportunity to talk about personal experiences with a neutral outsider is often appreciated in cancer patients and their families (Elliott, Kealey, & Olver, 2008; Elliott & Olver, 2008), it would have been possible that the participation could have triggered negative emotions for the male affected with cancer and his SO. At the close of the interview, participants were provided with information regarding credible sources of information about CAM (e.g., Cancer Council Australia (CCA), National Institute of Complementary Medicine (NICM), National Center for Complementary and Alternative Medicine (NCCAM), Memorial Sloan-Kettering Cancer Center). Participants were also provided with contact details for the Cancer Council Helpline, and informed that any individuals who have questions or issues arising from the interview could contact the principal supervisor JE, who is experienced in discussing potentially sensitive topics in relation to cancer, for further discussion, or for referral to appropriate support services. None of the participants exhibited or reported distress during the interviews, thus no referrals were deemed necessary. Four participants, three SOs (spouses/partners) and one man (diagnosed with non-metastatic colorectal cancer), wanted to receive further information about CAM and were provided with the above mentioned information sources. All participants expressed that they were interested to hear about the study outcomes and three dyads provided NK their email addresses to contact them in the future, indicating further interest to participate in research about CAM.

2.1.4 Data analysis.

2.1.4.1 Study 1 – statistical analysis.

Prior to analyses, variables were examined for data entry and missing values. All data were entered correctly and there were no missing values for participants with regard to the socio-demographic, personal, and clinical variables. There were missing values for some participants in survey sections 3 (assessing information, discussion, intrapersonal and interpersonal conflicts about CAM used by the patient) and 4 (assessing information, discussion, intrapersonal and interpersonal conflicts about CAM not used by the patient); these participants were excluded from the analyses. Descriptive statistics were obtained for each variable before conducting further statistical tests.

Chi-square tests were performed to compare the socio-demographic and medical characteristics between CAM users and non-users. A power calculation revealed that at least 152 participants were required for comparisons between the categorical variables. According to Cohen's (1969, 1988, 1992) convention, a small effect size is defined as $w = 0.1$, a medium effect size as $w = 0.3$, and a large effect size as $w = 0.5$. Thus, to detect a medium degree of association in the population, for a power of 80% at the 5% significance level, including 6 degrees of freedom, a sample of 152 is required. The effect size of $w = 0.3$ corresponds to a risk difference (difference in proportions) of 0.225. As the final sample included 403 male cancer patients, all statistical tests had enough statistical power.

Chi-square tests assessed differences between CAM users and nonusers with regard to socio-demographic (age group, relationship status, country of birth, geographical area, religion, private health insurance, socioeconomic status (based on postcode), actively practising religion, education) and medical variables (type of cancer, past and present medical treatment, stage of cancer). All variables were categorical.

Significant variables ($p < .05$) were analysed in univariate and multivariate logistic regression analyses to assess their association with general use of CAM (coded as a dichotomous outcome variable), as well as with specific CAM categories. All analyses provided an odds ratio and were reported with 95% CI (confidence interval) for each variable. P values were two-sided. The multivariate logistic regression analysis was conducted by using the forced entry method. This is an appropriate method for theory testing, in which all potential predictor

variables are put into one block to analyse their own contribution to the final model while simultaneously controlling for the effect of other variables (Tabachnik & Fidell, 2007b). Finally, the Hosmer-Lemeshow χ^2 test was performed to assess how well the predictors fit the model. Since this statistic tests the hypotheses that the predicted outcomes differ significantly from the observed outcomes, a p value $> .05$ is considered as a good fit (Hosmer & Lemeshow, 2000). All data analyses were conducted by using the Statistical Package for Social Science (SPSS) software program (PASW Statistics 17, IBM Corporation, Armonk, New York).

Results of Study 1 are reported in Chapter Four (paper two [published] – Prevalence and predictors of complementary and alternative medicine (CAM) use by men in Australian cancer outpatient services) (Klafke, Elliott, Wittert, & Olver, 2012).

2.1.4.2 Study 2 – qualitative analysis.

All interviews were audio-recorded and transcribed verbatim, following the simplified/modified transcription convention by Gail Jefferson (Atkinson & Heritage, 1984; Potter & Wetherell, 1987; Seymour-Smith, et al., 2002), then imported into NVivo9 (QSR International Pty Ltd, Doncaster, Victoria, Australia) to facilitate analysis. Identifying information (including names of hospitals and participants) were changed. NVivo9 is a software program designed for organizing and analysing qualitative data material by creating nodes for coding, and classifying codes into sets, relationships, and themes.

As it is common practice when conducting a qualitative research study, data analysis began inductively during data collection (Pope & Mays, 2006), so that emerging concepts could be early discovered and further explored during the process of data collection. This also meant that during the process of data collection, the interview questions were refined to address findings derived from the preliminary analysis (Glaser, 1978). The first and final version of the interview schedules are to be found in Appendices F and G. Early data analysis also involved keeping a research journal (Grbich, 1999), where NK noted new ideas, interesting examples, any modification of the interview questions, as well as emerging concepts and explanations for the phenomenon of CAM use in men with cancer. Subsequent data analysis involved reading and rereading of each interview transcript, writing notes, and discussing patterns and concepts of the

interview data within the research team. Finally, all interview data were systematically analysed (Grbich, 1999; Rice & Ezzy, 1999).

Data were analysed according to discursive analytical principles (Potter & Wetherell, 1987), to identify patterns of meaning in participants' talk about CAM use after a diagnosis of cancer. Social constructionist (Berger & Luckmann, 1966; Kenneth J. Gergen, 2001; Kenneth J. Gergen, 2009) is the theoretical approach underpinning the specific technique of discourse analysis, an established method in analysing individuals' language as topic, to explore how they perceive, categorize, and interpret the social world as constructed through language (Edwards & Potter, 1992; Potter & Wetherell, 1987). By considering language as action-oriented, discursive analysis focuses on how people perform social actions via language in use, and how accounts vary with regard to specific situations and functions (Edwards & Potter, 1992; Potter & Wetherell, 1987).

According to Discursive Psychology (DP) (Edwards & Potter, 1992; Potter & Edwards, 2001), individuals' accounts do not reveal cognitive constructs such as attitudes and beliefs, indicating that their language in use should rather be studied as topic. This model of DP was a fundamental re-conceptualisation of cognitive psychology where individuals' accounts are taken to reflect their mental representations of the social world. In contrast, DP focuses, first, on actions done in discourse, and second, on individuals' reality and cognition, thereby aiming to identify "how events are described and explained, how factual reports are constructed, how cognitive states are attributed" (Edwards & Potter, 1992, p. 2).

Discursive Psychology (DP) provides a systematic framework for analysing interview data, particularly for understanding how individuals perform and construct their social world through interpretative repertoires (Potter & Wetherell, 1987) and subject positions (Davies & Harre, 1990). Interpretative repertoires (Billig, 1991; Edley, 2001; Potter & Wetherell, 1987) are descriptions, arguments and evaluations that everyone within a particular cultural group knows through a shared social consensus. Individuals make use of interpretative repertoires to give an account of and perform social life. Subject positions (Davies & Harre, 1990) are an individual's discursive strategy to position themselves within their stories and in relation to other people. Hence, identities are constructed through talk, interactions, and conversations, implying that identities may shift depending on relations and situations. In considering individual's language as epistemic and action-oriented, it is possible to examine how individuals' talk about attitudes,

memories, and emotions are constructed in talk, and what their social implications are. Data analysis according to discursive analytical principles enables the search for patterns, and formation of hypotheses based on consistencies and variations of language in use.

It has been noted that discourse analysis comprises a plurality of different methods with two distinct approaches identified (Willig, 1999b), namely conversation analysis (Atkinson & Heritage, 1984; Schegloff & Sacks, 1973), and Foucauldian or poststructuralist analysis (Foucault, 1973). The former approach examines talk in interactions, analysing what local talk is doing at each moment, considering language from a micro-perspective. The latter approach analyses language as part of a wider socio-cultural context, considering power relations and restrictions of what can be said and done. Although these two approaches have traditionally been positioned as opposition, this thesis applied a synthetic approach to discourse analysis, which combines these two traditions, so that analysis can focus on participants' talk in situ, and additionally take account of the wider socio-cultural context. Such an integrative strategy is increasingly applied in healthcare research (e.g., Edley, 2001; Elliott & Olver, 2007b, 2007c; Riley, 2002; Seymour-Smith & Wetherell, 2006; Seymour-Smith, et al., 2002). Results of Study 2 are reported in:

- Chapter Five (paper three [submitted for publication] – How social reasons impact on Complementary and Alternative Medicine (CAM) decision-making processes in men with cancer: a qualitative study),
- Chapter Six (paper four [submitted for publication] – How men with cancer and their significant others practice Complementary and Alternative Medicine (CAM): exploration of shared and private CAM use), and
- Chapter Seven (paper five [submitted for publication] – The routine and ritualized practice of Complementary and Alternative Medicine (CAM): individual and interpersonal implications in men affected with cancer).

CHAPTER THREE: PAPER ONE – PUBLISHED
(LITERATURE REVIEW)

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Author Contributions

By signing the Statement of Authorship, each author certifies that their stated contribution to the publication is accurate and that permission is granted for the publication to be included in the candidate's thesis.

Name of Principal Author	Jaklin Elliott	
Contribution to the Paper	Supervised work, interpreted and summarized data, wrote manuscript and acted as corresponding author.	
Signature		Date 11-04-13

Name of Co-Author (Candidate)	Nadja Klafke	
Contribution to the Paper	Performed literature review, interpreted and summarized data, and wrote manuscript.	
Signature		Date 10/04/13

This Chapter presents the results of the published integrative review of the literature about family involvement in cancer patients' decisions about CAM. This literature review summarizes the key literature related to family involvement in cancer patients' decisions about CAM; synthesizing the evidence from quantitative as well as qualitative studies to provide a comprehensive understanding about familial impact in patients' CAM decisions. Although there is anecdotal evidence that family members often participate in cancer patients' CAM decisions, this significant social process has not been systematically investigated in research studies. In summary then, this literature review seeks to set the foundation for the subsequent mixed-methods research that examines how family members impact on men's uptake and maintenance of CAM.

(Please see Appendix R for the published version of this manuscript.)

3.1 Abstract

Families of patients with cancer shape and share in the many and difficult decisions faced following diagnosis, with significant involvement in decisions regarding Complementary and Alternative Medicine (CAM). Such decisions may be particularly difficult due to conflicting opinions regarding CAM and relative lack of medical guidance. Family may act as information seekers, advocates, and/or roles models, either prompting, enabling, or discouraging CAM use by the patient. CAM use within a family may promote familial cohesion and functioning or increase familial distress and conflict. Where outcomes are poor, the ability of the family to care for themselves and the patient may be compromised, adding to the burden of cancer within the community. Some CAM may offer benefits to family members themselves, either with or without patient use. Evidence is lacking, however, regarding the effect of differences in the experiences or perceptions of CAM use by individuals in different familial relationships to the patient, or in differences associated with gender, socio-economic or geographical status, ethnic or cultural background, or non-traditional family structure. Little is known moreover about how families negotiate decisions about CAM, nor of the long-term consequences of these decisions upon family well-being and functioning. Such knowledge would enable clinicians to better advise patients and their families on treatment choices following a cancer diagnosis.

3.2 Introduction

Complementary and Alternative Medicine (CAM) use is common in cancer patients with evidence that, at least in breast cancer patients, CAM use has increased significantly over time (Boon, et al., 2007; Ernst & Cassileth, 1998). In Australia, the prevalence of CAM use in cancer patients has been reported to range from 22% to 82% (Begbie, Kerestes, & Bell, 1996; Miller, et al., 1998). There is a considerable body of research focusing on the reasons for, and socio-demographic or disease correlates of, CAM use in cancer patients (Bishop, Yardley, & Lewith, 2007; Verhoef, et al., 2005). Yet despite reported high prevalence rates, discussions about CAM infrequently occur in the oncology setting, such that patients are often left alone to seek information about CAM, and take responsibility for making safe and informed decisions (Öhlén, Balneaves,

Bottorff, & Brazier, 2006; Schofield, Diggins, Charleson, Marigliani, & Jefford, 2010; Schofield, Juraskova, & Butow, 2003; Truant & Bottorff, 1999).

It has been suggested that decisions about CAM are likely to be particularly difficult for patients, in part because there is conflicting information about CAM, as well as varying levels of support for, and divergent perceptions of CAM within scientific and lay discourse (Elliott, et al., 2008; Öhlén, et al., 2006; Truant & Bottorff, 1999). In making such decisions, patients often rely upon information provided by family members (Boon, Brown, Gavin, Kennard, & Stewart, 1999; Elliott, et al., 2008; M. Evans et al., 2007b). This is unsurprising given familial involvement in cancer care in general: family not only support, but shape and share in patients' decisions, with their involvement in the decision-making process desired and taken for granted (Elliott & Olver, 2007a; Thomas, Morris, & Harman, 2002). Following a cancer diagnosis, both patients and their families seek out information about treatment options, drawing on various sources such as medical staff, family, friends, and the Internet (Pecchioni & Sparks, 2007). Indeed, sometimes family members may be as, if not more, actively involved in searching for information regarding CAM than the patient: Boudioni (2001) reported that the majority of enquiries about CAM at a British cancer information service came from relatives and friends of patients (47.9%), and not from diagnosed patients themselves (35.2%). Evidence further suggests that family members can play a crucial role when cancer patients decide to use CAM instead of conventional medical treatment, decisions that may reduce the likelihood of cure (Montbriand, 1995b, 1998; Verhoef & White, 2002; White & Verhoef, 2003).

Within the medical literature on CAM, family are most commonly discussed in terms of important sources of information, but often within the category "family and friends" making accurate appraisal of their status difficult (Balneaves, Truant, Kelly, Verhoef, & Davison, 2007; Begbie, et al., 1996; Eng et al., 2003; Engdal, Steinsbekk, Klepp, & Nilsen, 2008; Hirai, et al., 2008; Porter, Kolva, Ahl, & Diefenbach, 2008). Nonetheless, Bennett's (2009) recent survey in New Zealand about information-seeking and CAM use in cancer patients indicated that surveyed patients mentioned "family and friends" most frequently as a primary information source. Similarly, a large European survey about CAM use in cancer patients reported that "friends" (56.5%) and "family" (29.1%) were most often named as information sources (Molassiotis, et al., 2005). Although friends appear to contribute information at a higher rate than family, family are likely to be more

affected by decisions made, and to have increased opportunities to support or subvert decisions (see Figure 3). Despite this, there are few studies explicitly examining familial involvement in making decisions about CAM, and none specifically exploring the consequences of those decisions upon the family.

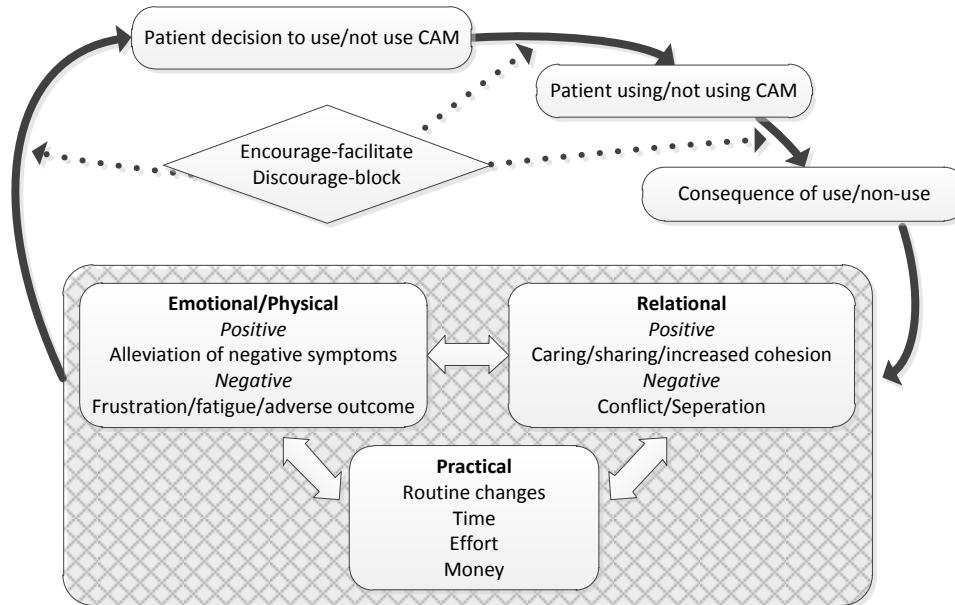


Figure 3. Familial involvement in patient decision-making about CAM

3.3 Family involvement in CAM decisions

Only one study conducted in Sweden has specifically examined the involvement of family in CAM decisions by cancer patients (Öhlén, et al., 2006). Based on interviews with 61 patients and 31 “significant others” (25 family, 6 friends), four types of “other” involvement were identified, all of which saw the family as acting to gather and review information. This process was often prompted by family members’ concern about the lack of evidence regarding CAM and consequent difficulties for the patient in making safe, informed choices. Some family chose to inform, but not overtly influence the patient’s decision, viewing this as a way of offering support and upholding patient autonomy. Others were more proactive in their assistance, particularly where they held concerns that fatigue or distress might lead patients to make a ‘wrong’ decision. Interventions varied from gentle suggestions to direct action to affect patient behaviour, sometimes taken without patient knowledge or consent (e.g., providing dietary supplements without patient knowledge). Some family members reported working collaboratively with the patient, sometimes mutually participating in chosen CAM practices, with

positive consequences including increased familial cohesion and reduced anxiety regarding CAM. Overall, patients in this study reported appreciating others' assistance in CAM decision-making, although it sometimes led to tension within their relationship. Some patients reported being bombarded with advice, causing feelings of resentment, anxiety, confusion, and guilt. Furthermore, while most patients invited family to participate in their decisions, some limited their discussions with family, either for fear of burdening them, or because patients characterised others as unwilling or unable to provide support. Finally, some patients acquiesced with family opinion or efforts, primarily in recognition of the caring it symbolised, some voicing concern that rejection of information given would be perceived as rejection of the informer.

Many of these themes emerge within other qualitative studies examining CAM use, though not explicitly focussing on familial involvement. An interview study about Chinese-Australians noted that most participants consulted a traditional Chinese herbalist because they were prompted to by family members or friends within the Chinese community, and another Canadian focus group study with women with breast cancer reported cases where family offered either financial or emotional support for participants' CAM use (Boon, et al., 1999; Chui, Donoghue, & Chenoweth, 2005). A further Australian interview study about treatment decision-making in palliative cancer patients reported instances wherein patients stated or implied that familial opinion influenced their decisions regarding CAM (Elliott, et al., 2008). Finally, a single case-study report from Sweden noted extensive familial involvement in a liver cancer patient's use of herbal tea, with her husband responsible for administering the tea after identifying, locating and purchasing it via the Internet (Hök, Wachtler, Falkenberg, & Tishelman, 2007).

Patients' evaluation and uptake of information provided by family, however, may vary dependant on disease or cultural characteristics. In a small qualitative study about CAM decision-making in cancer patients, Verhoef et al. (2007) reported that while new CAM users valued anecdotal information from family and friends, experienced CAM users tempered such advice with their own body knowledge, suggesting that information from family may become less valued over time, or with increased experience of disease and treatment. Similarly, patient responses to CAM introduced by family may be influenced by cultural beliefs about associations between particular CAM and gender roles (Broom & Tovey, 2008b). Broom and Tovey (2008b) documented how one male cancer patient described

his wife's introduction of aromatherapy to him, but rejected it, observing "Well, why would men want to do that?" (p. 132).

Sometimes family involvement in CAM use is problematic: in a qualitative study involving 26 families (including 37 patients with advanced lung cancer and 40 caregivers), Zhang and Siminoff (2003) reported three cases wherein patients reported familial coercion to take dietary supplements, with a further instance of a daughter who was physically and verbally insistent that her mother take vitamins. Since it is known that family members are often involved in patients' nutritional choices, some have asserted the importance of including and training family members as peer health educators in order to minimise the possibility of adversely comprising patient well-being (Bevan & Pecchioni, 2008; Macario, Emmons, Sorensen, Hunt, & Rudd, 1998; Maliski, Connor, Fink, & Litwin, 2006).

There is implicit evidence of familial involvement in cancer patients' CAM decisions in studies assessing "marital status" in CAM use, though there are differences across studies. For example, Fouladbakhsh et al. (2005) reported that American cancer patients who are separated or divorced are more likely to use CAM than married cancer patients, whereas Correa-Velez et al. (2003) found no difference in marital status between Australian CAM users and non-users, suggesting that CAM use was associated with the number of people living in the house of the cancer patient. In an earlier Australian study, Begbie et al. (1996) found that CAM use was positively associated with being married, also suggesting this may be linked to the number of household members, which in turn could stimulate and encourage people to try new things including CAM.

Further evidence of familial involvement in CAM decisions can be surmised in reports of paediatric cancer patients wherein parents administer CAM, with mothers typically primary in such decision-making (Laengler et al., 2008; Steinsbekk, Bentzen, & Brien, 2006). A recent systematic review indicated that CAM use, particularly use of herbs and dietary/nutritional supplementation, is common in children with cancer, with prevalence rates up to 91% (Bishop et al., 2010). Despite this, parents' decisions to use CAM for their diagnosed child often happens without the involvement of the paediatrician, and data regarding the decision-making processes and outcomes for families is sparse (Ottolini et al., 2001). Lorenc et al. (2009) recently observed that the field of CAM decision-making for children (with or without cancer) is under-theorised, recommending the use of qualitative methods to redress this. Adolescent use of CAM during cancer

treatment is similarly unexplored. A single study examining the use of CAM by adolescents without a cancer diagnosis reported that parental use of CAM significantly predicted its use in adolescents (Wilson & Klein, 2002). It was suggested that some adolescents are explicitly introduced to CAM use by their parents, while others imitate the self-care behaviour of their parents without direct recommendation. Data on such choices within the context of a cancer diagnosis is absent.

3.4 Consequences of CAM use in the family

Little is known about the prevalence of CAM use by family caregivers of cancer patients, of any impact on patient use, or on patient and/or familial well-being (Kozachik, Wyatt, Given, & Given, 2006). A study about CAM decisions by male cancer patients reported that female family members acted as role models and sources of information, prompting patients' use of CAM (M. Evans, et al., 2007a). Alternatively, some cancer patients who refuse conventional cancer treatment and use CAM instead, may do so because of experiences with close family members affected with cancer who died following biomedical treatment only (Verhoef & White, 2002). Only one American study by Kozachik et al. (2006) has explored the patterns of CAM use by cancer patients and their family caregivers following an 8-week nurse-delivered CAM intervention (guided imagery, reflexology, and reminiscence therapy). This study found that participants who chose to use a single CAM therapy used it more consistently over time, suggesting that it is easier to integrate a single CAM therapy into day-to-day life rather than several therapies.

Some studies support observations by Öhlén et al. (2006) that family provision of CAM might have beneficial consequences for the family, increasing familial cohesion through demonstration of caring for and about the patient, and increased opportunity for active involvement in patient care and treatment (Bishop & Yardley, 2004; Broom, 2009). Perceived positive effects of CAM use for the family has been reported by Broom and Tovey (2008b) who quote a female cancer patient as saying

I think that CAMs, they're such a benefit. Not just for the patient but they could be for the whole family. And when they saw that

their mother, father or husband or wife was coping better, it would make it easier to care for them. (p.114)

Potential benefit of CAM was similarly reported by a female cancer patient using and encouraging her spouse suffering with multiple sclerosis to use CAM, as she was convinced that it might also help him (Bishop & Yardley, 2004). It seems likely, moreover, that reported high levels of distress in caregivers might be helped through use of CAM found to improve psychological status, well-being, or overall quality of life in cancer patients, such as aromatherapy, exercise, guided imagery, massage, music therapy, Qigong, or Tai Chi (Ernst, 2010; Hodges, et al., 2005; Pitceathly & Maguire, 2003).

Some negative consequences for family of patient use of CAM have also been identified, and these may compromise the ability of the family to care for themselves and the patient, adding to the burden of cancer within the community. Broom and Tovey (2008a) applied an innovative solicited diary/unstructured interview approach to explore CAM user's experiences over time, observing that, for some cancer patients, the use of CAM incurred costs of time, money, and effort that sometimes proved onerous for the whole family. This was particular evident when CAM included adherence to a strict dietary regime. An American population-based study examining psycho-social correlates of CAM use in adults also reported that perceived spouse/partner strain and family strain were associated respectively with increased use of biologically-based therapies (including special dietary regimes) and manipulative body-based CAM (Honda & Jacobson, 2005). However, whether partner or family stress prompt CAM use or are a consequence of CAM use is unknown.

3.5 Issues for future research

Clearly there are significant gaps in our knowledge of CAM use within families facing a diagnosis of cancer. In addition to those alluded above, there has been no examination of whether there are differences in the perceptions or experiences of CAM use in spouses, siblings, or children of cancer patients, or the effect of any differences upon the use of CAM by patients themselves – despite evidence in other contexts that adult children can experience more conflict with regard to treatment decision-making than spouses of cancer patients (Kramer, Kavanaugh, Trentham-Dietz, Walsh, & Yonker, 2010).

Research examining these questions with regard to specific cancer diagnoses and stages, as well as gender, socio-economic status, and geographical location is similarly absent, as are studies examining CAM use within non-traditional families (e.g., same-sex or step/combined families, single parent or separated families, or those without partners) (Broom & Tovey, 2008b). Similarly, consideration of ethnic differences in familial involvement in CAM use (either with regard to patient or familial use or both) is vital in multicultural nations such as Australia, since the familial input into decision-making as well as perceptions about and use of CAM varies between ethnical and cultural groups (Kakai, Maskarinec, Shumay, Tatsumura, & Tasaki, 2003; Kwak & Haley, 2005; M. M. Lee, Chang, Jacobs, & Wrensch, 2002).

Finally, longitudinal studies investigating the nature, extent, and effect of positive and negative consequences of CAM use within the cancer patient's family, or examining how CAM use is negotiated within the family, are required. Knowing if, or under what circumstances, use of particular CAM (either by the patient or other family members) will likely add to familial distress and conflict, or alternatively, may promote familial cohesion and functioning – with inevitable impact on patient well-being – will enable clinicians to better advise patients and their families on treatment choices following a cancer diagnosis.

CHAPTER FOUR: PAPER TWO – PUBLISHED
(STUDY 1 SURVEY)

Statement of Authorship

Title of Paper	Prevalence and predictors of Complementary and Alternative Medicine (CAM) use by men in Australian cancer outpatient services
Publication Status	<input checked="" type="radio"/> Published <input type="radio"/> Accepted for Publication <input type="radio"/> Submitted for Publication <input type="radio"/> Publication Style
Publication Details	Klafke, N., Elliott, J., Wittert, G., & Oliver, I., (2012). Prevalence and predictors of complementary and alternative medicine (CAM) use by men in Australian cancer outpatient services. <i>Ann Oncol</i> , 23(6), 1571-1578

Author Contributions

By signing the Statement of Authorship, each author certifies that their stated contribution to the publication is accurate and that permission is granted for the publication to be included in the candidate's thesis.

Name of Principal Author (Candidate)	Nedja Klafke	
Contribution to the Paper	Performed analysis on all samples, interpreted data, wrote manuscript and acted as corresponding author.	
Signature		Date 10/04/13

Name of Co-Author	Jaklin Effott	
Contribution to the Paper	Supervised development of work, helped in data interpretation and manuscript evaluation.	
Signature		Date 11-04-13

Name of Co-Author	Gary Wittert	
Contribution to the Paper	Helped to evaluate and edit the manuscript.	
Signature		Date 23-05-13

Name of Co-Author	Ian Oliver	
Contribution to the Paper	Helped to evaluate and edit the manuscript.	
Signature		Date 20/5/13

This Chapter presents the published results (see Appendix S) of the first empirical study in this research program about male cancer patients' use of CAM. It is a quantitative investigation to provide an overview about the prevalence of CAM, the most popular CAMs, and to present which CAMs have been discussed within the cancer patients' social network.

A survey has been designed and distributed to 428 Australian men affected with cancer, a convenience sample of consecutive patients visiting two public and two private outpatient cancer clinics in Metropolitan Adelaide. The results indicate that the majority of male cancer patients (61.5%) have experience with CAM at some point during their cancer treatment, while more than half of the study sample (52.9%) was currently using CAM whilst receiving conventional medical treatment. Multivariate logistic regression analysis identified metastatic cancer ($p = 0.022$), actively practising religion ($p = 0.008$), and tertiary education ($p = 0.007$) as independent predictors of men's CAM use. The most popular CAM treatments were dietary supplements (36.1%), prayer (25.9%), herbs and botanicals (21.4%), and relaxation techniques/meditation (15.2%). It was also shown that family were the most frequent providers of information about CAM, and were significantly more often involved in patients' discussions about CAM use than medical professionals. In summary, this study is the first to specifically assess CAM use by men with a variety of cancers in Australia, and it is one of the few representative studies available about men's use of CAM during cancer treatment. The study also discusses Lazarus and Folkman's (1984; 1999) coping model to explain the findings and further explore the research questions, aiming to understand why and how a substantial number of men decide to use therapies outside the conventional medical system.

(Please see Appendix S for the published version of this manuscript.)

4.1 Abstract

Background

Although studies have shown that complementary and alternative medicine (CAM) use is common in cancer patients, no survey has assessed CAM use in men with a variety of cancers. In Australia, no data exist about male cancer patients' use of CAM.

Patients and methods

A self-administered questionnaire was completed by 403 men attending four cancer outpatient services in Metropolitan Adelaide. Data were analysed using Pearson χ^2 tests and multivariate logistic regression analysis.

Results

CAMs were currently used by 52.9%, or used at some point by 61.5%, of respondents. The most popular CAM treatments were dietary supplements (36.1%), prayer (25.9%), herbs and botanicals (21.4%), and relaxation techniques/meditation (15.2%). CAM use was directed by a cancer specialist in 9.9% of respondents. Independent predictors of CAM use were metastatic cancer ($p = .022$), actively practising religion ($p = .008$), and tertiary education ($p = .007$).

Conclusion

CAM use in males is equally common across all cancer diagnoses, namely prostate, haematological malignancies, colorectal, lung and other cancers. Oncologists should be aware that a third of male patients modify their diet and/or search for spiritual guidance, particularly when diagnosed with metastatic cancer.

Keywords

alternative medicine, Australia, complementary medicine, male cancer patients, outpatients, prevalence

4.2 Introduction

Complementary and Alternative Medicines (CAMs) are defined as “diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine” (National Center for Complementary and Alternative Medicine, 2013). There is some data to suggest that, as a complement to conventional treatment, their use may be beneficial to reduce common treatment side-effects and disease symptoms (Deng, Cassileth, & Yeung, 2004; Deng, et al., 2009; Ernst, 2010). For example, acupuncture and acupressure may relieve chemotherapy-induced nausea and vomiting (Bao, 2009; Klein & Griffiths, 2004), and cancer-related pain can be reduced by acupuncture (Pan, et al., 2000), hypnosis (Bardia, et al., 2006), therapeutic touch (Jain & Mills, 2010), and massage (Pan, et al., 2000). Exercise (Cramp & Daniel, 2008), therapeutic touch (Aghabati, Mohammadi, & Pour Esmail, 2008), meditation and relaxation techniques (Carlson & Garland, 2005) benefit fatigue.

There is also evidence that CAMs contribute to mental health and emotional well-being in cancer patients. Yoga (Moadel, et al., 2007), meditation (Carlson & Garland, 2005), and exercise (Conn, et al., 2006) help to reduce stress in cancer patients and contribute to patients’ quality of life. Meditation and relaxation techniques (Carlson & Garland, 2005; Smith, et al., 2005) can also reduce anxiety and depressive symptoms in cancer patients.

The popularity of CAM use in cancer sufferers presumably reflects the benefits, real or perceived, by those who use them. In a 1998 systematic review including 26 surveys from 13 countries, between 7% to 64% (average of 31.4%) of adult cancer patients used CAMs (Ernst & Cassileth, 1998). There is evidence that rate of CAM use has increased, at least in breast cancer populations, from 67% to 82% during the years 1998-2005 (Boon, et al., 2007). In the USA, where most studies relating to CAM use have been conducted, up to 90% of cancer patients use CAM (Fouladbakhsh, et al., 2005; Patterson, et al., 2002; Rausch et al., 2010; Richardson, et al., 2000; J. Yates et al., 2005). In Australia, there are limited data available for cancer patients’ use of CAM; older studies reported that they are used by 22% to 85% of patients (Begbie, et al., 1996; Miller, et al., 1998). Recent studies, ranging in size from 200 to 381 participants, reported that 30% to 65% of cancer patients use CAM (Oh, Butow, Mullan, Beale, et al., 2010; C. Pirri et al., 2008). Among CAM users, 61% were breast cancer patients, consistent with the

observation that the majority of studies relating to CAM use in cancer sufferers have been undertaken in women (Boon et al., 2000; Burstein, Gelber, Guadagnoli, & Weeks, 1999; Molassiotis et al., 2006). North American and European surveys including men, almost exclusively those with prostate cancer, suggest that CAM use in men ranges from 25% to 40% (Eng, et al., 2003; Ponholzer, Struhal, & Madersbacher, 2003; Wilkinson, Farrelly, Low, Chakraborty, & Williams, 2008). In patients (mostly men) with head and neck cancer, CAM use has been reported to be under 25% (Amin et al., 2010; Warrick et al., 1999).

The objective of this study was to determine, in men attending Australian cancer outpatient services, (i) the extent and types of CAM used (ii) the socio-demographic, personal, and clinical characteristics associated with use of CAM, and (iii) to identify which CAMs have been discussed within the cancer patient's social network.

4.3 Patients and methods

4.3.1 Participants.

A consecutive series of males with cancer receiving chemotherapy or/and radiotherapy at two public and two private outpatient cancer clinics in Adelaide, South Australia, were approached by the researcher NK and asked to complete a questionnaire. Additional inclusion criteria included age over 18 years, ability to provide informed consent, and communicate in English. Those who were particularly unwell were excluded. The study was approved by the Human Research Ethics Committees at both hospitals and The University of Adelaide.

4.3.2 Questionnaire.

The research team used a modified version of two questionnaires published by Richardson et al. (2000) and Miller et al. (1998). The questionnaire was developed through a systematic literature review, discussions by experienced medical oncologists and health professionals, and input from a cancer advocacy organisation.

The first section of the questionnaire asked patients about socio-demographic details. The second section assessed patients' use of CAM. Categories of CAM (see Tables 8 and 9 for full list) were based on the widely established taxonomy of the National Center for Complementary and Alternative

Medicine (NCCAM) (2013) but also included CAM described within the literature as used by cancer patients to help manage or cope with their disease or treatment side-effects, including prayer, psychological therapies, support groups, and physiotherapy. In the third section, patients indicating having ever used any CAM (i.e., CAM users, CAM ex-users) were specifically asked: which of the CAM therapies (to a maximum of three) they used had evoked the strongest reaction in other people; the information source for this CAM; and, who was involved in any discussions about its use. In the fourth section, all patients were asked which CAM therapy anyone suggested they should use, but they did not use.

Demographic information collected included birth date, marital status, country of birth, postcode, religion, actively practising religion, education level, and private health insurance. Socio-economic status (SES) was determined from the Australian Bureau of Statistics (ABS) (2006) Socio-economic Index of relative socio-economic advantage and disadvantage (SEIFA). The postcode of patients' residence was used to allocate a SEIFA score ranging from 1 to 10, with a lower score indicating more social and economic disadvantage. These scores were used to create the categories of the variable SES: SEIFA scores 1-3, 4-7, 8-10, were classified as low, moderate, and high SES, respectively. Patient postcode was also used to allocate Rural, Remote, and Metropolitan Area (RRMA) scores developed by the Australian Government Department of Health and Ageing (AIHW, 2004). The three zones of the RRMA classification were used as categories for the variable geographical area. The variable education consisted of the categories primary, secondary (year 10, year 12), and tertiary (tertiary non-University, tertiary University, post-grad) education. Medical information (type of cancer, stage of cancer, past and present medical treatment received) was extracted from patients' medical records within the clinics' databases.

4.3.3 Statistical analysis.

Differences between CAM users and nonusers with regard to socio-demographic (age group, relationship status, country of birth, geographical area, religion, private health insurance, SES, actively practising religion, education) and medical variables (type of cancer, past and present medical treatment, stage of cancer) were assessed using Pearson χ^2 tests. All variables were categorical.

Significant variables ($p < .05$) were analysed in univariate and multivariate logistic regression analyses to assess their association with general use of CAM

(coded as a dichotomous outcome variable), as well as with specific CAM categories. All analyses provided an odds ratio and were reported with 95% CI (confidence interval) for each variable. *P* values were two-sided.

The multivariate logistic regression analysis was conducted by using the forced entry method. This is an appropriate method for theory testing, in which all potential predictor variables are put into one block to analyse their own contribution to the final model while simultaneously controlling for the effect of other variables (Tabachnik & Fidell, 2007b). Finally, the Hosmer-Lemeshow χ^2 test was performed to assess how well the predictors fit the model (Hosmer & Lemeshow, 2000). Since this statistic tests the hypotheses that the predicted outcomes differ significantly from the observed outcomes, a *P* value > .05 is considered a good fit. All data analyses were conducted by using the Statistical Package for Social Science (SPSS) software program (PASW Statistics 17).

4.4 Results

4.4.1 Response rate and prevalence of CAM.

Between November 22, 2010 and February 22, 2011, 428 male patients were identified as eligible and invited to participate. Of this convenience sample of consecutive patients, 403 completed (94% response rate) the questionnaire. Forty-nine percent of study participants were aged 61-75 years, with a median age of 66 years. The sample represented a varied cancer population including 18.9% haematological malignancies, 18.9% prostate cancer, 18.9% colorectal cancer, 11.4% lung cancer, and 33.5% other cancer types.

In this male cancer population, 81.4% reported that they had heard about using CAM as a complement for cancer treatment, 61.5% reported that they have experience with CAM during cancer treatment, and 52.9% indicated that they were currently using CAM while receiving conventional medical treatment.

4.4.2 Differences between CAM users and nonusers.

By χ^2 tests CAM users differed from nonusers with regard to four variables: stage of cancer ($p = .045$), SES ($p = .047$), actively practising religion ($p < .001$), and education ($p = .043$) (see Table 2). There were no differences with respect to type of cancer, past and present medical treatment, cancer clinic, hospital, age

group, relationship status, country of birth, geographical area, religion, and private health insurance.

Univariate logistic regression analyses indicated that patients with metastatic cancer were 1.54 times (95% CI 1.03-2.31, $p = .035$) more likely to use CAM than patients with non-metastatic cancer; patients of moderate SES were 1.84 times (95% CI 1.13-2.98, $p = .014$) more likely to use CAM than patients with lower SES; patients actively practising religion were 4.79 times (95% CI 2.72-8.43, $p < .001$) more likely to use CAM than patients not actively practising religion; and patients with primary education were less likely (95% CI 0.36-0.9, $p = .016$) to use CAM than patients with tertiary education (see Table 3).

Table 2

Differences between CAM users and nonusers

Variable	All Respondents (n=403) (%)	CAM users (n=248) (%)	CAM nonusers (n=155) (%)	χ^2	Degrees of Freedom	<i>p</i>
Stage of cancer				4.034	1	0.045
Non-metastatic	50.1	28.3	21.8			
Metastatic	49.9	33.3	16.6			
Socio-economic status				6.123	2	0.047
Low	28.9	15.2	13.7			
Moderate	42.3	28.4	13.9			
High	28.8	17.9	10.9			
Actively practising religion				31.693	1	0.001
No	73	38.7	34.2			
Yes	27	22.8	4.2			
Education				6.302	2	0.043
Primary	17.1	9.9	7.2			
Secondary	44.9	25.3	19.6			
Tertiary	38	26.3	11.7			

Note. CAM users and nonusers did not differ on type of cancer (prostate, haematological malignancies, colorectal, lung, other), past and present medical treatment, cancer clinic, hospital (private, public), age group (25-45 years, 46-60 years, 61-75 years, 76-90 years), relationship status (living with spouse/partner, not living with spouse/partner), country of birth, geographical area (rural/remote, metropolitan), religion (none, Christian, other), private health insurance.

Table 3

Predictors of CAM use

Variable	CAM users (n=248) (%)	Univariate analysis			Multivariate analysis		
		OR	95% CI	p	OR	95% CI	p
Stage of cancer							
Non-metastatic	28.3	1.0	(Ref)		1.0	(Ref)	
Metastatic	33.3	1.54	1.03-2.31	0.035	1.68	1.08-2.61	0.022
Socio-economic status							
Low	15.2	1.0	(Ref)	0.048	1	(Ref)	0.213
Moderate	28.4	1.84	1.13-2.98	0.014	2.71	0.84-8.72	0.094
High	17.9	1.48	0.88-2.49	0.145	1.08	0.23-4.95	0.923
Actively practising religion							
No	38.7	1.0	(Ref)		1.0	(Ref)	
Yes	22.8	4.79	2.72-8.43	0.001	4.92	1.51-16.07	0.008
Education							
Primary	9.9	0.57	0.36-0.9	0.016	1.0	(Ref)	0.003
Secondary	25.3	0.61	0.34-1.1	0.102	0.86	0.31-2.45	0.784
Tertiary	26.3	1	(Ref)	0.044	5.54	1.58-19.4	0.007
Education (primary) by socio-economic status (low)							
Tertiary education by moderate socio-economic status					0.14	0.027-0.675	0.015

CAM users and nonusers of the CAM category *mind-body medicine* differed (χ^2 , $p < .05$) with regard to actively practising religion, education, SES, geographical area, religion, and hormonal therapy (see Table 4). This analysis was repeated excluding psychology/counselling, support groups, and prayer as some have suggested that these therapies do not belong to CAM, with differences found (χ^2 , $p < .05$) with regard to age group, education, and actively practising religion (see Table 5). There were no differences (χ^2 , $p > .05$) found in the use of different CAM categories, or the use of the most popular CAM therapies with regard to type of cancer.

Table 4

Differences between users and nonusers of the CAM category mind-body medicine

Variable	All Respondents (n=403) (%)	Users of mind-body medicine (n=170) (%)	Nonusers of mind- body medicine (n=233) (%)	χ^2	Degrees of Freedom	<i>p</i>
Actively practising religion				61.443	1	0.001
No	73	22.1	50.9			
Yes	27	20.1	6.9			
Education				12.19	2	0.002
Primary	17.1	6.7	10.4			
Secondary	44.9	15.4	29.5			
Tertiary	38	20.1	17.9			
Socio-economic status				7.437	2	0.024
Low	28.9	9.7	19.2			
Moderate	42.3	20.9	21.4			
High	28.8	11.4	17.4			
Geographical area				4.29	1	0.038
Rural/remote	27.6	9.2	18.4			
Metropolitan	72.4	32.8	39.6			
Religion				7.439	2	0.024
None	29.6	9.1	20.5			
Christian	69.5	31.6	37.9			
Other	1	0.5	0.5			
Hormonal therapy				4.237	1	0.04
No	93.1	38	55.1			
Yes	6.9	4.2	2.7			

Note. Users and nonusers of the CAM category mind-body medicine did not differ on type of cancer (prostate, haematological malignancies, colorectal, lung, other), stage of cancer (non-metastatic, metastatic), cancer clinic, hospital (private, public), age group (25-45 years, 46-60 years, 61-75 years, 76-90 years), relationship status (living with spouse/partner, not living with spouse/partner), country of birth, private health insurance.

Table 5

Differences between users and nonusers of the CAM category mind-body medicine (excluding psychology/counselling, support groups, prayer)

Variable	All Respondents (n=403) (%)	Users of mind-body medicine (n=97) (%)	Nonusers of mind- body medicine (n=306) (%)	χ^2	Degrees of Freedom	p
Age group				16.337	3	0.001
25-45 years	7.2	3	4.2			
46-60 years	25.3	8.4	16.9			
61-75 years	48.9	10.4	38.5			
76-90 years	18.6	2.2	16.4			
Education				25.25	2	0.001
Primary	17.1	1.7	15.4			
Secondary	44.9	8.2	36.7			
Tertiary	37.9	14.1	23.8			
Actively practising religion				4.7	1	0.022
No	73	15.4	57.6			
Yes	27.1	8.7	18.4			

Note. CAM users and nonusers of the CAM category mind-body medicine (excluding psychology/counselling, support groups, prayer) did not differ on type of cancer (prostate, haematological malignancies, colorectal, lung, other), stage of cancer (non-metastatic, metastatic), socio-economic status (low, moderate, high), past and present medical treatment, cancer clinic, hospital (private, public), relationship status (living with spouse/partner, not living with spouse/partner), country of birth, geographical area (rural/remote, metropolitan), religion (none, Christian, other), private health insurance.

4.4.3 Predictors of CAM use.

When the four potential predictor variables (stage of cancer, SES, actively practising religion, education), and two interactions between the potential predictors (education by SES, actively practising religion by education) were entered into a multivariate logistic regression model, use of CAM was predicted ($\chi^2(12) = 64.16$; $p < .001$) by stage of cancer, actively practising religion, and education only (see Table 3). The interaction education by SES was significant ($p = .025$), while actively practising religion by education was not significant ($p = .784$) in the multivariate analysis.

Patients with metastatic cancer were 1.68 times (95% CI 1.08-2.61, $p < .022$) more likely to use CAM than patients with non-metastatic cancer; patients actively practising religion were 4.92 times (95% CI 1.51-16.07, $p < .008$) more likely to use CAM than patients not actively practising religion; and patients with tertiary education were 5.54 times (95% CI 1.58-19.04, $p < .007$) more likely to use CAM than patients with primary education. The multivariate logistic regression model suggested a satisfactory fit ($\chi^2(8) = 6.9$; $p = .55$) between the predicted and observed outcomes for the final model.

Within the category *mind-body medicine*, CAM use was predicted ($\chi^2(15) = 94.94$; $p < .001$) by actively practising religion ($p = .01$), and tertiary education ($p = .016$) only (see Table 6). The interaction effect education by SES was significant ($p = 0.037$), while the interaction actively practising religion by education was not significant ($p = 0.383$) in the multivariate analysis. The final model indicated a satisfactory fit ($\chi^2(7) = 2.78$; $p = .91$) between obtained and observed outcomes. When psychology/counselling, support groups, and prayer were excluded, use of mind-body medicine was predicted ($\chi^2(11) = 48.84$; $p < .001$) by younger age group ($p = .007$) and higher education ($p = .039$) (see Table 7). Both interactions actively practising religion by education ($p = .607$), and actively practising religion by age group ($p = .572$) were not significant in the multivariate analysis. A satisfactory fit ($\chi^2(7) = 1.99$; $p = .96$) between the obtained and expected outcomes for the final model was obtained.

Table 6

Predictors of CAM use - category mind-body medicine

Variable	Users of mind-body medicine (n=170) (%)	Univariate analysis			Multivariate analysis		
		OR	95% CI	p	OR	95% CI	p
Actively practising religion							
No	22.1	1.0	(Ref)		1.0	(Ref)	
Yes	20.1	6.66	4.06-10.95	0.001	4.33	1.41-13.3	0.01
Education							
Primary	6.7	1.0	(Ref)	0.002	1.0	(Ref)	0.001
Secondary	15.4	0.81	0.46-1.44	0.472	0.48	0.13-1.75	0.267
Tertiary	20.1	1.75	0.98-3.12	0.058	4.68	1.33-16.45	0.016
Socio-economic status							
Low	9.7	1.0	(Ref)	0.025	1.0	(Ref)	0.488
Moderate	20.9	1.93	1.18-3.14	0.008	1.87	0.57-6.17	0.304
High	11.4	1.3	0.76-2.22	0.341	0.9	0.18-4.52	0.894
Geographical area							
Rural/remote	9.2	1.0	(Ref)		1.0	(Ref)	
Metropolitan	32.8	1.66	1.05-2.62	0.03	1.67	0.9-3.11	0.108
Religion							
None	9.1	1.0	(Ref)	0.026	1.0	(Ref)	0.716
Christian	31.6	1.88	1.19-2.97	0.007	1.22	0.72-2.1	0.461
Other	0.5	2.25	0.31-16.61	0.427	0.84	0.1-7.51	0.878
Hormonal therapy							
No	38	1.0	(Ref)		1.0	(Ref)	
Yes	4.2	2.24	1.02-4.92	0.044	2.11	0.88-5.1	0.096
Education (tertiary) by socio-economic status (low)							
Primary education by moderate socio-economic status					1.0	(Ref)	0.037
					9.11	2.31-36.01	0.002

Table 7

Predictors of CAM use - category mind-body medicine (excluding psychology/counselling, support groups, prayer)

Variable	Users of mind-body medicine (n=97) (%)	Univariate analysis			Multivariate analysis		
		OR	95% CI	p	OR	95% CI	p
Age group							
25-45 years	3	1.0	(Ref)	0.001	1.0	(Ref)	0.004
46-60 years	8.4	0.71	0.30-1.65	0.424	0.61	0.24-1.59	0.313
61-75 years	10.4	0.38	0.17-0.87	0.021	0.26	0.1-0.68	0.006
76-90 years	2.2	0.19	0.07-0.53	0.002	0.18	0.05-0.63	0.007
Education							
Primary	1.7	1.0	(Ref)	0.001	1.0	(Ref)	0.013
Secondary	8.2	1.98	0.83-4.7	0.124	1.47	0.47-4.62	0.511
Tertiary	14.1	5.26	2.25-12.27	0.001	3.3	1.06-10.23	0.039
Actively practising religion							
No	15.4	1.0	(Ref)		1.0	(Ref)	
Yes	8.7	1.77	1.08-2.89	0.022	0.45	0.03-6.45	0.558

4.4.4 Types of CAM used by patients.

The frequencies of all CAM therapies used are listed in Tables 8 and 9. The most popular CAM was dietary supplements: 26.6% of participants were currently using products ranging from Aloe Vera to vitamins concurrent with conventional medical treatment, and 36.6% used them at some stage. A further 19.7% had heard about its use during cancer treatment. Regarding other most popular CAMs, between 15% and 26% of respondents reported having ever used prayer, herbs and botanicals, and relaxation techniques/ meditation during cancer treatment.

Table 8 specifically highlights those natural products which are known to interact with conventional medical treatment. Clinicians should advise their patients that, for example, Echinacea or St John's wort, might interact with chemotherapy agents (Clarke & McLachlan, 2011), and Ginseng or Gingko biloba with other prescribed medication (Carlo Pirri, 2011).

Table 8

Types of CAM used by patients - category natural products

<u>CAM use overall</u>				Heard about CAM for use during cancer treatment (n=328) (81.4%)	Used CAM during cancer treatment (n=248) (61.5%)	Still using CAM during cancer treatment (n=213) (52.9%)
<u>Natural products</u>						
Herbs and botanicals						
				114 (28.4)	28 (7)	58 (14.4)
Aloe Vera	Echinacea	Ginkgo biloba	Mistletoe	Stinging nettle		
Astragalus	Essiac	Gotu kola	Olive leaf extract	St John's wort		
Bach plants	Flaxseed	Green tea	PSK mushroom			
Boswellia	Garlic	Kombucha	Saw Palmetto			
Cat's claw	Ginseng	Marihuana	Seaweed extract			
Chamomile	Ginger	Mint	Shitake mushroom			
Natural medication						
				94 (23.4)	12 (3)	9 (2.2)
Cansema, black salve	Royal Jelly					
Laetrile	Shark cartilage					
Special diet						
				99 (24.6)	9 (2.2)	25 (6.2)
Alkaline food diet	Pritikin diet					
Gerson diet	Vegetarian diet					
Macrobiotic diet	Vegan diet					

Table 8 (continued)

<u>CAM use overall</u>			Heard about CAM for use during cancer treatment (<i>n</i> =328) (81.4%)	Used CAM during cancer treatment (<i>n</i> =248) (61.5%)	Still using CAM during cancer treatment (<i>n</i> =213) (52.9%)
Dietary supplements			79 (19.7)	40 (10)	107 (26.6)
Aloe Vera + honey drink	Glucosamine	Nutra-Life Prostate Complete			
Carb Soda / Maple Elixer	Jason Winters Tea + Tablets	Pectin			
Dr Red Ginger Prostate Formula	Mannatech products	Rye bread and canned tuna			
Fruit juicing	Minerals	Vitamins			
Apple juice Asparagus juice Beetroot juice Carrot juice Cranberry juice Noni juice Pomegranate juice	Entelev 50 MMS (Miracle Mineral Supplement) Percy's Powder Silver	Vitamin B6 Vitamin D3 Vitamin E			

Note. Natural products where caution is suggested because of interaction with biomedical treatment or/and because of toxicity are highlighted in bold italic.

Table 9

Types of CAM used by patients - categories mind-body medicine, manipulative and body-based practices, and other CAM

<u>CAM use overall</u>	Heard about CAM for use during cancer treatment (n=328) (81.4%)	Used CAM during cancer treatment (n=248) (61.5%)	Still using CAM during cancer treatment (n=213) (52.9%)
<u>Mind-body medicine</u>			
Relaxation techniques/ meditation	104 (25.9)	16 (4)	45 (11.2)
Prayer	78 (19.4)	18 (4.5)	86 (21.4)
Psychology and counselling	121 (30.1)	19 (4.7)	17 (4.2)
Support groups	149 (37.1)	13 (3.2)	18 (4.5)
Journaling	43 (10.7)	5 (1.2)	16 (4)
Imagery techniques	41 (10.2)	10 (2.5)	11 (2.7)
Hypnotherapy	78 (19.4)	4 (1)	3 (0.7)
Aromatherapy	69 (17.2)	2 (0.5)	0 (0)
Biofeedback	33 (8.2)	0 (0)	0 (0)
Art/ music/ dance therapy	48 (11.9)	9 (2.2)	21 (5.2)
Yoga	98 (24.4)	2 (0.5)	3 (0.7)
Tai Chi	82 (20.4)	2 (0.5)	4 (1)

<u>Manipulative and body-based practices</u>			
Reflexology	59 (14.7)	3 (0.7)	6 (1.5)
Kinesiology	32 (8)	4 (1)	0 (0)
Osteopathy	37 (9.2)	2 (0.5)	1 (0.2)
Chiropractic	61 (15.2)	9 (2.2)	8 (2)
Massage therapy	84 (20.9)	8 (2)	22 (5.5)
Physiotherapy	76 (18.9)	16 (4)	8 (2)
Acupuncture/acupressure	85 (21.1)	15 (3.7)	5 (1.2)

<u>Other CAM</u>			
Acupuncture/ acupressure	85 (21.1)	15 (3.7)	5 (1.2)
Homeopathy	60 (14.9)	2 (0.5)	2 (0.5)
Naturopathy	84 (20.9)	9 (2.2)	15 (3.7)
Exercise techniques	50 (12.4)	10 (2.5)	39 (9.7)
Reiki	40 (10)	8 (2)	5 (1.2)
Magnets	64 (15.9)	5 (1.2)	3 (0.7)
Therapeutic touch	34 (8.5)	2 (0.5)	1 (0.2)
Crystal healing	40 (10)	2 (0.5)	3 (0.7)

<u>Other CAM (specified by patients)</u>			
Bowen therapy			
DCA (dichloroacetate)			
Dowsing			
Gardening			
Heat therapy			
Machines			
Radiowave therapy			
Seawater			
Snake venom			

4.4.5 Which CAMs have been discussed, and used by patients.

Only 9.9% of patients reported that their cancer specialist referred them to use CAM. CAM users and ex-users specified up to three therapies which they have discussed with other people: dietary supplement use was mentioned most often, namely by 29% of male CAM users and ex-users, followed by herbs and botanicals (16%), prayer (13.5%), and relaxation techniques/meditation (13%). Nonparametric χ^2 tests ($\chi^2 = 46.11$, 6 df, $p < .001$) indicated that family (35.8%) most often provided information about CAM treatments compared to friends (29.2%), medical professionals (23.1%), other sources (19.9%), media (8.5%), cancer patients (7.6%), and the Internet (4.3%). Family members (85.7%) were significantly more often ($\chi^2 = 10.78$, 1 df, $p < .001$) involved in patients' discussions about CAM use than medical professionals (48.4%) including also healthcare staff other than oncologists and haematologists.

Information sources differed with regard to type of CAM: the use of dietary supplements was significantly more often ($\chi^2 = 68.31$, 6 df, $p = .001$) informed by family (46%), compared to medical professionals (30%), friends (22%), media (15%), other sources (12%), cancer patients (6%), and the Internet (4%). Users of herbs and botanicals were significantly more often ($\chi^2 = 29.19$, 3 df, $p = .001$) informed by friends (43%), compared to family (38%), media (8%), cancer patients (8%), the Internet (8%), other (8%), and medical professionals (5%). Patients using prayer found information about its use significantly more often ($\chi^2 = 42.39$, 3 df, $p = .001$) provided by family (55%), compared to other sources (39%), friends (24%), medical professionals (3%), and the media (3%).

4.4.6 Which CAMs have been discussed, but not used by patients.

All participants – CAM users, ex-users, and nonusers – specified one CAM therapy which was strongly recommended by other people, but not used by the patient: dietary supplement use was mentioned by 3.5% of the whole study sample, followed by herbs and botanicals (2%), and natural medication (1.5%). Nonparametric χ^2 tests ($\chi^2 = 125.3$, 6 df, $p < .001$) revealed that friends (63.1%) most often provided information about CAM therapies not used by the patients, followed by family (30.8%), medical persons (13.8%), media (12.3%), cancer patients (10.8%), Internet (9.2%), and other sources (3.1%).

4.5 Discussion

This study is the first to specifically assess CAM use by men with a variety of cancers in Australia, and it is one amongst the few representative studies available about men's use of CAM during cancer treatment. Previous North American and European studies specifically looking at the use of CAM by men have only included prostate and head and neck cancer patients. The observation that two thirds of the surveyed population had ever used CAM during cancer treatment, is similar to recent data from cancer patients (men and women) in Sydney, Australia (Oh, Butow, Mullan, Beale, et al., 2010), but higher than that reported in previous studies which included men only (Amin, et al., 2010; Eng, et al., 2003; Ponholzer, et al., 2003; Warrick, et al., 1999; Wilkinson, et al., 2008). This may be influenced by the overall increase in the popularity of CAM since the 1990s (ABS, 2008; Eisenberg, et al., 1998). Despite advances in medical treatment for cancer that have seen improvements in cure rates and survivorship (AIHW, 2010c) the incidence of cancer is increasing, and it remains a leading cause of death (WHO, 2012). At the same time, the use of CAM has increased in the cancer population (Boon, et al., 2007). From a clinical perspective, it is important to know why a substantial and increasing number of cancer patients decide to use treatments in addition to, but independent of the conventional medical system.

Several reasons for cancer patients' use of CAM have been suggested, including perceived benefit from CAMs, wanting control about cancer diagnosis and its treatment, belief in the effectiveness of CAM, using CAM to try everything possible to increase survival, and receiving hope from CAM use. Cancer patients' use of CAM might also be explained with Lazarus and Folkman's (1984; 1999) theory about stress and coping. According to these authors, coping is important for patients' functioning in daily life despite a chronic illness. They identified two general types of coping strategies: problem-solving efforts and emotion-focused coping. The use of dietary supplements, or herbs and botanicals might reflect an attempt to ameliorate disease related symptoms or side-effects of treatment. Practising prayer, or meditation techniques/relaxation might constitute emotion-focused coping, as patients embark on a spiritual search for meaning of life. Alternatively, Furnham and Smith (1988) have suggested that patients are either: 1) *pushed* toward CAM because of dissatisfaction with conventional medical

treatment, or 2) *pulled* toward CAM because their philosophical beliefs and values are congruent with the paradigm proposed by CAM treatments. There are conflicting results within the academic literature regarding whether men with prostate cancer are pushed or pulled toward the use of CAM: Boon et al. (2003) indicated in a qualitative focus group study that prostate cancer patients seem to be more *pushed* rather than *pulled* toward CAM. In contrast, Porter and Diefenbach (2009) reported that CAM use in men with prostate cancer is better predicted by positive representations of CAM (pulling effect) than by negative representations of conventional medicine (pushing effect). The current study suggests that CAM use in males is widespread and common, not only in prostate cancer patients, but across all cancer types. More research is needed to better understand why a substantial number of men with cancer use CAM. While neither push nor pull factors appear to affect decisions about CAM use amongst breast cancer patients (Boon, et al., 1999), push factors appear important in prostate cancer patients' choice to use CAM (Boon, Westlake, et al., 2003). Other data suggests that male cancer patients used CAM because of dissatisfaction with conventional treatment, related more to the social and emotional process of care than the treatment itself, or because of a strong spousal influence (M. Evans, et al., 2007a). The current study supports the finding that significant others are involved in cancer patients' decision to use CAM (Öhlén, et al., 2006). The data show that information from friends is more likely to inform than promote use of CAMs whereas a recommendation from family members is more likely to be followed.

The study highlights that dietary supplements, prayer, herbs and botanicals, and relaxation techniques/meditation are the most popular CAM therapies in this male cancer population. It is difficult to compare the popularity of CAM types with other male cancer populations in Europe or the USA, due to different measurements of CAM (Amin, et al., 2010; Eng, et al., 2003; Ponholzer, et al., 2003; Warrick, et al., 1999; Wilkinson, et al., 2008). The use of CAM in men seems to differ between ethnical groups (M. M. Lee, et al., 2002), and in particular the use of herbs and botanicals seems to be dependent upon tradition and thus varies between countries (Molassiotis, et al., 2005). For example, mistletoe has a long tradition in German-speaking countries (Eustachi, Pajtler, Linde, Melchart, & Weidenhammer, 2009; Laengler, et al., 2008) and has been reported to be beneficial as a complement during cancer treatment (Kienle & Kiene, 2010;

Seifert, Tautz, Seeger, Henze, & Laengler, 2007). Although the questionnaire used in the current study did not ask patients to report about specific herbs, in future research, it might be interesting to elucidate the most popular herbs in Australian cancer patients. Comparisons between countries might be better conducted when focusing on specific herbs, so that cultural differences of cancer incidence and/or preferences of herbal medicine might be better understood. In multicultural Australia, future research about CAM use in cancer patients might also focus on comparisons between different ethnic groups.

The broad definition of CAM used in the present study is clearly a limitation and the higher prevalence of CAM use in this sample compared to previous studies may be due to use of different measures of CAM (Kristoffersen, et al., 2008). Recently, there have been attempts to establish a standardized questionnaire about CAM (Quandt, et al., 2009). As this questionnaire has not yet been validated in English, and was not specifically developed for cancer patients, it was not applied in this study. Another limitation is the inclusion of only English-speaking, Caucasian cancer patients visiting outpatient cancer services. The sample was representative of the range and distribution of cancers that would be expected in men (AIHW, 2010d), that is, prostate, haematological malignancies, colorectal, lung, and other types, with the exception of melanoma, which is not typically treated in cancer outpatient services. The study participants were also representative with regard to age, geographical area, country of birth, and religion (ABS, 2010a, 2011; AIHW, 2010c, 2010d). As 94% of the approached patients agreed to participate, the results of the survey can be generalized to male cancer populations visiting public and private outpatient cancer services.

Oncologists should be aware that the majority of male cancer patients use CAM. Clinical consultations might benefit from an open discussion between clinicians and patients about the efficacy and safety about CAM. A better understanding of the role, reasons for use, and benefits of CAMs, may lead to more holistic approaches to care, and in particular opportunities to better address the social and emotional needs of men.

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**CHAPTER FIVE: PAPER FOUR – SUBMITTED FOR PUBLICATION
(STUDY 2 INTERVIEWS)**

Statement of Authorship

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Author Contributions

By signing the Statement of Authorship, each author certifies that their stated contribution to the publication is accurate and that permission is granted for the publication to be included in the candidate's thesis.

Name of Principal Author (Candidate)	Nadja Klafke	
Contribution to the Paper	Performed analysis on all samples, interpreted data, wrote manuscript and acted as corresponding author.	
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Contribution to the Paper	Supervised development of work, helped in data interpretation and manuscript evaluation.	
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This Chapter presents the results of the second empirical study of this research program. It was a follow-up study of the survey reported in the preceding Chapter Four, thereby conducting a qualitative investigation of participants' survey answers, to better understand men's perceptions and experiences about specific CAM therapies.

Therefore, survey participants were purposefully sampled and invited for an interview including themselves and a SO involved in their CAM decisions. Overall, 43 semi-structured interviews, involving 26 men and 24 SOs, were conducted in hospital, home, or University settings. All interviews were audio-recorded, transcribed verbatim, and then analysed according to discursive analytical principles. The novel approach of this interview study was to include the viewpoints of men's SOs as well, so that the social context of men's CAM use can be understood comprehensively. Interview data were analysed discursively, as this is an established technique to investigate how individuals' language constructs facts and events, and further to reveal the according interpersonal implications.

The discursive analysis found that social/interpersonal factors were relevant for male patients' CAM decisions, as men commonly stated that they used CAM 1) because it was given to them as a gift, 2) as a supporting action for a friend with cancer, and 3) because of a strong spousal influence. It was further analysed that the use of CAM socially connected the male cancer patient and his SO, a beneficial effect of CAM use, which has not been reported so far.

In summary, the study results indicate the significance of the interpersonal dimensions impacting on men's CAM decisions, which will be further examined in the following Chapters Six and Seven.

5.1 Abstract

The majority of patients with cancer use Complementary and Alternative Medicine (CAM) in addition to conventional care. Although studies have explored reasons for using CAM, the role social factors (Öhlén, et al., 2006) play in patients' use of CAM has not been systematically examined. Semi-structured interviews were conducted with 26 men affected by cancer, and 24 significant others (SOs), to explore how patients and their SOs perform CAM decisions within the *therapeutic management group* (Janzen, 1978; Nichter, 2002). Using a discursive analytic perspective (Potter & Wetherell, 1987), *social reasons* were identified as a salient factor in patients' accounts of CAM use. Three forms of social reasons with different functions and consequences were common: men used CAM 1) when given as a gift 2) to indicate support for fellow male patients 3) in response to a strong spousal influence. The findings indicate an important interpersonal dimension impacting on cancer patients' use of CAM, and highlight how the use of CAM functions as a tool for social connectedness for men and his SOs.

Keywords:

Complementary and Alternative Medicine (CAM), healthcare, cancer, holistic care, psychosocial, men's health, relationships, family, Australia

5.2 Introduction

In Australia, as has been described for other 'Western' industrialized multi-ethnic societies like the United States, medical pluralism is prevalent. This is evident despite a dominance of biomedicine over various medical subsystems (Baer, 2009a). Nevertheless, there is growing consumer and state interest, promoting consumer choice and empowerment, in treatments outside biomedicine (Baer, 2009b). The term Complementary and Alternative Medicine (CAM), defined as "diverse and medical health care systems, practices, and products that are not generally considered part of conventional medicine" (National Center for Complementary and Alternative Medicine, 2013), has become widely established in describing healthcare services and treatments outside mainstream medicine. CAM use is increasing in the general (Eisenberg, et al., 1998) and cancer (Boon, et al., 2007) populations. Recent studies provide evidence that up to 60% of Australian patients with cancer have used CAM (Klafke, Elliott, Wittert, et al., 2012; Oh, Butow, Mullan, Beale, et al., 2010). There is high-level evidence that, when used as a complement to conventional cancer treatment, some CAM can relieve physical symptoms such as pain, nausea, and fatigue; reduce negative psychosocial states such as stress, anxiety, depression; and increase overall quality of life (Deng, et al., 2004; Ernst, 2010).

Several studies indicate a gender difference in rates of CAM use, with typical CAM users being young educated females (Fouladbakhsh, et al., 2005). In part, men's lower participation in CAM practices is commensurate with findings that men access healthcare services less often, die younger, and have higher disease and injury prevalence rates than women (AIHW, 2010a; WHO, 2010). One theoretical explanation for men's lower use of CAM and conventional healthcare services centres on a hegemonic view of masculinity which constructs men as independent, autonomous, tough, strong, in control, dominant, and superior (Connell & Messerschmidt, 2005; Courtenay, 2000). It has been suggested, therefore, that men do not seek help for physical and psychological symptoms and delay healthcare seeking, because this constitutes part of their masculine identity (Kimmel, et al., 2005). Smith et al. (2006) have argued that this "victim-blaming" approach is insufficient and unproductive in improving men's health, arguing that biological factors (e.g., age, hormones), and socio-cultural factors (e.g., asking partners and friends for help), impact on men's healthcare behaviour. Their

qualitative study of South Australian men, provides evidence that men do actively self-monitor their health before seeking help (Smith, Braunack-Mayer, Wittert, & Warin, 2008b), indicating their interest in their health and frequent need to communicate about it within their social networks.

Modelling medical pluralism in complex societies, Kleinman (1980) defined three overlapping sectors of healthcare; the *popular sector*, the *folk sector*, and the *professional sector*. He suggested that 70 to 90% of illness treatments occur in the popular sector, featuring family as its main sphere where ill health is treated. Within family structures, women traditionally act as the family caregiver for both children and their male partner (Norcross, et al., 1996; Seymour-Smith & Wetherell, 2006; Waldron, 1976). Some research indicates that women often influence their male partners' healthcare decisions. For example, men are commonly positioned, by both women and healthcare professionals, as childlike, with their female partners as actively responsible for supervising their health (Seymour-Smith, et al., 2002; Smith, Braunack-Mayer, Wittert, & Warin, 2007). Other social contexts and relationships also impact on men's healthcare decisions, and these may be better explained with the concept of *therapeutic management group* which implies that patients perform healthcare along with their families, social networks, and communities (Janzen, 1978). There is limited evidence, however, regarding the involvement of Significant Others (SOs) in men's healthcare decisions regarding CAM. A Swedish-Canadian interview study of breast and prostate cancer patients, and SOs, reported that the role of SOs included supporting, co-decision making, persuading, and directing patients' CAM use (Nichter, 2002; Öhlén, et al., 2006). The only reported gender difference was that men never perceived that they were moved towards a CAM decision by their SO. The authors argued that male participants generally were restrained about talking of their SOs' active dominant role in their CAM decisions, suggesting this as congruent with the literature positioning men as underestimating their partners' role in decisions about conventional cancer treatment (Boehmer & Clark, 2001; O'Rourke & Germino, 1998), in turn reflecting a dominant discourse of independent masculinity (Courtenay, 2000). Further research, however, is needed to clarify how social factors influence men's CAM use during cancer treatment, as well as the CAM decision-making process in men across a variety of cancers and social relationships.

Considerable attention has been devoted to analysing cancer patients' physical and psychological reasons and motivations for CAM use (Boon, Brown, et al., 2003; Correa-Velez, Clavarino, & Eastwood, 2005; M. Evans, et al., 2007a; Verhoef, et al., 2005), and is illustrated in Figure 4. Most qualitative studies have examined the personal viewpoints, perceptions and belief systems contributing to cancer patients' use or non-use of CAM, thereby overlooking the contribution of patients' interpersonal relationships. Few qualitative studies have considered familial influence in cancer patients' CAM use. Elliott et al. (2008) reported that some patients with advanced cancer were influenced to use CAM by close family members, arguing that CAM decisions were associated with personal consequences for the patient, and with interpersonal consequences for the familial relationship. Similarly, Evans et al. (2007a) reported that men with cancer used CAM because of a strong spousal influence. There is little research explicitly examining the interpersonal context of CAM decisions (Elliott & Klafke, 2011), namely, how male patients with cancer and their SOs talk about CAM decisions, how they justify these decisions, and any consequences these may have on their interpersonal relationships.

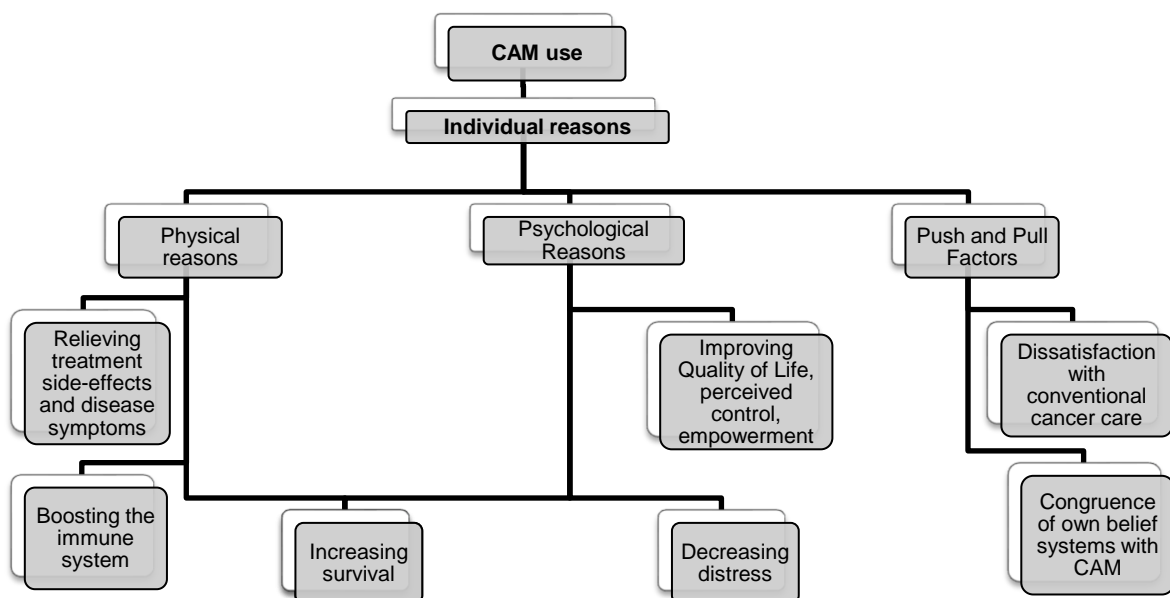


Figure 4. Individual reasons/motivations for male patients' CAM use

The authors have previously reported the prevalence and predictors of CAM use in Australian men affected by cancer (Klafke, Elliott, Wittert, et al., 2012) indicating that the use of CAM in patients with cancer is normative not exceptional; and also that SOs are more often involved in providing information and discussing CAMs with patients than medical professionals. Here, the researchers analyse data from interviews with men and their SOs to provide an in-depth analysis of men's CAM use during cancer treatment, with particular focus on the forms and contexts of social interactions impacting on their CAM use.

5.3 Methods

This was a mixed-methods study examining the use of CAM in men with cancer and the involvement of SOs. Participants were recruited through four cancer outpatient services in Metropolitan Adelaide, more precisely, at two public cancer services and two private public cancer services (each providing both chemotherapy and radiotherapy). CAM services were not integrated in any service. The project was approved by the relevant institutional Human Research Ethics Committees. Study 1 [reported elsewhere (Klafke, Elliott, Wittert, et al., 2012)] involved administering and analysing a survey completed by 403 Australian men affected with cancer, to assess the prevalence and predictors of CAM use, and to describe how cancer patients' social network affected uptake of specific CAM therapies and CAM categories. Here, results from Study 2 are reported, involving semi-structured interviews conducted between July 2011 and January 2012 by NK, a researcher having no prior or subsequent contact with the participants, with 26 male cancer patients and 24 female SOs (see Table 10). Joint interviews provide the opportunity to sample interactions of how men and their SOs discuss CAM together, whilst the whole database enables an analysis of how men and their SOs talk about how they made decisions about CAM.

Table 10

Demographic and disease-related details of men with cancer

Details	Patients with curable cancer <i>Number</i> (9)	Patients with incurable cancer <i>Number</i> (17)
Age (<i>n</i> = 26)		
Mean (SD)		68 (9.9)
Range		61-75
Site of primary cancer		
Prostate	2	5
Haematological malignancies	2	4
Colorectal	2	3
Lung	2	1
Other	1	4
Conventional cancer treatment		
Chemotherapy	8	16
Radiotherapy	6	8
Surgery	5	11
Hormonal therapy	/	9
Level of CAM use		
High (5-...)	7	12
Low (0-5)	2	5
Partner status		
Married/partnered	8	14
Other	1	3
SO participating in interview		
Spouse/partner	7	12
Adult daughter	/	2
Ex-wife/ ex-partner	/	2
Close friend	1	/
None present	1	1
Interview situation		
No SO involved	1	1
Together	5	3
Separate	3	13
Level of intrapersonal conflict		
High	6	4
Moderate	1	4
Low	/	/
Not indicated	2	9
Level of interpersonal conflict		
High	5	11
Moderate	2	4
Low	/	2
Not indicated	2	/

Survey participants were sampled purposively, using a maximum variation technique to select for variety in stage and type of cancer, high and low CAM use, and perceived levels of intrapersonal and interpersonal levels of conflict regarding CAM use (Patton, 2002). Forty patients were selected for an interview, but nine patients died before the interview, and five declined participation due to disease progression, so that the remaining sample consisted of 26 men affected with cancer (see Table 10), and additionally their 24 SOs. Twenty-four out of the 26 participating patients had experience of CAM use in conjunction with conventional cancer treatment. As data collection and preliminary analysis progressed,

sampling became more theoretical (Patton, 2002), targeting high CAM users for their insights into regular CAM use. As this study seeks to understand how SOs are involved in male cancer CAM decisions, the research team trialled whether interviewing SOs and patients together (dyads) or separately provided the most informative data. After interviewing 11 dyads (7 together and 4 separately), the researchers identified separate interviews as preferable. The following 13 dyads were interviewed separately, and 2 patients attended the interview alone as their SOs were unable to attend. Informed consent preceded all interviews. Participants' travel expenses were reimbursed.

Interviews lasted between 40 and 90 minutes, and were guided by the research question: How do SOs impact on men's decision to use CAM during cancer treatment? Specific interview questions focused on expectations and experiences of CAM use, as well as decisions to use, not use, or continue specific CAMs. The interviews were audio-recorded and transcribed verbatim (by NK), then imported into NVivo 9 (QSR International Pty Ltd, Doncaster, Victoria, Australia) to facilitate analysis. Identifying information (including names of hospitals and participants) were changed. Preliminary analysis was conducted by NK, with all authors contributing to discussion of patterns and themes identified within the interview data.

Following discursive analytical principles (Potter & Wetherell, 1987), data were coded into categories based upon the functions and consequences of social reasons impacting on men's CAM decisions. Discourse analysis falls under the branch of social constructionism, and is an established approach in analysing language to examine how individuals perceive, categorize, and interpret the social world (Edwards & Potter, 1992; Potter & Wetherell, 1987). Our analysis focused on the particular ways in which individuals, events, or actions were discussed in the context of the cancer diagnosis and CAM decision-making. We used an integrative approach to discourse analysis (Elliott & Olver, 2007b, 2007c; Seymour-Smith & Wetherell, 2006; Seymour-Smith, et al., 2002), examining the interactional implications of participants' talk in situ, whilst considering the wider socio-cultural context.

5.4 Results and discussion

Selected demographic and clinical characteristics of participants are described in Table 10. Participants from the preceding survey (Klafke, Elliott,

Wittert, et al., 2012) who indicated using or having used more than 5 CAM therapies, and identified as experienced with and receptive about CAM were categorized as “high CAM use.” Similarly, “low CAM use” was defined when patients reported using 0 to 5 CAMs, and identified as sceptical and inexperienced about CAM.

The analysis focused on the influence of the social network (Janzen, 1978; Nichter, 2002) of male patients with cancer upon their CAM use. Men with cancer reported discussing CAM treatments with family members, friends, acquaintances, colleagues, and CAM practitioners, who often provided information or made direct recommendations about (specific) CAM therapies. These sometimes, but not always, resulted in decisions to use CAM, often representing an initial step into the world of CAM use. We analysed what successful CAM recommendations and suggestions entailed and how they were described by men with cancer and their SOs. Three identified contexts within social/interpersonal reasons were: gift transactions, enactment of social support between fellow patients, and female partner exhortations/actions (see Figure 5), and data illustrating these are discursively analysed below.

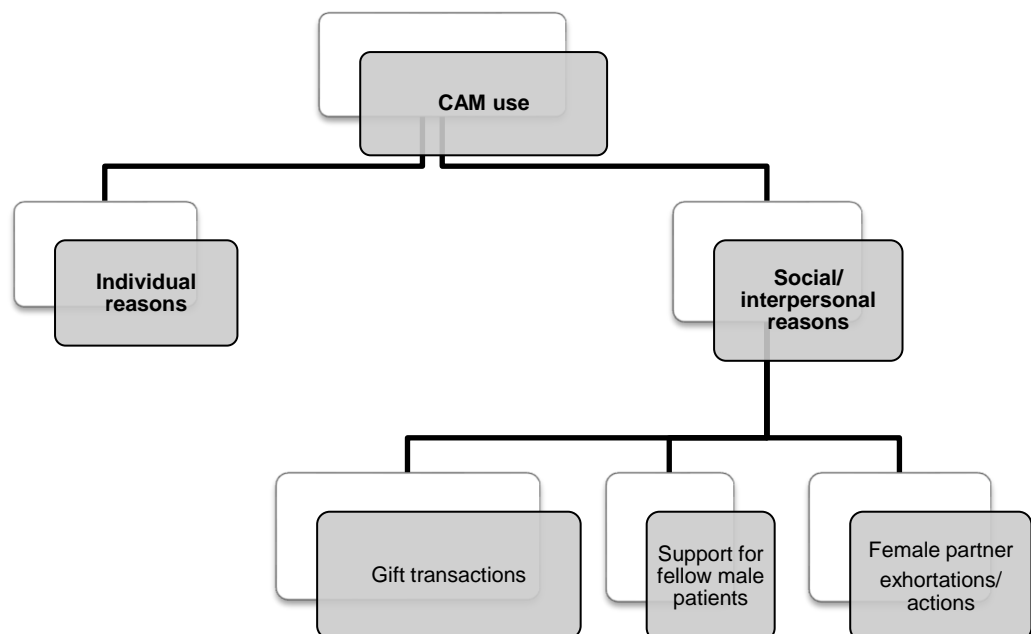


Figure 5. Social/interpersonal reasons/motivations for male patients' CAM use

5.4.1 A gift of CAM.

Receipt of a personalized tangible gift from SOs, of a specific product or a gift certificate for specific services (e.g., massage), was consistently associated with subsequent CAM use. This was evidently not dependent on the nature of the gift, with examples including a voucher for CAM therapies (e.g., Yoga, meditation, Reiki, or Kinesiology); enclosed health products (e.g., cranberries, or oysters); specific herbs (e.g., herb Robert, dandelion, or Purple leaves for preparing teas); and a whole package containing lots of different dietary supplements and herbs.

In contrast, recommendations to use CAM that did not specify a particular CAM did not always result in their uptake. Patients undergoing cancer treatment are typically energy-depleted (Hofman, Ryan, Figueroa-Moseley, Jean-Pierre, & Morrow, 2007), and it is likely that the provision of a tangible object rather than an abstracted reference facilitates uptake, through reduced effort (in identifying both the CAM and steps needed to undertake use).

1 LILY: ... she [sister] just sort of said that there were things [dietary
2 supplements] available, but she still didn't name them much or list
3 anything or suggested where to get it or anything like that, she just said
4 that it was available.

(Partner of patient with non-metastatic head and neck cancer,
inexperienced with CAM)³

There were differences in the context and consequences of CAM use, between men classified as experienced/receptive vs. inexperienced/sceptical about CAM. The former attributed several benefits to CAM, for example “I wasn't as sick as many patients are when they're experiencing chemotherapy,” “I feel more energetic, and I don't feel so nauseous,” “it just helped me to release tension from

³ Transcription protocol: Words included to make sense of the quotation are presented within square brackets, thus: [Like this]. Omission of some speech is indicated by an ellipsis, thus: my wife and I ... decided to use CAM. Idiosyncratic speech like “you know” and “like” and repeated phrases like “she said, she, she, she...” are deleted to facilitate readability. Extended square brackets mark overlap between utterances, thus:

A: [I used CAM.

B: [I pushed him to use CAM.

my body, and sleep well,” “I completely feel different after I have a Reiki session, ... you’re just so charged full of energy, and you just leave feeling really good.” These men presented the process of gifting as unproblematic and pragmatic.

1 INTERVIEWER: And how did you find out about Reiki?

2 THOMAS: ... once again, through family, through colleagues of mine at
3 work, friends, they ... purchased me a voucher for this House of
4 Healing [name of CAM centre], and I went there and enjoyed it, and so I
5 go there.

(Patient with non-metastatic colorectal cancer, experienced with CAM)

In the context of a patient’s and his SOs’ previous history of CAM use, the gift of CAM functioned as further encouragement, support, or confirmation of their mutual belief and trust in the benefits of CAM.

1 NORA: ... Prior to [diagnosis] we had been using and looking at
2 different medicines when Lucas wasn’t well and couldn’t work out why,
3 and so it’s sort of been something that I was always interested in was
4 diet and supplements and complementary therapies, so that wasn’t
5 something that was new, that was already part of what we were doing.
6 But once Lucas was diagnosed, certainly we’re more looking into some
7 alternatives, doing research, and the family all joined in, our daughter
8 was researching and sons, everyone was sort of “Have you tried this?
9 Have you looked at that?” I did a lot of reading of books of people that
10 have had cancer and what they had done, and also then looking on the
11 Internet. ... I think we had a very open mind, through all those research.
(Wife of patient with metastatic prostate cancer, experienced with CAM)

In Nora's speech, the subject pronoun "we" functions to construe the decision to uptake CAM as a shared event, ultimately involving herself, her husband, and their children. Nora initially positions herself as an interested experienced CAM consumer who actively recommended and encouraged CAM use for her husband (lines 3-7). She strengthens the position of active familial involvement by quoting speech of other family members who supported and encouraged their use of CAM (lines 7-9), a device which functions to make Nora's account vivid and believable (Wooffitt, 1992), simultaneously presenting the patient's decision to undertake more CAM as an issue involving the whole family. This extract thus highlights how the cancer diagnosis led to an increased familial engagement with CAM, with the patient's CAM use encouraged, arguably influenced, by his wife and children.

Participants identified as inexperienced/sceptical about CAM, frequently described themselves as being "a technical person," "mainstream man," "pragmatic person," or "believer in mainstream medicine," thereby positioning themselves as a person with traditional masculine traits (Courtenay, 2000), and as a supporter of conventional medicine rather than a believer of CAM. This positioning, however, meant that men experienced a dilemma when they used a gift of CAM, as this required some justification for use beyond actual efficacy. Patients had to negotiate their decision of using CAM with themselves and to others in a plausible and coherent way, thus accounting for CAM use despite their scepticism whilst maintaining a construction of the masculine individual. One common strategy drew upon the positioning of SOs as caring and the gift as signifying enactment of helping and supporting. The concept of adjacency pairs (Schegloff & Sacks, 1973) may have some explanatory power here as the social process of gift-giving and gift-receiving elicits an expectation and some interpersonal pressure to use CAM following gift-giving. Thus, uptake of a gift of CAM was constructed as a positive and respectful reply to SOs' action of presenting the gift of CAM.

- 1 HENRY: I have tried a tea, ... [my friend] also read information about it,
- 2 that it's supposed to be beneficial with the cancer, but I didn't follow up
- 3 much about how it's supposed to treat you, but they actually bought
- 4 some for me, [it] was a large amount. ... as a present, and I was

- 5 supposed to drink about three or four cups a day. ... There's no marked
6 improvement or worsening of the problem. It's just something I thought I
7 should try seeing as how they've gone to the extent of buying it for me.
8 INTERVIEWER: So what would you say was the main reason why you
9 started drinking it?
10 HENRY: Eh possibly for their benefit I think. More so than, I don't know
11 enough about its properties or how it reacted ..., they got the
12 recommendation from an uncle of theirs who had cancer and who did
13 go with natural medicines as well as chemotherapy. ... Ah well they
14 said it's up to me, it's my decision, but I think they really wanted me to
15 try it. Because they, of course they would like me to get better, and get
16 rid of the cancer. But myself I'm a bit sort of sceptical I guess, but I did
17 give it a go for a while but then I've sort of died off and I've sort of
18 stopped taking it now.
(Patient with metastatic bladder cancer, inexperienced with CAM)

Here, Henry constructed the action of gift-giving as enacting SOs' actively caring and loving behaviour, as well as entailing their wish to be involved and to contribute to his recovery (lines 1-7, 15-16). In return, Henry acknowledged and respected his SOs' caring behaviour, using the CAM as it is the expected reciprocal action (lines 6-7, 8-10). Throughout, Henry positions himself as choosing to use CAM for his SOs' benefit, thereby balancing the dual roles of autonomy: namely, to take responsibility for decisions whilst considering the feelings of his SO (Elliott & Olver, 2007a). The reference to the SO's uncle successfully using conventional and complementary treatment for his cancer functions as a further source of credibility for the effectiveness of that CAM (lines 12-14), and strengthens the patient's justification of its uptake, despite his scepticism (lines 16-18). Interpersonally, as the appreciation/use of the gift is the expected (or linguistically preferred) response (Schegloff & Sacks, 1973), the gifter can exploit this function to prompt the patient towards CAM use. Nonetheless, it appears that there is no obligation to continue use, as indicated by Henry's statement "I did give it a go for a while but ... I've sort of stopped taking it now," (lines 16-18) which sees him return to and reaffirm his identified scepticism towards therapies outside the conventional medical system.

5.4.2 CAM use to indicate support for fellow male patients.

CAM users frequently mentioned relationships with fellow patients as playing a central role in their decision to uptake CAM. The supportive use of CAM between fellow patients can function as a vehicle to maintain, or establish new relationships between men.

1 WILLIAM: ... a good friend suggested that Jack who had the lung
 2 cancer, should be drinking Purpure leaf tea [Echinacea Purpurea Leaf]
 3 ..., tastes dreadful, but as a support for Jack, I thought “Well, if it does
 4 him some good, it can’t do me any harm either.” So pretty well since I
 5 got home [from hospital] ... we’ve been both going down to a friend’s
 6 place who has a number of Purpure plants, we’ve picked leaves and
 7 boil them up, and bottle it, and drink it through the week. Next week
 8 we’ll go through the next cycle again. ... I mean if it weren’t for Jack, I
 9 think I would stop. ... Like, it tastes dreadful (laughs). Yeah, if it weren’t
 10 for Jack, I think I’d stop. If Jack said “Look, I don’t want to continue with
 11 the Purpure leaves tea,” I don’t think I would continue. I don’t think it’s
 12 necessarily having any profound impact, but then you don’t know.
 (Patient with leukaemia, in remission, experienced with CAM)

Here, William positions himself as using CAM both with and for his friend and fellow patient, constructing his use of CAM as an act of support and solidarity (lines 1-4). With repeated assertions that “if it weren’t for Jack, I think I would stop” (lines 8-10). William effectively establishes that his desire to enact a supportive relationship with his friend was a primary motivator for his CAM uptake, thereby positioning himself as both a kind, altruistic, and good-natured friend, and a CAM sceptic. William thus presents his relationship with his friend as more important than his scepticism towards CAM, discernible in the phrase “I don’t think I would continue. I don’t think it’s necessarily having any profound impact” (lines 11-12). He further strengthens his position of support by describing in some detail the effort involved in this shared CAM use, which requires on-going weekly practical and time-consuming tasks involving travel, picking leaves, and preparing the

special tea before the actual CAM consumption (lines 5-8). William's account indicates that their shared CAM use functioned as a tool for regular social meetings, structured activities, and contact time. This suggests that CAM may have facilitated their interaction maintaining and increasing their social bond, with potential benefits for both parties in terms of coping with uncertainty and anxiety (Han et al., 2011; Mishel, 1988).

The need for social connection is also reflected in cancer support group attendance (Davison, Pennebaker, & Dickerson, 2000). It has been suggested that women favour emotional-focused coping, while men prefer problem-focused coping in support groups, employing a shared practice of processing information and solving problems to form bonds (Adamsen, Rasmussen, & Pedersen, 2001). This process may be evident in the following:

1 IRVINE: I started going to a prostate cancer support group, and I found
 2 there was a man sitting at the back of the class of the group. ... I got to
 3 know that he was into alternative food stuff ... he was an advocate for
 4 the zone diet by Dr Barry Sears. ... the idea of the zone diet is to
 5 stabilize your insulin level, so for each meal you balance the amounts of
 6 protein, carbohydrate and fat in recommended proportions, and he also,
 7 this guy also advocated lots of green tea, apricot kernels, fish oil, I think
 8 I got the main items there. So I have been on that sort of diet ever
 9 since. ... I kept going and going [to the support group] because, partly
 10 because I wanted to meet this guy every week and speak to him about
 11 how are you going and how was I going. ...
 (Patient with metastatic prostate cancer, experienced with CAM)

Irvine here presents his decision to uptake CAM (zone diet) as influenced by a fellow cancer patient. He begins by establishing his decision to use CAM (in addition to attending the support group) as a casual and unplanned event (lines 1-3), indicating that he was not specifically searching for more CAM, but generally open towards its use. Further on, Irvine draws upon language from a biomedical discourse to present himself as thoughtful, independent and relying on scientific facts. For example, in referring to "Dr Barry Sears" (line 4), Irvine

suggests that a medical authority supports the recommended zone diet. This, combined with his detailed description of the diet, including “to stabilize your insulin,” “balance the amounts” in “recommended proportions” (lines 5-6) works to position himself as oriented towards, and his decision to use CAM as based upon, rational and authoritative facts, whilst also enacting a problem-focused interactional style, deemed familiar to and common in men (Zhang, Galanek, Strauss, & Siminoff, 2008).

Irvine’s account suggests that his CAM use functioned as a vehicle to establish and maintain a relationship between an experienced CAM user and himself attending the same support group. Their regular communication about CAM use may have functioned to mutually support and encourage CAM use (Olliffe, Davison, Pickles, & Mróz, 2009), to establish mutual understanding, normalcy and certainty to create a bond (Festinger, 1954). It has been suggested that the positive experience of social bonding is necessary for male cancer patients’ continued attendance at support groups (Zhang, et al., 2008). This is evident at the end of Irvine’s account, “I kept going and going because, partly because I wanted to meet this guy every week and speak to him about how are you going and how was I going” (lines 9-11), suggesting that the greeting phrase functioned as an opening for both men to report on and share their experiences. Subsequent responding may then have resulted in a deeper conversation that further established their social bond. This statement also suggests that Irvine valued “social reasons,” at least in part involving discussions of CAM, as a crucial motivator to further attendance at support group meetings.

5.4.3 CAM use because of a strong spousal/partner’s influence.

Female spouses or partners played an important role in influencing men with cancer to use CAM. Some engaged in decision-making for the patient, arguably bypassing the patient’s active choice. Sometimes, patient’s agency was even more limited, as for example, when a SO used CAM for/on the patient, when he was not consciously aware of it.

- 1 LUCAS: ... it’s her [my wife], it’s definitely she’s the one that pushed,
- 2 she pushed for a lot of these things [e.g., consulting a naturopath,
- 3 practicing meditation/ relaxation, swallowing dietary supplements,

4 changing the diet, receiving Vitamin C injections, snake venom etc.] ... I
5 just agreed, agreed straight away. I mean she was keen, even with
6 food, she prepares special dishes, ... she's gone vegetarian as well,
7 even though she didn't have to, she's gone vegetarian and she helps
8 pushing me to stay, on the straight and narrow a little, and even
9 preparing special foods, she prepares special, she does a culture, it's a
10 milk drink that, it's a culture, it breathes, ... that I have two or three
11 times a day which helps my stomach. ... it's not easy, I won't say that
12 it's easy, but ... again if it wasn't for my wife, I probably wouldn't do half
13 of those things.

(Patient with metastatic prostate cancer, experienced with CAM)

In this excerpt, Lucas presents his CAM use as influenced by his wife, positioning her as agentic and responsible for his CAM uptake, and himself as acquiescent: "I just agreed, agreed straight away" (lines 4-5). Further on, he depicts his wife's own CAM interest and consumption as a support specifically for him, indicated through his use of the word "special" (line 6), which functions to underline his wife's effort as out of the norm. Lucas further strengthens the significance of his wife's work and commitment by highlighting her actual participation in these practices, as he acknowledges "she's gone vegetarian as well, even though she didn't have to" (lines 6-7). This phrase also works to position his wife as a supportive co-CAM consumer, thereby constructing his and her CAM use as a shared event, with potential benefit for maintaining or increasing the bond within their marital relationship. Lucas' CAM use, as well as Henry's CAM uptake analysed above, may be non-verbal functional equivalents of adjacency pairs (Schegloff & Sacks, 1973), as there may have been an expectation on the patient to use CAM, following evidence of others' efforts to procure or motivate CAM use.

Despite Lucas' depiction of accord between himself and his wife, there is some suggestion, however, that his CAM use is not entirely unproblematic. His description of CAM as "the straight and narrow" path (line 8), followed by the repeated (thus strengthened) assertion that "it's not easy" (line 11), simultaneously identifies CAM use as a difficult but preferred, even righteous option and indicates his commitment to it. Thus, Lucas establishes his endorsement of a perceived benefit in CAM, justifying his use of it. His wife's active CAM involvement is

construed as helping him to stay on this difficult path, formulated by “she helps pushing me to stay” (lines 7-8), whilst the statement “if it wasn’t for my wife, I probably wouldn’t do half of those things” (lines 12-13) again reinforces that his wife was the motivator for his CAM uptake and continuation, whilst strengthening his position as being committed for CAM use, and ultimately, presenting CAM use as a joint decision and enterprise. In a separate interview, Luca’s wife also presented her influencing role in her husband’s CAM use as potentially problematic, but justified.

1 NORA: ... well Lucas needed to sort of say “Yes, he wanted to do it
2 [consulting the naturopath],” but then I go and forced him ahead like it
3 happened that day (laughs). ... I think because I was preparing the food
4 or the juices or whatever ... he was having it. But I think there were
5 times that, I’d admit and say to people that he misses not having his
6 wine or his steak or on that level there was stuff that he missed even
7 though he knew that he needed to give this a good try. It would be very
8 easy for him to be tempted to go back, so if he didn’t have family doing
9 it and me completely changing as well, I don’t think he would have
10 stayed there.

(Wife of patient with metastatic prostate cancer, experienced with CAM)

At the beginning of this extract, Nora is doing stake inoculation (Potter, 1996), pre-emptively defending herself from accusations that she is overriding her husband’s free will (lines 1-3). Nora’s laughter after the phrase “but then I go and forced him ...” (lines 2-3) indicates, and functions to ease tension over this directive behaviour (Jefferson, 1984). Her laughter may also indicate some intrapersonal conflict, arguably guilt, from being perceived as bullying her seriously ill husband into CAM use. Lucas’ choice was presented as equivocal, but sufficient: “he ‘sort of’” said yes (line 1). In representing this conflict, Nora positions herself as in charge of her husband’s food choices (lines 3-4), thereby constructing a normative picture in traditional family households (Norcross, et al., 1996; Warde & Hetherington, 1994). Although this entails giving her husband a limited choice about what he eats, Nora softens this potentially coercive aspect by showing how

she makes these sacrifices, too (lines 8-10). Her own CAM consumption functions as a support and role model for her husband's CAM uptake and CAM maintenance, thereby positioning herself as caring for and supporting her husband in what they both acknowledge as a difficult choice. Additionally, Nora positions herself as understanding and being in solidarity with her husband, when she states "I'd admit and say to people that he misses not having his wine or his steak ... even though he knew that he needed to give this a good try" (lines 5-7). This signals her awareness of his difficulties adhering to CAM practices, simultaneously establishing herself as the caring expert who knows what he really needs to get better.

Nora's use of the word "admit" (line 5) may further indicate an aspect of guilt, as it could be perceived that she coerced Lucas to use CAM despite his difficulties and his desire/wish to make other choices. In negotiating this conflict, Nora positions herself as being aware and in charge of his long-term goals, namely to "give CAM a good try" (lines 6-7) with the implicit message that this will improve his health in the longer term. Accordingly, it can be understood that Nora chooses to prioritize Lucas' *dispositional autonomy* over his *occurrent autonomy* (Young, 1986), that is, over-riding his desire to have "his wine or his steak" (line 6) through recourse to consideration of long-term life goals. By positioning her husband as having difficulties in adhering to using CAM, Nora depicts her strong involvement in her husband's CAM decisions as a necessity. In saying that "if he didn't have family doing it and me completely changing as well, I don't think he would have stayed there" (lines 8-10) she establishes that her strong influence, which is construed as benevolent and helpful behaviour, was corroborated and supported by the whole family, thereby further strengthening her dominant behaviour as acceptable and ethical. Nora's account also indicates that Lucas himself shared this perspective of the need both for CAM and her/family engagement, indicated by her statement "he knew that he needed to give this a good try" (line 7). Thus the familial actions of changing their own behaviour is construed as functioning as a role model, and ultimately an effective and caring strategy for encouraging the patients' maintenance of CAM use (Bishop, Yardley, & Lewith, 2010).

The authors also identified the strong influence of female SOs' behaviour, when they used or performed CAM for the patient, without the patient's conscious

awareness of it. The following extract illustrates how Vicky performed Reiki on her husband every night while he was asleep.

- 1 VICKY: Yeah I just do Reiki healing every night for him ...
- 2 ETHAN: That's why I got a pain in my leg (laughs)
- 3 VICKY: (laughs)
- 4 INTERVIEWER: And can you describe what's your experience? How do
- 5 you generally feel after a Reiki session?
- 6 ETHAN: Usually she does it when I'm sleeping.
- 7 VICKY: ... I just do a mental Reiki on him because he doesn't like to sit
- 8 for too long, so I just do it mentally on him every night. So I don't know
- 9 how he feels really but yeah (laughs) hopefully relaxes him and [eh
- 10 ETHAN: [I'll probably sleep better ...
- 11 VICKY: Sleeps better (laughs) ...
- 12 INTERVIEWER: Did you directly agree that Vicky is practicing Reiki on
- 13 you, or have you been sceptical?
- 14 ETHAN: Ah it doesn't bother me, it doesn't bother me.
- 15 VICKY: He says that it won't hurt him, so I'll do it (laughs), but I know
- 16 that he doesn't really believe in it, but then he says that it won't hurt, so
- 17 he's not against it either.
- (Patient with metastatic breast cancer, and his wife, experienced with CAM)

The use of laughter demonstrates that both Ethan and Vicky experienced the need to ease tension in talking about the wife's responsibility of her husband's CAM use, and his limited autonomy (Jefferson, 1984). Vicky's behaviour could be perceived as an unethical intrusion upon an individual's agency, and limiting an individual's autonomy, but she presents her active involvement as caring and benevolent behaviour. This is done by initially characterizing her husband as a person who "doesn't like to sit for too long" (lines 7-8) which contributes to a picture of her suffering husband, who would benefit most from her CAM practice while lying in bed. Additionally, she states that her CAM practice "hopefully relaxes him" (line 9) implying by the word "hopefully" that she wishes and expects a

positive outcome for her husband (Elliott & Olver, 2007b; Potter & Wetherell, 1987). Her statement “He says that it won’t hurt him, so I’ll do it” (line 15) implies that Ethan had the possibility to express his opinion, and also that he was not harmed from her CAM practice, which functions as a further endorsement for her to continue. Vicky’s as well as Nora’s accounts provide evidence that they accept a lack of their husband’s active opposition as endorsement for their CAM practice.

Ethan did not challenge his wife’s active involvement, so that his talk functioned to construct the cancer journey as a shared experience, which he and his wife faced in a positive and harmonious relationship. Nonetheless, in saying “That’s why I got a pain in my leg (laughs)” (line 2), Ethan positions himself as not believing in Reiki, as aware of being influenced to use CAM by his wife, and that this is problematic, probably as it is not in accordance with hegemonic views of masculinity (Connell & Messerschmidt, 2005). Even when directly asked, Ethan actively avoids commitment in positioning himself as sceptical or supportive of his wife’s CAM practice. Rather, he frames his opinion about CAM with hedging assertions (Lakoff, 1975): he “probably sleep[s] better” (line 11) and “it doesn’t bother” (line 14) him. Such constructions again contribute to the presentation of their marital relationship as marked by harmony, unity and trust, establishing this as superseding enactment of hegemonic masculinity. Accordingly, despite lack of clear evidence of physical or emotional gains, the couple may have experienced social benefits from CAM use, as it connected both the husband and his wife on a daily basis. In addition, Vicky’s CAM practice may have positive consequences personally, as through the daily practice of Reiki on her husband, she had a means to regularly connect with him and express her care, possibly contributing to her emotional and spiritual well-being (Hodges, et al., 2005; Kozachik, et al., 2006). We note that while the SO’s practice of Reiki without the recipient’s knowledge may be uncommon, the use of intercessory prayer may be a common modality with similar consequences of enactment of interpersonal care between families dealing with cancer.

Within this population, a strongly influential behaviour of spouses or partners was commonly constructed and acknowledged as supportive and benevolent by the study participants, rather than a source of conflict or disagreement in the relationship. It seems that, when these men are confronted with a life-threatening illness, or in particular with issues regarding the end of life, the relationship with their SOs becomes more important than identifying with

masculine traits of being strong, independent, or in control (Connell & Messerschmidt, 2005; Öhlén, et al., 2006). Previous research about cancer patients' decisions has indicated that interpersonal conflicts can follow decisions about CAM use (Öhlén, et al., 2006; Zhang & Siminoff, 2003). In our study, participants present their harmonious relationship as more important, avoiding articulation of conflicts or tensions following forced CAM use. This may be explained, at least partly, by gender difference, as Öhlén et al. (2006) noted that only breast cancer patients claimed that others prompted their CAM decisions, sometimes reporting anxiety, confusion, and guilt when they were bombarded with CAM recommendations by their SOs. It may be that, due to the traditional gender role behaviour in food provision (A. H. Baker & Wardle, 2003; Courtenay, 2000; Warde & Hetherington, 1994), men are used to the involvement of SOs in their food choices, and in their healthcare, while women are not. Another social explanation could be found in that women often feel the need to please others to maintain a stable relationship (Kaplan, 1986), so that they might use CAM even though they do not want to. As the men in our and previous studies, do not express negative emotions after being influenced to use CAM, it may have contributed to their framing of the relationships with their SOs as conflict-free and harmonious. Alternatively, it may be that these men, although not fully in control of their CAM use, wanted to demonstrate that CAM can function as a beneficial tool to maintain or increase the social bond between them and their SOs. As the interviewer NK was female, it is also possible that men chose to frame their responses from an abstract viewpoint rejecting stereotypical gender roles, thereby presenting themselves as thoughtful within an academic discourse (Sallee & Harris, 2011).

5.5 Conclusion

The findings from this study provide insight into the healthcare practices within the *popular sector* of healthcare (Kleinman, 1980), highlighting that men's CAM decisions are not solely individual decisions. Men with cancer and their SOs spoke about the involvement of the social network impacting on uptake and maintenance of CAM use, thereby providing evidence for the interpersonal context of CAM decisions and practice. We suggest that SOs play an important role with regard to cancer patients' uptake and maintenance of CAM, which is in accordance with Nichter's (2002) findings about the *social relations of therapy*

management. Healthcare choices and therapy management are influenced and negotiated in households and larger networks, which may again be influenced by the broader social and political context. Öhlén, et al. (2006) have described how SOs are involved in patients' CAM decisions. What this discursive analysis adds is clarification of how the patient and his SOs negotiate and justify their CAM decisions, thereby looking more closely at the social interactions and forms resulting in men's CAM uptake and maintenance. The use of CAM functioned to re-establish and rehearse an interpersonal relationship between the patient and their SOs, facilitating connection.

The authors have identified three interpersonal factors (gift-giving, support between fellow patients, strong spousal influence) within the talk of men with cancer and their SOs (see Figure 5) and suggest that the use of CAM often functions as a tool to socially connect the individual affected by cancer and his SOs. The identification of social reasons support the concept of *relational autonomy* (Mackenzie & Stoljar, 2000; Meyers, 1987) which argues that patients are defined by their interpersonal relationships and make decisions in relation to others. Thus, these study findings extend previous research identifying individual reasons (physical, psychological, push and pull factors) to be crucial in cancer patients' CAM decisions (see Figure 4), all of which position the patient as independently exercising individual autonomy (Boon, Brown, et al., 2003; Correa-Velez, et al., 2005; M. Evans, et al., 2007a; Verhoef, et al., 2005).

The future of CAM use in Australia's medical pluralism will remain difficult (Baer, 2009a, 2009b), and particularly for clinicians from the professional sector of healthcare (Kleinman, 1980), the consultation about CAM use may be complicated. Some CAMs are potentially harmful for individuals diagnosed with, and receiving conventional treatment for, cancer (Clarke & McLachlan, 2011). Research suggests, however, that the majority of patients with cancer use CAM, and that patients' CAM decisions are often discussed and decided within their social network (Klafke, Elliott, Olver, & Wittert, 2012b). Here, we argue that CAM can function positively as a tool to establish, maintain, or increase the social bond in men's interpersonal relationships, and suggest that, rather than ignoring or dissuading patients from CAM use, healthcare professionals might more comprehensively acknowledge the benefits of the individual and relational functions and consequences of CAM use in men with cancer. Indeed, specialists' acknowledgement of the importance and value of the cancer patients' social

network impacting on their CAM decisions may improve the clinical-relationship and address the psycho-social needs of cancer patients (Steginga et al., 2001) and their carers (Sinfield, Baker, Ali, & Richardson, 2012).

Although the use of qualitative methodology enabled an in-depth analysis of the CAM decision-making process perceived by men and their SOs, we note that our participants were exclusively white Australian men diagnosed with cancer and receiving conventional medical treatment; thus the extent to which these findings apply to men from other ethnic backgrounds living in multicultural Australia, or elsewhere, or to female cancer patients, is limited. Future research should focus on sample group comparisons, including different populations and diagnoses. Additionally, future research of interpersonal dimensions in cancer patients' CAM decisions should analyse how patients negotiate and justify their accounts when they reject use of CAM, or indeed, reject conventional medicine, as well as whether and how these rejections lead to conflicts and tensions with SOs. Finally, individuals with a cancer diagnosis living in different relationships and in different socio-cultural environments, may communicate with, and be influenced by, their SOs in different ways, with different functions and consequences for their interpersonal relationships. Future exploration of these interpersonal processes, as well as those with their healthcare professionals would contribute to a better understanding of CAM use in cancer patients, and inform holistic forms of healthcare where the health and wellbeing of individuals with cancer are considered as an interplay of physical, psychological, social, and spiritual factors.

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CHAPTER SIX: PAPER FOUR – SUBMITTED FOR PUBLICATION
(STUDY 2 INTERVIEWS)

Statement of Authorship

Title of Paper	How men with cancer and their significant others practice Complementary and Alternative Medicine (CAM): exploration of shared and private CAM use
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Author Contributions

By signing the Statement of Authorship, each author certifies that their stated contribution to the publication is accurate and that permission is granted for the publication to be included in the candidate's thesis.

Name of Principal Author (Candidate)	Nadja Klafke	
Contribution to the Paper	Performed analysis on all samples, interpreted data, wrote manuscript and acted as corresponding author.	
Signature		Date 10/04/13
Name of Co-Author	Jaskin Elliott	
Contribution to the Paper	Supervised development of work, helped in data interpretation and manuscript evaluation.	
Signature		Date 11-04-13
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Contribution to the Paper	Helped to evaluate and edit the manuscript.	
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Contribution to the Paper	Helped to evaluate and edit the manuscript.	
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This Chapter further examines how, when, and why SOs contribute to men's uptake and maintenance of CAM.

The discursive analysis of the 43 interview transcripts from the Study 2 interview study found a salient pattern: SOs are consistently actively involved in men's use of CAM/*Natural products* (special diet, dietary supplements, herbs and botanicals), and sometimes in their use of CAM/*Mind-body medicine* (meditation/relaxation, Yoga, prayer, psychology/counselling). The shared practice of CAM Natural products (e.g., special diet, dietary supplements, herbs and botanicals), as well as the shared practice of CAM Mind-body medicine (e.g., meditation/relaxation, Yoga, prayer, psychology/counselling) was associated with interpersonal benefits for men and their SOs, as it strengthened their social bond. Results also indicated that there were instances when men expressed a need to practice CAM as a private activity to cope with uncertainty and loss of control. Further, the results were explained with Lazarus and Folkman's (1984; 1999) coping model, as CAM use within this study sample constituted problem-focused and/or emotion-focused coping.

In summary, the involvement of SOs in men's CAM use differs with regard to specific CAM categories. Performing CAM together as a shared coping practice (Natural products, Mind-body medicine) contributes to and strengthens interactions in men and their SOs, that will be further analysed in the subsequent Chapter Seven, focusing on how men and their SOs continuously practise CAM in everyday life, and use CAM over time.

6.1 Abstract

Little is known about the involvement of Significant Others (SOs), including family members, close friends, and caregivers, in male cancer patients' uptake and maintenance of Complementary and Alternative Medicine (CAM). This study aimed to address this gap by conducting semi-structured interviews among 26 men with a variety of cancers and 24 SOs. The results, part of a mixed-methods research about the contribution of SOs in men's CAM decisions, highlight that men and their SOs practice CAM either as a (1) shared activity, or/and (2) private activity. SOs were consistently actively involved in men's use of CAM/Natural products (special diet, dietary supplements, herbs and botanicals), and sometimes in their use of CAM/Mind-body medicine (meditation/relaxation, Yoga, prayer, psychology/counselling). The shared practice of CAM was associated with interpersonal benefits, working to strengthen the bond between men and their SOs, but there were instances when men expressed a need to practice CAM as a private activity. CAM use helped both men and their SOs to cope with uncertainty and to regain control. Findings have clinical implications regarding targeting CAM services to men with cancer and their SOs.

Keywords

cancer, complementary therapy, families, psychological, supportive care, male cancers

6.2 Introduction

Complementary and Alternative Medicine (CAM), defined as “diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine” (National Center for Complementary and Alternative Medicine, 2013), is frequently and increasingly used in cancer populations (Boon, et al., 2007; Ernst & Cassileth, 1998). A recent meta-analysis suggests an increase in CAM use by patients with cancer from 25% to 49% from 1970 onward (Horneber, et al., 2012). CAM can be categorized as *Natural products* (e.g., dietary supplements, herbs and botanicals), *Mind-body medicine (MBM)* (e.g., prayer, meditation/relaxation), *Manipulative and body-based practices* (e.g., massage, physiotherapy, acupuncture), and *Other* (e.g., exercise, naturopathy, Reiki) (Klafke, Elliott, Wittert, et al., 2012; National Center for Complementary and Alternative Medicine, 2013). Evidence-based studies suggest that CAM may help patients to cope with treatment side-effects and disease symptoms, and contribute to patients’ psychological well-being and quality of life (Cassileth & Deng, 2004; Ernst, 2010). Furthermore, CAM may also benefit patients’ Significant Others (SOs), including family members, close friends, and caregivers (Pitceathly & Maguire, 2003), who are faced with the burden of caregiving and/or preparing for the loss of a loved one with cancer (Girgis et al., 2012; Kozachik, et al., 2006).

Most CAM research has focused on female patients with breast cancer, thereby excluding men, with prevalence rates increasing from 67% to 82% between 1998-2005 (Boon, et al., 2007). A systematic review of CAM use by men with prostate cancer suggests the median prevalence rate is 30% (Bishop, et al., 2011). A recent Australian survey indicated that up to 60% of male cancer patients with a variety of cancers use CAM at some point during their cancer treatment (Klafke, Elliott, Wittert, et al., 2012). It is therefore important to know more about men’s perceptions, experiences, and decisions related to CAM, as well as their CAM practices over time. We have previously argued (Klafke, Elliott, Wittert, et al., 2012) that men with cancer use CAM within the category *Natural products*, as part of problem-focused coping (Lazarus & Folkman, 1984) to relieve disease-related symptoms or treatment side-effects. In addition, CAM from the category *Mind-body medicine* might be used to embark on a spiritual search of meaning in life, as part of emotion-focused coping (Lazarus, 1999). The reasons for use of CAM following

a cancer diagnosis can be summarized into physical, psychological, push-and-pull factors, and social/interpersonal factors (Klafke, Elliott, et al., 2012b). The latter category includes individuals' social networks, for example, family members are involved in cancer patients' CAM decisions (Öhlén, et al., 2006), as they are part of the individual's therapeutic management group (Janzen, 1978; Nichter, 2002). Although previous studies involving male and female cancer patients have provided evidence for the influence of family members (Öhlén, et al., 2006; Zhang & Siminoff, 2003), none have systematically analysed how SOs are involved in CAM decisions in men with a variety of cancers, and none have specifically examined differences of SOs' involvement with different CAM therapies. Here, we explore the contribution of SOs' CAM uptake by men in order to better understand the intrapersonal and interpersonal implications of CAM use.

6.3 Methods

A mixed-methods study design was used to investigate CAM use in men with cancer and the involvement of their SOs. Participants were recruited at two private and two public cancer outpatient services providing conventional cancer care in Metropolitan Adelaide. The project was approved by the relevant institutional Human Research Ethics Committees, and all participants gave written informed consent. We used a survey to assess the prevalence and predictors of CAM use, and to describe how cancer patients' social networks impact on uptake of specific CAMs [reported elsewhere; (Klafke, Elliott, Wittert, et al., 2012)]. Here, we report results from semi-structured interviews, to explore in depth how men with cancer and their SOs talk about their CAM decisions, how they practice CAM in everyday life, and how this might affect their interpersonal relationships. Survey participants were sampled purposefully (Patton, 2002) using a maximum variation technique to produce variety in stage and type of cancer, high and low levels of CAM use, and perceived levels of intrapersonal and interpersonal levels of conflict regarding CAM use. The final sample consisted of 26 men affected with cancer and 24 female SOs (see Table 11).

Semi-structured interviews were conducted by NK (who had no prior or subsequent contact with the participants) in hospital, home, or University of Adelaide settings. The majority of study participants were interviewed separately for 40-90 minutes. Interviews were guided by the research question "How do SOs contribute to men's decision to (continue to) use CAM after a diagnosis of

cancer?” Specific interview questions focused on expectations and experiences of CAM use, as well as decisions around specific CAMs. Study participants are identified by pseudonyms. All interviews were audio-recorded, transcribed verbatim, and imported into NVivo9 (QSR International Pty Ltd, Doncaster, Victoria, Australia) to facilitate the coding of the interview data.

Data were coded into categories representing participants’ ways of talking about their perceptions and experiences with CAM following the diagnosis of cancer. Thematic analysis (Braun & Clarke, 2006) focused on finding differences and similarities within and between participants’ speech, so that patterned responses could be identified as themes. In conducting the thematic analysis from a constructionist perspective (Berger & Luckmann, 1966; Potter & Wetherell, 1987), we took account of the assumption that individuals use and produce language in ways that are socio-culturally and historically shaped. Hence, individuals’ talk does not directly reveal their motivations or opinions, but it is rather used to achieve certain things. In considering participants’ language as action-oriented and epistemic, we were able to inductively explore men’s and their SOs’ CAM practices. Preliminary analysis was conducted by NK with all authors contributing to discussion of patterns and themes identified within the interview data. Conclusions were regularly reviewed and discussed between the authors and in consultation with other researchers specialized in men’s health and psycho-oncology.

Table 11

Patient characteristics

Details	Men diagnosed with cancer <i>Number</i> (26)
Age	
Mean (SD)	68 (9.9)
Range	61-75
Site of primary cancer	
Prostate	7
Haematological malignancies	6
Colorectal	5
Lung	3
Other	5
Stage of disease	
Curable cancer	9
Incurable cancer	17
Conventional cancer treatment	
Chemotherapy	24
Radiotherapy	14
Surgery	16
Hormonal therapy	9
Level of CAM use	
High (5-...)	19
Low (0-5)	7
Level of intrapersonal conflict	
High	10
Moderate	5
Low	/
Not indicated	11
Level of interpersonal conflict	
High	16
Moderate	6
Low	2
Not indicated	2
Partner status	
Married/partnered	22
Other	4
SO participating in interview	
Spouse/partner	19
Adult daughter	2
Ex-wife/ex-partner	2
Close friend	1
None present	2

6.4 Results and Discussion

Participants reported variations in SOs' involvement in CAM uptake and maintenance. Most examples given by men and their SOs centred around the CAM categories Natural products, and Mind-body medicine, reflecting the two most popular CAM categories in this male cancer population (Klafke, Elliott, Wittert, et al., 2012).

There were two distinct versions of CAM use within participants' speech: CAM as a "shared activity"; and CAM as a "private activity." The involvement of SOs varied with different CAM therapies. Drawing on Lazarus and Folkman's (1984; 1999) model of coping, we argue that the shared practice of CAM Natural products constitutes problem-focused coping, while the shared/private practice of CAM Mind-body medicine constitutes emotion-focused coping. Shared and private CAM practices were associated with interpersonal and intrapersonal consequences respectively, as illustrated below.

6.4.1 CAM as a shared activity.

The joint practice of CAM involved the direction and guidance of SOs that was accepted by the recipient. Phrases like "I had no trouble at all," "It's no problem at all," or "I just agreed" were commonly used by men to convey their agreement with their SOs, thereby emphasizing a conflict-free and harmonious relationship.

6.4.1.1 CAM Natural products (special diet, dietary supplements, herbs and botanicals).

Men commonly justified their acceptance of SOs' active contribution to CAM decision-making by likening them to responsibilities for food choices, an area traditionally associated with the female gender role (Norcross, et al., 1996; Warde & Hetherington, 1994).

- 1 JAMES: ... my wife is a health nut ... we do not have any processed
- 2 foods in the house ... I'm a mainstream man really, it could be that
- 3 some alternative therapies might help you with pain ... My wife said that
- 4 "This is what's going to happen" and I said "Well, let's give it our best

5 shot.” ... She probably talked me into it a bit, but basically we’ve said “If
 6 we gonna get in with a chance, we better do it.” ... I was hoping we
 7 could find something that would complement the mainstream ... so that
 8 it would work a bit better. ... anything that helps your body to build up its
 9 resistance.
 (Patient with metastatic prostate cancer)⁴

In this extract, James accepts his wife’s influence in changing lifetime eating and food patterns after the cancer diagnosis. His account, however, suggests that this is difficult for him because he is sceptical about CAM for cancer (lines 2-3), but wishes to maintain a harmonious relationship with his wife (lines 3-6). He begins by describing his wife in a humorous way as a “health nut” (line 1), implying criticism of her strong interest in a healthy life-style. James uses humour to differentiate his own position from his wife (lines 2-3), and to formulate his criticism in a tolerant and soft way (Jefferson, 1984). As it has been suggested that humour is ego-enhancing by being in control of interaction situations (Olliffe, Ogradniczuk, Bottorff, Hislop, & Halpin, 2009), it might be inferred that James uses humour in a safe, pleasant and mature way for him to present his masculine identity despite his wife’s strong influence.

It becomes clear that his wife’s interest in living healthily has been projected onto James, when faced with cancer. This is highlighted by the deontic phrase “This is what’s going to happen” (line 4), which indicates that James had to change his eating and lifestyle behaviour, with no room for protest or negotiation. James’ use of cited speech works to make his account vivid and believable (Wooffitt, 1992), constructing the plan for action as not open for negotiation. His reply towards his wife’s strong position is phrased as agreeable “let’s give it our best shot” (lines 4-5), indicating support and trust in his wife’s decision-making, which may have been associated with interpersonal benefits for their marital relationship.

⁴ Transcription protocol: Words included to make sense of the quotation are presented within square brackets, thus: [Like this]. Omission of some speech is indicated by an ellipsis, thus: “my wife and I ... decided to use CAM.” Idiosyncratic speech like “you know” and “like” and repeated phrases like “she said, she, she, she...” are deleted to facilitate readability. Extended square brackets mark overlap between utterances, thus:

A: [I used CAM.

B: [I pushed him to use CAM.

James may have prioritized a conflict-free relationship with his wife as well as treating and recovering from cancer over his scepticism towards natural health, food, and lifestyle choices. He indicates, however, that “she probably talked me into it a bit, but basically we’ve said ‘If we gonna get in with a chance, we better do it’”(lines 5-6), thereby first positioning his wife’s influence as a persuasion process, which has then become a joint CAM decision-process indicated by the change of the pronoun from “she” to “we.” Thus, James construes the influence of his wife in his CAM uptake and maintenance as acceptable and agreeable, even though men, in general, aim to be perceived as an active and independent decision-maker (Connell & Messerschmidt, 2005; Courtenay, 2000).

James’ account suggests that he and his wife practice dietary-based CAMs together to address a particular perceived problem (lines 6-9), namely, to complement mainstream cancer treatment, and to physically support the body (Correa-Velez, et al., 2005; Klafke, Elliott, et al., 2012b; Verhoef, et al., 2005). This can be construed as problem-focused coping (Klafke, Elliott, Wittert, et al., 2012; Lazarus & Folkman, 1984), where coping behaviour aims to reduce the cancer as well as strengthen the body’s resistance. The following account, however, might reflect both shared problem-solving and emotion-focused coping CAM practices (Lazarus, 1999; Lazarus & Folkman, 1984), the latter involves managing one’s own distressing emotions associated with the cancer.

1 ULRIKE: ... it (special diet) was a joint decision because it was pretty
 2 obvious that we’re going to have to work together with the medical
 3 profession to try and get a positive outcome, and that was something
 4 we could have control of. Although there wasn’t much we could have
 5 control of, but we can have control of diet and try and keep yourself as
 6 healthy as you can.

(Wife of patient with Multiple Myeloma)

Here, Ulrike talks of a special diet, recommended by a CAM practitioner (naturopath) and supported by healthcare professionals at their cancer clinic. Ulrike uses the subject pronoun “we” to construe the diet as a joint decision, on the basis that both she and her husband needed to work together with the “medical profession” (lines 2-3). In referring to this category entitlement (Sacks, 1992), Ulrike presents healthcare professionals as experts with the knowledge and authority to advise cancer patients and their SOs. As the medical profession, a reliable and trustful source, supported their diet change, its uptake and maintenance is constructed as reasonable. In justifying her involvement “it was pretty obvious that we’re going to have to work together...” (lines 1-2) Ulrike constructs her active contribution as a normal action and a necessary partnership to support her husband and better his health. Ulrike then emphasizes that they used this CAM “to try and get a positive outcome” (line 3) indicating that this CAM use is an attempt to prevent the cancer from returning or spreading. This intention implies a shared problem-solving coping strategy to deal with the cancer from a physical perspective (Lazarus & Folkman, 1984). Ulrike’s repeated use of the verb “to try” (lines 3, 5), however, suggests difficulties, effort, and problematic uncertainties in adhering to this regimen, thereby presenting herself as thoughtful – as anticipating and acknowledging potential non-desired outcomes.

Ulrike also presents the decision to adopt and maintain a specialized CAM-based diet as a mechanism to gain or regain control, a psychological state often associated with CAM uptake in cancer patients (Montbriand, 1995a; Verhoef, et al., 2005; White & Verhoef, 2003). Research suggests that a sense of control reduces anxiety and uncertainty in cancer patients, while gaining hope (Truant & Bottorff, 1999), but SOs psychological behaviour has not yet been examined under the issue of control. Ulrike’s account indicates that she wants to be involved in this process of gaining or regaining control (lines 3-5), possibly to empower herself (Girgis, et al., 2012; Kozachik, et al., 2006). As it is an accepted social norm that women are responsible for food choices within a household (Norcross, et al., 1996; Warde & Hetherington, 1994), Ulrike’s statement “we can have control of diet and try and keep yourself as healthy as you can” (lines 5-6) corroborates her active and ongoing involvement as a necessity, an unquestioned obligation for her. This shared CAM practice may strengthen the social bond in the dyad (Nichter,

2002), and act as a shared coping strategy to deal with life after the cancer diagnosis.

6.4.1.2 CAM Mind-body medicine (meditation/relaxation, Yoga, prayer, psychology/counselling).

Men regularly spoke of the involvement of their SOs within the CAM category Mind-body medicine (MBM), depicting SOs as information sources, initiators, or co-CAM-consumers (Öhlén, et al., 2006). For example, in the following, Amelia presents the uptake of counselling following the cancer diagnosis as involving herself and her husband.

- 1 AMELIA: ... I was a little bit dented about what to do next and so I said
 2 “I’m going to do this counselling” and then I afterwards I decided that he
 3 was going to come too, if he wants to or not (laughs). So we went
 4 together, and yeah that’s how it happened ...
 5 ZAC: I just, I just got told (laughs)
 6 AMELIA: He agreed, yes (laughs)
 (Wife and patient with non-metastatic colorectal cancer)

Amelia begins by establishing that she felt “dented” or distressed (line 1), thereby justifying her interest and need for counselling after her husband’s cancer diagnosis. Further on, Amelia then discusses her desire to include her husband in these counselling sessions (lines 1-3) “if he wants to or not”. She positions her husband as possibly sceptical about CAM uptake, requiring her direct and directing contribution to ensure his participation, a dominant involvement which is eased by shared laughter (Jefferson, 1984). Thus, Amelia’s initiation of joint counselling is justified as a normal action to support and help her husband, which in turn may also benefit their relationship. Zac corroborates his wife’s active CAM involvement by stating “I just got told” (line 5) which indicates strong agreement and trust in his wife’s guidance about CAM use. The use of laughter (Jefferson, 1984) signals that this CAM decision has been a sensitive topic, defused by perceiving it in a humorous way. In social interactions, laughter functions to build

compliance and increase social bonding (Bloch, Browning, & McGrath, 1983). Hence, this shared CAM practice may offer an opportunity for the couple to enact and experience positive and intimate marital affiliation, providing mutual benefit (Jefferson, Sacks, & Schegloff, 1987). Thus, even though the decision to uptake counselling was initiated and directed by the wife, both she and her husband frame this CAM uptake as a shared and joint event, demonstrating harmony, unity, and trust. The following extract provides further evidence about interpersonal benefits of shared CAM MBM practices.

1 NORA: ... he'd [Lucas] agreed. ... I do the research and I've read stuff
 2 to him, and he said "You organize it, whatever you think, I'll just go
 3 along." ... I've read several books to Lucas ... he was not keen on
 4 reading. So I would read or I'd do a guided meditation, or get like a DVD
 5 or a tape or something and put that on to him ... we did practice it a little
 6 bit together ... but I meditate very regularly and continue to meditate
 7 regularly ...
 (Wife of patient with metastatic prostate cancer)

Here, Nora reports that she initiated and guided the shared practice of meditation with the support of her husband. She cites Lucas as saying "You organize it, whatever you think, I'll just go along" (lines 2-3) to demonstrate her husband approved her involvement and did not perceive it as nagging or harassing. Thus, her CAM knowledge, encouragement and participation in her husband's CAM use might have strengthened the social bond (Nichter, 2002). Nonetheless, encouraging and directing a man towards CAM use does not automatically and ultimately imply his maintenance of CAM use. Nora's statement which began "we did practice it a little bit together" (lines 5-6) indicates that the shared MBM practice has become a private MBM practice for her. Apparently, her husband did not continue to practice MBM, possibly perceiving it as too difficult, boring, or lacking perceived benefit. Regardless, Nora presents the regular practice of MBM as personally beneficial which suggests it is an effective emotion-

focused coping strategy for herself (Lazarus, 1999), improving her quality of life and emotional well-being (Cassileth & Deng, 2004; Ernst, 2010).

6.4.2 CAM as a private activity.

The second version of CAM use was as a private practice in men diagnosed with cancer, without involvement or awareness of their SOs.

6.4.2.1 CAM Mind-body medicine (meditation/relaxation, Yoga, prayer, psychology/counselling).

Men exclusively spoke about private activities within the CAM category Mind-body medicine (MBM), commonly used to improve emotional well-being in cancer patients (Cassileth & Deng, 2004; Ernst, 2010), and thus enacting emotion-based coping (Lazarus, 1999). In the following extract Franklin presents his use of MBM as a private event excluding his wife.

1 FRANKLIN: ... we've discussed all aspects, and Ulrike's been involved
2 in treatment, and attended almost every appointment that I've ever had
3 ... but in terms of visualization and meditation, that's something that I
4 see as being intensely personal and so we haven't really discussed it at
5 all. ... it's my part of doing something for the disease, or against the
6 disease, and it's my path, it's me, it's not Ulrike ... it's not difficult [to
7 practice visualization and meditation], if I got a quiet time, that's all I
8 need, just a quiet time.

(Patient with Multiple Myeloma)

In responding to a query about his discussions with his wife about MBM, Franklin makes a clear distinction about the contribution of his wife in his cancer recovery (lines 1-5): his wife provides practical and emotional support for his conventional cancer treatment, but not for his practice of visualization and meditation. Franklin constructs his private practice as intensely personal and not needing to be shared with his wife. This is despite his assertions that Ulrike assisted him during conventional cancer care, indicative of a trustful and

supportive relationship. Franklin repeatedly uses personal pronoun phrases, such as, “it’s my part,” “it’s my path,” and “it’s me” (lines 5-6) to affirm that dealing with “the disease” is his responsibility. Franklin repeatedly states that he only needs “quiet time” (line 8) for this private practice of MBM, thereby suggesting the calming and relaxing benefits of the practice of visualization and meditation (Cassileth & Deng, 2004; Ernst, 2010), while justifying his wife’s exclusion from this quiet private activity.

Practicing CAM privately might allow men to feel independent, autonomous, in control, thereby reflecting emotion-focused coping (Lazarus, 1999). These traditional male traits may be difficult to maintain after a cancer diagnosis (Ollife, Ogrodniczuk, et al., 2009). The following account of Kevin further exemplifies the emotion-focused benefits of MBM without involvement of his wife.

1 KEVIN: No, she [his wife Olivia] hasn’t been involved [in meditation,
2 Yoga], that’s just something I’ve done by myself. ... it’s me. That’s
3 something I can do myself, I don’t need anyone else to deal with me,
4 and I know I can make my mind just switch off and just centre and just
5 feel it, this flow through my body. ... it’s something I’ve practiced for a
6 long time and I’ll continue to do.
 (Patient with metastatic prostate cancer)

Here, Kevin construes his regular private practice of meditation and Yoga as an individual coping strategy. He specifically excludes his wife from the CAM activities he used before his cancer diagnosis (line 1), indicating his long-term satisfaction and established application of these MBM techniques (lines 5-6). As with Franklin, Kevin uses personal pronoun phrases such as “by myself,” “it’s me” (line 2), indicating a need for a personal and private space. This enables him to “deal” and “centre” (lines 3, 4) practices that indicate emotion-focused coping (Lazarus, 1999), and presumably provide sufficient personal benefit to justify their maintenance. His private practice of MBM might also have contributed to (the maintenance of) his positive feeling of control, discernible in the phrase “That’s something I can do myself ...” (lines 2-3).

This suggests that Kevin favours maintaining independence and autonomy despite his cancer diagnosis (Montbriand, 1995a). The regular practice of MBM may have provided him with feelings of certainty, stability, control, and therefore satisfaction.

6.5 Conclusion

The findings from this study demonstrate that men with cancer and their SOs experience intrapersonal and interpersonal benefits from shared and private CAM practices. There was, however, variation in SOs' involvement in specific CAM therapies. SOs were consistently involved in patients' uptake of CAM Natural products, and we suggest that this may be a shared problem-focused coping strategy (Lazarus & Folkman, 1984). The male cancer patient and his family could focus on physical body aspects: for example, herbs and botanicals are consumed to prevent cancer recurrence; dietary supplements are consumed to boost the immune system; or a special diet is followed to stay healthy (Correa-Velez, et al., 2005). As these practices impact on dietary habits, an area traditionally controlled by females, in this context, CAM use may facilitate a shared problem-solving approach. This in turn may increase interaction, discussion, and overall communication between men and female SOs, and strengthen their social bond (Nichter, 2002).

The involvement of SOs varied with regard to CAM Mind-body medicine (MBM). Men and their SOs practice MBM together as part of shared emotion-focused coping (Lazarus, 1999), but men also practiced it alone. The shared practice of MBM might have benefits for the relationship between men and their SOs, as it involves spending time together, discussing, preparing for and practicing meditation, or attending counselling sessions together. Nonetheless, many men held that the private practice of MBM enabled them to focus on dealing with the cancer diagnosis themselves. This private emotion-focused coping strategy may be especially helpful for men, commonly depicted as reluctant to express emotions (Connell & Messerschmidt, 2005; Courtenay, 2000; Seymour-Smith, et al., 2002).

The authors acknowledge that the study sample was homogenous, comprised of white Australian men receiving conventional cancer treatment. Nonetheless, the study findings confirm previous research (Nichter, 2002;

Öhlén, et al., 2006), indicating that SOs are often involved in cancer patients' healthcare decisions regarding CAM, but further indicating how and when female SOs contribute to male cancer patients' CAM uptake.

The implications of these findings are, first, that clinicians could speak with male cancer patients and their SOs about the benefits of shared and private practice of CAM. Second, integrative cancer clinics could design supportive programs, not only targeting male cancer patients but involving their SOs. Intervention programs could include both emotion-focused techniques like meditation/relaxation, Yoga; and, problem-focused strategies like diet and exercise programs. Finally, future research about the involvement of SOs in cancer patients' CAM decisions may focus on the implications on family dynamics. As the majority of men with cancer use CAM (Klafke, Elliott, Wittert, et al., 2012), it is important that comprehensive cancer care is wide-ranging and tailored to the psychological needs of both men and their SOs.

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**CHAPTER SEVEN: PAPER FOUR – SUBMITTED FOR
PUBLICATION (STUDY 2 INTERVIEWS)**

Statement of Authorship

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Author Contributions

By signing the Statement of Authorship, each author certifies that their stated contribution to the publication is accurate and that permission is granted for the publication to be included in the candidate's thesis.

Name of Principal Author (Candidate)	Nadja Klafke	
Contribution to the Paper	Performed analysis on all samples, interpreted data, wrote manuscript and acted as corresponding author.	
Signature		Date 10/04/13

Name of Co-Author	Jaklin Elliott	
Contribution to the Paper	Supervised development of work, helped in data interpretation and manuscript evaluation.	
Signature		Date 11-04-13

Name of Co-Author	Ian Oliver	
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Signature		Date 23-05-13

This Chapter focuses on how men with cancer integrate and practise CAM over time, aiming to further understand the intrapersonal and interpersonal benefits of regular and constant CAM use.

Discursive analysis found that regular and habitual male CAM users integrate CAM routines and CAM rituals in their everyday life. CAM routines provide men with cancer with certainty and control, while CAM rituals function for cancer patients and their SOs as a means to create and maintain meaning, thereby working to counter fear and uncertainty consequent upon a diagnosis of cancer. This study also explored that satisfied CAM users combine and practice several CAMs (from different CAM categories) in their everyday life, thereby perceiving their constant use of CAMs as their lifestyle.

In summary, CAM routines and CAM rituals are associated with intrapersonal and interpersonal benefits for male cancer patients and their SOs, adding to a better psychosocial understanding of cancer patients' long-term CAM use. (Please see Appendix T for the revised and published version of this manuscript.)

7.1 Abstract

Complementary and Alternative Medicine (CAM) is frequently used in cancer patients, often with involvement of Significant Others (SOs), but without consultation of healthcare professionals. There has been little exploration of how cancer patients integrate and maintain CAM use in their everyday life, and how SOs are involved in this. This qualitative study analyses the speech of 26 men affected with cancer, and 24 SOs, demonstrating ways in which CAM routines and CAM rituals are constructed as beneficial for regular and satisfied CAM users. The authors argue that CAM routines provide men with certainty and control, and that CAM rituals function for cancer patients and their SOs as a means to create and maintain meaning, thereby working to counter fear and uncertainty consequent upon a diagnosis of cancer. The results contribute to a better psychosocial understanding of how men with cancer and their SOs integrate a combination of several CAMs in their everyday life. Healthcare professionals can be informed about the benefits of practicing CAM as routines and rituals, constituting key elements in cancer patients' regular and satisfied use of CAM.

Keywords

cancer, psychosocial aspects, health care, alternative and complementary, holistic care, families, men's health, relationships, ritual

7.2 Introduction

Following diagnosis and during conventional cancer treatment, cancer patients often experience a number of adverse consequences, including shock, anxiety, uncertainty, distress, and depression, in addition to the burden of physical treatment and disease symptoms (Bailey, Wallace, & Mishel, 2007; Massie, 2004; Olver, 2011; van't Spijker, et al., 1997). Complementary and Alternative Medicine (CAM), commonly defined as “diverse and medical health care systems, practices, and products that are not generally considered part of conventional medicine” (National Center for Complementary and Alternative Medicine, 2013), is increasingly used in cancer populations (Boon, et al., 2007; Horneber, et al., 2012; Klafke, Elliott, Wittert, et al., 2012). A growing number of evidence-based studies attest to the efficacy of CAM use as a complement to conventional cancer treatment (Cassileth & Deng, 2004; Ernst, 2010), and there is emerging evidence about cost-effectiveness of several CAM therapies (Herman, et al., 2012), contributing to support for the integration of CAM services within pluralistic healthcare systems (Baer, 2009).

Cancer specialists, however, generally do not consult or guide cancer patients about their CAM consumption, so that decisions about CAM take place at patients' homes, often shared and encouraged by their Significant Others (SOs), such as family members and/or close friends (Nichter, 2002; Öhlén, et al., 2006). Family members often act as information sources, active decision-makers, and/or co-CAM consumers regarding cancer patients' CAM use (Elliott & Klafke, 2011; Öhlén, et al., 2006). The interpersonal context matters in male cancer patients' CAM uptake and maintenance, as the use of CAM functions as a means to socially connect the cancer patient with their SOs, benefiting harmony and trust in spousal or friendship relationships (Klafke, Elliott, Olver, & Wittert, 2012a; Klafke, Elliott, et al., 2012b; Nichter, 2002). The forms and functions of regular CAM use within everyday family life, however, has not been clearly examined in the literature, so that there remains a lack of understanding if CAM use contributes to familial cohesion and functioning (Klafke, Elliott, et al., 2012a, 2012b), or increases familial distress and conflict (Zhang & Siminoff, 2003). Only one qualitative study employing a diary approach (Broom & Tovey, 2008b) examined cancer patients' CAM experiences over time, but did not specifically focus on the interpersonal implications of daily CAM activities. The authors found that in their sample of eight

cancer patients close to death, the use of CAM was associated with empowerment, but also required discipline. The difficulties maintaining CAM use might have been further complicated when SOs expressed concerns about continuing CAM use to the patient. No other studies, however, have included the perceptions of both cancer patients and their SOs about regular and daily CAM practices and examined the interpersonal implications.

Despite the non-involvement of medical professionals, and the potential danger of using CAMs offering cure by charlatans, or consuming CAM with adverse effects (Clarke & McLachlan, 2011; C. Pirri, 2012), cancer patients continue to use CAM, to cope with physical, and psychological concerns, because of push-and-pull factors, or a strong social influence (Verhoef, et al., 2005; Klafke et al., 2012 paper under review [Chapter Five]). Committed CAM users may be more drawn into using more CAM over the long-term, presumably because their belief in the holistic treatment of illness is congruent with many CAM paradigms (Bishop, Yardley, et al., 2010; M. C. Porter & Diefenbach, 2009). For committed and long-term CAM users, constant CAM utilization may reflect part of a lifestyle choice, which is only recently explored in the literature (Klafke, Elliott, et al., 2012a; Mao et al., 2010).

In reading the accounts of men and their SOs regarding CAM, the authors were struck by the similarity of form and function between routines and/or rituals and CAM practices. Here, we seek to understand men's regular and satisfied CAM use as consisting of a set of actions that become routine and ritualized. *Routines* can be defined as actions with a functional and instrumental aim, that can become a habit (Bourdieu, 1977), and *rituals* as activities filled with meaning that require ongoing interaction about its symbolic activities (Boyce, Jensen, James, & Peacock, 1983; Durkheim, 1971; Goffman, 1972; Turner, 1969). A routine can become a ritual when an instrumental function contributes symbolically to other social values like identity, or interpersonal communication (Peacock, 1975). Alternatively, a ritual can become a routine, if the performative and symbolic actions are considered less meaningful over time, or if it has been replaced by another meaningful ritual (Spagnola & Fiese, 2007). The main common characteristic of routines and rituals is the regular repetitive use; social actions are performed on a constant and continuous basis with according intrapersonal and interpersonal consequences.

Sociological and anthropological research has suggested that family routines provide stability and continuity for family members (Boyce, et al., 1983; Jensen, James, Boyce, & Hartnett, 1983; Segal, 2004; Wolin & Bennett, 1984). Healing rituals have always been important in human cultures to facilitate coping with dangers and uncertainties, as well as to celebrate and maintain what is valued in the world (Turner, 1969). Routines and rituals reportedly can help to reduce anxiety and uncertainty in everyday life for individuals diagnosed with autism spectrum disorder and obsessive compulsive disorder (Brooks, 2011; Marquenie, Rodger, Mangohig, & Cronin, 2011; Rodger & Umaibalan, 2011). Examining cancer patients' regular and high CAM use through the concept of the establishment of routines and rituals may provide new insights into cancer patients' coping strategies for reducing negative psychosocial states and strengthening the social bond with their SOs, with potential benefit when facing a life-threatening disease.

7.3 Methods

The results reported here are drawn from a two-phase mixed-methods research project on the use of CAM in men with cancer and the involvement of SOs. Participants were recruited from two public and two private cancer outpatient services in Metropolitan Adelaide, South Australia. Ethical approval was gained by the relevant institutional Human Research Ethics Committees, and all participants gave written informed consent before study entry.

In Study 1, the research team administered and analysed a survey to 403 Australian men affected with cancer, reporting prevalence and predictors of CAM use, as well as the influence of cancer patients' social network within a male cancer population [reported elsewhere (Klafke, Elliott, Wittert, et al., 2012)]. Here, the authors report results from Study 2. The research team conducted 43 semi-structured interviews with 26 male cancer patients, and 24 female close family members/friends, to better understand how men with cancer practice CAM over time, and how SOs are involved in men's CAM uptake and maintenance. Survey participants were sampled purposively, using a maximum variation technique (Patton, 2002) to produce variety in stage and type of cancer, and perceived levels of intrapersonal and interpersonal levels of conflict regarding CAM use. During data collection, sampling became more theoretical; in particular high CAM users

were recruited for an in-depth interview, as these cases provided most information-rich data (Patton, 2002). Interview data were collected until data saturation was reached and no new themes were disclosed during the interviews (Morse, 1995). Demographic and disease-related details of the men participating in the interview-study are summarized in Table 12.

Table 12

Demographic and disease-related details of sampled men with cancer

Details	Patients with curable cancer Number (9)	Patients with incurable cancer Number (17)
Age		
Mean (SD)		68 (9.9)
Range		61-75
Site of primary cancer		
Prostate	2	5
Hematological malignancies	2	4
Colorectal	2	3
Lung	2	1
Other	1	4
Conventional cancer treatment		
Chemotherapy	8	16
Radiotherapy	6	8
Surgery	5	11
Hormonal therapy	/	9
Level of CAM use		
High (5-...)	7	12
Low (0-5)	2	5
Partner status		
Married/partnered	8	14
Other	1	3
SO participating in interview		
Spouse/partner	7	12
Adult daughter	/	2
Ex-wife/ex-partner	/	2
Close friend	1	/
None present	1	1
Interview situation		
No SO involved	1	1
Together	5	3
Separate	3	13
Level of intrapersonal conflict		
High	6	4
Moderate	1	4
Low	/	/
Not indicated	2	9
Level of interpersonal conflict		
High	5	11
Moderate	2	4
Low	/	2
Not indicated	2	/

The patient and his SO were interviewed separately or together for 40-90 minutes by NK at participants' preferred venue (home, cancer clinic, or university interview room). The interview schedule (see Table 13) was guided by the research questions "How do SOs impact on men's decision to (continue to) use CAM after a diagnosis of cancer?" and "How do men and their SOs integrate CAM in their everyday life?" Interviews were audio-recorded, transcribed verbatim, then entered into NVivo9 (QSR International Pty Ltd, Doncaster, Victoria, Australia) to facilitate analysis. Identifying information (including names of hospitals and participants) were replaced by pseudonyms. NK was responsible for conducting the preliminary analysis, which was regularly discussed and refined with the other authors.

Following discursive analytical principles, interview data were coded into categories based upon the functions and consequences of men's regular CAM use in everyday life (Potter & Wetherell, 1987). The analysis of discursive patterns in individuals' speech enables greater understanding of how they perceive, categorize, and interpret the social world (Edwards & Potter, 1992; Potter & Wetherell, 1987). In considering language as action-oriented, the discursive analysis focuses on individuals' interpretative repertoires (Potter & Wetherell, 1987) and subject positions (Davies & Harre, 1990), as well as the search for patterns, and formation of hypotheses based on variations of language in use (Edwards & Potter, 1992; Potter & Wetherell, 1987). Discourse analysis comprises a plurality of different methods with two distinct approaches often identified as oppositional (Willig, 1999a): conversation analysis, and Foucauldian or poststructuralist analysis. The former approach examines talk in interactions, analysing what local talk is doing at each moment, considering language from a micro-perspective. The latter approach analyses language as part of a wider socio-cultural context, considering power relations and restrictions on what can be said and done, and by whom. Following previous research examining the speech of cancer patients and their significant others (Elliott & Olver, 2007a), the authors used an integrated approach to discourse analysis (Willig, 1999a), thereby analysing participants' talk about CAM practices in situ, whilst acknowledging the socio-cultural dimension promoting and restraining particular discourses in talk.

Table 13

Interview schedule

1. Introduction	Can you tell me a little bit about what has happened to you since your cancer diagnosis?
2. Opening development of the interview - Definition of CAM	What do you understand by the term “complementary and alternative medicine”?
3. Central core of the interview (Exploration of data from survey)	I can see from the answers you’ve given on the questionnaire that you’ve used CAM... Which one of those was the most helpful for you?
A) Information-seeking	How did you find out about this CAM?
B) Experience	Before you started to use this CAM, what did you expect? What were you hoping for? And what was your experience: How did you feel? (Physically? Emotionally? Spiritually?) What convinced you about continuing to use this CAM? Would you recommend it to other male cancer patients? Do you apply this CAM more often since you’ve been diagnosed with cancer? How does it help? What is it that works for you?
C) Social influence/involvement	I noticed that you were quite keen on the use of this CAM... What was your wife’s/daughters’ position about this CAM? What was the oncologist’s position? How did you deal with opposing positions? How did you discuss/talk about the use of this CAM with your wife? Friend? Other family members? How did you decide what to do? What was it like once you’d made a decision about what to do? Was it ever difficult to follow through? How do you perceive the involvement of your wife in your healthcare decisions, in particular with regard to the

use of CAM? (Supporting? Actively involved? Own decisions?)

D) Conflict

Have you ever experienced that a close family member/friend strongly recommended CAM for you to deal with your cancer, but you decided not to use it?

I noticed that you were not keen on the use of this CAM...

Was this CAM recommended by a family member/friend?

How did you discuss it together with family members/friends?

What were your feelings about it? What were your thoughts? What were you hoping for?

Did you discuss CAM with your healthcare professionals?

How did you decide what to do? Was it ever difficult to follow through?

E) Integration of CAM in everyday life

I wonder if you could talk to me about how CAM fits/fitted into your everyday life.

Did it change things? How did that affect you?

Is it always easy to use this CAM?

What is practically involved? (Time? Effort? Money?)

Problems? Difficulties? Barriers?

How do you and your wife talk about the practice of CAM together?

How is your wife involved in the daily use of CAM?

F) Increase or decrease of CAM consumption

What sort of things might try you using more CAM? (Recommendations? Disease progress?)

What sort of things might stop you using CAM? (Side-effects? Costs? Disease progress?)

4. Close

What was the most helpful thing outside conventional medical treatment that you, or both you and your wife have done (or learned) following the cancer diagnosis?

Is there anything else you'd like to say?

Note. The interview questions were slightly modified according to the interview situation, that was, joint or individual interviews for patient and significant other.

7.4 Results

Of the 26 interviewed men, 18 used at least one CAM therapy in a routinized or ritualized way (see Figure 6) (of the other eight men, two were CAM non-users, and the others had tried, but not continued CAM). Sixteen men practiced a combination of three CAM therapies, with varying routine and ritual elements, to address a range of physical, mental, and spiritual needs (see Figure 7), that became integrated in their lifestyle. Routines and rituals were invented following diagnosis, and were associated with dietary-based CAMs (e.g., special diet, dietary supplements, herbs and botanicals), mind-body medicine (e.g., relaxation/meditation, prayer), and other CAM (e.g., exercise).

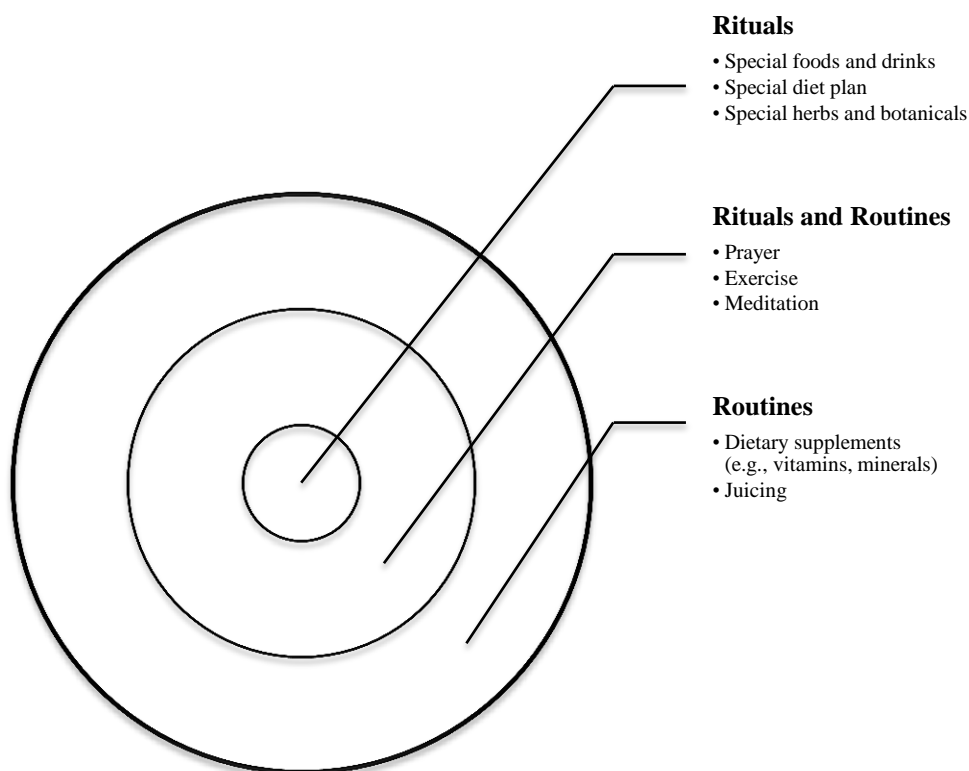


Figure 6. Cancer patients' CAM routines and CAM rituals

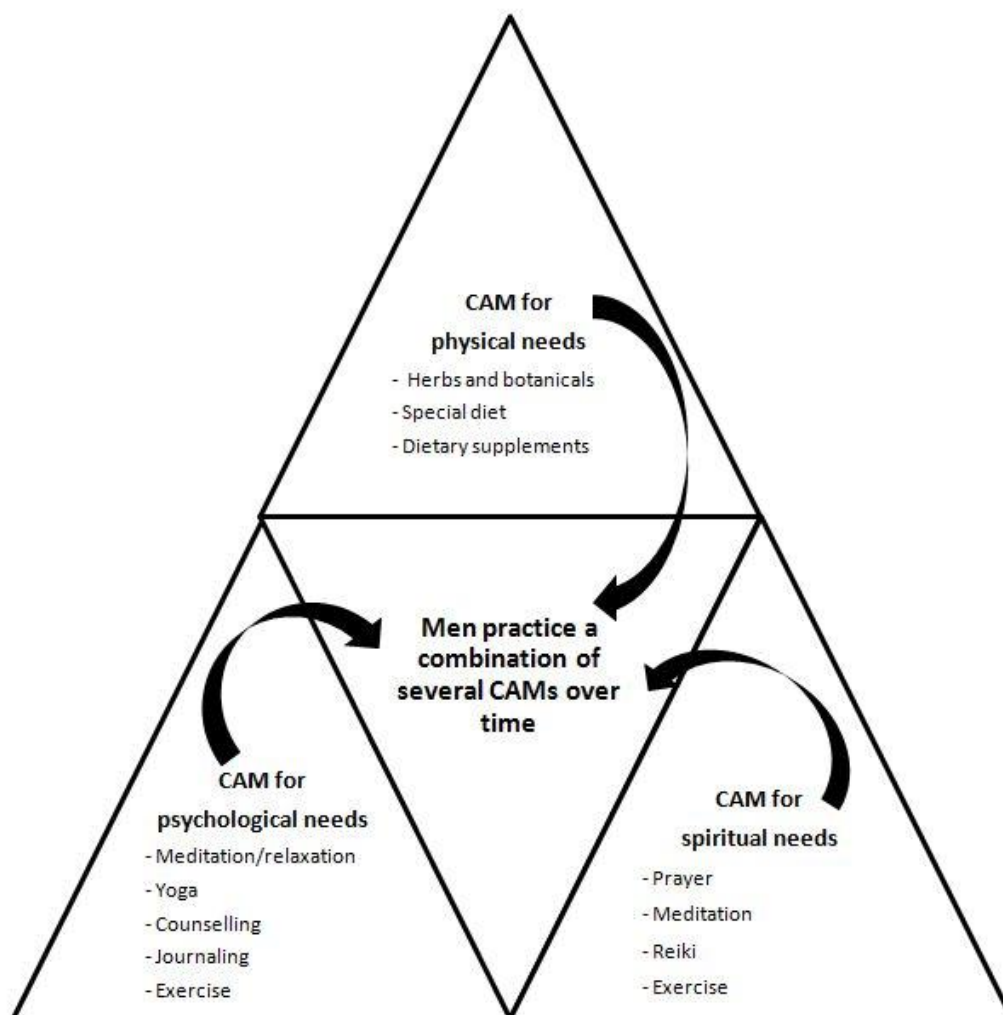


Figure 7. Men’s combined CAM use addressing physical, psychological, and spiritual needs

The consumption of dietary supplements, minerals, and juicing was consistently associated with a routinised practice, while the intake of special drinks and foods, herbs and botanicals, as well as a special diet was practiced as a ritual. Men with cancer practiced prayer, meditation, exercise and physical activities as routines as well as rituals, reflecting individual differences and preferences. During the interviews, the study participants located prayer, dietary changes, and exercise as belonging to their regular CAM practices, regarding these activities as an effective means for managing their cancer treatment outside conventional medicine. Thus, the definition of CAM practices used in this study is rather broad, but consistent with other studies that have included spiritual practices (Richardson,

et al., 2000), diet (Broom & Tovey, 2008b), and exercise (Bussing, Ostermann, Heusser, & Matthiessen, 2011) as CAM.

7.4.1 Functional routines.

Patients with curable and incurable cancer differed in their expectations of use of dietary supplements (e.g., taking vitamins, minerals in tablet, powdered or liquid form, and fruit or vegetable juicing). Both groups stated that they used these CAMs “for health reasons,” reflecting a responsible and health-conscious position, that may have been shaped by the prevalent healthism discourse (Cheek, 2008; Crawford, 2000; Lyons & Chamberlain, 2006). Other justifications such as “to help the body to be as healthy as possible during conventional cancer treatment,” or “to maximize the effect of the chemotherapy/radiotherapy, to make it as effective as possible,” can be categorized as *physical reasons* (Correa-Velez, et al., 2005; Klafke et al., 2012 paper under review (Chapter Five)). Men with metastatic cancer stated that they initially used these CAMs to cure their cancer, but this expectation changed over time, shifting from “in hope of a cure” to “health reasons.” This shift may reflect a strong desire for survival in patients with incurable cancer (Correa-Velez, et al., 2005), with subsequent acceptance that their disease is incurable resulting in a shorter life expectancy. By contrast, men with non-metastatic and therefore probably curable cancer consistently stated that they also used these CAMs “to prevent the cancer from coming back,” emphasizing the importance of their belief in and enactment of effective prevention strategies for cancer (Ma & Chapman, 2009). Both patients with curable and those with incurable cancer, stated that the consumption of dietary supplements and juicing had become a routine in their everyday life. The structured use was generally experienced as “easy,” “not a problem,” or as a “habit,” providing further justification for maintaining CAM use.

1 OLIVER: ... it's morning, you wake up, and you have them. ... there's
2 about four different bottles of them, like bovine cartilage, ... flaxseed oil,
3 and then there's a couple of herbs, a lot of lung supplements that build
4 the lungs up, and the others for the cancer sort of things. And then
5 there's the tablets ... that I have a dozen bottles of those. So you have

6 them in the morning, you have them lunch time, you have them in the
 7 evening sort of thing. It's not too hard, you just gotta have to measure
 8 them out sort of thing. But yeah it's fairly easy to do once you get into a
 9 routine, it's just the cost of them
 (Patient with non-metastatic lung cancer)⁵

In this excerpt, Oliver positions himself as a satisfied and high CAM-user, consuming multiple CAMs on a routine basis. His regular use of CAM is construed as unproblematic, despite the many (and costly) different CAMs that he measures and self-administers throughout the day. He describes the daily use of dietary supplements through quantifying doses and formulations like “four different bottles,” “couple of herbs,” “dozen tablets” (lines 2-5), that function to construct his everyday use of CAM as involving effort and careful thought about the correct measurements of different products for different symptoms. Throughout his account, Oliver repeatedly emphasizes his strategy to control and maintain this high CAM uptake on a daily basis: the statement “it's morning, you wake up, and you have them” (line 1) allows the inference that he starts his day with the first dose of CAM supplements. Consequently, this morning routine prepares and reminds him of the following structured CAM uptakes: “in the morning ... at lunch time ... in the evening” (lines 6-7). It could be argued that Oliver is orienting to the possibility that this CAM regimen would be seen as onerous and perhaps excessive, but he downplays this by asserting “it's not too hard” (line 7).

Research suggests that routines function to order and structure life for families and for individuals with special psychological needs (Jensen, et al., 1983; Segal, 2004). Oliver's CAM consumption may be better understood in this light, as these daily highly structured CAM practices may provide him with a certain, unproblematic, controllable and regular means to structure the day, fostering feelings of stability and predictability (Boyce, et al., 1983). His statement “it's fairly

⁵ Transcription protocol: Words included to make sense of the quotation are presented within square brackets, thus: [Like this]. Omission of some speech is indicated by an ellipsis, thus: my wife and I . . . decided to use CAM. Idiosyncratic speech like “you know” and “like” and repeated phrases like “she said, she, she, she...” are deleted to facilitate readability. Extended square brackets mark overlap between utterances, thus:

A: [I used CAM.

B: [I pushed him to use CAM.

easy once you get into a routine” (lines 8-9) specifically highlights that it is the routinized practice that contributes to his perception of regular CAM usage as easy and unproblematic, thereby justifying persistence on a daily basis. Additionally, Oliver positions himself as an informed user of CAM, consuming each CAM for different reasons, for example, “lung supplements that build the lungs up” (lines 3-4) and CAMs “for the cancer sort of things” (line 4). The belief in the perceived benefit from these dietary supplements consumed as part of a daily routine, without involvement of healthcare professionals or family members, may facilitate the individual’s perceptions of agency and self-help, potentially contributing to increased wellbeing (Montbriand, 1995a; Truant & Bottorff, 1999). It has been suggested that routines are a precondition for rituals (Segal, 2004; Spagnola & Fiese, 2007), a point now further explored.

7.4.2 Meaningful rituals.

The majority of CAM users stated that they had consciously changed their diet to a more healthy and organic eating plan, often including specific foods and food rituals which were shared and co-consumed with their SOs. In addition, most CAM users spoke of how they regularly consumed special beverages, for example, teas or brews consisting of special herbs and spices. In the following extract, Irvine presents his regular CAM practice as including important ritualistic elements, associated with intrapersonal and interpersonal consequences.

1 IRVINE: ... My breakfast or our breakfast is the same thing, every
 2 single day, and it doesn’t matter if we’re at home or go on holiday, it’s
 3 the same thing. Sometimes there may be bits we can’t get but there’s
 4 always always ways around it. ... my wife Rachel makes that [breakfast]
 5 every night before we go to bed and it’s got things like steamed carrots,
 6 protein powder, it’s difficult to find a protein for the morning that’s not
 7 egg or bacon ... so I have steamed carrots as the main carbohydrate
 8 with protein powder and added into that are things like ginger, turmeric
 9 ... cinnamon, fish oil ... and on top of that goes frozen berries. ... it’s a
 10 work of art to make that every night. ... it stops your thinking, you don’t
 11 have to think about it ... some people might say “What would you like

12 for breakfast today?” I don’t have a problem, it’s the same breakfast
13 every single day. ... lunch ... usually it’s [lunch] the same thing ... if it’s
14 something you know, you don’t have to think about, that saves a lot of
15 bother.

(Patient with metastatic prostate cancer)

Here, Irvine states that certain ingredients are part of his regular breakfast, presenting his breakfast as multi-faceted and interesting (lines 1-9). The repeated phrase “it’s the same thing” (lines 1-3) highlights the importance of this routinized pattern for Irvine. As noted for Oliver, this regular practice may have benefit, engendering feelings of certainty, stability, and control. In lines 5-10, Irvine construes this practice as requiring special ingredients, tasks, work, attention, and thus imbued with meaning. He describes his breakfast as a “work of art” (line 10), as an act of artistic creation involving creativity and symbolic interpretation (Durkheim, 1971; Goffman, 1972), indicating that preparing and consuming the special breakfast is more than just a routine to satisfy hunger (Bourdieu, 1977), but arguably constitutes a ritual. While Oliver states that his CAM routines are “fairly easy,” and therefore require no further thought or engagement, the descriptor a “work of art” suggests that it is imbued with meaning, values, and personal significance. Irvine’s additional statement “it’s difficult to find a protein for the morning that’s not egg or bacon” (lines 6-7) further construes this CAM ritual as an everyday performance requiring work and effort, whilst pointing to a need for help and involvement of his wife.

Indeed, throughout his discussion, Irvine constructs the maintenance of this CAM ritual as a shared event, frequently talking about his wife’s involvement in preparing and consuming the special breakfast concoction (e.g., lines 1-4). The emphasis on the shared activity, accentuated by Irvine’s use of the personal pronoun “we” (lines 2-3) functions to construct consensus and corroboration (Potter, 1996) of Irvine’s positive endorsement and enactment of this CAM ritual. His high CAM use is thus construed as reasonable and unproblematic, as he establishes the couple’s shared endorsement of a perceived benefit in these CAMs, simultaneously indicating their shared commitment to maintain this. Research into family rituals confirms that the regularity of ritual performances

contribute to strengthening the bonds between family members, as it reinforces family identity and provides family members with a sense of belonging (Schuck & Bucy, 1997; Segal, 2004; Wolin & Bennett, 1984). It seems plausible, therefore, that the daily shared CAM use may be associated with interpersonal benefits for their marital relationship, as the patterned symbolic interaction, including talking about mutually shared attitudes and endorsements of CAM use, might have contributed to the maintenance or strengthening of their social bond (Goffman, 1972; Nichter, 2002; Klafke et al., 2012 paper under review [Chapter Five]).

Towards the end of his account, Irvine reveals further benefits that he personally experiences from this CAM use in ritualistic form. The statements “it stops your thinking” (line 10) and “if it’s something you know, you don’t have to think about, that saves a lot of bother” (lines 13-15) are strong indicators of psychological benefits he values as significant for continuing this daily and integrated CAM ritual. Relieved of the need for continual decision-making about food choices and confident that he and his wife have found and established a healthy diet plan to maintain health and wellbeing, Irvine may have time to focus on other things. Irvine’s emphasis of “it’s the same breakfast every single day” (lines 12-13) and “it’s the same thing” (line 13) further supports the conclusion that it is the repetition and regularity of the continuous and unchanging CAM ritual that is beneficial for his wellbeing in everyday life.

Throughout the data, female spouses and partners were consistently actively involved in the preparation and maintenance of male cancer patients’ drink and food rituals, as illustrated in the following:

1 MADISON: ... when Max was diagnosed with Non-Hodgkin’s-
 2 Lymphoma ... it was quite a shock and quite a distressing experience,
 3 so what you need, what we, what I, what I felt what I needed to do was
 4 to research, what we must, what we could do for him. ... in that
 5 research it became apparent that you could help yourself by changing
 6 your diet, to involve a more raw diet, a more vegetable raw diet, reduce
 7 the meat content in your food, and supplement your food with
 8 superfoods ... support the immune system and detox from the
 9 chemicals ... I sourced a raw food cooking class here that gave me

10 information on not just raw foods, but how to use superfoods with high
11 anti-oxidant qualities in your daily life ... and we incorporated those into
12 our daily life. ... I bought a dehydrator, activated nuts and pulses and
13 then dehydrated them and turned them into a muesli which I make ...
14 and incorporated superfoods into that recipe ... we used a combination
15 of bee-pollen, macropowder ... purple corn powder, cacao powder and
16 nibs, herbal nibs of cacao, all organic cacaos, and sprouted seeds, so
17 ... they're activated, and then used the dehydrator to make up, to which
18 it was set up to 110 degrees so it didn't zap the goodness out of the
19 food, and blackstrap molasses, honey, ... buckwheat, almonds,
20 sunflowers, pepitas ... It's quite a strong mix. ... it's not always easy [to
21 get all the ingredients], but we found a source, ... Max starts his day
22 with this muesli which has eight different superfoods in it, plus sprouted
23 nuts, ... an organic injection into his body first thing in the morning. ...
24 Max doesn't take any tablets at all, or in form of health pills or anything.
25 These are all natural foods that he has, the tea that he has is his
26 infusion, is his turmeric infusion with honey is probably the biggest
27 thing, he has three or four of these cups with warm tea a day ...
(Wife of patient with Non-Hodgkin Lymphoma)

In this excerpt, Madison positions herself as an agent in her husband Max's performance and maintenance of CAM rituals. She is doing stake confession (Potter, 1996) by acknowledging her personal interest to contribute to Max's CAM uptake, whilst simultaneously creating the impression that her involvement resulted because of serious, thoughtful, and therefore plausible concern. In lines 1-2, Madison constructs the cancer diagnosis as causing negative emotions, namely shock and distress, establishing justification for her decision to become involved in Max' CAM uptake. Her regular use of the pronoun "we" (e.g., lines 3, 4, 11, 14) functions to construct the cancer diagnosis and subsequent CAM behaviours as shared events, and the switching from "we" to "I" to "we" (e.g., lines 3-4, but throughout) indicates some vacillation about agent responsibility, but underlines her intention to include herself in her husband's CAM use. Madison talks in detail about the beneficial expectations of incorporating a healthy diet in

daily family life, including to “help yourself” (line 5) with superfoods that help the system, support the immune system and detox from the chemicals” (lines 8-9), thereby adding further credibility to her active involvement in her husband’s CAM use, and positioning herself as a caring supportive partner.

Madison’s account depicts a process entailing much daily thought, effort, belief, and communication to maintain this diet change. This constructs the food regimen as consisting of CAM food rituals involving special ingredients and special meanings. Madison regularly prepares a special muesli for Max, including foods with quasi-mystical qualities like “activated nuts and pulses” (line 12) and several specialized “superfoods” like “bee-pollen, macropowder ... purple corn powder, cacao powder and nibs ... sprouted seeds, blackstrap molasses, honey ... buckwheat, almonds, sunflowers, pepitas” (lines 15-20). She frames this muesli as “quite a strong mix” (line 20) consisting of “all natural foods” (line 25), thereby presenting a belief in the benefits of the muesli’s ingredients, presumably intended to help her husband to recover and maintain his health in a manner deemed to be strong and effective, and treated in a natural and therefore safe and non-toxic way. Her adherence to this regimen gains even more value and meaning through Madison’s utilization of special kitchen utensils like the dehydrator (line 12), thereby further distinguishing her individually created muesli concoction from an ordinary muesli that may be available in the supermarket. Throughout this account, Madison presents herself as informed, reliable and responsible, functioning to further strengthen and justify her initiation of active involvement in her husband’s CAM use. The detailed descriptions may also function as a guideline for Madison herself, reminding her to apply them on a regular basis (Daly, 1996; Gillis, 1996).

Madison draws upon language from a biomedical discourse to present CAM practices as legitimate. In so doing, she emphasizes her strong belief in the efficacy of CAM, whilst also demonstrating acceptance of conventional medicine. For example, she uses the biomedical term “injection” to construe her husband’s daily muesli consumption as an ordinary, and therefore acceptable, act commonly done in health care. In framing it, however, as “an organic injection into his body first thing in the morning” (line 23), Madison fills this ordinary medical act with symbolic meaning, whilst establishing a strong belief in natural and organic products. Likewise, she uses the biomedical term “infusion” to present her

husband's repeated daily consumption of tea with turmeric and honey consumption as a required medical activity done for health reasons (lines 25-27). As the label "infusion" is also used by traditional herbalists to refer to an herbal tea, it has to be acknowledged that Madison could have used this expression to further endorse holistic health treatments, additionally highlighting that both conventional and complementary treatments apply a similar vocabulary.

Durkheim (1971) argued that the endless repetition of rituals function to strengthen the social bonds attaching the individual to his society. We analyse this bonding effect on an interpersonal level between Madison and Max, surmising that the regular performance of these CAM rituals might have contributed to interpersonal benefits in their marital relationship, thereby helping establish and maintain a family's bond and identity (Schuck & Bucy, 1997; Klafke et al., 2012 paper under review (Chapter Five)).

7.4.3 Mental/spiritual routines or/and rituals.

The majority of these experienced CAM users also practiced a CAM therapy for their mental and spiritual needs: prayer, relaxation/meditation, exercise and physical activities were sometimes used as a routine, and sometimes as a ritual. All stated that they used these mental/spiritual CAM therapies "to calm down," "to relax," "to relieve stress and pressure," and "to not think," reflecting the category *psychological reasons* impacting on cancer patients' decision to use CAM (Verhoef, et al., 2005; Klafke et al., 2012 paper under review [Chapter Five]). Some patients with incurable cancer also stated that they used these CAMs in hope of a "cure of cancer," indicating their strong desire for survival (Correa-Velez, et al., 2005). The following account of Irvine exemplifies how his regular and (arguably) extreme cycling activities constitute a psychologically motivated physical exercise ritual, consistent with research identifying exercise techniques as a beneficial and popular CAM technique in cancer patients and survivors (Horowitz, 2012).

- 1 IRVINE: ... somewhere along the line I also decided to do a lot of
- 2 physical activity, like predominantly cycling, but also table tennis, bush
- 3 walking and swimming. ... cycling has really become my main hobby

4 now, and I regularly cycle 50km per week, or at least 15km on Monday,
5 Wednesday, and Sunday. ... I assume my wife is much better at
6 knowing with dates and things (laughs) ... To me it's not important ... I
7 don't focus on cancer, it doesn't bother me, I'm fit and well, I'm just
8 gonna go and live life to its fullest. ... what we're doing [activities like
9 bush-walking, training at the gym, catching up with family and friends] is
10 changing the whole time but that what doesn't seem to be changing too
11 much is cycling, that's the one thing I'm fighting really really hard to
12 keep that even though the doctors might say "Take it easy, don't do too
13 much."

(Patient with metastatic prostate cancer)

In this excerpt, Irvine states that his cycling activity was not consequent on a specific decision with a clear cut moment of choice. Therefore he uses the temporal indication "somewhere along the line" (line 1) demonstrating that time is not as important for him as the cycling activity itself. In talking about his regular physical activities functioning to keep him physically and mentally busy (lines 3-8), Irvine positions himself as an active and healthy man enjoying and fighting for life (lines 6-10). His statement "I don't focus on cancer ... I'm fit and well" (lines 6-7) underlines that cancer is not preventing him from doing physical activities, in particular cycling. This positions him as active, healthy, and motivated to get well. In addition, Irvine identifies himself as a physically and mentally strong athlete, thereby constructing himself a stronger identity than the sick patient role (Parsons, 1951). The resistance towards the weak patient identity impacts on Irvine's everyday life, and also in his interactions with his doctors (lines 11-13). Irvine orders his week with regular cycling activities reflecting a routinized use (Boyce, et al., 1983; Jensen, et al., 1983). Here, as with Oliver, and Madison above, the aspect of regularity appears significant, as the continuous CAM practice contributes to a sense of control in uncertain states. His personal target is to cycle 50km per week, which functions as a schedule for him, guiding and reminding him every day.

Irvine's regular cycling activities may also be understood as a ritual, as he constructs cycling as a meaningful action for his life that he frames as his "main

hobby” (line 3). This construes cycling as an activity that he values and desires to practice regularly, rather than as an activity that he only performs because of health duties. In stating that cycling is his favourite activity, Irvine intimates that enthusiasm and a strong personal interest motivate his regular cycling activities, which appear to be an integrated part of his lifestyle. Irvine strengthens his position as an enthusiastic CAM user by contrasting cycling to other physical activities shared with his wife (e.g., bush-walking, training at the gym), thereby emphasizing the personal significance of cycling (lines 8-11). Irvine indicates that these other physical activities continue, or stop at unpredictable dates and times, perhaps indicating the difficulty of dealing with uncertainty, change, and instability commonly experienced in cancer patients (Mishel, 1988; Oliffe, Davison, Pickles, & Mróz, 2009; Truant & Bottorff, 1999). By referring to his cycling activities as a buffer to protect him against the irregularity and constant changing of other life activities (lines 10-11), he again emphasizes the meaningful functions of his cycling activities, that can now be clearly interpreted as rituals protecting him against negative psychological states.

7.4.4 Combined use of CAM routines and rituals.

The authors found that 16 out of the 26 interviewed men used a combination of three CAM therapies, variously addressing physical, psychological, and spiritual concerns (Verhoef, et al., 2005; Klafke et al., 2012 paper under review [Chapter Five]) (see Figure 7). The practice of these CAM therapies was associated with routine and ritual elements, and was experienced as beneficial by men with cancer and their SOs. Men and their SOs consistently stated that they perceived the combined and regular use of several CAM therapies as their “lifestyle,” “way of life,” or as “part of their life,” implying that they had successfully integrated and maintained the use of CAM into their everyday life. For example, in the following, Wilson emphasizes the combined use of several CAMs as a necessary component in his everyday life.

- 1 WILSON: Well I take that [supplements] first, then I go and do the
- 2 exercise, and then after that I eat, and when I'm eating I do the
- 3 meditation and reading and prayer and all that sort of stuff. ... it's the

4 whole package, it's not just one thing, it's the whole package ... I have
5 my special things in the morning like the Noni juice and this boost
6 supplement, and I make up a special porridge and stuff with fruit and all
7 good stuff in it, honey and things in the morning, ... then I do exercise
8 and the reading and meditation, I think that's very important because if I
9 don't do it, my day doesn't feel quite complete ...
(Patient with metastatic colorectal cancer)

Wilson's account suggests that he likes to "do" CAMs – taking supplements, doing exercise, practicing meditation, prayer – every day in the same order, reflecting a structured, routinized and established CAM use. His statement "I think it's the whole package, it's not just one thing" (lines 3-4) indicates that Wilson experiences the combined use of dietary-based CAMs, exercise, and prayer, as beneficial and effective for his life after the cancer diagnosis. The combined use of multiple CAM practices might help cancer patients to cope with the cancer for physical as well as psychological symptoms, thereby employing problem-focused and emotion-focused coping (Lazarus, 1999; Lazarus & Folkman, 1984). In talking about his "special things in the morning" (line 5) and his "special porridge" (lines 6-7), Wilson's regular dietary-based CAM consumption reflects a ritualistic use, similar to that enacted by Irvine and Madison, as these foods and ingredients are not simply consumed to satisfy feelings of hunger, but also, arguably predominantly because of a strong belief in meaningful health benefits. At the end of this account, Wilson empathizes the significance of the continuation of his combined CAM rituals by stating "I think that's very important because if I don't do it, my day doesn't feel quite complete" (lines 8-9), thereby indicating that the combined use of CAMs has become an integrated and meaningful part in his life. As Wilson's CAM use both structures and imparts meaning to his day, it seems plausible to reason that he derives benefit from them, and aims to continue practicing them in the future.

7.5 Conclusion

Rituals are fundamental for individuals' socio-cultural life, as they create and maintain meaning, and can be regularly communicated between individuals

(Durkheim, 1971; Turner, 1969). The constancy and consistency of performing rituals and routines provide individuals with security and trust (Boyce, et al., 1983; Jensen, et al., 1983; Segal, 2004; Wolin & Bennett, 1984), thereby contributing to positive psychological states. This study is the first attempt to apply the concepts of rituals and routines as a framework to understand part of the motivation for CAM practices in men with cancer and their significant others (SOs). The discursive analysis demonstrated that satisfied and long-term CAM users practice CAM in a routinized or ritualized form, with associated intrapersonal and interpersonal benefits.

The findings provide novel insights into cancer patients' everyday CAM use, in highlighting how and why men with cancer use CAM over time (Bishop, Yardley, et al., 2010; Broom & Tovey, 2008b; M. C. Porter & Diefenbach, 2009). CAM routines provided men diagnosed with cancer with certainty and control, while CAM rituals additionally functioned as a means to create and maintain meaning in men and their SOs, thereby working to counter fear and uncertainty consequent upon a diagnosis of cancer. Many studies have reported that cancer patients suffer feelings of uncertainty or a loss of control that might be helped through CAM practices (Montbriand, 1995a; Truant & Bottorff, 1999; P. Yates, et al., 1993). The current data analysis builds upon this research and provides concrete examples about the psychological and interpersonal benefits experienced by male cancer patients who were eager to continue using CAM in a routinized or ritualized form.

The authors also investigated how cancer patients' SOs are involved in men's CAM routines and CAM rituals, as they often influence men's CAM uptake and maintenance (Nichter, 2002; Öhlén, et al., 2006; Klafke et al., 2012 paper under review [Chapter Five]). The results suggest that family members are mainly involved in cancer patients' CAM practices when they function as rituals (dietary-based CAMs, food and drink rituals), associated with regular discussion, communication, and often laborious preparation shared between family members. These CAM rituals may be an effective strategy to create and meaning in families where life has become disrupted after the cancer diagnosis (Baider, et al., 2000; Burton & Watson, 1998; Holland, et al., 2010). While urging and insisting a patient to use CAM may result in family conflicts or disagreements (Zhang & Siminoff, 2003), shared CAM rituals may function to strengthen the bond between men and

their SOs (Goffman, 1972; Nichter, 2002; Klafke et al., 2012 paper under review [Chapter Five]).

The study results indicated that satisfied and long-term CAM users practice a combination of CAMs in their everyday life. As those men framed this integrated CAM use as their lifestyle (Cassileth, 1989), the authors suggest that by construing CAM practices as part of lifestyle choices, CAM can be better constantly and continuously practiced over time. The combined use of CAM may also reflect the complexity of reasons impacting on cancer patients' decisions to use and continue to use CAM, including physical reasons, psychological reasons, push-and-pull factors, and social/interpersonal factors (Verhoef, et al., 2005; Klafke et al., 2012 paper under review [Chapter Five]). The authors suggest that these reasons reflect a desire, respectively, to cope with treatment side-effects and disease symptoms, to improve quality of life and reduce distress, to gain or regain control of at least part of their therapy, because of dissatisfaction with conventional cancer care, and because of a strong belief in the holistic paradigm applied by many CAM therapies. There is also increasing evidence that cancer patients use CAM because of the influence of their social network (Öhlén, et al., 2006; Klafke et al., 2012 paper under review [Chapter Five]), as family members often want to contribute to their loved one's recovery. By combining and using several CAMs, cancer patients may address a range of different concerns: relieving physical and psychological symptoms, maintaining or increasing their belief in the holistic treatment of illness, and responding to and bonding with their social network.

The authors acknowledge that the study sample consisting of 26 men affected with cancer and 24 SOs was homogenous, exclusively including white Australian men receiving conventional cancer care, and their female SOs. Thus, the viewpoints from other ethnic groups living in multi-cultural Australia are not included and represented in the data analysis, restricting the extent to which the findings may apply elsewhere (Kakai, et al., 2003; M. M. Lee, et al., 2002). Future research might also include male SOs, address different interpersonal relationships, sample women with different cancer types, as well as cancer patients with different ethnic backgrounds, recruited at integrative cancer clinics as well as conventional cancer clinics, to reflect a heterogeneous population, and allow comparisons between specific groups. In addition, more research could be

conducted involving SOs of cancer patients, to explore gender differences in SOs' CAM involvement, CAM uptake, and CAM maintenance.

The study findings may have implications for clinicians and healthcare professionals involved in cancer patients' medical treatment. First, cancer patients could be both asked and advised about CAM use in clinical consultations. For example, clinicians may advise patients about side-effects of some herb-drug interactions (Clarke & McLachlan, 2011), and consult potential interested CAM users about safe and beneficial forms of CAM use (C. Pirri, 2012). If a cancer patient refers to difficulties in adhering to using CAM known to be beneficial, clinicians may suggest the use of CAM in either a routine or ritual way, and inform them about other useful CAMs. Second, family members should be included in these clinical consultations, as they are often involved in men's healthcare decisions (Öhlén, et al., 2006; Seymour-Smith, et al., 2002; Klafke et al., 2012 paper under review (Chapter Five)), and appear to play some role in patients' use of CAM effectively over time. Given that some CAM appear to address psychological distress, the cancer patient's SOs may have as much need for CAM as the patient himself (Pitceathly & Maguire, 2003), with some CAMs particularly suitable for these individuals. Third, both the patient and his carer might be consulted about the benefits of using CAM as a shared ritual, as it may strengthen their social bond (Klafke, Elliott, et al., 2012a; Klafke et al., 2012 paper under review (Chapter Five)). Finally, the authors note that acknowledging the benefits of regular CAM use as part of a routine or ritual, might further support the development of comprehensive cancer care, integrating best of conventional cancer treatment in combination with evidence-based CAMs.

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CHAPTER EIGHT: GENERAL DISCUSSION AND OVERALL CONCLUSION

This thesis aimed to contribute to knowledge about men's use of CAM after a diagnosis of cancer, in particular by investigating how men's decisions to uptake and maintain CAM are influenced by their social network. One integrative literature review, one quantitative study, and one qualitative study were conducted to produce five papers. Results suggested that the majority of male cancer patients have experience with CAM in addition to conventional cancer treatment. Cancer patients' Significant Others (SOs), like family members, close friends, were often involved in cancer patients' uptake and maintenance of CAM, associated with interpersonal benefits, as it strengthened their social bond. In addition, it was found that CAM use had personal benefits for men when they practiced CAM as a sole activity, as it increased a sense of control and reduced uncertainty. This chapter will provide an overview about the main findings of the thesis, and then discuss general conclusions and implications for future research.

8.1 Overview of thesis

A mixed-methods research design was applied to address these specific research questions:

1. What is the prevalence of CAM use in Australian men visiting outpatient cancer services?
2. What are the socio-demographic, personal, and clinical characteristics of CAM users and CAM non-users?
3. Which CAMs have been discussed within the cancer patient's social network?
4. How do SOs impact on men's decision to use CAM during cancer treatment? How do men and their SOs talk about and negotiate about CAM?
5. How do SOs contribute to uptake and maintenance of specific CAMs? How and when do men practice CAM as a shared or individual activity?

6. How do men with cancer integrate CAM in their everyday life, and use it over time? How do SOs benefit from long-term use of CAM?

Research questions 1-3 were addressed by using survey data gained from 403 Australian men affected with cancer undergoing conventional cancer treatment. Research questions 4-6 were addressed by conducting 43 semi-structured interviews to understand in-depth men's perceptions, expectations, and experiences about CAM use, and further to explore how their SOs contribute to their CAM uptake and maintenance. Before these two studies were conducted, the literature was systematically researched to indicate the gaps of knowledge about SOs' involvement in CAM use in men with cancer, to provide justification for the research.

8.1.1 Literature review.

Paper one (Chapter Three) was an integrative review of the literature summarizing the role of the family in the context of cancer patients' CAM use. By synthesizing the evidence from quantitative as well as qualitative research studies, it was evaluated that family influence was a salient factor for cancer patients' healthcare decisions regarding CAM. It was found that family members often act as information seekers, advocates and/or role models, thereby impacting on individuals' healthcare choices. Particularly, family members' behaviour was identified as encouraging/facilitating or discouraging/blocking cancer patients' CAM use. Family members are often involved in cancer patients' CAM use, but how they negotiate and talk about CAM has not yet been addressed in the literature. There was insufficient evidence in the literature to determine if CAM use contributes to familial cohesion or increases family conflicts and disagreements. In addition, there was a lack of studies including men with a variety of cancers. The mixed-methods approach in this thesis aimed to address these gaps in the literature.

8.1.2 Quantitative study.

Paper two (Chapter Four) reported the results of the quantitative study employing a self-administered survey. The study's aims were to (a) describe the prevalence of CAM use within a male cancer population, (b) assess independent

predictors of CAM use, (c) investigate the most popular CAM therapies, and (d) describe the involvement of patients' social networks with regard to specific CAMs. Therefore, 428 Australian men affected with cancer, visiting two public and two private outpatient cancer services in Metropolitan Adelaide, were invited to answer the questionnaire. The response rate with 94% was very high, suggesting that men were interested to take part in the current research about CAM. It was found that the majority of men with cancer were experienced in using CAM for cancer, while more than half of the study sample was currently using CAM in addition to conventional cancer treatment. Using multivariate logistic regression analysis, it was assessed that metastatic cancer, actively practising religion, and tertiary education independently predicted CAM use in this male cancer population. Further, the data analysis found that family most often provided information about CAM treatments compared with friends, medical professionals, other sources, media, cancer patients, and the Internet. Family members were also significantly more often involved in patients' discussions about CAM use than medical professionals. These results indicate that there is high prevalence of CAM use in men with a variety of cancers, and that family members are significantly more influential in cancer patients' CAM uptake than healthcare professionals.

8.1.3 Qualitative study.

Papers three, four, and five (Chapters Five, Six, Seven) reported the findings from the qualitative study, employing 43 semi-structured interviews. This study aimed to understand how SOs contribute to men's CAM uptake and maintenance, and included 26 men with cancer and 24 SOs. The sample consisted of purposefully selected survey participants from the quantitative study and additionally involved men's SOs. For these interviews, men exclusively selected female SOs, mainly female spouses/partners, indicating that in the current homogenous sample, CAM decisions are talked about and negotiated with female SOs rather than male SOs.

Paper three (Chapter Five) highlighted the significance of social/interpersonal factors impacting on men's CAM uptake. Drawing on discursive analytical principles, it was identified that men with cancer use CAM a) as a result of gift transactions, b) to indicate support for a cancer fellow, or c) because of a strong spousal influence. The interpersonal context matters in men's

CAM uptake and adds to current understanding of men's motivations/reasons for using CAM. Findings suggest that the use of CAM functions as a tool of social connectedness in men and their SOs, thereby contributing to strengthen their social bond, a potentially beneficial outcome for families faced with a life-threatening disease.

Paper four (Chapter Six) reported in more detail on how and when SOs are involved in men's use and maintenance of CAM. The discursive analysis found that the involvement of SOs varied with regard to different CAM therapies. SOs were consistently actively involved in men's use of *CAM/Natural products* (special diet, dietary supplements, herbs and botanicals), and sometimes in their use of *CAM/Mind-body medicine* (meditation/relaxation, Yoga, prayer, psychology/counselling). CAM use of the category *CAM/Natural products* was interpreted as problem-focused coping, while CAM use of the category *CAM/Mind-body medicine* was identified as emotion-focused coping. Practising CAM together as a shared coping activity was associated with interpersonal benefits, as it strengthened the social bond in men and their SOs. Practising CAM as a sole activity helped men to cope with uncertainty and to regain control. The results suggest that the shared CAM use is beneficial for men and their SOs, but that there are instances when men need to practice CAM alone without any involvement of their SOs. In addition, it was identified for the first time that men and their SOs use different CAMs for different reasons, indicating that CAM should not be treated as a homogenous category when examining the complex uptake of CAM in cancer patients. These aspects might be useful for designing supportive cancer programmes tailored to the needs of men, and their SOs.

Paper five (Chapter Seven) analysed how men with cancer and their SOs practice CAM in everyday life and over time. The accounts of men who were identified as high and satisfied CAM user, along with those of their SOs, were discursively examined under the concepts of routinized and ritualised behaviour. The data analysis elucidated how men with cancer integrate CAM rituals and CAM routines in their everyday life, supported by their SOs. In particular, CAM routines provided men with certainty and control, while CAM rituals helped men and their SOs to create and maintain meaning, thereby contributing to increase positive psychological states and strengthen their social bond. In addition, it was found that long-term CAM users practised a combination of several CAMs over time, each

addressing specific needs; physical, psychological, and spiritual. The findings suggest that healthcare professionals could inform interested and potential CAM users about the benefits of practising CAM as routines and rituals, and of the combined use of CAMs over time, with or without the involvement of their SOs.

8.2 Theoretical framework

Lazarus and Folkman's (1984; 1999) model of coping provided the framework for the discussion of men's high CAM uptake, and has been documented in the papers (particularly papers two and four). This model differentiates individual's coping behaviour, by arguing that individuals apply *problem-focused coping*, or *emotion-focused coping*. Problem-focused coping behaviour aims to reduce a perceived stressor, while emotion-focused coping behaviour aims to manage one's own emotional responses to a stressor. Within the psychological literature, this coping model has become well established, particularly by demonstrating the coping mechanisms of individuals faced with a chronic illness (Adamsen, et al., 2001; Holland, 2010; Moynihan, 1987, 2002). There are not, however, any studies published in the literature investigating CAM use in men diagnosed with cancer and their SOs with this established theoretical framework. This model was applied to explore why men with cancer used specific CAM therapies. The findings of Study 1 were used to argue that men's use of the four most popular CAM therapies, namely dietary supplements, prayer, herbs and botanicals, meditation techniques/relaxation, could be explained with Lazarus and Folkman's (1984; 1999) theory. The use of dietary supplements or herbs and botanicals might constitute problem-focused coping, as patients use these CAMs to relieve treatment side-effects or ameliorate disease symptoms (Correa-Velez, et al., 2005). Practising prayer or meditation techniques/relaxation might constitute emotion-focused coping, as patients use these therapies to reduce distressing emotions and to increase quality of life (Cassileth, 1996; Ernst, 2010). Physical concerns might be best relieved by problem-focused activities, while psychological and emotional needs might be best addressed with emotion-focused techniques.

The findings of study two reported the involvement of cancer patients' SOs in men's CAM use, specifically arguing that men and their SOs practice CAM as a shared and/or private activity, constituting problem-focused as well as emotion-focused coping (Lazarus, 1999; Lazarus & Folkman, 1984). The shared practice of

CAM/*Natural products* was analysed as shared problem-focused coping, while the shared or private practice of CAM/*Mind-body medicine* was identified as emotion-focused coping.

The application of this coping model was used to indicate that men with cancer use different CAMs for different reasons, broadly divided into physical and psychological. Another important reason is due to congruence with belief systems, which have been termed as *push-and-pull factors* (Furnham & Smith, 1988; Vincent & Furnham, 1996), implying that individuals use CAM because of dissatisfaction with conventional medicine, or because of a strong belief in the holistic paradigm offered by CAM therapies. The discursive analysis of study two did not find a pattern in participants' speech attesting to dissatisfaction with conventional cancer care. All study participants were recruited at conventional cancer clinics, and had received at least one of the biomedical treatments: chemotherapy, radiotherapy, surgery, or hormonal therapy. No participant reported being frustrated or dissatisfied with conventional cancer care, thereby indicating that the "push-and-pull" model was not sufficient for discussing CAM use in cancer patients. This model might be more applicable for explaining CAM use in individuals with chronic diseases other than cancer (Eardley, et al., 2012; Eisenberg, et al., 1993). The complexity of reasons and motivations responsible for cancer patients' CAM uptake has been analysed in study two (particularly reported in paper three), suggesting that social/interpersonal factors are a unique category augmenting the other categories, such as physical reasons, psychological reasons, and push-and-pull factors. Prior research has created models explaining that healthcare decisions of individuals are often shaped and discussed within their social networks. For example, Kleinman's (1980) *model of healthcare sectors* includes the *popular sector*, the *folk sector*, and the *professional sector*. He suggested that 70 to 90 percent of illness treatments occur in the popular sector, featuring family as the main sphere where ill health is treated. Similarly, Janzen (1978) coined the term *therapeutic management group*, implying that patients perform healthcare along with their families, social networks, and communities. In confirming the social relations of therapy management, Nichter (2002) has pointed out that individuals' healthcare choices and therapy management are often influenced and negotiated in households, and are also shaped by the socio-cultural context. These concepts provided support for

analysing in-depth the accounts of men and their SOs with regard to CAM uptake, as this has not been examined before. Thus, the striking pattern about social/interpersonal reasons, which have been found in the accounts of men and their SOs, was in accordance with Kleinman's (1980) and Janzen's (1978) concepts about the influence of family households and contribution of social networks in individuals' healthcare decisions. Hence, the study findings confirm these established social theories and concepts about the significance of processes of social influence. However, by analysing participants' language in situ, the functions and consequences of language about CAM decisions were analysed, suggesting that men's and their SOs' CAM use helped them to strengthen their social bond. This is a new finding, highlighting the benefits of shared problem-focused and emotion-focused CAM use, particularly helpful for cancer patients and their families faced with a life-threatening disease (Baider, et al., 2000; Burton & Watson, 1998; Holland, et al., 2010).

8.3 Methodological approach

The semi-structured interviews from the qualitative interview study were analysed according to discursive analytical principles as outlined by Potter and Wetherell (1987) and applied and established within healthcare research (Bishop & Yardley, 2004; Elliott & Olver, 2007b, 2007c; Seymour-Smith & Wetherell, 2006; Seymour-Smith, et al., 2002). This study was the first of its kind to investigate men's and their SOs' perceptions and experiences regarding CAM use from a micro-perspective (Atkinson & Heritage, 1984; Jefferson, 1984; Schegloff & Sacks, 1973) focusing on how language is used to explain social actions. The linguistic data was also put into a wider socio-cultural context, taking account of social norms and power relations impacting on participants' talk of what can be said and done (Burr, 1995; Foucault, 1973; Parker, 1992; Riley, 2002; Widdicombe & Wooffitt, 1995). By employing such a synthetic approach, analysing language in situ as well as acknowledging social norms and orders defining socio-cultural life, the data analysis critically considered that individuals are both the producers and products of language (Billig, 1991). Discursive analysis has been shown to be particularly valuable in research involving cancer patients (Elliott, et al., 2008; Seymour-Smith & Wetherell, 2006; Wilkinson & Kitzinger, 2000) contributing to knowledge about how individuals affected with cancer construct meaning through

language, thereby revealing how they cope with concerns associated with the cancer diagnosis. Prior discursive research involving men (Edley, 2001; Wetherell & Edley, 1999) has reported that men tend to present themselves as masculine, which is partly in accordance with hegemonic masculinity (Connell, 1995, 2000). Connell (1995; 2005) described the concept of hegemonic masculinity depicting men's behaviour as influenced by masculine stereotypes expecting men to be tough, independent, strong, in control, active, and to make autonomous decisions. Other research confirmed this well-known concept of masculinity, in particular by highlighting that men tend to avoid emotional talk (Seidler, 1989; Seymour-Smith, et al., 2002), delay healthcare seeking (Kimmel, et al., 2005), and engage in risk-taking behaviour (Mahalik, et al., 2007), because this constitutes part of their masculine identity. There is, however, evidence that men have an interest in self-monitoring their health and communicate about their ailments with their healthcare professionals and family members (Smith, Braunack-Mayer, Wittert, & Warin, 2008a; Smith, et al., 2008b), which contradicts or expands the concept of hegemonic masculinity. The findings generated in this thesis provide support for the argument outlined by Smith et al. (2008a, 2008b), demonstrating that men are interested in improving and monitoring their health behaviour, which might not be sufficiently addressed in conventional cancer care. As argued in papers three and four, men tended to present themselves as masculine individuals, but they also depicted themselves as being influenced by their social network to try to use and to continue to use CAM. These findings suggest that when men are faced with a life-threatening disease such as cancer, they are primarily interested in achieving a good status of health as well as having stable relationships marked by harmony and trust. CAM might help men with cancer to achieve these aims, as it provides men with a coping tool for physical and psychological symptoms (Lazarus, 1999; Lazarus & Folkman, 1984), and additionally functions as a tool for social connectedness for men and their SOs. Being perceived as masculine was still relevant for men, analysed by men's use of laughter or the positioning of their SOs in a humorous way, which functioned to present the influence of their SOs in their CAM uptake as normal and acceptable (paper three and four). Thus, the thesis findings challenge the traditional concept of masculinity by providing evidence that men negotiate and experience masculinity in a different way, with a strong interest

in recovering from a dangerous disease and tolerating the contribution of their SOs.

In addition, the findings in this thesis outlined how some men deal with emotional concerns (paper four), particularly coping with uncertainty and regaining control, commonly experienced in men upon the cancer diagnosis (Bailey, et al., 2007; Massie, 2004; Oliffe, Davison, Pickles, & Mroz, 2009; Raison & Miller, 2003; Sellick & Crooks, 1999; van't Spijker, et al., 1997). The use of CAM helped men to cope with distressing emotions either individually or together with their SOs, indicating that men talked about emotions with their SOs and were able to confirm this during the interview situation. The discursive analysis of the interview data found that many men practice CAM such as meditation/relaxation, Yoga, prayer, psychology/counselling as a sole coping activity, without any involvement, of their SOs. This regular and continuous practice enabled men to find space and time for themselves, constituting a functional strategy to reduce uncertainty and regain control after the cancer diagnosis. These novel findings have neither been reported in the literature about comprehensive cancer care, and suggest the need to devise supportive care programmes tailored to the specific psychological and physical needs of men.

8.4 Implications for integrative cancer care

The results from this thesis confirm that comprehensive cancer care, including conventional cancer treatment and evidence-based CAMs, must be wide-ranging to take account of gender differences, as well as include cancer patients' SOs. The research undertaken for this thesis was based on the prevailing evidence of gender differences in cancer patients' CAM use (Fouladbakhsh, et al., 2005; Hann, et al., 2005; Hedderson, et al., 2004; Kristoffersen & Norheim, 2012; Molassiotis, et al., 2005; Verhoef, et al., 2005), particularly acknowledging women as higher consumers of CAM. The findings of Study 1 (paper two) demonstrated, however, that the majority of men were experienced and informed about CAM in addition to cancer care, reflecting a possible change in men's healthcare interest. Further, the findings of study two (paper three, four, five) confirmed that men were eager to practice CAM even when it involved effort and the acceptance of social influence processes from their SOs. Thus, the use of CAM in men with cancer seems to be much more common than assumed (Cassileth & Chapman, 1996;

Ernst & Cassileth, 1998), even though CAM is still not usually discussed within clinical consultations (Boon, et al., 2000; Eisenberg, et al., 1993; Klafke, Elliott, Wittert, et al., 2012; Schofield, et al., 2010; Tasaki, Maskarinec, Shumay, Tatsumura, & Kakai, 2002). In addition, it was reported that there were no differences in CAM uptake in men with a variety of cancers (paper two). This novel finding means that high CAM use is equally common in men with prostate cancer, haematological malignancies, colorectal, lung, and other cancers. The independent predictor of metastatic cancer implies that particularly men with incurable cancer might turn to CAM over time.

The findings have important implications for progressing comprehensive cancer care: First, in clinical consultations, all male cancer patients regardless of cancer type should be asked and advised about using CAM in addition to conventional cancer treatment. It is particularly important that patients receive expert advice about potential side-effects of some herb-drug interactions (Clarke & McLachlan, 2011), and that patients are informed about the risk of substituting a CAM for a proven evidence-based therapy (C. Pirri, 2012), to ensure patient safety and wellbeing. It may also be beneficial for interested and potential CAM users to receive trusted and evidence-based information about safe and effective CAMs (C. Pirri, 2012). Second, supportive cancer care programs need to be tailored to the specific needs of men, and their SOs. For example, the findings of study two (paper four) suggest that men practice CAM Mind-body medicine as an individual or shared coping technique to deal with uncertainty and to regain control. Further, it has been highlighted that the routinized and ritualised practice of CAMs might help men to use and combine CAMs over time, so that they become part of their lifestyle (paper four, paper five). As well as providing individual benefits for men, shared CAM use is also beneficial for the relationship between men and their SOs, as the talk and actions involved contribute to strengthen their social bond. To take these findings from research into clinical practice would imply that comprehensive cancer centres not only offer a range of different CAM therapies to cancer patients (Joske, 2012; Memorial Sloan-Kettering Cancer Center, 2013c), but also encourage CAM use in a familial setting, involving men and their significant others. In addition, CAM services should take account of gender differences, so that the specific needs as well as coping strategies of men and women will be considered. As demonstrated by Adamsen et al. (2001), men favour problem-focused coping

support groups, while women like to share and talk about emotions in support groups. Thus, CAM services including CAM Mind-body medicine should take into account if men like to share their emotion-focused coping or prefer a sole activity to deal with distressing emotions. Hence, men could be informed and consulted about the different options and consequences of using different CAMs. In any case, the current results provide evidence that men have a strong interest in practising CAM Mind-body medicine, and reveal concrete tips and examples about how satisfied and long-term CAM users might practice and combine several CAMs over time. Third, supportive care programmes should also be offered to cancer patients' SOs, as there is evidence that they suffer and are in need of emotional and practical support as well (Pitceathly & Maguire, 2003). There have been attempts at including SOs in CAM services (Cronfalk, Strang, & Ternestedt, 2009; Hudson, Remedios, & Thomas, 2010; Kozachik, et al., 2006), indicating that SOs benefit from shared or individual CAM use. The findings from this thesis contributed to the psycho-oncology literature (Baider, et al., 2000; Burton & Watson, 1998; Holland, et al., 2010), confirming that cancer affects the whole cancer patient's social network that often wants to be involved and contribute to the recovery of their loved one affected with cancer. Often, this family and friends' involvement includes the impact in healthcare choices regarding CAM (Elliott, et al., 2008; Klafke, Elliott, et al., 2012b; Zhang & Siminoff, 2003). The findings in the present thesis provide evidence that SOs of cancer patients inform and consult patients about using CAM, but also that they direct and influence them to use CAM over time. In addition, the thesis findings demonstrated that SOs practising CAM, either on the patient without his conscious awareness of it (paper three), or as an individual practice (paper four), may have been helped themselves to cope with the burden of cancer. To summarize, future comprehensive cancer services might include individual CAM services for cancer patients' SOs, as well as incorporate shared CAM services for both cancer patients and their SOs. In any case, SOs of cancer patients should be included in clinical consultations, and informed about the possibility of receiving support through programmes thereby increasing the provision of comprehensive cancer care.

8.5 Strengths, limitations, and implications for future research

The strengths of this thesis were, first, that the sample in Study 1 was representative with regard to the range and distribution of cancers that would be expected in men (AIHW, 2010d), that is, prostate, haematological malignancies, colorectal, lung, and other types, with the exception of melanoma, which is not typically treated in cancer outpatient services. In addition, men were also representative with regard to age, geographical area, country of birth, and religion (ABS, 2010a, 2010c, 2011; AIHW, 2010c, 2010d). The high response rate and survey results (paper two) suggest that the high prevalence of CAM use and the predictors for CAM uptake could be generalized to male cancer populations visiting public and private outpatient cancer services in Australia. It has to be acknowledged, however, that the male sample of studies one and two was homogenous as the Australian men were predominantly English-speaking Caucasian cancer patients. Future research about men's CAM use might take account of ethnic differences, as it has been reported that the use of CAM differs between ethnic groups (M. M. Lee, et al., 2002) particularly with regard to the use of herbs and botanicals (Molassiotis, et al., 2005). Thus, future research about CAM might also survey cancer patients' use of herbs and botanicals specifically, as this is one of the most commonly used CAM therapies in cancer patients (Klafke, Elliott, Wittert, et al., 2012; Olaku & White, 2011), and provides a means for cross-cultural comparisons in cancer patients' CAM preferences. Therefore, however, it is essential that CAM use is measured worldwide with a standardized questionnaire (Quandt, et al., 2009) to enable meaningful comparisons across various demographic factors.

Second, the findings of study two demonstrated that even within a homogenous sample, there exists a diversity of perceptions, expectations, and experiences with regard to men's CAM use. This implies that comprehensive cancer care must be wide-ranging, flexible, and tailored to the individual needs prevalent even in a homogenous population. Nonetheless, it has to be acknowledged that the study sample may have overrepresented the viewpoints of satisfied CAM users from conventional cancer centres, but underrepresented perceptions of (satisfied) CAM users from CAM centres, or comprehensive cancer centres/integrative cancer centres. The consistency of the discursive pattern across the study sample, however, suggests a striking finding: SOs are often

involved in male cancer patients' CAM uptake and maintenance, but their contribution varies with regard to different CAM therapies (paper three, four, and five). The discursive analysis of the accounts of this homogenous group also clearly indicated that shared CAM use was associated with interpersonal benefits for men and their SOs, as it strengthened their social bond, thereby increasing harmony and trust instead of conflict and contention. Future CAM research could further explore the long-term consequences of CAM use, particularly how men's belief systems about practicing CAM form, establish, and change over time.

Third, the interview study was the second CAM study available including cancer patients' SOs. At the time of writing, there had been only one previous study investigating CAM use involving the viewpoints of cancer patients SOs (Öhlén, et al., 2006). This Swedish-Canadian qualitative study, however, included only breast and prostate cancer patients, and inconsistently involved their SOs. Their qualitative data analysis indicates that cancer patients often make CAM healthcare decisions in relation to their SOs. The current interview study, however, aimed to investigate the contribution of men's SOs consistently (except for two cases, these men were not able to attend the interview with a SO), and the systematic discourse analysis found that CAM use benefited both male cancer patients and their SOs. It must be acknowledged, however, that, with the inclusion of mainly female SOs of male cancer patients, the sample did not represent the whole range of SOs varying from female/male partners, siblings, parents, carers, or close friends. Future research involving SOs should include a variety of genders and relationships, so that comparisons can be made, and specific needs of SOs can be highlighted and addressed in supportive cancer care. There is evidence that female carers suffer more than their male counterpart (Baider & Bengel, 2001; Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000; Matthews, Baker, & Spillers, 2003), but this needs to be confirmed in studies examining CAM use in cancer patients and their carers, so that concrete implications can be made for comprehensive cancer care involving cancer patients' SOs, that take account of gender differences as well.

8.6 Concluding statement

This dissertation has explored male cancer patients' use and maintenance of CAM in addition to conventional cancer care, particularly by investigating the

contribution of men's Significant Others (SOs). The findings contribute to the growing evidence-base of cancer patients' social networks impacting on their healthcare decisions. This dissertation represents the perspectives of men with a variety of stages and types of cancers and additionally their SOs, demonstrating that CAM use was associated with intrapersonal and interpersonal benefits. Shared CAM use strengthened the social bond in men and their SOs, and this is likely to be particularly beneficial when individuals have to cope with a life-threatening disease such as cancer. CAM use empowered both men and their SOs in terms of regaining control and increasing certainty, demonstrating beneficial effects of CAM uptake and maintenance. The novel study findings can be used to design supportive cancer care programmes tailored to the needs of men with cancer, and additionally their SOs.

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Appendix A: Questionnaire (Study 1)



What is your name?

What is your date of birth? (dd/mm/yy)

Patient survey of the use of complementary and alternative medicine

This survey is part of a research project about understanding the use of complementary and alternative medicine by men with cancer.

Answering this questionnaire will take approximately 10 minutes.

All your answers are treated confidentially.

The first section asks about you and your medical treatment.

The second section asks about any complementary/alternative treatments that you know and/or used.

The third section asks about the therapies you used which have evoked the strongest reaction in other people.

The final section asks about a therapy someone suggested you should use, but you didn't.

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Dr Anne Taylor (MBBS, FRACP)

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Dr Martin Borg (MD, FRANZCR)

Radiation Oncologist

Dr Hsiang Tan (MBBS, FRACP)

Registrar

Dr Michael Penniment (FRANZCR, MBA)

Deputy Director of Radiation Oncology

Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR)

Director of Radiation Oncology

1) Identification number _____
(will be filled out by the researcher)

2) What is your marital status?

- Never married
- Married/de facto relationship

- Divorced/separated
- Widowed

3) In what country were you born?

- Australia
- Other (please specify): _____

4) What is your postcode? _____

5) What religion are you?

- None
- Anglican
- Roman Catholic
- Other Christian
- Jewish

- Moslem
- Hindu
- Buddhist
- Other (please specify): _____

6) Do you actively practice your religion?

- Yes
- No

7) What is the highest education level you have reached?

- Primary
- Year 10
- Year 12

- Tertiary non-University
- Tertiary University (e.g., BA, BSc)
- Post-grad (e.g., MA, PhD)

8) Do you have private health insurance?

- Yes
- No

9) Below are listed a number of therapies that patients sometimes use to help them fight cancer and/or cope with it. If you have heard or used any of the following therapies, please tick the boxes; otherwise leave them blank.

<u>Therapy</u>	Have you heard about using this during cancer treatment?	Have you used it?	Are you still using it?	Did your cancer specialist refer you to use it?
Herbs and botanicals (e.g., saw palmetto, ginseng, St John's wort, Essiac, garlic, green tea, mistletoe)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Natural medication (e.g., laetrile, shark cartilage, chelation therapy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Special diet (e.g., Gerson, macrobiotics, Vegan, Vegetarian)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dietary supplements (e.g., vitamins, minerals, fruit juicing)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relaxation techniques/ meditation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Prayer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychology and counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support groups (e.g., self-help groups, online support groups)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Journaling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Imagery techniques (e.g., visualization)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hypnotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Aromatherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Biofeedback	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Art/ music/ dance therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Yoga	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tai Chi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reflexology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kinesiology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Osteopathy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chiropractic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Have you heard about using this during cancer treatment?	Have you used it?	Are you still using it?	Did your cancer specialist refer you to use it?
Massage therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Acupuncture/ acupressure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Homeopathy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Naturopathy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Exercise techniques (e.g., fitness assessment, Alexander technique, Feldenkrais, Pilates)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reiki	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Magnets	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Therapeutic touch	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Crystal healing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify): _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you answered having used any of these complementary/alternative therapies, please continue.

If you haven't used any of these therapies, please go to question 37) on page 17.

I'd like to ask you about the complementary/alternative therapies you used, and then about a therapy which someone suggested you should use, but you didn't.

Please select up to three therapies from the above list (including any in the 'other' category) which you have used, according to this question:

In thinking about others' opinions, which of the therapies prompted the strongest reaction either in yourself or in the other people?

Their opinions can be either for or against using the therapy.

Please write them down here so you can refer back to them easily:

1.

2.

3.

Please answer one questionnaire for each therapy.

- Questionnaire for first therapy is on page 5 (SECTION 1)
- Questionnaire for second therapy is on page 9 (SECTION 2)
- Questionnaire for third therapy is on page 13 (SECTION 3)

If there have been less than three therapies, then fill out less than three questionnaires.

SECTION 1

Questionnaire for first therapy you listed on page 4.

10) What is the name of this complementary/alternative therapy? _____

11) Did you use it before your cancer diagnosis?

- Regularly
- Often
- Sometimes
- Occasionally
- Never

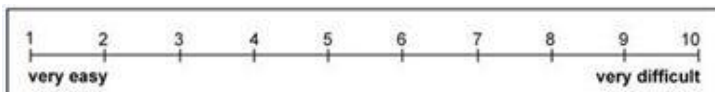
12) How did you find out about the therapy? (Please tick all that apply.)

- Media
- Internet
- Cancer patient
- Medical person
- Family
- Friend
- Other: _____

13) Approximately how much money did you spend on this complementary/alternative therapy per month?

- < \$20
- \$20 – \$50
- \$50 – \$100
- > \$100

14) How easy or difficult was it for you to continue this therapy? Please mark on the scale.

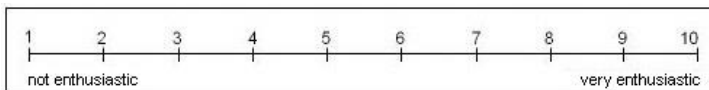


15) Please tick the box of any person that you've talked with about using this complementary/alternative therapy. Then mark on the scale how you think they felt about you using it following your cancer diagnosis.

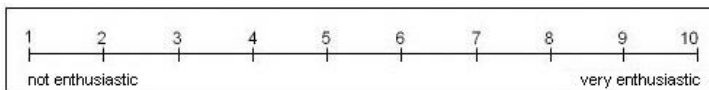
If there has been more than just one person in each category you talked with about this therapy, please choose the person who had a stronger opinion for or against the use of this therapy. For example, if you talked with more than one friend, please choose the friend who had a more radical opinion.

A) Immediate family/household members

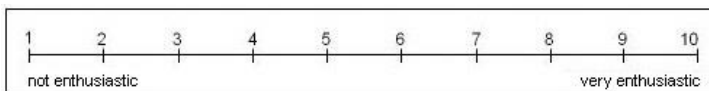
Wife/partner



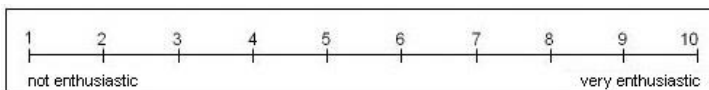
Child



Parent

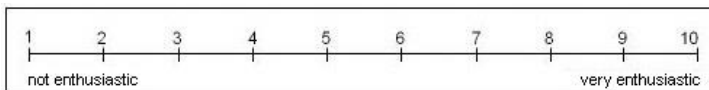


Other: _____

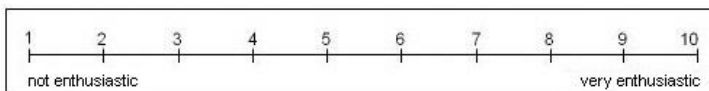


B) Proximal family member

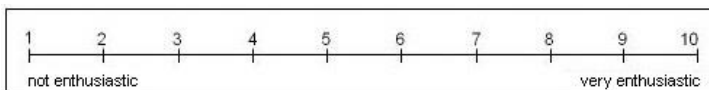
Sibling (female)



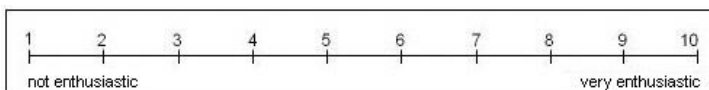
Sibling (male)



Grandparent

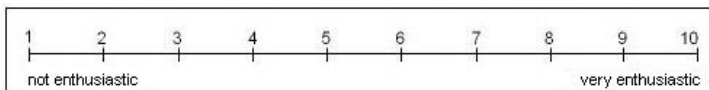


Other: _____

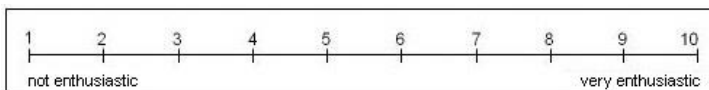


C) Friends or acquaintances

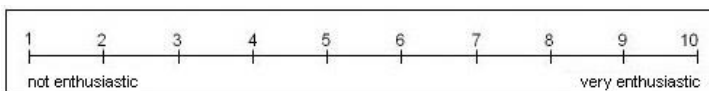
Friend



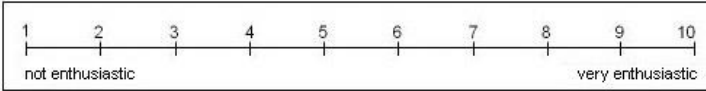
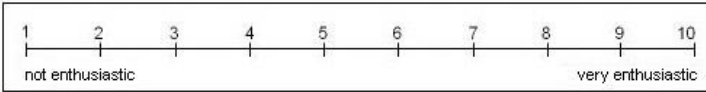
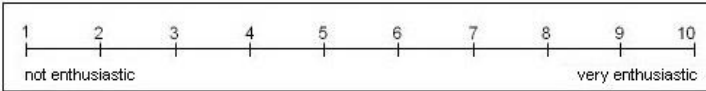
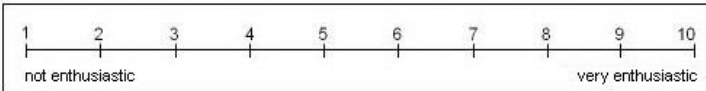
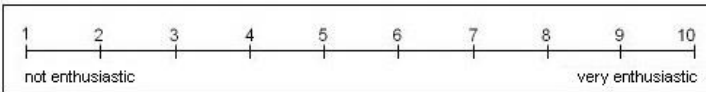
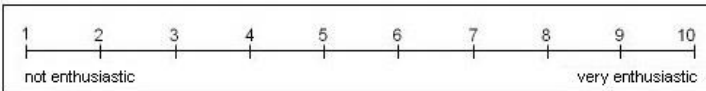
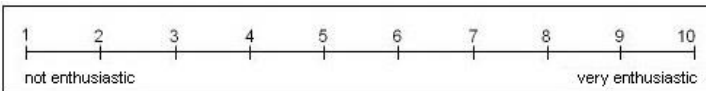
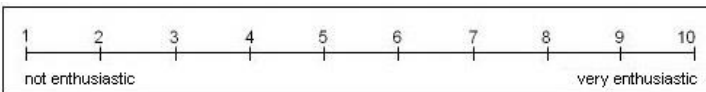
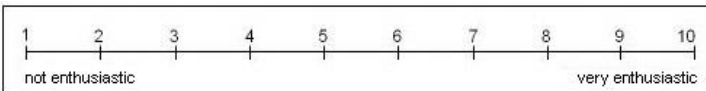
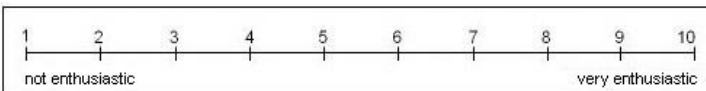
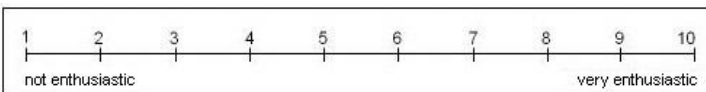
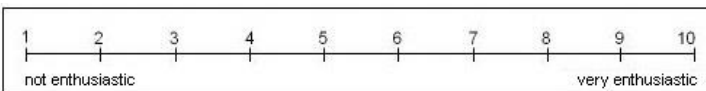
Cancer patient



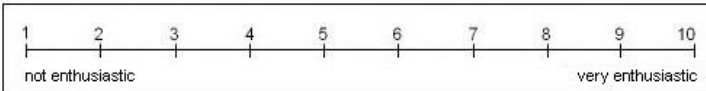
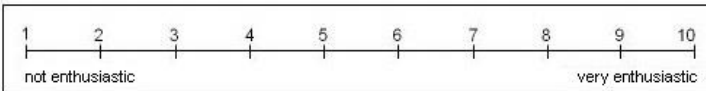
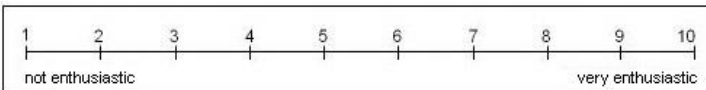
Other: _____



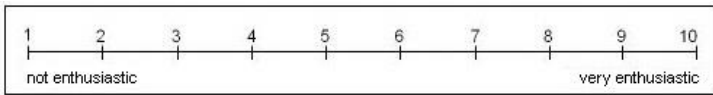
D) Medical professionals

<input type="checkbox"/> Oncologist	
<input type="checkbox"/> Haematologist	
<input type="checkbox"/> Surgeon	
<input type="checkbox"/> Urologist	
<input type="checkbox"/> Gastroenterologist	
<input type="checkbox"/> Dermatologist	
<input type="checkbox"/> Pulmonary physician	
<input type="checkbox"/> General Practitioner	
<input type="checkbox"/> Psychologist	
<input type="checkbox"/> Pharmacist	
<input type="checkbox"/> Nurse	
<input type="checkbox"/> Other: _____	

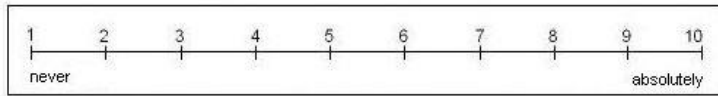
E) If you talked with any complementary/alternative practitioners, please provide their name and rate how he/she felt about you using it following your cancer diagnosis:

<input type="checkbox"/> _____	
<input type="checkbox"/> _____	
<input type="checkbox"/> _____	

16) When you made your decision to use this complementary/alternative therapy (before starting the therapy), how enthusiastic were you about the therapy? Please mark your feelings on the scale.



17) After using this therapy, would you recommend this therapy to another patient?



18) Do you have any other comments you'd like to make?

SECTION 2

Questionnaire for second therapy you listed on page 4.

19) What is the name of this complementary/alternative therapy? _____

20) Did you use it before your cancer diagnosis?

- Regularly
- Often
- Sometimes
- Occasionally
- Never

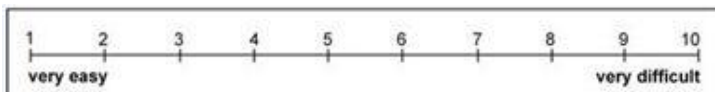
21) How did you find out about the therapy? (Please tick all that apply.)

- Media
- Internet
- Cancer patient
- Medical person
- Family
- Friend
- Other: _____

22) Approximately how much money did you spend on this complementary/alternative therapy per month?

- < \$20
- \$20 – \$50
- \$50 – \$100
- > \$100

23) How easy or difficult was it for you to continue this therapy? Please mark on the scale.

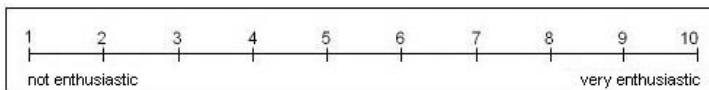


24) Please tick the box of any person that you've talked with about using this complementary/alternative therapy. Then mark on the scale how you think they felt about you using it following your cancer diagnosis.

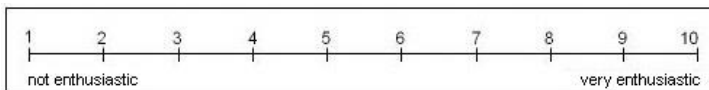
If there has been more than just one person in each category you talked with about this therapy, please choose the person who had a stronger opinion for or against the use of this therapy. For example, if you talked with more than one friend, please choose the friend who had a more radical opinion.

A) Immediate family/household members

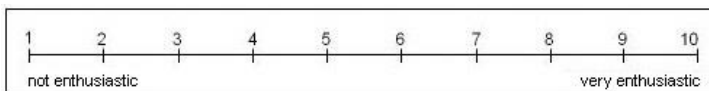
Wife/partner



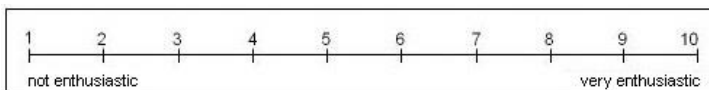
Child



Parent

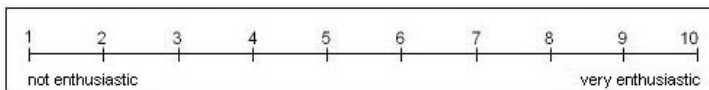


Other: _____

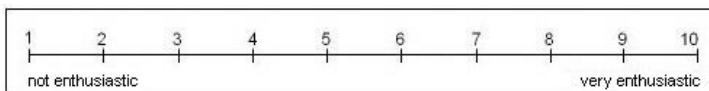


B) Proximal family member

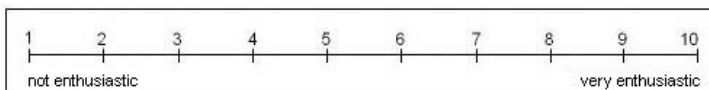
Sibling (female)



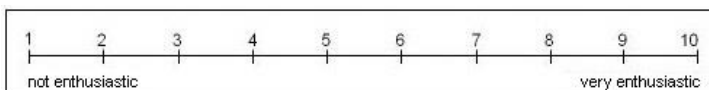
Sibling (male)



Grandparent

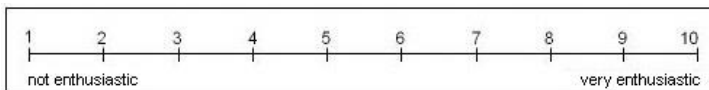


Other: _____

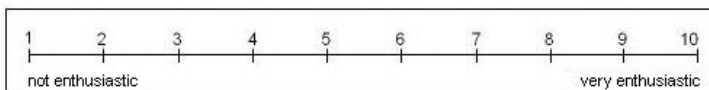


C) Friends or acquaintances

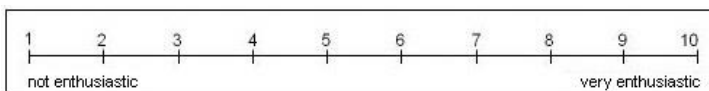
Friend



Cancer patient



Other: _____



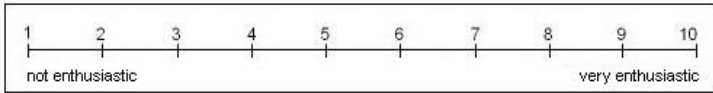
D) Medical professionals

<input type="checkbox"/> Oncologist	
<input type="checkbox"/> Haematologist	
<input type="checkbox"/> Surgeon	
<input type="checkbox"/> Urologist	
<input type="checkbox"/> Gastroenterologist	
<input type="checkbox"/> Dermatologist	
<input type="checkbox"/> Pulmonary physician	
<input type="checkbox"/> General Practitioner	
<input type="checkbox"/> Psychologist	
<input type="checkbox"/> Pharmacist	
<input type="checkbox"/> Nurse	
<input type="checkbox"/> Other: _____	

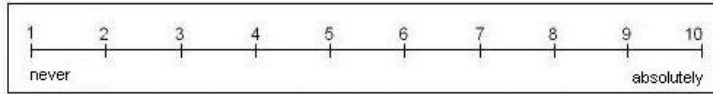
E) If you talked with any complementary/alternative practitioners, please provide their name and rate how he/she felt about you using it following your cancer diagnosis:

<input type="checkbox"/> _____	
<input type="checkbox"/> _____	
<input type="checkbox"/> _____	

25) When you made your decision to use this complementary/alternative therapy (before starting the therapy), how enthusiastic were you about the therapy? Please mark your feelings on the scale.



26) After using this therapy, would you recommend this therapy to another patient?



27) Do you have any other comments you'd like to make?

SECTION 3

Questionnaire for third therapy you listed on page 4.

28) What is the name of this complementary/alternative therapy? _____

29) Did you use it before your cancer diagnosis?

- Regularly
- Often
- Sometimes
- Occasionally
- Never

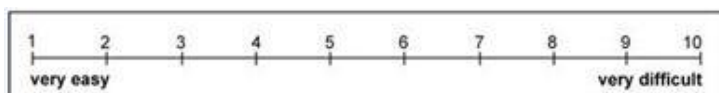
30) How did you find out about the therapy? (Please tick all that apply.)

- Media
- Internet
- Cancer patient
- Medical person
- Family
- Friend
- Other: _____

31) Approximately how much money did you spend on this complementary/alternative therapy per month?

- < \$20
- \$20 – \$50
- \$50 – \$100
- > \$100

32) How easy or difficult was it for you to continue this therapy? Please mark on the scale.

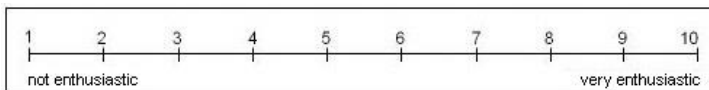


33) Please tick the box of any person that you've talked with about using this complementary/alternative therapy. Then mark on the scale how you think they felt about you using it following your cancer diagnosis.

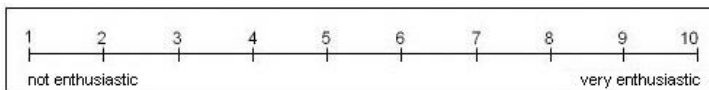
If there has been more than just one person in each category you talked with about this therapy, please choose the person who had a stronger opinion for or against the use of this therapy. For example, if you talked with more than one friend, please choose the friend who had a more radical opinion.

A) Immediate family/household members

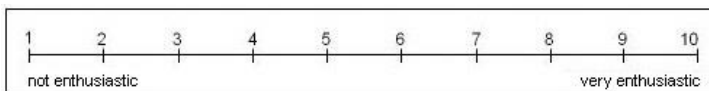
Wife/partner



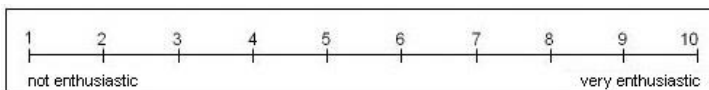
Child



Parent

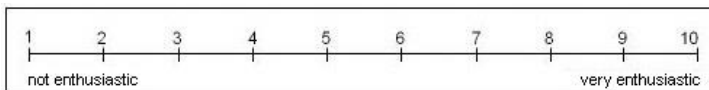


Other: _____

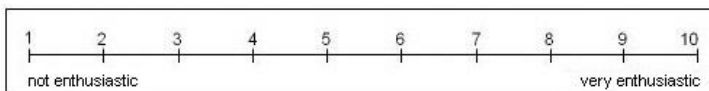


B) Proximal family member

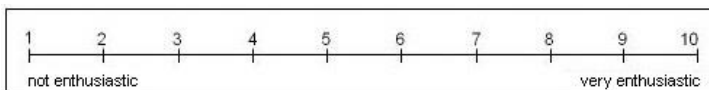
Sibling (female)



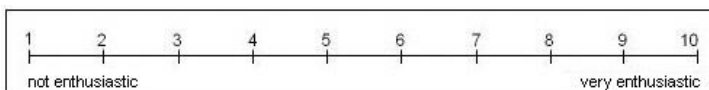
Sibling (male)



Grandparent

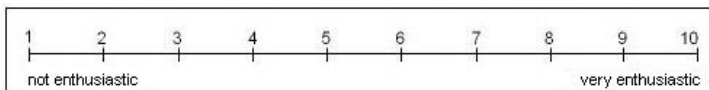


Other: _____

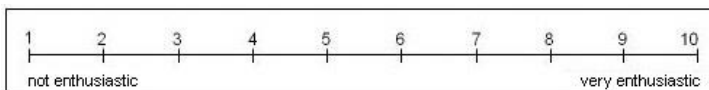


C) Friends or acquaintances

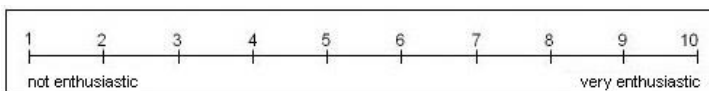
Friend



Cancer patient



Other: _____



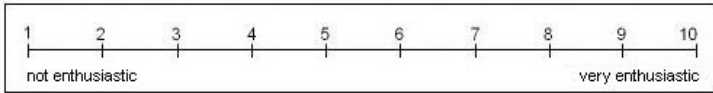
D) Medical professionals

<input type="checkbox"/> Oncologist	
<input type="checkbox"/> Haematologist	
<input type="checkbox"/> Surgeon	
<input type="checkbox"/> Urologist	
<input type="checkbox"/> Gastroenterologist	
<input type="checkbox"/> Dermatologist	
<input type="checkbox"/> Pulmonary physician	
<input type="checkbox"/> General Practitioner	
<input type="checkbox"/> Psychologist	
<input type="checkbox"/> Pharmacist	
<input type="checkbox"/> Nurse	
<input type="checkbox"/> Other: _____	

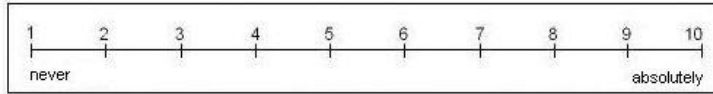
E) If you talked with any complementary/alternative practitioners, please provide their name and rate how he/she felt about you using it following your cancer diagnosis:

<input type="checkbox"/> _____	
<input type="checkbox"/> _____	
<input type="checkbox"/> _____	

34) When you made your decision to use this complementary/alternative therapy (before starting the therapy), how enthusiastic were you about the therapy? Please mark your feelings on the scale.



35) After using this therapy, would you recommend this therapy to another patient?



36) Do you have any other comments you'd like to make?

37) Has anyone suggested that you should use one of the therapies listed on pages 2 and 3, but you didn't use it? If there is more than one, pick the one that was most strongly or most often recommended.

If yes, please fill in the following questions:

What is the name of this complementary/alternative therapy? _____

38) Did you use it before your cancer diagnosis?

- Regularly
- Often
- Sometimes
- Occasionally
- Never

39) How did you find out about this therapy? (Please tick all that apply.)

- Media
- Internet
- Cancer patient
- Medical person
- Family
- Friend
- Other: _____

40) About how much do you think it would cost per month?

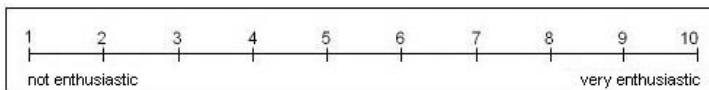
- < \$20
- \$20 – \$50
- \$50 – \$100
- > \$100

41) Please tick the box of any person that you've talked with about using this complementary/alternative therapy that you didn't use. Then mark on the scale how you think they felt about you using it following your cancer diagnosis.

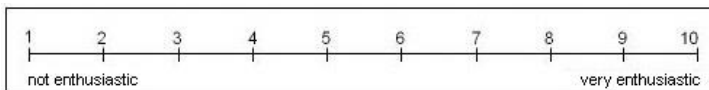
If there has been more than just one person in each category you talked with about this therapy, please choose the person who had a stronger opinion for or against the use of this therapy. For example, if you talked with more than one friend, please choose the friend who had a more radical opinion.

A) Immediate family/household members

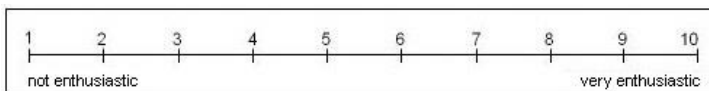
Wife/partner



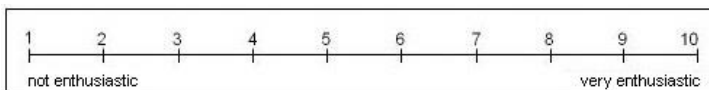
Child



Parent

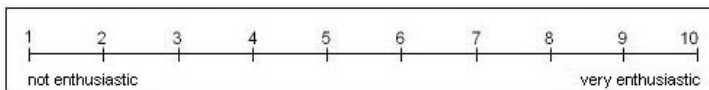


Other: _____

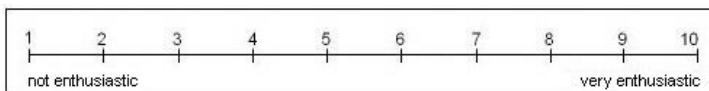


B) Proximal family member

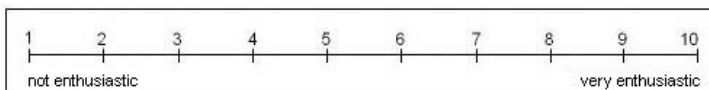
Sibling (female)



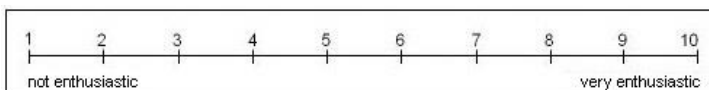
Sibling (male)



Grandparent

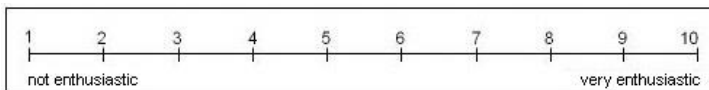


Other: _____

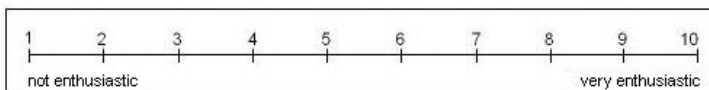


C) Friends or acquaintances

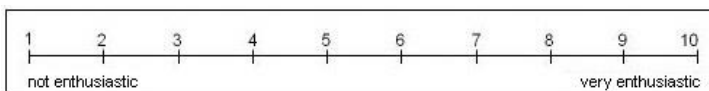
Friend



Cancer patient



Other: _____



D) Medical professionals

<input type="checkbox"/> Oncologist	
<input type="checkbox"/> Haematologist	
<input type="checkbox"/> Surgeon	
<input type="checkbox"/> Urologist	
<input type="checkbox"/> Gastroenterologist	
<input type="checkbox"/> Dermatologist	
<input type="checkbox"/> Pulmonary physician	
<input type="checkbox"/> General practitioner	
<input type="checkbox"/> Psychologist	
<input type="checkbox"/> Pharmacist	
<input type="checkbox"/> Nurse	
<input type="checkbox"/> Other: _____	

E) If you talked with any complementary/alternative practitioners, please provide their name and rate how he/she felt about you using it following your cancer diagnosis:

<input type="checkbox"/> _____	
<input type="checkbox"/> _____	
<input type="checkbox"/> _____	

42) When you talked with others about this therapy that you didn't use, how enthusiastic were you about the therapy? Please mark your feelings on the scale.

1	2	3	4	5	6	7	8	9	10	
not enthusiastic										very enthusiastic

43) Would you recommend this therapy to another patient?

1	2	3	4	5	6	7	8	9	10
never									absolutely

44) Do you have any other comments you'd like to make?

Thank you for being part of this study! We will combine this information with the information about your cancer diagnosis and treatment within your case-notes, as mentioned in the Information Sheet and Consent Form.

If you do not give your consent for a follow-up interview about this questionnaire in the coming months, please tick the box.

For more information about complementary/alternative therapies for cancer treatment, please visit the following websites:

Cancer Council Australia

www.cancer.org.au

National Institute of Complementary Medicine (NICM)

www.nicm.edu.au

National Center for Complementary and Alternative Medicine (NCCAM)

www.nccam.nih.gov

Memorial Sloan-Kettering Cancer Center

www.mskcc.org/mskcc/html/11570.cfm

If you have any questions about cancer or its treatment, please see your health professional or call the Cancer Council Helpline: 13 11 20.



Instructions to database staff:

Please complete the following for the patient with this name _____

Date of birth _____

45) Past and present medical treatment: (Please tick all relevant boxes.)

- Chemotherapy
- Radiotherapy
- Surgery

- Hormonal therapy
- Not currently receiving any conventional treatment

46) Type of cancer

- Prostate
- Colorectal (colon, rectum, appendix)
- Lung
- Melanoma
- Brain

- Head and neck
- Hematological malignancies
- Other: _____

47) Stage of cancer

- Stage I
- Stage II
- Stage III
- Stage IV

**Appendix B: Information sheet and consent form (Study 1, RAH,
Medical Oncology Unit)**



INFORMATION SHEET

Project title: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Phase 1: Patient survey about men's use of complementary and alternative medicine

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MBBch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FACHPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (BMBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

Introduction:

The following information describes the study and your role as a participant.

This study seeks to understand how men with cancer use complementary and alternative medicine. Your participation in this study will involve completing a questionnaire.

You can choose to answer the questionnaire at the clinic or at your home. Answering the questions will not take more than 15 minutes to complete.

Your study investigator will answer any further questions you may have about the study. The information contained in this Information Sheet will help you to understand the possible risks and benefits involved in the study. Please note you *cannot* receive any reward for being a part of this study.

Purpose of the Study:

You are invited to participate in a research study, which is being conducted in order to better understand the use of complementary and alternative medicine by men with cancer. Your participation would contribute to what we know about understanding men's health care decisions with regard to the use of complementary/alternative therapies. The results of this project will further our knowledge about men with cancer and can be used for improvements in cancer care.

Voluntary Participation/Right to Refuse or Withdraw:

This is a research project and you do not have to be involved. If you do not wish to participate, your medical care will not be affected in any way. Also, you may withdraw from the project at any time after you have commenced.

Confidentiality:

Your records relating to this study and any other information received will be kept strictly confidential. Your identity will not be revealed and your confidentiality will be protected in any reviews and reports of this study which may be published. Only medical staff involved in your healthcare will combine the information you have given on the survey with the medical information from their medical records within the clinic's database.

At the end of the questionnaire you can decide to take part in a follow-up interview. If you give your consent, then medical staff involved in your healthcare will provide



the investigator Nadja Klafke with your contact details. You do not have to agree to be involved in this interview.

Results of Project:

This study is part of a research project divided into three Phases. Data collection of all three Phases will continue until approx. August 2012. Results of all three Phases will be published or presented during the years 2011 – 2013. You will not be identified in any of these publications or presentations and your personal results will not be divulged. If you wish to be informed about the study results, publications, and presentations, or have any questions, please contact the study investigator Nadja Klafke:

E-mail: nadja.klafke@adelaide.edu.au

Telephone: 0420 705062

Consent:

Your study investigator is required to provide you with all information regarding the nature and purpose of the research study and you should be given the opportunity to discuss these. It must be stated that you are free to withdraw anytime and that if you do not participate you will not suffer any prejudice.

Advice and Information:

If you have any further questions regarding this study, please do not hesitate to contact

Nadja Klafke, Ph: 0420 705062

Dr Jaklin Elliott, Ph: 08 8303 3855

The Royal Adelaide Hospital Ethics Committee has reviewed this study in accordance with the National Statement on Ethical Conduct in Human Research (2007). Should you wish to discuss the study or view a copy of the Complaint procedure with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139.



CONSENT FORM

PROTOCOL NAME: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MBBch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FChPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (BMBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.
2. I understand that I may not benefit from taking part in the trial.
3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
4. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.
5. I have had the opportunity to discuss taking part in this investigation with a family member or friend.
6. I understand that medical staff involved in my healthcare will combine the information given on the survey with medical information from their medical records within the clinic's database.

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the patient/volunteer and consider that he/she understands what is involved.

Signed: _____

Dated: _____

(Investigator)

**Appendix C: Information sheet and consent form (Study 1, RAH,
Radiation Oncology)**

INFORMATION SHEET

Project title: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Phase 1: Patient survey about men's use of complementary and alternative medicine

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MBBch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FChPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (MBBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

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Purpose of the Study:

You are invited to participate in a research study, which is being conducted in order to better understand the use of complementary and alternative medicine by men with cancer. Your participation would contribute to what we know about understanding men's health care decisions with regard to the use of complementary/alternative therapies. The results of this project will further our knowledge about men with cancer and can be used for improvements in cancer care.

Voluntary Participation/Right to Refuse or Withdraw:

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At the end of the questionnaire you can decide to take part in a follow-up interview. If you give your consent, then medical staff involved in your healthcare will provide



the investigator Nadja Klafke with your contact details. You do not have to agree to be involved in this interview.

Results of Project:

This study is part of a research project divided into three Phases. Data collection of all three Phases will continue until approx. August 2012. Results of all three Phases will be published or presented during the years 2011 – 2013. You will not be identified in any of these publications or presentations and your personal results will not be divulged. If you wish to be informed about the study results, publications, and presentations, or have any questions, please contact the study investigator Nadja Klafke:

E-mail: nadja.klafke@adelaide.edu.au

Telephone: 0420 705062

Consent:

Your study investigator is required to provide you with all information regarding the nature and purpose of the research study and you should be given the opportunity to discuss these. It must be stated that you are free to withdraw anytime and that if you do not participate you will not suffer any prejudice.

Advice and Information:

If you have any further questions regarding this study, please do not hesitate to contact

Nadja Klafke, Ph: 0420 705062

Dr Jaklin Elliott, Ph: 08 8303 3855

The Royal Adelaide Hospital Ethics Committee has reviewed this study in accordance with the National Statement on Ethical Conduct in Human Research (2007). Should you wish to discuss the study or view a copy of the Complaint procedure with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139.

CONSENT FORM

PROTOCOL NAME: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MBBch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FChPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (BMBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.
2. I understand that I may not benefit from taking part in the trial.
3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
4. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.
5. I have had the opportunity to discuss taking part in this investigation with a family member or friend.
6. I understand that medical staff involved in my healthcare will combine the information given on the survey with medical information from their medical records within the clinic's database.

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the patient/volunteer and consider that he/she understands what is involved.

Signed: _____

Dated: _____
(Investigator)

**Appendix D: Information sheet and consent form (Study 1,
Tennyson Centre, Adelaide Cancer Centre)**



INFORMATION SHEET

Project title: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Phase 1: Patient survey about men's use of complementary and alternative medicine

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MBBch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FChPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singh (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (MBBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

Introduction:

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Purpose of the Study:

You are invited to participate in a research study, which is being conducted in order to better understand the use of complementary and alternative medicine by men with cancer. Your participation would contribute to what we know about understanding men's health care decisions with regard to the use of complementary/alternative therapies. The results of this project will further our knowledge about men with cancer and can be used for improvements in cancer care.

Voluntary Participation/Right to Refuse or Withdraw:

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Confidentiality:

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At the end of the questionnaire you can decide to take part in a follow-up interview. If you give your consent, then medical staff involved in your healthcare will provide the investigator Nadja Klafke with your contact details. You do not have to agree to be involved in this interview.

Results of Project:



This study is part of a research project divided into three Phases. Data collection of all three Phases will continue until approx. August 2012. Results of all three Phases will be published or presented during the years 2011 – 2013. You will not be identified in any of these publications or presentations and your personal results will not be divulged. If you wish to be informed about the study results, publications, and presentations, or have any questions, please contact the study investigator Nadja Klafke:

E-mail: nadja.klafke@adelaide.edu.au

Telephone: 0420 705062

Consent:

Your study investigator is required to provide you with all information regarding the nature and purpose of the research study and you should be given the opportunity to discuss these. It must be stated that you are free to withdraw anytime and that if you do not participate you will not suffer any prejudice.

Advice and Information:

If you have any further questions regarding this study, please do not hesitate to contact

Nadja Klafke, Ph: 0420 705062

Dr Jaklin Elliott, Ph: 08 8303 3855

The Royal Adelaide Hospital Ethics Committee has reviewed this study in accordance with the National Statement on Ethical Conduct in Human Research (2007). Should you wish to discuss the study or view a copy of the Complaint procedure with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139.



CONSENT FORM

PROTOCOL NAME: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MB Bch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FACHPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (BMBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.
2. I understand that I may not benefit from taking part in the trial.
3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
4. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.
5. I have had the opportunity to discuss taking part in this investigation with a family member or friend.
6. I understand that medical staff involved in my healthcare will combine the information given on the survey with medical information from their medical records within the clinic's database.

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the patient/volunteer and consider that he/she understands what is involved.

Signed: _____

Dated: _____
(Investigator)

**Appendix E: Information sheet and consent form (Study 1,
Tennyson Centre, Adelaide Radiotherapy Centre)**



INFORMATION SHEET

Project title: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Phase 1: Patient survey about men's use of complementary and alternative medicine

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MBBch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FACHPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (MBBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

Introduction:

The following information describes the study and your role as a participant.

This study seeks to understand how men with cancer use complementary and alternative medicine. Your participation in this study will involve completing a questionnaire.

You can choose to answer the questionnaire at the clinic or at your home. Answering the questions will not take more than 15 minutes to complete.

Your study investigator will answer any further questions you may have about the study. The information contained in this Information Sheet will help you to understand the possible risks and benefits involved in the study. Please note you *cannot* receive any reward for being a part of this study.

Purpose of the Study:

You are invited to participate in a research study, which is being conducted in order to better understand the use of complementary and alternative medicine by men with cancer. Your participation would contribute to what we know about understanding men's health care decisions with regard to the use of complementary/alternative therapies. The results of this project will further our knowledge about men with cancer and can be used for improvements in cancer care.

Voluntary Participation/Right to Refuse or Withdraw:

This is a research project and you do not have to be involved. If you do not wish to participate, your medical care will not be affected in any way. Also, you may withdraw from the project at any time after you have commenced.

Confidentiality:

Your records relating to this study and any other information received will be kept strictly confidential. Your identity will not be revealed and your confidentiality will be protected in any reviews and reports of this study which may be published. Only medical staff involved in your healthcare will combine the information you have given on the survey with the medical information from their medical records within the clinic's database.

At the end of the questionnaire you can decide to take part in a follow-up interview. If you give your consent, then medical staff involved in your healthcare will provide



the investigator Nadja Klafke with your contact details. You do not have to agree to be involved in this interview.

Results of Project:

This study is part of a research project divided into three Phases. Data collection of all three Phases will continue until approx. August 2012. Results of all three Phases will be published or presented during the years 2011 – 2013. You will not be identified in any of these publications or presentations and your personal results will not be divulged. If you wish to be informed about the study results, publications, and presentations, or have any questions, please contact the study investigator Nadja Klafke:

E-mail: nadja.klafke@adelaide.edu.au

Telephone: 0420 705062

Consent:

Your study investigator is required to provide you with all information regarding the nature and purpose of the research study and you should be given the opportunity to discuss these. It must be stated that you are free to withdraw anytime and that if you do not participate you will not suffer any prejudice.

Advice and Information:

If you have any further questions regarding this study, please do not hesitate to contact

Nadja Klafke, Ph: 0420 705062

Dr Jaklin Elliott, Ph: 08 8303 3855

The Royal Adelaide Hospital Ethics Committee has reviewed this study in accordance with the National Statement on Ethical Conduct in Human Research (2007). Should you wish to discuss the study or view a copy of the Complaint procedure with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139.

CONSENT FORM

PROTOCOL NAME: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MB Bch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FACHPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (BMBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.
2. I understand that I may not benefit from taking part in the trial.
3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
4. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.
5. I have had the opportunity to discuss taking part in this investigation with a family member or friend.
6. I understand that medical staff involved in my healthcare will combine the information given on the survey with medical information from their medical records within the clinic's database.

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the patient/volunteer and consider that he/she understands what is involved.

Signed: _____

Dated: _____
(Investigator)

Appendix F: Interview schedule (Study 2, first version)

1) Introduction

Can you tell me a little bit about what has happened to you since your cancer diagnosis?

2) Opening development of the interview

- General beliefs about health and illness

One of the things we know about cancer is that there seems to be many different explanations for it, why some people get cancer, and others don't. What are your thoughts about that?

- Definition of CAM

What do you understand by the term "complementary and alternative medicine"?

3) Central core of the interview
Exploration of data from survey

I can see from the answers you've given on the questionnaire that you've used CAM...

A) Information-seeking about CAM

Before you started to use that CAM, how did you learn about it? And after you've heard about it, did you then find out more? How? Did you talk about it together with your wife/friend?

B) Experience with CAM

When you first started using CAM, what did you expect? (Process? Outcome?) And what was your experience: How did you feel? What did you think? What was involved? What did you have to do?

C) Decision-making process and outcome

I noticed that you were quite/not keen on the use of this CAM. Did you discuss it together? What were your feelings about it? What were your thoughts? What were you hoping for?

How did you decide what to do? What was it like once you'd made a decision about what to do? Was it ever difficult to follow through?

I wonder if you could talk to me about how CAM fitted into your everyday life. Did it change things? How did that affect you? Has it been what you expected?

How are you both involved in the daily use of CAM?
Did you see any problems with using CAM? Is it ever hard?

Did you ever have second thoughts? What was going on there? How did you resolve differences? What would have helped? What did help?

Did you know how she/he felt about this CAM? How did this affect your relationship?

D) Future

What sort of things might stop/try you using CAM? (Cost? Disease progress? Information? Person?)

4) Close

What was the most helpful thing outside medical treatment that you've both done (or learned) following the cancer diagnosis?

Is there anything you'd like to say?

Appendix G: Interview schedule (Study 2, final version)

1) Introduction

Can you tell me a little bit about what has happened to you since your cancer diagnosis?

2) Opening development of the interview

- Definition of CAM

What do you understand by the term “complementary and alternative medicine”?

**3) Central core of the interview
Exploration of data from survey**

I can see from the answers you’ve given on the questionnaire that you’ve used CAM...
Which one of those was the most helpful for you?

- A) Information-seeking

How did you find out about this CAM?

- B) Experience

Before you started to use this CAM, what did you expect? What were you hoping for?

And what was your experience: How did you feel? (Physically? Emotionally? Spiritually?)

What convinced you about continuing to use this CAM?
Would you recommend it to other male cancer patients?

Do you apply this CAM more often since you’ve been diagnosed with cancer?
How does it help? What is it that works for you?

- C) Social influence/involvement

I noticed that you were quite keen on the use of this CAM...
What was your wife’s/daughters’ position about this CAM? What was the oncologist’s position? How did you deal with opposing positions?

How did you talk/discuss about the use of this CAM with your wife? Friend?
Other family members?

How did you decide what to do?
What was it like once you'd made a decision about what to do? Was it ever
difficult to follow through?

How do you perceive the involvement of your wife in your healthcare decisions,
in particular with regard to the use of CAM? (Supporting? Actively involved?
Own decisions?)

D) Conflict

Have you ever experienced that a close family member/friend strongly
recommended CAM for you to deal with your cancer, but you decided not to
use it?

I noticed that you were not keen on the use of this CAM...
Was this CAM recommended by a family member/friend?
How did you discuss it together with family members/friends?
What were your feelings about it? What were your thoughts? What were you
hoping for?

Did you discuss CAM with your healthcare professionals?
How did you decide what to do? Was it ever difficult to follow through?

E) Integration of CAM in everyday life

I wonder if you could talk to me about how CAM fits/fitted into your everyday
life.
Did it change things? How did that affect you?

Is it always easy to use this CAM?
What is practically involved? (Time? Effort? Money?)
Problems? Difficulties? Barriers?
How do you and your wife talk about the practice of CAM together?

- F) Increase or decrease of CAM consumption
- How is your wife involved in the daily use of CAM?
- What sort of things might try you using more CAM? (Recommendations? Disease progress?)
- What sort of things might stop you using CAM? (Side-effects? Costs? Disease progress?)
- G) Cancer experience
- Did you suffer any physical side-effects of your conventional cancer treatment?
- How did you cope emotionally? Did you ever feel stressed, angry, depressed, overwhelmed?
- What did help you? How did you cope?
What would have helped?
- Would you consider cancer as a lifestyle?
- H) General beliefs about health and illness
- One of the things we know about cancer is that there seems to be many different explanations for it, why some people get cancer, and others don't. What are your thoughts about that?
- Do you think that body and mind function together in terms of health?
Do you think that illness develops because of imbalances within the human body?
- What are your thoughts about what makes us healthy? Do you think your thoughts or your attitude are important to stay healthy?
- 4) Close**
- What was the most helpful thing outside conventional medical treatment that you, or both you and your wife have done (or learned) following the cancer diagnosis?
Is there anything else you'd like to say?
-

Appendix H: Invitation letter (Study 2, interviewing separately)

Interpersonal factors impacting the decision to (continue to) use Complementary and Alternative Medicine (CAM) by men diagnosed with cancer

Phase 2: Interviews about how men and their close family members/friends perceive their health care decisions regarding CAM use

You are invited to participate in an interview about the use of Complementary and Alternative Medicine (CAM) by men with cancer. This interview study is part of a PhD project by Nadja Klafke, School of Psychology, The University of Adelaide. We specifically want to learn more about how men with cancer and their close family members or friends perceive their health care decisions with regard to CAM use.

Some months ago you completed a survey at the Royal Adelaide Hospital Cancer Centre, Adelaide Cancer Centre, or Adelaide Radiotherapy Centre, and gave your consent for a follow-up interview to help us know more about some of your answers marked on the questionnaire. We feel that your perspective of the use of complementary and alternative medicine is extremely important in exploring the perceptions that men with cancer and their close family members/friends may have had. To date there has not been much research done in this area, and we are keen to add to our knowledge.

We would be most grateful if you and a nominated family member or friend could spare the time to assist in this project by granting us an interview touching upon certain aspects of the topic.

If you agree to be part of this study, Nadja Klafke will talk with you both separately about your perceptions regarding the use of CAM in the context of your cancer diagnosis. This could happen either at a family/friend's home, at the cancer clinic, or within The University of Adelaide (whichever was most convenient for you and your family member/friend). If you wish to be interviewed at The University of Adelaide, emerging travel costs will be reimbursed. We expect that each interview would take between half an hour and one hour, but you can choose to stop it, or leave, whenever you want to. If you do agree to participate, you can change your mind at any time without giving a reason – it is completely up to you.

Before we begin the interview with you, we will ask you to sign a consent form. We will audio-record and then transcribe the interview session. This is so we can make sure that we accurately record how you and your family member/friend felt about and dealt with the cancer diagnosis and the decision to use or not to use CAM, and so we can look at it in more detail later. Only people directly involved in the research will be able to access the audio-recordings, or transcriptions. In addition, all information in the interview will be confidential, and we will change any identifying information (such as names or places), so that you and your family member/friend will not be personally identified as having contributed to the project. We will keep the information associated with this project securely stored at The University of Adelaide.

Based on all the interviews that are part of this study, Nadja Klafke will prepare a paper to suggest how health care professionals and organisations can better support males affected with cancer and their families/friends following a cancer diagnosis. There may also be an option to present these results in an academic journal or at a conference (but you and your family/friends will not be personally identified in any way in these presentations). It would not involve any financial gain for us.

If, after the interview, you or your family member/friend has any questions or issues arising out of the discussion, you are welcome to call Nadja Klafke, (mobile) 0420 705062 for answers or suggestions on who to contact for assistance. If you require any further information about this project, you may contact the principal investigator, Dr Jaklin Elliott, (work) 08 8303 3855, (mobile) 0413 565 637. If you have any questions about the ethical nature of this study, you may contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 08 8222 4139.

Appendix I: Invitation letter (Study 2, interviewing together)

Interpersonal factors impacting the decision to (continue to) use Complementary and Alternative Medicine (CAM) by men diagnosed with cancer

Phase 2: Interviews about how men and their close family members/friends perceive their health care decisions regarding CAM use

You are invited to participate in an interview about the use of Complementary and Alternative Medicine (CAM) by men with cancer. This interview study is part of a PhD project by Nadja Klafke, School of Psychology, The University of Adelaide. We specifically want to learn more about how men with cancer and their close family members or friends perceive their health care decisions with regard to CAM use.

Some months ago you completed a survey at the Royal Adelaide Hospital Cancer Centre, Adelaide Cancer Centre, or Adelaide Radiotherapy Centre, and gave your consent for a follow-up interview to help us know more about some of your answers marked on the questionnaire. We feel that your perspective of the use of complementary and alternative medicine is extremely important in exploring the perceptions that men with cancer and their close family members/friends may have had. To date there has not been much research done in this area, and we are keen to add to our knowledge.

We would be most grateful if you and a nominated family member or friend could spare the time to assist in this project by granting us an interview touching upon certain aspects of the topic.

If you agree to be part of this study, Nadja Klafke will talk with you both together about your perceptions regarding the use of CAM in the context of your cancer diagnosis. This could happen either at a family/friend's home, at the cancer clinic, or within The University of Adelaide (whichever was most convenient for you and your family member/friend). If you wish to be interviewed at The University of Adelaide, emerging travel costs will be reimbursed. We expect that each interview would take between half an hour and one hour, but you can choose to stop it, or leave, whenever you want to. If you do agree to participate, you can change your mind at any time without giving a reason – it is completely up to you.

Before we begin the interview with you, we will ask you to sign a consent form. We will audio-record and then transcribe the interview session. This is so we can make sure that we accurately record how you and your family member/friend felt about and dealt with the cancer diagnosis and the decision to use or not to use CAM, and so we can look at it in more detail later. Only people directly involved in the research will be able to access the audio-recordings, or transcriptions. In addition, all information in the interview will be confidential, and we will change any identifying information (such as names or places), so that you and your family member/friend will not be personally identified as having contributed to the project. We will keep the information associated with this project securely stored at The University of Adelaide.

Based on all the interviews that are part of this study, Nadja Klafke will prepare a paper to suggest how health care professionals and organisations can better support males affected with cancer and their families/friends following a cancer diagnosis. There may also be an option to present these results in an academic journal or at a conference (but you and your family/friends will not be personally identified in any way in these presentations). It would not involve any financial gain for us.

If, after the interview, you or your family member/friend has any questions or issues arising out of the discussion, you are welcome to call Nadja Klafke, (mobile) 0420 705062 for answers or suggestions on who to contact for assistance. If you require any further information about this project, you may contact the principal investigator, Dr Jaklin Elliott, (work) 08 8303 3855, (mobile) 0413 565 637. If you have any questions about the ethical nature of this study, you may contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 08 8222 4139.

**Appendix J: Information sheet and consent form (Study 2, RAH,
male patient, interviewing separately)**



INFORMATION SHEET

Project title: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Phase 2: Interviews about how men and their close family members/friends perceive their health care decisions regarding CAM use

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MBBch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FChPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (MBBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

Introduction:

The following information describes the study and your role as a participant. This study seeks to understand how men with cancer and their close family members/friends experienced the cancer diagnosis and its related healthcare decisions. We are particularly interested in your experiences and perceptions about the use of complementary and alternative medicine. Your participation in this study will involve taking part in an interview. We will also separately interview your nominated close family member/friend.

You can choose to be interviewed either at your home, at the Royal Adelaide Hospital Cancer Centre, or at The University of Adelaide. The interview will last for 30-60 minutes.

More information about this study is provided in the attached invitation. Your study investigator will answer any further questions you may have about the study. The information contained in this Information Sheet will help you to understand the possible risks and benefits involved in the study. Please note you *cannot* receive any reward for being a part of this study.

Purpose of the Study:

You are invited to participate in a research study, which is being conducted in order to better understand the use of complementary and alternative medicine by men with cancer.

Your participation would contribute to our research about understanding men's health care decisions with regard to the use of complementary/alternative therapies. The results of this project will further our knowledge about men with cancer and can be used for improvements in cancer care.

Voluntary Participation/Right to Refuse or Withdraw:

This is a research project and you do not have to be involved. If you do not wish to participate, your medical care will not be affected in any way. Also, you may withdraw from the project at any time after you have commenced.



Confidentiality:

Your records relating to this study and any other information received will be kept strictly confidential. Your identity will not be revealed and your confidentiality will be protected in any reviews and reports of this study which may be published.

At the close of the interview you can decide if you wish to receive a copy of the transcript of the interview, and request that some or all of the interview content be removed from the dataset before analysis.

Results of Project:

This study is part of a research project divided into three Phases. Data collection of all three Phases will continue until approx. August 2012. Results of all three Phases will be published or presented during the years 2011 – 2013. You will not be identified in any of these publications or presentations and your personal results will not be divulged. If you wish to be informed about the study results, publications, and presentations, or have any questions, please contact the study investigator Nadja Klafke:

E-mail: nadja.klafke@adelaide.edu.au

Telephone: 0420 705062

Consent:

Your study investigator is required to provide you with all information regarding the nature and purpose of the research study and you should be given the opportunity to discuss these. It must be stated that you are free to withdraw anytime and that if you do not participate you will not suffer any prejudice.

Advice and Information:

If you have any further questions regarding this study, please do not hesitate to contact

Nadja Klafke, Ph: 0420 705062

If you are concerned about any aspect of the interview or the interview has distressed you or your family member/friend, you may contact Dr Elliott who will discuss these issues with you.

Dr Jaklin Elliott, Ph: 08 8303 3855

The Royal Adelaide Hospital Ethics Committee has reviewed this study in accordance with the National Statement on Ethical Conduct in Human Research (2007). Should you wish to discuss the study or view a copy of the Complaint procedure with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139.

CONSENT FORM

PROTOCOL NAME: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MB Bch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FChPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (MBBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.
2. I understand that I may not benefit from taking part in the trial.
3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
4. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.
5. I have had the opportunity to discuss taking part in this investigation with a family member or friend.
6. I understand that my interview will be audio-recorded and that I will be given the opportunity to review a transcript of the interview.

I give my consent to take part in a follow-up study about the interview (i.e., video-journaling).

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the patient/volunteer and consider that he/she understands what is involved.

Signed: _____

Dated: _____
(Investigator)

**Appendix K: Information sheet and consent form (Study 2, RAH,
male patient's SO, interviewing separately)**

INFORMATION SHEET

Project title: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Phase 2: Interviews about how men and their close family members/friends perceive their health care decisions regarding CAM use

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MBBCh, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FACHPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singh (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (MBBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

Introduction:

The following information describes the study and your role as a participant. This study seeks to understand how men with cancer and their close family members/friends experienced the cancer diagnosis and its related healthcare decisions. We are particularly interested in your experiences and perceptions about the use of complementary and alternative medicine. Your participation in this study will involve taking part in an interview. We will also separately interview your close family member/friend affected with cancer.

You can choose to be interviewed either at your home, at the Royal Adelaide Hospital Cancer Centre, or at The University of Adelaide. The interview will last for 30-60 minutes.

More information about this study is provided in the attached invitation. Your study investigator will answer any further questions you may have about the study. The information contained in this Information Sheet will help you to understand the possible risks and benefits involved in the study. Please note you *cannot* receive any reward for being a part of this study.

Purpose of the Study:

You are invited to participate in a research study, which is being conducted in order to better understand the use of complementary and alternative medicine by men with cancer.

Your participation would contribute to our research about understanding men's health care decisions with regard to the use of complementary/alternative therapies. The results of this project will further our knowledge about men with cancer and can be used for improvements in cancer care.

Voluntary Participation/Right to Refuse or Withdraw:

This is a research project and you do not have to be involved. If you do not wish to participate, your medical care will not be affected in any way. Also, you may withdraw from the project at any time after you have commenced.



Confidentiality:

Your records relating to this study and any other information received will be kept strictly confidential. Your identity will not be revealed and your confidentiality will be protected in any reviews and reports of this study which may be published.

At the close of the interview you can decide if you wish to receive a copy of the transcript of the interview, and request that some or all of the interview content be removed from the dataset before analysis.

Results of Project:

This study is part of a research project divided into three Phases. Data collection of all three Phases will continue until approx. August 2012. Results of all three Phases will be published or presented during the years 2011 – 2013. You will not be identified in any of these publications or presentations and your personal results will not be divulged. If you wish to be informed about the study results, publications, and presentations, or have any questions, please contact the study investigator Nadja Klafke:

E-mail: nadja.klafke@adelaide.edu.au

Telephone: 0420 705062

Consent:

Your study investigator is required to provide you with all information regarding the nature and purpose of the research study and you should be given the opportunity to discuss these. It must be stated that you are free to withdraw anytime and that if you do not participate you will not suffer any prejudice.

Advice and Information:

If you have any further questions regarding this study, please do not hesitate to contact

Nadja Klafke, Ph: 0420 705062.

If you are concerned about any aspect of the interview or the interview has distressed you or your family member/friend, you may contact Dr Elliott who will discuss these issues with you.

Dr Jaklin Elliott, Ph: 08 8303 3855

The Royal Adelaide Hospital Ethics Committee has reviewed this study in accordance with the National Statement on Ethical Conduct in Human Research (2007). Should you wish to discuss the study or view a copy of the Complaint procedure with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139.

CONSENT FORM

PROTOCOL NAME: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MB Bch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FACHPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (BMBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.
2. I understand that I may not benefit from taking part in the trial.
3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
4. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.
5. I have had the opportunity to discuss taking part in this investigation with a family member or friend.
6. I understand that my interview will be audio-recorded and that I will be given the opportunity to review a transcript of the interview.

I give my consent to take part in a follow-up study about the interview (i.e., video-journaling).

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the patient/volunteer and consider that he/she understands what is involved.

Signed: _____

Dated: _____
(Investigator)

**Appendix L: Information sheet and consent form (Study 2, RAH,
male patient, interviewing together)**

INFORMATION SHEET

Project title: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Phase 2: Interviews about how men and their close family members/friends perceive their health care decisions regarding CAM use

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MBBch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FACHPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singh (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (BMBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCP, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

Introduction:

The following information describes the study and your role as a participant.

This study seeks to understand how men with cancer and their close family members/friends experienced the cancer diagnosis and its related healthcare decisions. We are particularly interested in your experiences and perceptions about the use of complementary and alternative medicine. Your participation in this study will involve taking part in an interview together with a nominated close family member/friend.

It is possible that as part of the interview some discussion may arise in which you and your family member/friend may disagree. If this occurs and you wish to terminate this part of the discussion, you should indicate this to the interviewer.

You can choose to be interviewed either at your home, at the Royal Adelaide Hospital Cancer Centre, or at The University of Adelaide. The interview will last for 30-60 minutes.

More information about this study is provided in the attached invitation. Your study investigator will answer any further questions you may have about the study. The information contained in this Information Sheet will help you to understand the possible risks and benefits involved in the study. Please note you *cannot* receive any reward for being a part of this study.

Purpose of the Study:

You are invited to participate in a research study, which is being conducted in order to better understand the use of complementary and alternative medicine by men with cancer.

Your participation would contribute to our research about understanding men's health care decisions with regard to the use of complementary/alternative therapies. The results of this project will further our knowledge about men with cancer and can be used for improvements in cancer care.

Voluntary Participation/Right to Refuse or Withdraw:

This is a research project and you do not have to be involved. If you do not wish to participate, your medical care will not be affected in any way. Also, you may withdraw from the project at any time after you have commenced.



Confidentiality:

Your records relating to this study and any other information received will be kept strictly confidential. Your identity will not be revealed and your confidentiality will be protected in any reviews and reports of this study which may be published.

At the close of the interview you can decide if you wish to receive a copy of the transcript of the interview, and request that some or all of the interview content be removed from the dataset before analysis.

Results of Project:

This study is part of a research project divided into three Phases. Data collection of all three Phases will continue until approx. August 2012. Results of all three Phases will be published or presented during the years 2011 – 2013. You will not be identified in any of these publications or presentations and your personal results will not be divulged. If you wish to be informed about the study results, publications, and presentations, or have any questions, please contact the study investigator Nadja Klafke:

E-mail: nadja.klafke@adelaide.edu.au

Telephone: 0420 705062

Consent:

Your study investigator is required to provide you with all information regarding the nature and purpose of the research study and you should be given the opportunity to discuss these. It must be stated that you are free to withdraw anytime and that if you do not participate you will not suffer any prejudice.

Advice and Information:

If you have any further questions regarding this study, please do not hesitate to contact

Nadja Klafke, Ph: 0420 705062

If you are concerned about any aspect of the interview or the interview has distressed you or your family member/friend, you may contact Dr Elliott who will discuss these issues with you.

Dr Jaklin Elliott, Ph: 08 8303 3855

The Royal Adelaide Hospital Ethics Committee has reviewed this study in accordance with the National Statement on Ethical Conduct in Human Research (2007). Should you wish to discuss the study or view a copy of the Complaint procedure with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139.



CONSENT FORM

PROTOCOL NAME: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MB Bch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FACHPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (MBBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.
 2. I understand that I may not benefit from taking part in the trial.
 3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
 4. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.
 5. I have had the opportunity to discuss taking part in this investigation with a family member or friend.
 6. I understand that my interview will be audio-recorded and that I will be given the opportunity to review a transcript of the interview.
- I give my consent to take part in a follow-up study about the interview (i.e., video-journaling).

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the patient/volunteer and consider that he/she understands what is involved.

Signed: _____

Dated: _____
(Investigator)

**Appendix M: Information sheet and consent form (Study 2, RAH,
male patient's SO, interviewing together)**



INFORMATION SHEET

Project title: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Phase 2: Interviews about how men and their close family members/friends perceive their health care decisions regarding CAM use

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MBBch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FACHPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (BMBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

Introduction:

The following information describes the study and your role as a participant.

This study seeks to understand how men with cancer and their close family members/friends experienced the cancer diagnosis and its related healthcare decisions. We are particularly interested in your experiences and perceptions about the use of complementary and alternative medicine. Your participation in this study will involve taking part in an interview together with a close family member/friend affected with cancer.

It is possible that as part of the interview some discussion may arise in which you and your family member/friend may disagree. If this occurs and you wish to terminate this part of the discussion, you should indicate this to the interviewer.

You can choose to be interviewed either at your home, at the Royal Adelaide Hospital Cancer Centre, or at The University of Adelaide. The interview will last for 30-60 minutes.

More information about this study is provided in the attached invitation. Your study investigator will answer any further questions you may have about the study. The information contained in this Information Sheet will help you to understand the possible risks and benefits involved in the study. Please note you *cannot* receive any reward for being a part of this study.

Purpose of the Study:

You are invited to participate in a research study, which is being conducted in order to better understand the use of complementary and alternative medicine by men with cancer.

Your participation would contribute to our research about understanding men's health care decisions with regard to the use of complementary/alternative therapies. The results of this project will further our knowledge about men with cancer and can be used for improvements in cancer care.

Voluntary Participation/Right to Refuse or Withdraw:

This is a research project and you do not have to be involved. If you do not wish to participate, your medical care will not be affected in any way. Also, you may withdraw from the project at any time after you have commenced.



Confidentiality:

Your records relating to this study and any other information received will be kept strictly confidential. Your identity will not be revealed and your confidentiality will be protected in any reviews and reports of this study which may be published.

At the close of the interview you can decide if you wish to receive a copy of the transcript of the interview, and request that some or all of the interview content be removed from the dataset before analysis.

Results of Project:

This study is part of a research project divided into three Phases. Data collection of all three Phases will continue until approx. August 2012. Results of all three Phases will be published or presented during the years 2011 – 2013. You will not be identified in any of these publications or presentations and your personal results will not be divulged. If you wish to be informed about the study results, publications, and presentations, or have any questions, please contact the study investigator Nadja Klafke:

E-mail: nadja.klafke@adelaide.edu.au

Telephone: 0420 705062

Consent:

Your study investigator is required to provide you with all information regarding the nature and purpose of the research study and you should be given the opportunity to discuss these. It must be stated that you are free to withdraw anytime and that if you do not participate you will not suffer any prejudice.

Advice and Information:

If you have any further questions regarding this study, please do not hesitate to contact

Nadja Klafke, Ph: 0420 705062

If you are concerned about any aspect of the interview or the interview has distressed you or your family member/friend, you may contact Dr Elliott who will discuss these issues with you.

Dr Jaklin Elliott, Ph: 08 8303 3855

The Royal Adelaide Hospital Ethics Committee has reviewed this study in accordance with the National Statement on Ethical Conduct in Human Research (2007). Should you wish to discuss the study or view a copy of the Complaint procedure with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139.

CONSENT FORM

PROTOCOL NAME: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MB Bch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FACHPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (BMBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.
 2. I understand that I may not benefit from taking part in the trial.
 3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
 4. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.
 5. I have had the opportunity to discuss taking part in this investigation with a family member or friend.
 6. I understand that my interview will be audio-recorded and that I will be given the opportunity to review a transcript of the interview.
- I give my consent to take part in a follow-up study about the interview (i.e., video-journaling).

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the patient/volunteer and consider that he/she understands what is involved.

Signed: _____

Dated: _____
(Investigator)

**Appendix N: Information sheet and consent form (Study 2,
Tennyson Centre, male patient, interviewing separately)**

INFORMATION SHEET

Project title: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Phase 2: Interviews about how men and their close family members/friends perceive their health care decisions regarding CAM use

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MBBch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FACHPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (MBBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

Introduction:

The following information describes the study and your role as a participant. This study seeks to understand how men with cancer and their close family members/friends experienced the cancer diagnosis and its related healthcare decisions. We are particularly interested in your experiences and perceptions about the use of complementary and alternative medicine. Your participation in this study will involve taking part in an interview. We will also separately interview your nominated close family member/friend.

You can choose to be interviewed either at your home, at the Adelaide Cancer Centre, Adelaide Radiotherapy Centre, or The University of Adelaide. The interview will last for 30-60 minutes.

More information about this study is provided in the attached invitation. Your study investigator will answer any further questions you may have about the study. The information contained in this Information Sheet will help you to understand the possible risks and benefits involved in the study. Please note you *cannot* receive any reward for being a part of this study.

Purpose of the Study:

You are invited to participate in a research study, which is being conducted in order to better understand the use of complementary and alternative medicine by men with cancer.

Your participation would contribute to our research about understanding men's health care decisions with regard to the use of complementary/alternative therapies. The results of this project will further our knowledge about men with cancer and can be used for improvements in cancer care.

Voluntary Participation/Right to Refuse or Withdraw:



**ADELAIDE CANCER CENTRE
ADELAIDE RADIOTHERAPY CENTRE**

This is a research project and you do not have to be involved. If you do not wish to participate, your medical care will not be affected in any way. Also, you may withdraw from the project at any time after you have commenced.

Confidentiality:

Your records relating to this study and any other information received will be kept strictly confidential. Your identity will not be revealed and your confidentiality will be protected in any reviews and reports of this study which may be published.

At the close of the interview you can decide if you wish to receive a copy of the transcript of the interview, and request that some or all of the interview content be removed from the dataset before analysis.

Results of Project:

This study is part of a research project divided into three Phases. Data collection of all three Phases will continue until approx. August 2012. Results of all three Phases will be published or presented during the years 2011 – 2013. You will not be identified in any of these publications or presentations and your personal results will not be divulged. If you wish to be informed about the study results, publications, and presentations, or have any questions, please contact the study investigator Nadja Klafke:

E-mail: nadja.klafke@adelaide.edu.au

Telephone: 0420 705062

Consent:

Your study investigator is required to provide you with all information regarding the nature and purpose of the research study and you should be given the opportunity to discuss these. It must be stated that you are free to withdraw anytime and that if you do not participate you will not suffer any prejudice.

Advice and Information:

If you have any further questions regarding this study, please do not hesitate to contact

Nadja Klafke, Ph: 0420 705062

If you are concerned about any aspect of the interview or the interview has distressed you or your family member/friend, you may contact Dr Elliott who will discuss these issues with you.

Dr Jaklin Elliott, Ph: 08 8303 3855

The Royal Adelaide Hospital Ethics Committee has reviewed this study in accordance with the National Statement on Ethical Conduct in Human Research (2007). Should you wish to discuss the study or view a copy of the Complaint procedure with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139.

CONSENT FORM

PROTOCOL NAME: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MB Bch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FACHPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (BMBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.
 2. I understand that I may not benefit from taking part in the trial.
 3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
 4. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.
 5. I have had the opportunity to discuss taking part in this investigation with a family member or friend.
 6. I understand that my interview will be audio-recorded and that I will be given the opportunity to review a transcript of the interview.
- I give my consent to take part in a follow-up study about the interview (i.e., video-journaling).

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the patient/volunteer and consider that he/she understands what is involved.

Signed: _____

Dated: _____
(Investigator)

**Appendix O: Information sheet and consent form (Study 2,
Tennyson Centre, male patient's SO, interviewing separately)**

INFORMATION SHEET

Project title: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Phase 2: Interviews about how men and their close family members/friends perceive their health care decisions regarding CAM use

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MBBch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FACHPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (MBBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

Introduction:

The following information describes the study and your role as a participant. This study seeks to understand how men with cancer and their close family members/friends experienced the cancer diagnosis and its related healthcare decisions. We are particularly interested in your experiences and perceptions about the use of complementary and alternative medicine. Your participation in this study will involve taking part in an interview. We will also separately interview your close family member/friend affected with cancer.

You can choose to be interviewed either at your home, at the Adelaide Cancer Centre, Adelaide Radiotherapy Centre, or The University of Adelaide. The interview will last for 30-60 minutes.

More information about this study is provided in the attached invitation. Your study investigator will answer any further questions you may have about the study. The information contained in this Information Sheet will help you to understand the possible risks and benefits involved in the study. Please note you *cannot* receive any reward for being a part of this study.

Purpose of the Study:

You are invited to participate in a research study, which is being conducted in order to better understand the use of complementary and alternative medicine by men with cancer.

Your participation would contribute to our research about understanding men's health care decisions with regard to the use of complementary/alternative therapies. The results of this project will further our knowledge about men with cancer and can be used for improvements in cancer care.

Voluntary Participation/Right to Refuse or Withdraw:

This is a research project and you do not have to be involved. If you do not wish to participate, your medical care will not be affected in any way. Also, you may withdraw from the project at any time after you have commenced.



Confidentiality:

Your records relating to this study and any other information received will be kept strictly confidential. Your identity will not be revealed and your confidentiality will be protected in any reviews and reports of this study which may be published. At the close of the interview you can decide if you wish to receive a copy of the transcript of the interview, and request that some or all of the interview content be removed from the dataset before analysis.

Results of Project:

This study is part of a research project divided into three Phases. Data collection of all three Phases will continue until approx. August 2012. Results of all three Phases will be published or presented during the years 2011 – 2013. You will not be identified in any of these publications or presentations and your personal results will not be divulged. If you wish to be informed about the study results, publications, and presentations, or have any questions, please contact the study investigator Nadja Klafke:

E-mail: nadja.klafke@adelaide.edu.au

Telephone: 0420 705062

Consent:

Your study investigator is required to provide you with all information regarding the nature and purpose of the research study and you should be given the opportunity to discuss these. It must be stated that you are free to withdraw anytime and that if you do not participate you will not suffer any prejudice.

Advice and Information:

If you have any further questions regarding this study, please do not hesitate to contact

Nadja Klafke, Ph: 0420 705062.

If you are concerned about any aspect of the interview or the interview has distressed you or your family member/friend, you may contact Dr Elliott who will discuss these issues with you.

Dr Jaklin Elliott, Ph: 08 8303 3855

The Royal Adelaide Hospital Ethics Committee has reviewed this study in accordance with the National Statement on Ethical Conduct in Human Research (2007). Should you wish to discuss the study or view a copy of the Complaint procedure with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139.



CONSENT FORM

PROTOCOL NAME: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MB Bch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FACHPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (BMBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.
 2. I understand that I may not benefit from taking part in the trial.
 3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
 4. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.
 5. I have had the opportunity to discuss taking part in this investigation with a family member or friend.
 6. I understand that my interview will be audio-recorded and that I will be given the opportunity to review a transcript of the interview.
- I give my consent to take part in a follow-up study about the interview (i.e., video-journaling).

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the patient/volunteer and consider that he/she understands what is involved.

Signed: _____

Dated: _____
(Investigator)

**Appendix P: Information sheet and consent form (Study 2,
Tennyson Centre, male patient, interviewing together)**

INFORMATION SHEET

Project title: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Phase 2: Interviews about how men and their close family members/friends perceive their health care decisions regarding CAM use

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MBBch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FACHPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (MBBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

Introduction:

The following information describes the study and your role as a participant.

This study seeks to understand how men with cancer and their close family members/friends experienced the cancer diagnosis and its related healthcare decisions. We are particularly interested in your experiences and perceptions about the use of complementary and alternative medicine. Your participation in this study will involve taking part in an interview together with a nominated close family member/friend.

It is possible that as part of the interview some discussion may arise in which you and your family member/friend may disagree. If this occurs and you wish to terminate this part of the discussion, you should indicate this to the interviewer.

You can choose to be interviewed either at your home, at the Adelaide Cancer Centre, Adelaide Radiotherapy Centre, or The University of Adelaide. The interview will last for 30-60 minutes.

More information about this study is provided in the attached invitation. Your study investigator will answer any further questions you may have about the study. The information contained in this Information Sheet will help you to understand the possible risks and benefits involved in the study. Please note you *cannot* receive any reward for being a part of this study.

Purpose of the Study:

You are invited to participate in a research study, which is being conducted in order to better understand the use of complementary and alternative medicine by men with cancer.

Your participation would contribute to our research about understanding men's health care decisions with regard to the use of complementary/alternative therapies. The results of this project will further our knowledge about men with cancer and can be used for improvements in cancer care.

Voluntary Participation/Right to Refuse or Withdraw:

This is a research project and you do not have to be involved. If you do not wish to participate, your medical care will not be affected in any way. Also, you may withdraw from the project at any time after you have commenced.



**ADELAIDE CANCER CENTRE
ADELAIDE RADIOTHERAPY CENTRE**

Confidentiality:

Your records relating to this study and any other information received will be kept strictly confidential. Your identity will not be revealed and your confidentiality will be protected in any reviews and reports of this study which may be published.

At the close of the interview you can decide if you wish to receive a copy of the transcript of the interview, and request that some or all of the interview content be removed from the dataset before analysis.

Results of Project:

This study is part of a research project divided into three Phases. Data collection of all three Phases will continue until approx. August 2012. Results of all three Phases will be published or presented during the years 2011 – 2013. You will not be identified in any of these publications or presentations and your personal results will not be divulged. If you wish to be informed about the study results, publications, and presentations, or have any questions, please contact the study investigator Nadja Klafke:

E-mail: nadja.klafke@adelaide.edu.au

Telephone: 0420 705062

Consent:

Your study investigator is required to provide you with all information regarding the nature and purpose of the research study and you should be given the opportunity to discuss these. It must be stated that you are free to withdraw anytime and that if you do not participate you will not suffer any prejudice.

Advice and Information:

If you have any further questions regarding this study, please do not hesitate to contact

Nadja Klafke, Ph: 0420 705062

If you are concerned about any aspect of the interview or the interview has distressed you or your family member/friend, you may contact Dr Elliott who will discuss these issues with you.

Dr Jaklin Elliott, Ph: 08 8303 3855

The Royal Adelaide Hospital Ethics Committee has reviewed this study in accordance with the National Statement on Ethical Conduct in Human Research (2007). Should you wish to discuss the study or view a copy of the Complaint procedure with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139.

CONSENT FORM

PROTOCOL NAME: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MB Bch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FACHPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (BMBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.
 2. I understand that I may not benefit from taking part in the trial.
 3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
 4. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.
 5. I have had the opportunity to discuss taking part in this investigation with a family member or friend.
 6. I understand that my interview will be audio-recorded and that I will be given the opportunity to review a transcript of the interview.
- I give my consent to take part in a follow-up study about the interview (i.e., video-journaling).

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the patient/volunteer and consider that he/she understands what is involved.

Signed: _____

Dated: _____
(Investigator)

**Appendix Q: Information sheet and consent form (Study 2,
Tennyson Centre, male patient's SO, interviewing together)**



INFORMATION SHEET

Project title: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Phase 2: Interviews about how men and their close family members/friends perceive their health care decisions regarding CAM use

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MBBch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FACHPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (MBBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

Introduction:

The following information describes the study and your role as a participant.

This study seeks to understand how men with cancer and their close family members/friends experienced the cancer diagnosis and its related healthcare decisions. We are particularly interested in your experiences and perceptions about the use of complementary and alternative medicine. Your participation in this study will involve taking part in an interview together with a close family member/friend affected with cancer.

It is possible that as part of the interview some discussion may arise in which you and your family member/friend may disagree. If this occurs and you wish to terminate this part of the discussion, you should indicate this to the interviewer.

You can choose to be interviewed either at your home, at the Adelaide Cancer Centre, Adelaide Radiotherapy Centre, or The University of Adelaide. The interview will last for 30-60 minutes.

More information about this study is provided in the attached invitation. Your study investigator will answer any further questions you may have about the study. The information contained in this Information Sheet will help you to understand the possible risks and benefits involved in the study. Please note you *cannot* receive any reward for being a part of this study.

Purpose of the Study:

You are invited to participate in a research study, which is being conducted in order to better understand the use of complementary and alternative medicine by men with cancer.

Your participation would contribute to our research about understanding men's health care decisions with regard to the use of complementary/alternative therapies. The results of this project will further our knowledge about men with cancer and can be used for improvements in cancer care.

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**ADELAIDE CANCER CENTRE
ADELAIDE RADIOTHERAPY CENTRE**

Confidentiality:

Your records relating to this study and any other information received will be kept strictly confidential. Your identity will not be revealed and your confidentiality will be protected in any reviews and reports of this study which may be published.

At the close of the interview you can decide if you wish to receive a copy of the transcript of the interview, and request that some or all of the interview content be removed from the dataset before analysis.

Results of Project:

This study is part of a research project divided into three Phases. Data collection of all three Phases will continue until approx. August 2012. Results of all three Phases will be published or presented during the years 2011 – 2013. You will not be identified in any of these publications or presentations and your personal results will not be divulged. If you wish to be informed about the study results, publications, and presentations, or have any questions, please contact the study investigator Nadja Klafke:

E-mail: nadja.klafke@adelaide.edu.au

Telephone: 0420 705062

Consent:

Your study investigator is required to provide you with all information regarding the nature and purpose of the research study and you should be given the opportunity to discuss these. It must be stated that you are free to withdraw anytime and that if you do not participate you will not suffer any prejudice.

Advice and Information:

If you have any further questions regarding this study, please do not hesitate to contact

Nadja Klafke, Ph: 0420 705062

If you are concerned about any aspect of the interview or the interview has distressed you or your family member/friend, you may contact Dr Elliott who will discuss these issues with you.

Dr Jaklin Elliott, Ph: 08 8303 3855

The Royal Adelaide Hospital Ethics Committee has reviewed this study in accordance with the National Statement on Ethical Conduct in Human Research (2007). Should you wish to discuss the study or view a copy of the Complaint procedure with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139.

CONSENT FORM

PROTOCOL NAME: Interpersonal factors impacting the decision to (continue to) use complementary and alternative medicine (CAM) by men diagnosed with cancer

Investigators: Dr Jaklin A. Elliott (PhD), Nadja Klafke (PhD Candidate), Prof Gary A. Wittert (MB Bch, FRACP, MD), Prof Ian N. Olver (MBBS, MD, PhD, CMin, FRACP, AFRACMA, FACHPM), Prof Dorothy Keefe (MBBS, MD, FRACP), Prof Michael P. Brown (MBBS, PhD, FRACP, FRCPA), Dr Sid Selva-Nayagam (MBBS, FRACP), Dr Nimit Singhal (MBBS, MD, DM), Dr Anne Taylor (MBBS, FRACP), Dr Thean Hsiang TAN (MBBS, FRACP), Dr Nick Murray (BMBS, MA, DPhil, FRCP), Prof Eric Yeoh (MD (Adel), FRCP (Edin), FRCR, FRANZCR), Dr Michael Penniment (FRANZCR, MBA), A/Prof Dusan Kotasek (MBBS (Hons), FRACP), Dr Martin Borg (MD, FRANZCR)

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.
2. I understand that I may not benefit from taking part in the trial.
3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
4. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.
5. I have had the opportunity to discuss taking part in this investigation with a family member or friend.
6. I understand that my interview will be audio-recorded and that I will be given the opportunity to review a transcript of the interview.

I give my consent to take part in a follow-up study about the interview (i.e., video-journaling).

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the patient/volunteer and consider that he/she understands what is involved.

Signed: _____

Dated: _____
(Investigator)

Appendix R: Published paper I (Chapter Three)

Elliott, J., & Klafke, N. (2011). Family and complementary and alternative medicine. *CancerForum*, 35(1), 40-43.

NOTE: This publication is included on pages 268 – 271 in the print copy of the thesis held in the University of Adelaide Library.

NOTE:

This publication is included on pages 298-271 in the print copy of the thesis held in the University of Adelaide Library.

Appendix S: Published paper II (Chapter Four)

Klafke, N., Elliott, J., Wittert, G., & Olver, I. (2012). Prevalence and predictors of complementary and alternative medicine (CAM) use by men in Australian cancer outpatient services. *Annals of Oncology*, 23(6), 1571-1578.

NOTE: This publication is included on pages 273 – 280 in the print copy of the thesis held in the University of Adelaide Library.

NOTE:

This publication is included on pages 273-280 in the print copy of the thesis held in the University of Adelaide Library.

It is also available online to authorised users at:

<http://dx.doi.org/10.1093/annonc/mdr521>

Appendix T: Published paper III (Chapter Seven)

Klafke, N., Elliott, J., Olver, I., & Wittert, G. (2013). The role of complementary and alternative medicine (CAM) routines and rituals in men with cancer and their significant others (SOs): a qualitative investigation. *Supportive Care Cancer* (accepted 5 Dec 2013)

NOTE: This publication is included on pages 282 – 295 in the print copy of the thesis held in the University of Adelaide Library.

NOTE:

This publication is included on pages 282-295 in the print copy of the thesis held in the University of Adelaide Library.

It is also available online to authorised users at:

<http://dx.doi.org/10.1007/s00520-013-2090-2>